ORIGINAL ARTICLE
AJH Educational Material

Women Leaders in Hematology: Inspirations & Insights

Doris Quon,[1] Meera Chitlur,[2] Madhvi Rajpurkar,[3] Mindy Simpson,[4] Sarah O'Brien,[5] Veronica Flood,[6] Loan Hsieh,[7] Suchitra Acharya,[8] Rebecca Kruse-Jarres,[9] Suman Sood,[10] and Jennifer Maahs[11]

Carol K. Kasper, MD

Interviewed by Doris Quon, MD, PhD

Carol K. Kasper, MD

Biography. Dr. Carol Kasper is a hematologist and Director Emeritus at the Orthopaedic Hemophilia Treatment Center in Los Angeles, California. Dr. Kasper is well known for her work on the diagnosis and treatment of hemophilia over the past 40 years. During her career, she has held numerous leadership positions within the field, including Vice President Medical of the World Federation of Hemophilia (WFH), Vice President of the National Hemophilia Foundation (NHF), and Chair of the Medical Advisory Board of the Hemophilia Foundation of Southern California. She has received many awards for her work, including two career achievement awards from the NHF (2000 and 2007), the Brinkhous Award for Excellence in Clinical Research (1992), the George F. Davignon Lifetime Professional Achievement Award (2005), and a lifetime achievement award from the Hemostasis & Thrombosis Research Society (HTRS; 2008).

Dr. Kasper received her undergraduate degree from the University of Chicago (1954) before completing her medical degree at the University of California, San Francisco (1959). She then completed a residency in internal medicine and a fellowship in hematology. Dr. Kasper later joined the faculty at the University of Southern California (USC) and became professor emerita in 1999. Over the course of her distinguished career, she has published over 200 scientific papers, monographs, and book articles in the field of hematology. Dr. Kasper currently trains hematology fellows at the Orthopaedic Hemophilia Treatment Center.

Q&A

Dr. Doris Quon: The first question is: how did you even get involved in medicine?

Dr. Carol Kasper: I was always interested in articles on medicine that I read in ordinary magazines, like *Time* or *Newsweek* or *Reader's Digest*. I realized that I had an interest, but it wasn't so strong. I knew I just wanted to do something worthwhile. I thought a little bit about the law, and [knew] that I wanted to do something challenging. A lot of my friends and relatives, my parents, thought that medicine would be good for me. And when the kids in the dorm said, "You really ought to be a doctor," then I thought, "Well, maybe they see something that I haven't completely seen [in] myself yet." I was more serious, I think, and they thought that's what a doctor ought to be. But there was no particular experience that led me to medicine. It was not a highly informed decision.

Dr. Quon: Looking back, would you change that?

[1]Orthopaedic Institute for Children, Orthopaedic Hemophilia Treatment Center, Los Angeles, California; [2]Children's Hospital of Michigan, Division of Hematology/Oncology, Detroit, Michigan; [3]Children's Hospital of Michigan, Hematology, Detroit, Michigan; [4]Rush University Medical Center, Department of Pediatrics, Chicago, Illinois; [5]Nationwide Children's Hospital, Department of Hematology & Oncology, Columbus, Ohio; [6]Medical College of Wisconsin, Department of Pediatrics, Milwaukee, Wisconsin; [7]Children's Hospital of Orange County, Hematology, Orange, California; [8]Northwell Health, Pediatric Hematology/Oncology, New Hyde Park, New York; [9]Washington Center for Bleeding Disorders at Bloodworks Northwest, Seattle, Washington; [10]University of Michigan, Department of Hematology, Ann Arbor, Michigan; [11]Indiana Hemophilia and Thrombosis Center, Indianapolis, Indiana

Guest Editors: Tammuella Singleton, MD; David L. Cooper, MD, MBA; Sriya Gunawardena, MD
Conflict of interest: Doris Quon, MD, PhD, serves on speakers bureaus for Baxter, Biogen, CSL, Grifols, and Novo Nordisk; and advisory boards for Baxter, Bayer, and Novo Nordisk. Meera Chitlur, MD, is a paid consultant for Novo Nordisk, Bayer, Baxter, Pfizer, and Biogen. Madhvi Rajpurkar, MD, has served on advisory boards for Novo Nordisk, Pfizer, Bayer, and Baxalta. Sarah O'Brien, MD, serves on advisory boards for the American Thrombosis & Hemostasis Network, Bristol-Myers Squibb, and Pfizer; and receives research funding from Bristol-Myers Squibb. Veronica Flood, MD, is a consultant for Baxter and CSL Behring; and receives grant funding from the National Institutes of Health (HL126810 and HL102260). Suchitra Acharya, MD, has received honoraria from Novo Nordisk and Bayer; and has served on advisory boards for Novo Nordisk and Bayer. Rebecca Kruse-Jarres, MD, MPH, is a paid consultant for Baxalta, Bayer, CSL Behring, Grifols, Novo Nordisk, Pfizer, and Roche; and has received research funding from Pfizer and Roche. Suman Sood, MD, has received research funding from Bayer. Jennifer Maahs, MSN, PNP, has served on an advisory board for Baxalta-Hemophilia Nurse Partnership and serves on speakers bureaus for Biogen and Novo Nordisk. Tammuella Singleton, MD, is a consultant for Baxter, Novo Nordisk, CSL Behring, Grifols, and Biogen; has served on advisory boards for Baxter, Novo Nordisk, Octapharma, Grifols, and Biogen; and has served on speakers bureaus for Baxter, Novo Nordisk, and Grifols. David L. Cooper, MD, MBA, and Sriya Gunawardena, MD, are employees of Novo Nordisk Inc. The other authors have declared no conflicts of interest.
Contract grant sponsor: Novo Nordisk Inc.
Received for publication: 0 Month 2015; **Revised:** 0 Month 2016; **Accepted:** 0 Month 2016
Am. J. Hematol. 91:S6–S34, 2016.
Published online: in Wiley Online Library (wileyonlinelibrary.com).
DOI: 10.1002/ajh.24316

Dr. Kasper: I've enjoyed it, so I don't think I would change it now. I must say that it was difficult at the time. I found medical school to be a hard slog because a great deal was expected of us to learn so much in such little time, and I had to study very hard. So it was difficult, but I'm glad I did it.

Dr. Quon: *How did you get into hematology?*

Dr. Kasper: I really don't quite know where the spark for hematology came from. I just picked up an interest as we went along. I used to joke a little bit about it—I joked that it was because blood was so pretty!

I was very fortunate when I thought about hematology as being attractive. At the time, I had met a lady who was a cardiologist and who was the wife of a hematologist, and she said, "Well, if you like hematology, this is where you should apply"; and I was really lucky because I had a fellowship with an excellent person. He was very big in coagulation, Dr. Paul Aggeler. He had tremendous integrity, and he was not at all a proud kind of a guy. So it was a wonderful experience for me.

Dr. Quon: *When you first got into medicine, did you think that it would be challenging given that you were a woman? Did you think it would be more challenging than it would have been for a man?*

Dr. Kasper: Well, I did... there were various snide remarks that people would make like, "You're taking up a man's place in medical school. The man will practice; a woman won't! She'll just get married and have children and drop out"—that was a common assumption, and one had to sort of fight that.

I remember one of my interviews, which was with the dean of a medical school who said, "What will you do if your husband doesn't allow you to work?" And I said, "I'm not going to marry somebody who doesn't *allow* me to work!" And he said, "Well, you have a lot to learn about life." I did get admitted to that medical school, so I can't say that any of the snide remarks that I've ever run into have kept me from a job or an appointment. They just told me what the attitude was of the questioner, but they didn't keep me out at any point that I know of.

Dr. Quon: *Do you remember your medical school class having very many women?*

Dr. Kasper: Mine had more than average. I think that this was very unusual. The class before had two or four, and ours had ten in a class of 80-something. But then, the following year, after us, they went back to only four females in the class.

Dr. Quon: *Interesting. Do you think the medical field is actually becoming more supportive of women in the field?*

Dr. Kasper: I think it's become more the norm to have women in the field. I hope that salaries can keep [us] supported. I remember once when an editor of the *New England Journal of Medicine* gave a talk at USC about the future in medicine. He said, "Well, now that we're getting all of these women in medicine, we won't have to pay them so much."

Dr. Quon: *There is a disparity between pay across all jobs, not just in medicine, unfortunately*.

Dr. Kasper: Yes; but, alas, it doesn't cost any less for women to go to medical school than it does for men.

Dr. Quon: *Yes. So for a lot of male doctors, they get married and they have the woman at home "to take care of the home." You think that was more difficult for you being a woman?*

Dr. Kasper: I think this is a major issue when both the man and the woman have professions. If you're a hematologist, it's a profession that requires a fairly big population to draw from. So you probably aren't going to get along in that profession in a small town. So I think the first big problem is, can you and your spouse both find jobs in the same town?

And then the next big thing is trying to take care of the children. The hard part, I think, is while they are young [since] they need so much attention. I was very fortunate because my parents lived less than a mile away. They were delighted and wanted to babysit. It certainly solved that huge problem for me.

I would say to any woman I'm advising that those are the hard years and they don't last forever. And once the children are teenagers, there's a lot they can do themselves. And even when you get to be, say, 50, that is not the end. In fact, for a lot of women, it's when they blossom because the kids are grown or grown enough and they don't have to take care of them every minute.

Dr. Quon: *We talked a little bit about why you went into hematology. What made you go into the area of coagulation?*

Dr. Kasper: I think that was more happenstance because my chief, Dr. Aggeler, was a big clotter. He was very well known in the clotting field. I didn't realize that. I was learning a lot of clotting while I was with him. We had patients with hemophilia in his small practice, and he was trying out the new concentrates on them. These were very early concentrates being made by Cutter Labs across the [San Francisco] Bay and [at] Berkeley. The patients would come in and we would do very nice, detailed half-lives on them. The patients were delighted and they were very interested. And I was learning a lot about coagulation.

And then, a mutual acquaintance of mine and of Dr. Sam Rapaport at USC knew that Dr. Rapaport was looking for somebody for Orthopaedic Hospital because, although the hemophilia program had been at USC since 1962, by 1966, he knew that concentrates would be coming out and [that] they were specific. There was one for factor VIII and another for factor IX, so you had to be sure what type of hemophilia the patient had; and then you had to be able to measure the clotting factors. There wasn't a coagulation laboratory at this center yet, so that was my job. I came here to be the first person trained as a hematologist to [establish] a coagulation lab [1].

Dr. Quon: *Is finding a mentor really important?*

Dr. Kasper: It certainly is, and I don't think people have just one. You meet people who are good to you, or you like them. You become friendly with them.

Somebody who did me favors was Dr. Judy Pool of Stanford University. She was in and out of the lab, and I became acquainted with her. Behind the scenes, she had arranged the committee that decided on the Bethesda assay. Before that, there was a multiplicity of inhibitor tests; and she said there should be *one*. And the NIH [National Institutes of Health] appointed a committee, and she had me appointed chair. And I said, "Who me? There are people on this committee who know more about it." And she said, "Just do it!" And, you know, it really was important to just do it because then my name was attached to it, and I got some credit out of it [2,3].

It's interesting—I find that, sometimes, people who are not closely related to you will sometimes just be helpful. Somebody who was helpful at USC was a pediatric hematologist, Dr. Darlene Powers. When we would go to the American Society of Hematology meetings, I would often room with her and with a couple of other women and she used to preach at us a little bit, the younger women. She'd say, "For a promotion, what you really need is papers, papers, papers! Don't just believe what the faculty handbook tells you." She told us what we really needed to get promoted. I appreciated that because the men in my department didn't come forth with that information quite as bluntly.

So there were these women who just sort of volunteered in their way. They were not responsible for me. They just put a little lesson in my ear.

Dr. Quon: *Do you think that women have a supportive attitude, to support other women?*

Dr. Kasper: I think there are some women who are nice and supportive and others who aren't, of course, but it's interesting that they can be supportive of people who are not just immediately under them. So your mentors may be scattered. I think you can't just focus on a single individual to be your mentor. You get your mentoring where you can and find friendly people where you can, and some of them will be men.

Dr. Quon: *Is there a best time to find a mentor, or do you just sort of take advice when it sounds like good advice?*

Dr. Kasper: I think you have to. I think you never know when somebody will come along who has some decent advice to hand you, and you just have to keep your ears open.

I think it's also okay for a younger woman to ask a more senior woman, "What do you think I need to do to get ahead?" It's okay if you just have a friendly conversation. If she doesn't know anything or she doesn't want to answer, she can brush it off kindly. But if she knows something, if she has some advice to give, she can give it.

Dr. Quon: *What is it like to be considered a pioneering woman in hematology?*

Dr. Kasper: I never thought of myself that way. I have never really thought about being a woman in some of the various positions that I've been in. Either they have been held in the past by women, or it felt quite natural to be in them. I know that I have wound up in some leadership positions. Sometimes I have felt underqualified and I've thought there could be somebody better to do this job but, at the moment, there isn't anybody available. So, okay, I'll do it, and I'll do it as best I can.

I should also say that I don't think people should necessarily think that they have to be in leadership positions because it can be a two-edged sword. If a woman wants to be a big academic success, she needs time to do research and write papers. Being the chair of this and the chair of that takes time and energy.

Dr. Quon: *Indeed. Do you think you were better equipped, because you're a woman, to take care of the patients with a chronic disorder such as hemophilia and von Willebrand disease?*

Dr. Kasper: I think that women, in general, are socialized to be patient in the moral sense, to have patience with sick people and irritable people more than men are. So I think that maybe, in general, women are well suited to [care for] the chronically ill, the people who never really get well.

At this hospital, I saw the contrast between the surgeons who wanted to fix the broken limb and then be very happy that the whole case was over with, and the patients were enormously grateful—they were just overflowing with gratitude because now they were better. The patients who have chronic illnesses don't necessarily ever get to the point of being so well that [they] have that tremendous relief, which would lead them to expressing a lot of gratitude. I think that the patients are grateful, it just doesn't come up a lot.

Dr. Quon: *I know patients are very grateful. Many of them who you've taken care of as children remember you and remember you fondly... What do you think about gene therapy now, and do you think that's the wave of the future or do you think there will be other sorts of therapeutics?*

Dr. Kasper: Some of these other therapeutics are really interesting. The fun thing is to see all these new approaches coming along. There have been so many drug developments in hemophilia; even some that are not clotting factors, which are other approaches to hemostasis. Regarding gene therapy, I have hopes that it should work. I'm aware of all of the obstacles and think eventually they'll be solved. It'll be here one of these days.

Dr. Quon: *Any final words of advice for young females like myself who are interested in going into hematology, hemophilia, or other leadership positions?*

Dr. Kasper: I hope that you enjoy it; and leadership is needed, even though it's not always easy, and it doesn't always come naturally.

Dr. Quon's Perspective

Dr. Kasper has dedicated her career to understanding and advancing the care of hemophilia patients from both a clinical and scientific standpoint. She has been involved with hematology since completing her fellowship in 1962 and starting at the Orthopaedic Hemophilia Treatment Center in Los Angeles in 1966. She has contributed tremendously to the field of hemophilia from her early work in establishing a coagulation laboratory at the Orthopaedic Hemophilia Treatment Center to help diagnose patients with bleeding disorders, to chairing a committee that defined the inhibitor assay, the Bethesda Unit, which is still in use today. Dr. Kasper has been involved in clinical research in the area of coagulation therapeutics, doing pioneering work on the use of desmopressin (DDAVP) in bleeding disorders [4], and publishing extensively on new factor concentrates [5]. However, I think her biggest and most impressive contribution is her leadership role, nationally and internationally, to improve the care of all hemophilia patients. She has served as Vice President Medical and member of the Medical Advisory Board of the WFH, Vice President of the NHF, and a member of the Medical and Scientific Advisory Council (MASAC) of the NHF. The end result of her efforts has been strengthening the community and expanding access of care to those with inherited bleeding disorders. She has given tirelessly to the hemophilia community and is indeed a role model for those who are entering the field of hemophilia, and to women in particular, having accomplished so much early on in a time when gender bias made it difficult for women to advance.

Mentorship is a critical component in the development of any career. I feel that I have been incredibly fortunate to have the benefit of Dr. Kasper's mentoring. She has been an integral part of my training since I was a fellow at UCLA and even to today! Dr. Kasper is well known to be a true pioneer in the field of hemophilia, and brings the full depth of her knowledge to teaching members of the hemophilia community. She enjoys imparting her extensive knowledge to junior trainees in a patient and stepwise fashion. Dr. Kasper is incredibly generous with her time; she realizes that we are not "self-made" and that it takes time for young people to develop and learn. Dr. Kasper incorporates the history of the field into her teaching style, which provides important context for understanding the unique challenges encountered by hemophilia patients and how best to help our patients overcome these challenges. She not only provides useful advice on "things to do" based on her past experiences, but also highlights what not to do to avoid costly mistakes. When I ask for her opinion on a subject, she has honest and helpful feedback. This feedback is instructive, but is also encouraging and supportive. Dr. Kasper has had an enormous impact on my growth professionally and I only hope that I can "groom" the next generation of hemophilia treaters with the same passion and enthusiasm that she used with me.

Jeanne M. Lusher, MD

Interviewed by Meera Chitlur, MD

Jeanne M. Lusher, MD

Biography. Dr. Jeanne Lusher is internationally recognized as an expert in the development and management of factor VIII (FVIII) and factor IX (FIX) inhibitors [6–8], as well as the analysis and clinical study

 doi:10.1002/ajh.24316

of new clotting factor concentrates for the treatment of bleeding disorders. Until her retirement in 2013 from Wayne State University School of Medicine in Detroit, Michigan, Dr. Lusher served as Co-Director of the Hematology/Oncology Division, Medical Director of the Special Coagulation Laboratory at Children's Hospital of Michigan, the Marion Barnhart Hemostasis Research Endowed Chair, and a Distinguished Professor of Pediatrics. Her main areas of interest have included immune thrombocytopenia, the etiology and pathogenesis of inhibitor antibodies against FVIII [9], splenic structural physiology in hematologic/oncologic disorders in children, platelet–vessel wall interactions, and the development of new assay methods in blood coagulation.

Over the course of her career, Dr. Lusher has taken on many leadership roles within the field, including serving as Chair of the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF), Chair of NHF's Education Committee, Chairman of the International Society on Thrombosis and Haemostasis (ISTH) FVIII/FIX Subcommittee, Chairman of the ISTH Scientific and Standardization Committee, member of ISTH's Council, Co-Chair of the American Thrombosis and Hemostasis Network (ATHN) Board, and Chair of the American Board of Pediatrics Sub-Board on Hematology/Oncology. She has received numerous awards for her work, including NHF's Brinkhous Award for Outstanding Clinical Research, Humanitarian Award, Career Achievement Award, and Visionary Award for Women's Bleeding Disorders; the Hemostasis & Thrombosis Research Society (HTRS) Distinguished Career Award; the American Society of Pediatric Hematology/Oncology (ASPHO) Distinguished Career Award; and was elected as a lifetime member of Wayne State University's Academy of Scholars, which is the highest honor to be bestowed upon a member of the faculty. In addition, she has published over 270 peer-reviewed publications, nine books, and over 60 book chapters. Although Dr. Lusher has retired, she remains an active member on committees of the NHF, ATHN, and HTRS, as well as holding a position on the editorial board of *Haemophilia*.

Dr. Lusher earned her medical degree from the University of Cincinnati College of Medicine (1960) and completed postgraduate training in pediatrics at the Charity Hospital of Louisiana at New Orleans. She received fellowship training in hematology/oncology at Tulane, Children's Hospital of Michigan, and Washington University in St. Louis.

Q&A

Dr. Meera Chitlur: Dr. Lusher, please tell us what made you go into the field of medicine.

Dr. Jeanne Lusher: When I was in high school, I envisioned myself having a career in music. My mother was a piano teacher and I was immersed in music, playing in the orchestra and the band. While I was in high school, I went down to the College of Music in Cincinnati for piano lessons and to play in their orchestra. I also played a very large pipe organ at our church. It was very good for me that I spent so much time down at the College of Music because I got to see a lot of students there who played much better than I did and couldn't find a job afterwards. And so I thought that while I can really enjoy music, I don't think it's a good career choice for me.

The other things I really loved in high school were the biological sciences. While I was in high school, I volunteered at a chronic disease hospital 2 days a week. I was interacting with a lot of elderly people with chronic disease problems and I found it very challenging and satisfying, so I thought I'd like to be a geriatrician. I then went into a premed program in college and continued to spend my time off doing things that were related to medicine. I worked in a research lab with animals at Proctor & Gamble. I spent my summers in Madison, Wisconsin where I worked in labs at the Wisconsin General Hospital; I had the opportunity to learn a number of lab techniques while I was there. So, it was kind of a natural progression that I went into medicine.

Dr. Chitlur: *What made you choose hematology as a specialty?*

Dr. Lusher: While I was the chief resident in pediatrics at the Charity Hospital in New Orleans, our staff hematologist left rather suddenly to take another job elsewhere. We had lots of children who were on chemotherapy research protocols of the Southwest Oncology Group, as well as children with hematologic problems, and no one who was in charge of them. So I thought I'd better take this on and become more knowledgeable about these protocols and so forth. I started going to the meetings of the Southwest Oncology Group. . .I got very involved in hematology and oncology the year that I was chief resident.

Then our chairman of pediatrics called me in and said, "We need a full-time hematologist here, so I've arranged for you to go to work with Dr. Wolf Zuelzer in Detroit as a hematology fellow. When you finish that, you will come back here to New Orleans." It's hard to imagine, but I said, "Okay, I'll do it." I had never been to Michigan, never heard of Dr. Zuelzer, never thought of doing something like that, but I went to Detroit and it was a wonderful experience!

Suddenly, I was in this top-notch fellowship program at the Children's Hospital of Michigan with all kinds of patients, all types of hematologic problems, including acute leukemia. I just found it very exciting to be there, with all the things that I could see and learn about and become involved with. There were some very good labs, including the coagulation laboratory, which was an excellent learning experience.

Dr. Chitlur: *I know you have mentioned another story about how your interest in coagulation started. Could you please tell us about that?*

Dr. Lusher: When I was a pediatric resident at Charity Hospital, a little girl was admitted through the emergency room and came to me as a patient. She came in with profuse bleeding and, after the work-up, it turned out that she was a rare girl with hemophilia (hemophilia A). I realized in the process of doing the work-up that I knew very little about coagulation. I tried to learn as much as I could while taking care of her, and ended up writing an article about her because she was such a rare case of hemophilia in a female [10]. So that was one reason I got interested in coagulation.

Then when I came to Detroit as a fellow, after I had been here for a relatively short period of time, I found out that the Department of Physiology at the medical school here had a major focus on blood coagulation. The Chairman (Dr. Walter Seegers) was a famous coagulation expert, and many people in his department were interested in various aspects of blood coagulation. I started going to the conferences and the programs that they had, which sparked my interest in hemostasis and blood coagulation. I also got involved with a couple of the faculty in that department, one of whom (Marion Barnhart, PhD) became one of my key mentors.

While I was a fellow, I realized that even though we had children with all sorts of hematologic disorders and leukemias, we rarely had solid tumor patients because, for some reason, either the surgeon or somebody else was taking care of them and we didn't see them. So, I arranged to go to Washington University in St. Louis as a trainee of the American Cancer Society, specifically to learn more about solid tumors. However, by the time I got there, I had become so interested in coagulation that I spent a lot of time going to the adult hemostasis rounds and conferences (headed by Dr. Sol Sherry)... I ended up spending more time with them than I did with childhood solid tumors.

When I came back to Detroit as a junior faculty person, I was doing a little bit of everything in hematology and leukemia, but certainly my major interest from that point on was in coagulation.

Dr. Chitlur: *What challenges did you encounter in the field of medicine because you were a woman? Did you ever feel like you were being held back because of that? Do you think that the medical field is becoming more open to having women in it?*

Dr. Lusher: I never felt like I was being discriminated against or had any problems because I was a woman. However, when I was a medical student, there were very few women students, and when I graduated from medical school in 1960, there weren't many women who went into fields other than pediatrics or OB/GYN [obstetrics/gynecology], sometimes internal medicine. I think most medical fields are now much more open to women; you see women physicians in a whole variety of specialties. And that's a very good thing!

Dr. Chitlur: *Who was your mentor and how did he or she contribute to your life? It looks like you've had maybe more than one mentor at different stages of your career.*

Dr. Lusher: Right. When I went to Charity Hospital as a pediatric resident, Dr. Norman Woody became my mentor. I really developed my self-confidence as a physician during the period that I was at Charity Hospital. I knew that I had somebody I could call on if I needed any help, someone who was always there and gave good advice; although, he wasn't in the field of hematology, he was in metabolic diseases and their genetic influences and was doing a lot of research. I was sent off doing part of his research, getting samples from patients and their families in outlying areas. He was a great mentor when I was a resident.

Then when I came to Detroit, Dr. Wolf Zuelzer, the head of the Child Research Center and Hematology/Oncology, was an excellent mentor, as was Dr. Marion Barnhart in the Physiology department—I did a lot of research with her. I had other mentors along the way, but those were the major ones.

Dr. Chitlur: *How important do you think it is for a person to find a mentor?*

Dr. Lusher: I think it's very important, personally. I really think you can gain a great deal from a mentor. I don't mean just in terms of didactic clinical things, but in having common interests and as someone who's been there and seen whatever problems there might be or how you should approach things going ahead. The mentor can help the mentee to see a better way to do things, even outside of the hospital.

Dr. Chitlur: *I can tell from my firsthand experience how important your mentorship has been in my career. What, in your opinion, would be the most important role of the mentor in the progress of the mentee?*

Dr. Lusher: I think it's important to have a mentor who is enthusiastic about your field and engages mentees to work on clinical and laboratory research projects and presentations early on and is able to nicely critique them in a positive way. I also think it's important for the mentor to convey to the mentee how essential it is to develop real expertise in some aspect of our specialty, so that you can be immediately recognized by peers around the country as a top expert in it.

Another example is encouraging mentees to sit near the front at meetings and ask questions... I've experienced this myself—if one is sitting further back in a large audience, it's intimidating as a junior person to stand up and ask a question or make a comment. But if you're sitting right near the front and not looking at all these people behind you, it really is easier to ask questions and make comments. And people see you, too. It's also important to convey to the mentee that they should go out of their way to meet as many colleagues as possible at meetings and to establish collaborations. That is extremely helpful for people who want to go into leadership positions.

Dr. Chitlur: *As my mentor, you went out of your way to take me around and introduce me to people... I cannot tell you how important that was, especially for me to establish those connections. I think that, without that step, it can be very hard for a mentee like me to find the right people to collaborate with. Do you have any specific advice for women, or anybody for that matter, who want to rise up to a leadership position in medicine?*

Dr. Lusher: I think it's very important to develop a real expertise in some area(s) so that you can be recognized as the expert, or one of the top experts, in some aspect of your specialty. I also suggest to meet as many colleagues as possible and establish collaborations; and if you are offered a leadership position, to take it with enthusiasm and determination. Even though a leadership position may take up a great deal of one's time, I think it is well worth the effort.

Dr. Chitlur: *What would your advice be to somebody entering the field of medicine now, and your advice on choosing a subspecialty in hemostasis or hematology?*

Dr. Lusher: I think for someone choosing a specialty, it's important to do what you're really passionate about, what you really love to do. You should think, "Oh, this is going to be a fascinating, interesting area to go into." There's the practical aspect, too; you don't want to go into something where you wouldn't have the opportunity for development. But I think the main thing is to go into something that you really love.

Dr. Chitlur: *If you had to start over, would you change your career path in any way at all?*

Dr. Lusher: Not really—I can honestly say that every day that I went in to work, I never thought of it as work. When I was a resident and a fellow, I loved to have the opportunity to learn as much as possible. Then, as a faculty person, I just really loved to go in and interact with all of you and see people blossoming in their careers, and enjoyed seeing the patients and their families, and being able to do clinical research as well. I just think I had the ideal career.

Dr. Chitlur: *What would you say has been your most rewarding experience so far?*

Dr. Lusher: Having wonderful fellows and trainees, like yourself, who over the years have contributed to our field with great enthusiasm and expertise. I also have really enjoyed the interaction with the other staff that we've had. We've had excellent people in hemostasis, all dedicated and working together as a team to enhance knowledge, and to provide excellent care for our patients. I found that very, very satisfying too.

Dr. Chitlur: *I know your enthusiasm is very infectious and I've always wondered where you find your motivation, how do you find so much enthusiasm?*

Dr. Lusher: I think if you enjoy what you're doing, and it's challenging and stimulating, it's just a great experience.

Dr. Chitlur: *Do you think you feel like your work and life are balanced? Do you ever feel like you've had to make choices that were detrimental to your personal life?*

Dr. Lusher: Through most of my career, I was a workaholic-type person. But I think it's important to take time off and do other things. For some time, I've lived surrounded by a "nature preserve," with 125 wild turkeys, deer, and all kinds of beautiful birds, and hills and trees everywhere. It's a very soothing atmosphere to come home to.

Whenever I could, when going off to an international meeting, I arranged to take some extra time to just relax and enjoy, often in the Swiss Alps. I also go up to a cottage on a large, inland lake in Michigan; I did that on weekends or whenever I could. Depending on your situation, it could be difficult, but I think it is important to take time off.

Dr. Chitlur: *I know this is probably a very difficult one, but if you had to summarize your career or your work in a few words, how would you do that?*

Dr. Lusher: A wonderful lifetime experience.

Dr. Chitlur's Perspective

Dr. Jeanne Lusher is perhaps one of the most distinguished figures in the hemophilia/bleeding disorders community. She is the embodiment of selfless service, and her mission is to improve the lives of patients with bleeding disorders. Her life is a beacon to others and, in itself, drives everyone around her to do better. I was fortunate to be one of those mentees whose life has been touched by Dr. Lusher. I remember as a fellow in training, Dr. Lusher would go out of her way to introduce me to her colleagues and friends who are experts in the field, from all over the world, and these connections have been the building blocks of my career. Further, she would gently push me

 doi:10.1002/ajh.24316

out of my comfort zone by making me sign up to give presentations and write papers. While at the time these seemed like arduous tasks, I am now grateful for the opportunities these experiences have opened up for me. Dr. Lusher displays a true sense of humility that I will remember and hope to take with me through my life. She will, however, not let a bad job pass. In her gentle but stern manner, she steers her mentees to a path that will ensure success. Dr. Lusher is always there to help me face my fears with a guiding hand. She has been the motivating force behind my work, constantly encouraging and helping me understand and believe in myself. Dr. Lusher's mentorship has given me confidence that I never knew I possessed, helped me to achieve more than I had ever thought I was capable of, and has me striving to constantly better myself. She has taught me to love life and enabled me to love my work. Words cannot express my gratitude for Dr. Lusher's mentorship, and I hope to repay this by being a mentor to someone else as she has been to me.

Roshni Kulkarni, MD

Interviewed by Madhvi Rajpurkar, MD

Roshni Kulkarni, MD

Biography. Dr. Roshni Kulkarni is Professor Emeritus (on recall) of Pediatrics and Human Development at the College of Human Medicine at Michigan State University (MSU; East Lansing, MI), and currently serves as the Director of the Centers for Bleeding and Clotting Disorders at MSU. She is a former Director of Pediatric and Adolescent Hematology/Oncology, as well as Director and Distinguished Hematology Consultant at the Division of Blood Disorders, Centers for Disease Control and Prevention (CDC; Atlanta, GA). Dr. Kulkarni's work includes raising global awareness regarding women/adolescents and babies with bleeding disorders [11,12], and her passion for her work led her to co-found the Foundation for Women & Girls with Blood Disorders.

Dr. Kulkarni is a member of many professional organizations, including the American Society of Pediatric Hematology/Oncology, the American Society of Hematology (ASH), the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF), the Hemostasis & Thrombosis Research Society (HTRS), Word Federation of Hemophilia (WFH), Global Sickle Cell Disease Network, and the Michigan Hemoglobinopathy Advisory Committee. Dr. Kulkarni has received numerous awards for her work, including the NHF's Award of Excellence as the Physician of the Year, and the US Food and Drug Administration and CDC award for distinguished service.

Dr. Kulkarni received her medical degree from Osmania Medical College Indian Institute of Medical Sciences (Hyderabad, India; 1968). She completed a residency in pediatrics and a fellowship in pediatric hematology/oncology at Children's Hospital of Michigan, Wayne State University School of Medicine (Detroit, MI).

Q&A

Dr. Madhvi Rajpurkar: What inspired you to go into medicine? Was there a single incident or a patient, or did you always want to go into medicine from childhood?

Dr. Roshni Kulkarni: There were a number of events and circumstances that inspired me to consider a career in medicine. I was always interested in botany and zoology. I lost two of my best friends in school to cancer; my grandfather, a physician in the British army, to poison gas; and my aunt to post-partum hemorrhage. My interest in hematology was piqued during my residency, as these were the children who had prolonged hospitalizations and gave me an opportunity to get to know them and their families better. I specifically liked the interaction of patient care and laboratory evaluation. The blood intrigued me. Prior to that, I was rather unfocused regarding my career decision since I loved every specialty I rotated through.

Dr. Rajpurkar: How did you choose hematology/oncology, and then specifically hematology? What drove you to choose hematology?

Dr. Kulkarni: It was during my pediatric residency that I spent long hours with hospitalized children (and families) with cancer and blood disorders. I came to know them personally, and shared their joy and grief. For a number of years, I did both oncology and hematology and I liked them both. One of the things I liked about hematology was the lack of preset protocols. One had to think through the problem, order appropriate tests, and interpret them, applying age-dependent values. Gradually, I began doing more hematology as I became involved with the NHF's Medical and Scientific Advisory Council [13], thanks to my mentor, Dr. Jeanne Lusher.

I recall infusing hemophilic patients with joint bleeds who, despite severe pain, patiently allowed me to find a venous access and struggle with infusing thick cryoprecipitate that would splatter all over me. The strength and resilience of these patients always inspired me. I watched my mentor, Dr. Lusher, treat them with so much kindness and grace; I wanted to be like her. It was on her and Dr. Bruce Evatt's advice that I did a sabbatical at the CDC that further cemented and enhanced my career [14]. Over the years, I have witnessed the progress in hemophilia care and am delighted that it is possible to dream of a cure. But, let's not forget those who have suffered in silence over the years—women, girls, babies, and those with poor access to care; no matter where they are in the world, they also need to benefit from this progress.

Dr. Rajpurkar: Do you think being a woman puts you at a specific advantage in taking care of some of these bleeding or clotting issues, and does it also come with its own set of challenges?

Dr. Kulkarni: Being a woman definitely puts one at an advantage when caring for women and girls with blood disorders since many of us have experienced menstrual and pregnancy issues [15]. Furthermore, many girls express that they want to be seen by female physicians. Women are natural team players and consensus builders, and future incorporation of other specialties, such as OB/GYN, into the team [providing care to women and girls] would be helpful. However, there are many male physicians who provide excellent, compassionate care and are interested in women's issues.

A challenge one sometimes faces is being recognized by patients and families as a physician. Oftentimes I am asked "So, when is the doctor going to come?" The concept that a woman can be a physician is gaining acceptance. Another challenge I am trying to address is care delivery to remote patients through telemedicine [16], which would ensure access to specialty care for all. With the current—and future—technology, it may be possible to expand this internationally.

Dr. Rajpurkar: There is a book by Sheryl Sandberg called Lean In, *and it's a fantastic book about women in the workforce. One of the things that she discusses is that if women want to "sit at the table"*

and be in leadership positions, many times they are deemed as aggressive. Have you ever faced such situations, where you felt that you should be "at the table" and that you were capable of making decisions, but perhaps were sidelined because of your gender?

Dr. Kulkarni: Oh, yes, definitely. I think most of us women are rather polite and appear timid. It's just our demeanor. I think, as you progress in your career, you gain self-confidence, become more assertive, and voice your opinion more often. In the past, women in leadership positions almost had to behave like men—aggressive and outspoken so as to be heard. Even though we still have some ways to go, in the current environment, more women are being accepted as equals. However, one can be kind and nice and persuasive, and yet not belligerent and mean and spread fear. A classic example is Dr. Jeanne Lusher. I think that women have an innate strength and can be very good leaders because we work by consensus development, and do not impose our views on others.

As for challenges, we have come a long way. Years ago, when I was in training and in the early part of my career, I faced micro-inequities. Job interviews were hard for me because I felt that I was denied a fair chance. It was very hurtful. Being a woman, a non-white, and from a developing country automatically meant that I did not know anything and could not speak English. Some made fun of my accent. In meetings, I felt ignored and that my opinions did not matter. I felt inconsequential. However, I took this as a challenge to prove to myself and others that I was perfectly capable of being a good academic physician. I knew that knowledge and hard work were great equalizers. Fortunately, over the years, I've seen many positive changes. It is wonderful to see that there are a lot more women in medical school—more than 50%. And a lot of women are in leadership roles, hopefully helping others to climb the ladder. It used to be an all-boys network, but now young women are coming up—they're smart, they're bright, they stand up for issues, and it's like, "Wow, yeah, we did it!"

Dr. Rajpurkar: *How important do you think it is to have a mentor, and specifically for a woman physician who is intending to pursue an academic career?*

Dr. Kulkarni: It is crucial to have more than one mentor to help facilitate your career. What the mentor does is basically help you focus on things, discusses opportunities, provides career counseling, and helps you realign your priorities. The mentor does not do your work for you, but instead says, "Hey, look, you might want to consider this, as it may be something important down the line." In fact, it was one of my mentors who emphasized to me the importance of taking a sabbatical, a decision that totally changed my career path. Another mentor encouraged me to consider job interviews to help gain insight about my current worth, as well as get an idea of how the world was outside of my institution.

Dr. Rajpurkar: *How important is it to be either focused on one area or should one be open to explore different areas?*

Dr. Kulkarni: During the early part of your career, it is perfectly okay to wander and explore options, but sooner or later you have to wind down your curiosity and say, "Alright, how does this relate to my area of interest? What am I most interested in?" However, I am aware of some of my friends who have totally changed their focus from their initial one and are perfectly happy.

Dr. Rajpurkar: *I am personally finding that there is a certain set of unique challenges for midcareer women especially. When you're a junior, you can have a mentor. When you're a senior, you can have a mentee and you can be the mentor. But for midcareer women, I find that many of us, especially in the hemostasis/thrombosis field, we sort of get lost. There are not many funding opportunities, and you can see a lot of people have been transitioning either back to oncology or moving away from academics into the pharmaceutical industry. What do you think midcareer women should do? What should they focus on? How should they go to the next stage?*

Dr. Kulkarni: A major challenge that women face is balancing career and family. Oftentimes, we bypass opportunities that may help our careers. Having a supportive family is crucial to success. During one's early career, the focus is on clinical work, publications, and grants. The mentor can help guide how to navigate the system and discuss opportunities.

A mentor can also help a midcareer person to learn how to be an administrator, appropriate committees to participate in, organize meetings, negotiate with the department, participate in training opportunities, learn about requirements for promotion, use strategies for conflict resolution, and mentor others. The career focus now shifts to a regional, national, and international involvement in one's area of expertise, and also involves working with advocacy groups and health departments, as well as exploring opportunities such as sabbaticals or specialized training for career development (such as leadership training, speaker training opportunities, etc). Delegating work and networking helps at this stage.

In the later stages of one's career, the mentor can help with discussing retirement, succession plans, and volunteer opportunities.

Dr. Rajpurkar: *What do you like to do outside of work, and how do you achieve a work/life balance*?

Dr. Kulkarni: Good question. Well, I love visiting my son in Chicago and my family in Utah, and I love to travel with my husband on vacation and experience different cultures and food. Besides travel, I like to read books, cook, and of course walk with friends and swim. There was a period when I did pottery, and maybe I'll go back to it. When I work, I put my heart and soul into it and try to "relax" when not working.

Lately, I have worked with the WFH at sites around the world. I met women I consider my heroines while addressing women's issues in Japan. Along with Dr. Bruce Evatt (one of my mentors), I have been working with the WFH to help the Ministry of Health in Bogota, Columbia address hemophilia care and treatment centers. During our two visits to Columbia, we worked from dawn to dusk and had no time to see things outside of our work, but could sense that we were surrounded by beauty, both people and places. This winter, my husband and I and Dr. Evatt and his wife are planning a vacation to tour Columbia to fully absorb the beauty of the country. Through these experiences, I have found that my work gives me the opportunity to visit wonderful places and meet people, but outside of my work I am able to explore them further.

Dr. Rajpurkar: *Any other advice for women in medicine, specifically in the area of hemostasis/thrombosis?*

Dr. Kulkarni: My advice to women in medicine is to continue to seriously pursue their academic career goals. We have come a long way and continue to progress. The field of thrombosis and hemostasis continues to remain enticing and is expanding in both basic and clinical sciences, with new innovations and delivery systems. Advances in information technology may make care delivery accessible to all one day. Women in medicine should be role models for future generations and spokeswomen nationally and internationally for issues concerning women, minorities, and disenfranchised people.

Dr. Rajpurkar's Perspective

A good mentor, apart from teaching the subject matter, often teaches how to conduct oneself in the field of medicine; and frequently, more than one mentor influences a person's career. I have been fortunate enough to be influenced by many strong pioneering women in medicine, one of whom is Dr. Kulkarni. Although we are not located at the same center, from very early on, Dr. Kulkarni took a keen interest in helping to develop and shape my career. Dr. Kulkarni has been more than willing to read my grants, give me critical feedback, and suggest various avenues of funding that she felt would be appropriate for me. She has been available whenever I needed

 doi:10.1002/ajh.24316

advice regarding scientific matters or just as a sounding board on some rough days. Her passion for teaching and learning has often fueled my development as a teacher. With her unfailing and infectious enthusiasm, she has often motivated me to do more and be more! I have learned the art of lateral thinking from her, and I feel extremely privileged to be mentored by her.

Dr. Kulkarni has taken the term "to go where no man (or woman in her case!) has gone before" to a new level. She truly believes that all should have equal access to health care regardless of their gender (hence her work with females with bleeding and clotting disorders) or location (with her application of, and work on, telemedicine). Dr. Kulkarni is known in the hemostasis/thrombosis community as a strong clinician, a superb mentor, an excellent researcher, and, above all, a fierce advocate for her patients. She completely expounds the philosophy of collaboration and teaching. From making animated videos on the coagulation cascade that can be easily understood by medical students, to co-founding the Foundation for Women & Girls with Blood Disorders, she has done it all. A recipient of numerous awards, Dr. Kulkarni serves as a role model for many (including me) in the field of hemostasis/thrombosis!

Marilyn Manco-Johnson, MD

Interviewed by Mindy Simpson, MD

Marilyn Manco-Johnson, MD

Biography. Dr. Marilyn Manco-Johnson is a Professor in the Department of Pediatrics-Hematology/Oncology at the University of Colorado School of Medicine in Aurora, CO. She is affiliated with the Children's Hospital Colorado and is the Director of the Hemophilia and Thrombosis Center of the University of Colorado. Dr. Manco-Johnson's clinical and research interests include diagnostic global assays for bleeding and clotting disorders [17], long-term joint outcomes in hemophilia [18,19], pediatric thrombotic disorders [20] and preventative treatments, neonatal hematology, and rare bleeding and clotting disorders. Dr. Manco-Johnson's interest in new factor concentrates is exemplified by her involvement in multiple clinical trials.

Dr. Manco-Johnson has contributed significantly to the treatment of children with severe hemophilia, particularly in the use of prophylaxis with clotting factor concentrates. Dr. Manco-Johnson has co-authored approximately 250 peer-reviewed publications and was named Researcher of the Year by the National Hemophilia Foundation (NHF) in 2007. Moreover, she is a member of several professional groups, including the Society for Pediatric Research, the International Society on Thrombosis and Haemostasis (ISTH), the American Society of Hematology (ASH), the Hemostasis & Thrombosis Research Society (HTRS), and the American Society of Pediatric Hematology/Oncology.

Dr. Manco-Johnson earned her MD degree from the Jefferson Medical College of Thomas Jefferson University (1974). She subsequently completed an internship (1975), residency in pediatrics (1977), and fellowship in pediatric hematology/oncology (1981), all at the University of Colorado.

Q&A

Dr. Mindy Simpson: Let's start with: Why did you go into medicine?

Dr. Marilyn Manco-Johnson: I knew when I was 6 years old that I wanted to be a pediatrician. I probably had more experiences with sick children than most people would have today, and I think that is a testimony to how far pediatrics has come. I lived on the same street as one of my first cousins. He was about my age and died of cyanotic congenital heart disease. As a very small child, I was aware of his parents' agony with his decline. On the other side of my house was a little boy who was my age and developed acute lymphocytic leukemia; unfortunately, he did not have a very successful course of treatment and he passed away. There was another boy in the neighborhood who was about my age and who had hemophilia. He died of an intracranial hemorrhage in about third grade because a teacher pushed his head into the blackboard when he didn't do his math correctly. So, I had lots of conversations in the kitchen with my mother and aunt and grandmother about children on the block who were sick. I think my response to all this was thinking that maybe I could do something to help.

At about that time and a little later, my dad worked at Hahnemann Medical School in the accounting office on nights and weekends, and on Saturdays he would bring me with him. I had a 4-week rotation; I used to spend 1 week delivering mail to patients, 1 helping in the laundry, 1 helping in pediatrics to bathe and feed babies, and the fourth week I would spend with a hematopathologist who was a friend of my dad's. He was a lovely person and would show me slides of blood and cancers, which got me very intrigued. My dad became a hospital administrator, and so I think that helped channel all of my energies into thinking that I might participate in that way.

Dr. Simpson: That leads into how you chose hematology, since you spent so much time with a hematopathologist. Was there any other reason that you ended up choosing hematology?

Dr. Manco-Johnson: Before college, I actually thought of being a civil rights lawyer or going into medicine. When I went to medical school, I tried to be very open-minded because pediatrics was considered the domain of women; I looked at other fields because I did not want to get pigeon-holed, but I really was attracted to pediatrics. And then when I went into pediatrics, I was very attracted to oncology. When I was in my first couple of months of internship, I got a call from Dr. Bill Hathaway, a hematologist, and he said, "I read your internship application. You said you were interested in leukemia and I want to tell you that hemophilia is like leukemia but just a little bit different. Why don't you come to our coagulation conferences and get to know people in hemophilia?" And so he paired me to work with a fellow who was a young woman doing a project on DIC [disseminated intravascular coagulation] in newborn babies. Dr. Dorothy Bernard was an incredibly lovely person and very enthusiastic and hardworking, and so I got into newborn clotting from that point on.

Dr. Simpson: So, the specific moment in focusing on hemostasis/thrombosis was Dr. Hathaway calling you and getting you involved?

Dr. Manco-Johnson: Exactly. He was a great recruiter. I had my first baby, Gemma, the July after I finished my residency, and so sometime shortly after learning that I was pregnant, I decided I would take that year off. I remember going to Dr. Hathaway and saying that I would like to defer the fellowship for a year. He had seven children, so he was very supportive of that.

Dr. Simpson: That is great. Do you think that being a woman in this field has either helped or hindered you in treating chronic bleeding disorders?

Dr. Manco-Johnson: I think that being a woman has helped me enormously in terms of having the temperament for chronic care, for

supporting parents, for lifelong genetic diseases where you're helping to carry someone through all of the life stages as a parent. In that way, I think that many of the best coagulation doctors have been women.

Dr. Simpson: *Were there specific challenges along your path through medicine that you think were made apparent because you are a woman? Do you feel as though you have been held back? Or were there benefits?*

Dr. Manco-Johnson: When I went to medical school, I was in a 5-year program in which we started right after high school and went to college for a year and then on to medical school. After the first year, only five in the whole group of 40 students were women. Starting medical school, I had a very hard time with classmates who were older and were all men; in my lab group of 50, I was the only woman. On my first day of school, some of them were very angry because they had friends who were in their mid- to late-20s with master's degrees and who they thought were highly qualified. From my perspective now, I can understand how they felt; at the time, it was harsh. Looking back now, though, what I perceived as a lot of persecution was probably much more like friendly teasing.

My dad was born in America to immigrant parents and really valued and pushed education, so I never perceived that as a woman it would be difficult to get an education. I do understand that a lot of my peers felt that an education in something like nursing, social work, or teaching was more appropriate for women than going into medicine. I never contemplated that at all.

I think that what was probably harder back then was finding mentors. I started medical school as a very young woman (at 19, and started my residency at almost 23), and I was shy to seek out mentors and support since most of those individuals were men. Dr. Hathaway was a very inviting and very encouraging person and, I think, I could have gotten a little better career counseling if I were a little more aggressive in pursuing people. But, I also had some wonderful mentors. Now, I think that women have more individuals, women and men, who are welcoming and supportive of them in medicine, than they did before.

Dr. Simpson: *How do you think that changes in medicine over the past several decades have affected women currently practicing? You had a lot of support along the way, which is fantastic, but I'm not sure that everyone had the same.*

Dr. Manco-Johnson: That is absolutely true. I think that for women today, things are much more open. I would hope that they are much easier. Life is never easy, but I came into medicine at the cusp of the "old boys' club," where men could get away with doing and saying some things that were considered very bad behavior. Looking back at what I was confronted with as a trainee and then as a young faculty person, there has been an incredible, cataclysmic change in the cultural rules, in a positive way.

One experience I had with a person, who I dearly love now, was when I was asked to be a chief resident. I had decided to take that year off as a mom and then come back for fellowship, so I declined the position. When I told him what I was doing, he just exploded with how he felt—that all the time he'd ever spent teaching me or mentoring me was wasted because I was just going to sit at home and raise children. It was a very disappointing and upsetting interaction. But, later on when I came back as a fellow and went to talk to him, he didn't even remember that encounter.

I think there was a lot of sense that if you were not working very long hours, you were depriving someone else of the position as a physician. That has really changed, and now women have helped men. In hem/onc [hematology/oncology] now, the majority of practitioners are women and the majority of these [women] are working less than full time and are job sharing. This practice has even spread to men, where more and more men are working less than full time. I think that is a wonderful place for culture to be, where women worked for the rights and then shared them with men.

Dr. Simpson: *Alright, so any advice on choosing specialties? How do you get people like me into hemostasis and thrombosis?*

Dr. Manco-Johnson: I think what I love about hemostasis and thrombosis is that is has something for everybody. It has laboratory questions and intrigue, it has acute care medicine, it has chronic care follow-up. It has very precise things for people who like to standardize laboratories, and it has the very bold side of some of the newer clinical trials, so I think it is an area that doesn't box you into a very narrow career.

Dr. Simpson: *Is finding a mentor important for women interested in academics? How do you think the mentor/mentee relationship helps?*

Dr. Manco-Johnson: For me, a mentor relationship was the central thing. Despite all of the things that led me into pediatric hematology, it was really Dr. Bill Hathaway who cemented the deal. He had me hooked on medicine, and I think it was more than just the scientific content; it was his personality and approach to people.

Dr. Simpson: *I think one of my favorite parts of training with you was seeing the generations of mentor/mentee relationships that persisted. I left training recognizing that when you are done, you are never really done; you still need your mentors throughout your career. It was great to be able to see how that relationship can continue throughout somebody's career. . . So, onto the next question: How have you managed to achieve a work/life balance?*

Dr. Manco-Johnson: I think it's different for every person. For me, my husband and I had five children, which is probably not what you would plan if you were going to have a busy academic career. My way of dealing with it was to integrate the children into my work. I had one son who would come on rounds with me on weekends and would play his video games with children on the hem/onc ward who were in bed. And all of the kids came to hemophilia summer camp. A couple of years ago, there was a dinner on the occasion of my having been there for 30 years, and one of my daughters, speaking for the group of them, talked about how hematology and hemophilia was the sixth child in the family; it was just known and accepted that on Thanksgiving, Christmas, and Easter, festivities wouldn't begin until I went to the hospital and saw everyone who was sick and then came home. And also that they didn't feel any resentment about that; they grew up understanding that a big part of life was extending yourself to help others. I think to the extent that you're enthusiastic on all sides, children will see it as a relative positive. Not everyone chooses to integrate their family into their work, but that worked out well for me.

Dr. Simpson: *Is there anything that sticks out in your career that you are most proud of, that you feel is important and part of your legacy?*

Dr. Manco-Johnson: For me, it was taking disorders that were very difficult to live with and seeing how much we can understand them and how good a life we could construct. We've gotten to the point where kids with hemophilia are growing up nearly completely well on prophylaxis. We also have adults doing well, such as a woman who graduated summa cum laude from college with severe protein C deficiency, and a young man with a similar condition who has gotten a master's degree and is very independent—seeing these individuals being contributing adults in our society with a very high quality of life, and knowing that we were able to have a part in helping create that for them. So, I would say that it is partnering with individuals afflicted with very severe genetic disorders and seeing how life can be maximized, and the other half of that is the relationships we have with our colleagues as we are helping patients. So, I think I would like the legacy of having been a supportive person to younger people coming along in the field, and also a supportive person to families who are struggling with difficult coagulation problems.

Dr. Simpson: *Any final thoughts on being chosen as a pioneering woman?*

Dr. Manco-Johnson: Well, it is a surprise. I have always felt that I have been privileged to be able to follow in the steps of giants in medicine ahead of me. I would hope that my colleagues and patients felt that I made it fun and rewarding to collaborate in different clinical trials; that I tried to help organize, to work together, and move the field forward a little bit. As I am toward the end of my career, I feel most proud of how many bright, creative, and talented

 doi:10.1002/ajh.24316

people there are like Mindy in the field. I feel like I can leave it because it is so well championed and so well taken care of now.

Dr. Simpson's Perspective

I am humbled and honored to have Dr. Marilyn Manco-Johnson as a personal friend and career mentor. Her approachable and infectious personality made learning a welcoming environment during my fellowship and beyond. She is a natural teacher where her breadth of knowledge of medicine, not only hematology, is evident in her ability to discuss topics in fine detail at any moment. Her passion for patient care and furthering knowledge through research while supporting those colleagues around her have led to an amazing career worthy of this honor as a pioneer for women in hematology.

As a woman whose career clearly spanned the time of the "old boys' club," Marilyn has been able to break down such gender barriers and show how dedication and perseverance can open opportunities for leadership and greatness. She has been an inspiration for many of us to pursue careers in hematology and dream for success. Her many contributions to the field of coagulation, regardless of any inequalities, are admirable and include clinical experience/patient care, clinical and laboratory research efforts, numerous publications, and educating future generations of hematologists. I believe that the Joint Outcome Study [18] was a defining moment for her career, as it led the charge for changing treatment practices toward prophylaxis for hemophilia and prevention of joint disease. Patients for generations to come will likely be impacted by these findings and the shift in the standard of care treatment strategy.

I am grateful to have experienced true mentorship from Marilyn and accept that learning and mentoring are lifelong processes. I believe that her legacy lies with the patients and families she helped along the way, as well as those of us who have learned from her how to care for such patients and continue to question what we can do better.

Margaret V. Ragni, MD, MPH

Interviewed by Sarah O'Brien, MD

Margaret V. Ragni, MD, MPH

Biography. Dr. Margaret Ragni is a Professor of Medicine in the Department of Medicine, Division of Hematology/Oncology, at the University of Pittsburgh. She is also the Director of the Hemophilia Center of Western Pennsylvania. Dr. Ragni's clinical and research interests include inhibitor formation in hemophilia, human immunodeficiency virus (HIV)/hepatitis C virus co-infection in hemophilia [21–23], bleeding disorders in women, and von Willebrand disease in women and children. She is actively involved in clinical translational research and is supported by several federal National Institutes of Health (NIH) research grants. Moreover, Dr. Ragni serves as a mentor to students, residents, and fellows in her department.

Dr. Ragni is the recipient of multiple awards and she has co-authored over 200 peer-reviewed publications. Dr. Ragni serves on multiple committees, including the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF), the Scientific Subcommittee on Hemostasis of the American Society of Hematology (ASH), and the Advisory Board of the Foundation for Women & Girls with Blood Disorders. She was a contributing editor to *The Hematologist* and is on the editorial boards of *Haemophilia* and the *Journal of Thrombosis and Haemostasis*. Furthermore, Dr. Ragni was nominated and now serves on the US Food and Drug Administration Blood Products Advisory Committee.

Dr. Ragni earned her MD degree from the University of Pittsburgh School of Medicine (1975); she then went on to complete her medical internship/residency (1978) and fellowship in hematology (1981) at the University of Pittsburgh Medical Center. She subsequently completed a fellowship in coagulation hematology at the Central Blood Bank in Pittsburgh (1982). More recently, Dr. Ragni earned her MPH degree from the University of Pittsburgh Graduate School of Public Health (1993).

Q&A

Dr. Sarah O'Brien: *I thought I would start at the beginning and ask: When did you become interested in pursuing a career in medicine?*

Dr. Margaret Ragni: I thought I was going to be a musician, actually. But in school, I really loved science and math. And, in my family, a number of people had clotting disorders and died when they were young. That had a great impact on me. I was always interested in the *why*. What is wrong and what can we do to fix it? Hemostasis and thrombosis really just happened. I didn't go out and say, "Because somebody had a clotting disorder in my family, I'm going to pursue a career in this area." I was very open. I was ready to do almost anything, as long as it included the ability to combine a career in taking care of patients and pursuing clinical research. I was actually more interested in clinical research at first—all those unanswered questions—before I had it figured out that I wanted to become a physician. Research was the driving force behind everything I pursued.

Dr. O'Brien: *When you were going through your school and training, were there women doing clinical research that inspired you?*

Dr. Ragni: Back when I started, many things were different. Specifically, clinical research was not thought to be a true science. It was hard to find the training in clinical research that is so wonderful now for residents and fellows in training. I remember writing a paper when I was a resident and I kept thinking, "When I get to fellowship, I'll have the training I need to pursue clinical research," but that was not the case! Instead, as a new Assistant Professor of Medicine, I walked across the street and took courses (in between seeing patients) at the Graduate School of Public Health, sitting in the front row wearing a beeper—whatever it took to learn how to combine a career in research and clinical research.

In my medical school class, it was the first time 20% of students were women, and we all had psychiatric interviews to be sure that we weren't off our rockers for going into medicine. But I thought, "no more so than men! How ridiculous!"

Were there any women doing research? Not really. I did not see a role model as a woman or a man, that was not the issue. The issue was the chance to do science alongside clinical care. When I was in medical school, a really great mentor not only invited me to work on research in kidney disease with him, but he also took me on rounds to see patients. When I realized you could do both together, I realized my passion and pursued it.

A lot of people discouraged combining a career in my younger years. I can still remember saying to myself, "The only way I'm going to get research done"—and that was my highest priority—"was do it at the same time I see patients in clinic," which I did. I just did it

and ignored the negative comments. I just don't believe in the word "no." I've found that if you pursue what you truly believe is right and you do it for the right reasons, things will work out for the best.

I can still remember when I was in organic chemistry class in college—I really loved it. And my professor, who was quite outstanding, said, "Women have too much on their minds to do medicine." And it was truly that day that I decided, well by golly, I'm going to do it anyhow!

Dr. O'Brien: *When I think about you, the word energy is the first word that comes to my mind. I think about the first time I saw you giving a lecture to my medical school class on the coagulation cascade. I was so struck by your energy and passion about your lecture. When people ask me what first got me interested in this field, I think about that lecture. And knowing you 20 years later, you are just as energetic and enthusiastic. How do you maintain that?*

Dr. Ragni: I think that all along, no matter what it is you do, it just takes courage and more effort than you ever imagine. But if your goal is to do the best you can, the rest of it (all the work and effort) comes along and gets done. I have this theory that if you want to interest others in your work and goals, you *yourself* have to be interested in it!

Dr. O'Brien: *I was struck in thinking about this project, about how easy it was to think of 10 women from your generation who have made a difference in hemophilia care. It's interesting because I can't draw that same parallel to other diseases as easily and because hemophilia is primarily a disease of men. How do you think this female leadership in the field of hemophilia came about?*

Dr. Ragni: You're asking a very interesting question. A lot of this disease really focuses on mom and son. We're often talking to moms and there's a lot of empathy. There's nothing I wouldn't do for my own kids and, in some ways, when I walk into that clinic, there's nothing I wouldn't do to help those kids. It's a kind of approach typical of women. I see hemophilia as a spectrum from birth to old age, so it's caring, empathizing, understanding, talking, listening, and making contact that is needed to make a difference for people and contribute to their lives. It's an opportunity to do what you really went into medicine to do.

Dr. O'Brien: *Looking at your career, what are the two or three moments that stand out to you as some of your proudest moments?*

Dr. Ragni: One of the proudest things is when I see my medical students or residents or fellows presenting an oral paper at the ASH meeting. It means we did something right—that, against all odds, we succeeded! It's interesting because when you ask that question, what you're really asking, I think, gets down to your own self-doubt. I often doubt that I know enough or that I'm good enough to take on the next thing on my plate. One of the most challenging things for me is to imagine I will really find the right answer, determine the best way to do something, finish writing that grant. I think that's true of many of us—we're smart women, but we have a lot of self-doubt—we doubt our own abilities, even after we have accomplished all types of challenging tasks, and afterward, I ask myself, "Now why did you doubt yourself?" Maybe that's a female thing. I don't know. It's also related to the field we went into, which is very challenging scientifically and emotionally. You are committed, spend a lot of time on your work, and give it your best but still second guess whether you are good enough for the task.

The proudest thing is, truthfully, just the opportunity to do what we do. To be able to serve patients and learn and conduct research with all the resources and clinical and research staff we have. It's amazing because it makes work really fun, like one of the most wonderful things in our lives.

Dr. O'Brien: *You've mentored so many people, both male and female. Do you find that it's different to mentor females? Is there advice that you think is important to pass on to your junior female physicians?*

Dr. Ragni: I say the same thing to both of them. I tell women and men, "Don't believe in the word 'no'—pursue your dream—go for it." I tell them both that you need to find a good mentor; you need to realize your passion, and do what you want to do. In terms of women, not uncommonly, we'll spend a minute or two talking about how hard it is to get ahead. I don't use a term like "glass ceiling," but it's just that there's this mentality out there that's going to take a long time to change... because women are the more nurturing, assisting, helping... they bring people together and make things happen.

It's how families work. We serve the same kinds of roles. It's that same thing that makes you a good mother that probably makes you a good physician. I do think there's something about how we approach life, maybe based on what we've experienced in our lives that just makes us look at things in a somewhat different way, a nurturing way. I don't think it is that we are any less well equipped to do research, or serve as leaders or administrators or scientists—we can do all these things—but we just do it differently: promoting, mentoring, empowering, validating, and helping those around us feel more comfortable and enabling them to pursue their goals.

Dr. O'Brien's Perspective

I still vividly remember the first time I met Maggie. It was 1998 and I was a second-year medical student at the University of Pittsburgh. We were sitting in the lecture auditorium, where I had spent much of the last 18 months of my life listening to lecturer after lecturer, many of whom I will admit I no longer remember.

When Maggie stood at the front of the room and reviewed the coagulation cascade step by step, I had no idea that I would be a hematologist someday, much less one who specializes in hemostasis and thrombosis. However, Maggie's enthusiasm and passion as she taught us was truly memorable. Memorizing pathways was one of my least favorite parts of medical training, but Maggie just seemed so excited about this particular one! I had to sit up and pay attention.

As a renowned expert who could have rested on her laurels long ago, Maggie has done anything but. Her enthusiasm and passion continues today, whether it is in patient care, mentoring trainees and junior faculty, or gathering colleagues together to tackle a new problem. Maggie's diversity of interests and expertise is also striking, and she seems to always be at the forefront of the field, as one of the earliest investigators of liver disease in hemophilia [24] and then bleeding disorders in women [25]. Almost 20 years later, Maggie still makes me, and the hemostasis/thrombosis community, sit up and pay attention.

Joan Cox Gill, MD

Interviewed by Veronica Flood, MD

Joan Cox Gill, MD

 doi:10.1002/ajh.24316

Biography. Dr. Joan Gill is Professor of Pediatrics, Medicine and Population Epidemiology at the Medical College of Wisconsin (Milwaukee, WI), and she is a Senior Investigator at the BloodCenter of Wisconsin and has served as the Director of the Comprehensive Center for Bleeding Disorders and Program Director of the hemophilia department at the Children's Hospital of Wisconsin for over 30 years. In addition to her clinical and academic positions, Dr. Gill continues to conduct pioneering research in hematology, which has led to great discoveries for patients with congenital heart disease [26], thrombotic disease, hemophilia, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) [27], and von Willebrand disease [28–30].

Dr. Gill has served as Treasurer of the Hemostasis & Thrombosis Research Society (HTRS) for over 25 years. In 2013, the HTRS presented her with an award for outstanding service that has since been named in her honor. Dr. Gill has been an invited guest speaker at national and international conferences, presenting on the treatment of bleeding in von Willebrand disease. In addition, she has received the honor of being named one of the Best Doctors in America continually since 1996.

Dr. Gill received her medical degree from the Medical College of Wisconsin in 1976, where she also completed a residency in pediatrics (1979) and a fellowship in pediatric hematology/oncology (1981). Dr. Gill's unwavering dedication to her patients and to furthering the clinical understanding of bleeding disorders is what makes her such a well-respected hematologist and researcher.

Q&A

Dr. Veronica Flood: Why did you go into medicine? What drew you to medicine?

Dr. Joan Gill: I really loved science and wanted to do something with my life in the science field because I loved asking and seeking answers to questions regarding biologic functions. I considered other science careers besides medicine: I was originally planning to become a laboratory technologist, and I actually got a summer job working as a technologist in a local hospital laboratory, but I found out through that experience that, although it was very interesting at first, I became quite frustrated doing the same thing over and over each day.

So, when I went to college, I was a biology major and that left me wide open for a lot of different possibilities. It was there that some of my mentors first suggested that I think about medicine. I hadn't seriously considered that myself at the time because there were very few women in the field, and it wasn't something that women were encouraged to pursue. In fact, when I started medical school, I was one of only 12 women in my class!

Dr. Flood: So you had your own mentors that encouraged you to start this career?

Dr. Gill: That's correct. I think mentors are very important, probably throughout life and not just in the midst of developing a career. For example, I think my first mentor was my mother. She was a mom of six children—I was the oldest—and she was a teacher. And although I grew up in a small town where people rarely considered going to college, in our family, college came after high school. We were raised in an environment, a loving environment that encouraged us to love learning and pursue education with our lives.

Dr. Flood: You said you were one of only 12 women in your class in medical school. What challenges did you face along the way? Did you ever feel like you were being held back because of your gender? Do you think the medical field is more welcoming to women now than it was before?

Dr. Gill: In addition to being a woman, I was also a mother at the time. I was 29 when I started medical school; my daughter was 6 years old and started first grade the year I started medical school. I think I was ignored more because no one thought that a person in my situation would consider going to medical school and would likely have difficulty being successful. When I was interviewing, one of my interviewers indicated to me that I was the first person they had ever considered who was a mother, who already had a child, who was looking to be admitted to medical school. My husband at the time later confided that his father suggested that he should support the decision because "I would fail, but be satisfied because I had tried."

Then during medical school, there was an attitude of "Well, you know, there aren't women in this field." For example, if you considered surgery, there were almost no female surgeons at the time. While I was going through my rotations as a third- and fourth-year student, I really liked just about everything I did and saw. At one point, I thought, "Oh, being a surgeon would be very exciting and interesting." But when I made an appointment with the Chair of the surgery department to discuss the possibility, he made it clear that I shouldn't even consider it because I was a female and a mother, and pretty much just ended the conversation there.

I think there was the attitude that women in medicine weren't necessarily very important and, with rare exceptions, probably weren't going to contribute a great deal to the field. I was much more welcomed when I decided to pursue pediatrics, but attitudes have changed immensely since then. Now, at least half of the students admitted to medical school are women, and women are making their mark in many fields of medicine. From that standpoint, the whole medical field has changed significantly for the better for women.

Dr. Flood: Is finding a mentor important for women who are interested in pursuing an academic career? How does this relationship help?

Dr. Gill: Oh yes, absolutely. When you're young and just starting out in a field and you see what some of the best people in the field have accomplished, it can be a bit daunting. There are some people who say, "Well, I can do that," and just go ahead and do it, but there are many others who need to have some encouragement and guidance. I think that's an important aspect of mentoring; and the sooner that begins, the better.

I also don't think that you need to have just one mentor for your entire career; instead, you can develop relationships with many people who are accomplishing things and being the type of people that you aspire to be. During different phases of life, that may be a different person or a group of people, so I don't think that finding your mentor is necessarily an "all or none" issue. As you go through life, there are different opportunities, different events that may change your appreciation of what you're doing, and there may be other people who are willing and able to help you along.

Dr. Flood: So there's not really any best time to be finding a mentor, it's something that should be more of a continuous process?

Dr. Gill: I agree, yes.

Dr. Flood: Do you think you're better equipped as a woman to take care of some of these chronic bleeding disorders?

Dr. Gill: I don't think it's necessarily whether you're a female or not. Many people would say, "Oh it's because females have a mothering instinct that males don't have," but I've known a lot of men who have been able to work well with their patients and, in addition to being a doctor and helping them with their health care, help them manage their lives with the chronic illness. I'm not sure that being a female necessarily makes you better equipped.

I think the ability to care for people with chronic illnesses is dependent on the kind of person you are, and what you think needs to be accomplished when working with people and families. It is critical to teach them about their disorder so that there is a clear understanding of the available treatment options and the impact of the disorder on their situation in life. This should result in a partnership between you and the patient and family, and it's much more likely that the patient is going to accept and carry out recommendations because they have been developed together with the patient's input. That kind of patient care philosophy is not necessarily done only by females; it's certainly done by males as well.

Dr. Flood: You alluded to your mom being a mentor for you. What kind of fabulous example is it for your daughter to have seen you go into medical school like this?

Dr. Gill: Many people questioned whether a mother going to medical school was a good idea at all; at the time, most women were expected to stay home and take care of their children. They might consider a career, but not in a field as challenging as medicine. I must admit I felt a bit guilty at times about missing some of the things that "stay-at-home" mothers were doing with their kids, but I was also providing her with an alternative role model, as my mother did for me.

As I attended medical school and beyond, my daughter was exposed to diverse people, from MDs to people in the neighborhood, and this provided her with the experience to be very comfortable with all kinds of people. That was probably an advantage for her. People have commented to me many times that she really is a very charming, caring person, and I hope I had something to do with that. I think a mentor is someone who not only encourages someone to pursue a particular goal in their life, but also sets an example so that the mentee has someone to look up to.

Dr. Flood: So on that theme of family, how do you achieve a work/life balance?

Dr. Gill: I think it's a matter of being open to all of the issues that come your way and trying to set priorities. In a way, I think one ends up almost compartmentalizing one's life, so that when you're at home as a mother and a family member, your brain turns everything else off and you focus on family. Whereas, when you're at work, you can focus on the things that need to be accomplished in your career.

And there certainly are conflicts, mainly for your time. I feel that family and career are both important and I could never say that one aspect of my life was more important than the other. You need to objectively view the challenges and opportunities available to you and then make choices to achieve what personally works for you. It is important to keep the members of each "compartment" aware of potential conflicts and enlist their assistance in managing them. This can be daunting at times but, if you love what you're doing, you can successfully navigate the rough spots.

Dr. Flood: *So, why hematology?*

Dr. Gill: Hematology started to interest me back when I was in college and did my summer job as a medical technologist; I was very interested in the hematologic aspects of that experience. After I finished college with my degree in biology, I worked as a research technologist in the hematology research department at the University of Wisconsin; that solidified my attraction and interest in hematology.

Then, in medical school, although I found many areas of medicine fun and interesting, when I finally chose pediatrics, during my residency, I had the opportunity to work with Dr. Donald Pinkel, a wonderful and caring pediatric oncologist. In those days, leukemia was a lethal diagnosis for children, and Dr. Pinkel designed studies to treat the central nervous system and cure children with leukemia. He showed me that it was possible to make significant improvements in clinical care through research carried out while providing medical treatment. His compassion and his dedication to making things better for the children were very inspiring; at that point, I decided to pursue a fellowship in pediatric hematology/oncology. I was fortunate to work in Dr. Richard Aster's lab, trying to unravel the etiology of childhood ITP [immune thrombocytopenia]; he taught me the importance of understanding the basic science underlying human disorders when designing approaches to rational treatment. During my fellowship, I became interested in hemophilia. During that time, I was fortunate to have two mentors: First, I studied with Dr. Jack Lazerson. He was a wonderful teacher; he provided me with the tools to teach hemostasis concepts to fellow students as well as families, fostering my interest in hemostasis. Shortly after Dr. Lazerson left the program, we were very fortunate to recruit Dr. Robert Montgomery. Dr. Montgomery taught me that we can learn something from each of our patients, and that research is the only way to improve the care we provide today. Since then, it has been a privilege to work with him to solve some of the mysteries of hemophilia and von Willebrand disease and improve the care of our patients [31].

At the time of my fellowship, hemophilia was an area where not only were there a lot of advances and improvements being made rapidly in the field, but you were treating a chronic illness, and hopefully helping your patients to live a full life. Shortly thereafter, HIV came along. That was devastating especially to our patients, but also the people who took care of the patients; there were many people in the field who left benign hematology at the time. But the courage of our patients, and the realization that I wanted to make a difference for our patients with hemophilia, inspired me to continue in the field. And today we've made wonderful advances in the care of hemophilia, von Willebrand disease, and other hemostatic disorders; and it's been very gratifying for me to be able to be a part of that.

Dr. Flood: Was there ever a specific moment that made you realize hemostasis and thrombosis was the perfect fit for you?

Dr. Gill: I don't think there was an actual moment. My view of the world and the decisions that lead to a particular path involves evaluating opportunities, identifying an area that is interesting and in which I have enough ability to make a difference, and then taking steps along the path; one soon discovers whether it is a good decision and whether one should continue or choose another option. Overall then, I guess I could say that I drifted into hemostasis and thrombosis and that I was fortunate to be in an environment that provided excellent support for achievement in the field.

Dr. Flood: What advice do you have for people choosing a specialty? How do you encourage young, female physicians to get into this area?

Dr. Gill: When choosing a specialty you have to choose something that excites you, that challenges you, something that you love delving into and in which you want to make a contribution. For example, when my daughter was very young, I asked her, "What do you think you want to do when you're an adult?" and she said, "Oh, I think I want to be a cheerleader or a waitress." I said, "That's fine. You can be whatever you want to be, but it has to be something that you love doing and it has to be something that you can feel good about and do well at." She had her initial career in music and entertainment and became the entertainment director for a renaissance fair, but then she changed course and is now a PhD in mental health. I try to encourage young people, males as well as females, to find an area that they want to explore; of course I provide a description of the excitement and interesting aspects of hemostasis and offer to help with projects and advise if they're interested, but the most important aspect of choosing a specialty is that you have to be really excited about what you're doing and really love to work in your field.

Dr. Flood: Any advice for young physicians who are interested in leadership?

Dr. Gill: That is another interesting issue, dependent on what you consider a leader. Some people think that being a leader is being named to be the head of an organization or project, and making all the decisions. But I think a leader is one who carefully evaluates the goals required to accomplish good work, but instead of dictating how their staff will carry out the work, they allow people working with them to form a team to achieve those goals, recognizing that each person has something unique to contribute and being open to others' ideas.

There are some "leaders" who think that their ideas are the only good ones and they need to assign the tasks to reach goals. In my opinion, that is the wrong approach. I think a real leader is a person who is open to others' ideas and can synthesize what the whole group

 doi:10.1002/ajh.24316

needs and would like to do to accomplish a particular goal; together, they can then design a better way to accomplish things, and because each has been provided the opportunity to express their ideas, there is improved motivation to perform the necessary tasks to achieve the desired outcome.

Dr. Flood: You've been the head of the Comprehensive Center for Bleeding Disorders for a long time. Any thoughts on how you've done it so successfully?

Dr. Gill: I like to think it's because I have gathered together a group of people who are dedicated to improving the lives of people with hemostasis and thrombosis issues and can work together to carry out that goal. Certainly, along the way, my staff and I have made poor decisions as well as good ones; but for the most part, we've put together a team of people who have common goals and who feel comfortable enough to let their ideas be heard. My success has been because of the efforts of the people who I've been working with just as much as my own efforts.

Dr. Flood: What do you consider your greatest professional accomplishment?

Dr. Gill: I don't think there is one well-defined, greatest accomplishment. One of my best accomplishments is that I've been able to work with many talented people to accomplish my goals, and I have been able to assist younger people progress in the field. As a founder and long-term officer of the HTRS, I am very pleased that my colleagues and I have provided significant financial and mentoring support to many fellows and junior faculty through our mentored research program; nearly all have gone on in academic careers in hemostasis and thrombosis. I consider another of my best accomplishments to be my ability to integrate research into clinical care. There are many who think one can only do one or the other and that they should never mix, but I think the ability to put research into the context of clinical care makes it possible for us to advance that care more efficiently and rapidly with the active participation of the patients.

Dr. Flood: What in your work gives you the most satisfaction?

Dr. Gill: Being able to identify a need in medical care (for instance, in the care of hemophilia or von Willebrand disease) and then being able to design research to try to answer a question or fill in the knowledge gap to fulfill the need, by carrying out clinical research while providing care to the patient.

For example, there are new extended half-life products for hemophilia and we don't really know the optimal way to use those products to treat our patients. Our regional group of physicians has gotten together and we are designing a study to try to identify what questions need to be answered in order for us to better utilize the tools that we have to take care of patients. My ability to carry out research that's going to answer a question and make things better gives me the most satisfaction.

Dr. Flood: What is it like to be considered a pioneering woman in hematology?

Dr. Gill: I was absolutely astounded when I was asked to participate in this project. When I consider people like Dr. Jeanne Lusher, Dr. Carol Kasper, and other women who've made significant contributions to hematology, I am truly honored to be considered a member of that group.

Dr. Flood's Perspective

Dr. Joan Gill is a true pioneer in hemostasis, but her impact on the field extends well beyond her expertise as a clinician and scientist. As someone lucky enough to have had her as a mentor, it is her generosity that stands out to me. She is always willing to take time to listen, both to patients and to colleagues, and most especially to mentees. She will interrupt her own work to give advice on a complicated patient issue, suggest direction for a research project, or talk to a concerned parent or patient. She has selflessly worked to improve the lives of patients with hemophilia, bleeding, and clotting disorders in Milwaukee and surrounding regions by directing the Comprehensive Center for Bleeding Disorders, and throughout the world with her research efforts [32]. Personally, I have benefitted from her fantastic mentoring in several ways: She is a fabulous role model, albeit one that will be hard to live up to, with clinical skills, research skills, and the ability to advance her career while raising a (now quite successful) daughter of her own. She has a vast repository of clinical knowledge when I have questions about the best treatment for a specific patient, and answers my calls for help even in the middle of the night. She is a research mentor for my budding career as a hematologist, as well as for many other students, residents, and junior faculty, ensuring that our field will be well staffed into the future. As befits such a pioneer, she has enriched the hemostasis community beyond measure.

Diane Nugent, MD

Interviewed by Loan Hsieh, MD

Diane Nugent, MD

Biography. Dr. Diane Nugent is Principle Investigator of the Western States MCHB Hemophilia Treatment Program for the Centers for Disease Control and Prevention (CDC) Cooperative Agreement in Prevention of Complications of Hemophilia, and Professor and Chief of the Hematology Division in the Department of Pediatrics at the University of California-Irvine School of Medicine. Dr. Nugent is also the Chair of Hematology at CHOC Children's, Medical Director of Blood and Donor/Apheresis Services and the CAP/CLIA-certified Hematology Advanced Diagnosis Laboratory, and Director of the Center of Inherited Blood Disorders, an ambulatory clinic for the adolescent and adult community. She is the current President of the Hemostasis & Thrombosis Research Society (HTRS). Dr. Nugent's research interests include blood disorders, bone marrow failure, bleeding and clotting disorders, and white cell and immune deficiencies. She has received many grants and participated in numerous clinical trials for rare blood disorders [33].

Dr. Nugent has authored more than 140 journal articles and book chapters. Her work as a physician has been recognized with awards, including the 2005 Physician of the Year in Orange County and for the National Hemophilia Foundation (NHF). Dr. Nugent is certified by the American Board of Pediatrics for pediatrics and pediatric hematology/oncology.

Dr. Nugent graduated from the University of California–Los Angeles (UCLA) School of Medicine (1977), and later completed her

residency and internship at Denver Affiliated Hospitals in Colorado. She then moved to the Fred Hutchinson Cancer Research Center and the Children's Hospital and Medical Center in Seattle, Washington for a pediatric hematology-oncology research fellowship.

Q&A

Dr. Loan Hsieh: *My first question for you is: why did you go into medicine?*

Dr. Diane Nugent: My initial goal in life was not to go into medicine. I actually got my degree in Fine Arts and did photography and printmaking for some time. But, I found that wasn't really satisfying in my life and, at the same time, I was translating in a free clinic. I had the good fortune to have one of the nurses there tell me, "Gee, you seem to be okay around patients, why don't you be a nurse?" At that time, the Vietnam War was happening and no one could go back to undergraduate university for ongoing education, so I returned to take the courses needed to get a degree in education and the undergraduate credits to apply for nursing school.

During this time, I found that I really enjoyed science, which was something that I hadn't been exposed to before. And, as everyone around me was applying to medical school, I thought, "I think that sounds more interesting than nursing school." And through a lot of work and good fortune, I was accepted to UCLA, and it has been the joy of my life ever since. I really do enjoy asking questions about health and disease, and I particularly like the challenges of, and the metamorphosis that happens in pediatrics. So that's what really drew me into medicine: the genetics, the development, and the evolution of disease with growth and maturation.

Dr. Hsieh: *What challenges did you face along the way as a woman?*

Dr. Nugent: At the time I went to medical school, there were very few women in medicine; 13 other women and I joined a class of 166. It didn't occur to me that getting into medical school would be a challenge for a woman. I come from a family that was very positive; my father promoted the fact that my sister and I could do whatever we thought we could do. So it was a surprise to me to see so few women in medicine.

And so myself and another woman, who was 1 year ahead of me in medical school, went to the admission's office and asked, "Why are there so few women in our class?" They said, "We admit the percentage of women that apply." At that time, 84% of the people who applied, apparently, were men, and 16% were women. And we said, "Why isn't it based on merit?" And they said, "Well, that's an idea to consider."

We felt that, by the time you go to school and apply to medicine, women had already made some lifestyle choices that would have put them in a category in which the majority who applied would likely do well. I'm proud to say that at UCLA, in the 3 years that followed, it went from being 16% women up to 35% because they decided to take the percentage methodology off the table and just accept students based on scores and grades.

Dr. Hsieh: *Did you feel like you were being held back just because you were a woman?*

Dr. Nugent: I've never felt that I've been held back because I'm a woman. I do think that challenges remain... women are not put in positions of leadership, and this is a challenge that goes far beyond medicine. I think part of the reason is the style of leadership that women gravitate towards, which is more collaborative and doesn't fit within the hierarchy that's in place right now. A lot of the same old mechanisms for advancement—whether it's in business, medicine, or law—fail to find the "collaborative approach" to be a good fit in the boardroom. In the places where collaboration has occurred, this allows for junior faculty to rise to the ranks of leadership and there's more consensus as part of decision making. This is true in both divisional and clinical arenas. Patient care is markedly improved if you don't have just one view of how medicine should be performed. I think the collaborative approach in medicine is really best, and we see it resulting in wonderful outcomes for our patients.

Dr. Hsieh: *Looking back from the time you applied to UCLA, do you feel that the medical field is now becoming more welcoming to women?*

Dr. Nugent: Absolutely. And I think that there are two things driving that. One is a good thing and one is a bad thing. The good thing is that people recognize that women are fully capable of doing a great job in medicine and have leadership skills that are very positive, especially in team-based medical care and comprehensive care.

The bad side or the unrecognized side, I think, is that salaries are falling in medicine. As we've seen in pediatrics, as salaries drop, women end up taking a lot of the positions and men tend to migrate out. And, until we recognize equal pay for equal jobs, unfortunately, there's still a real disadvantage for women to go into medical fields where there is a higher pay scale.

Dr. Hsieh: *Medicine is such a demanding career—how do you achieve your work/life balance?*

Dr. Nugent: I don't think I've done that very well, to be honest. I try to leave as much of work at the workplace as possible but, I think, like many other people who are trying to improve care in hematology and in medicine in general, 8 hours is just not enough. And so we end up either staying late or taking work home. I think that the best advice that was ever given to me is the following: "If you say 'yes' to work, you are saying 'no' to your family." You just can't be in two places at once, physically or mentally. So if that's the case, then staying at work better be pretty valuable and very important. You have to sit down and make that choice every single day. It's a personal choice, clearly, but it's a very serious choice. And I think that, looking back, any working woman with a family would say, "I could have done a better job at that."

Dr. Hsieh: *Of all the fields in medicine, what made you choose hematology?*

Dr. Nugent: Great mentors, great leaders. For me, it was Dr. Bill Hathaway and Dr. Jack Githins, when I was a resident in Colorado. I knew by my second year that I wanted to do hematology based on the commitment that they had to hematology, and to the manner in which they made hematology fascinating to me. I think everybody is drawn to one specialty or another, so the combination of my interest and their excellent mentorship probably made it inevitable.

Dr. Hsieh: *What made you focus on the area of coagulation?*

Dr. Nugent: I think the area of coagulation is most interesting to me because it interfaces so much with inflammation and our understanding of the way our bodies deal with infection. It's also interesting that many of the factors that I'm interested in are very important for the development of the fetus and the blastocyst, and the establishment of the placenta. These factors also regulate angiogenesis and produce tolerance in mothers to prevent rejection of the fetus.

There's a very rich area of research—molecular, cellular, as well as the clotting proteins themselves—that is endlessly fascinating to me. And it has an impact on long-term maternal health, fetal and neonatal health, and is really rich and fascinating, particularly in the area of platelets [34,35] and factor XIII [36]. So that's where my interest in hemostasis has come from over the years.

I also had the good fortune of having a very dedicated group of patients with hemophilia in the late 70s/early 80s, who raised money to support fellows with an interest in hemostasis. By sheer serendipity, when I started my fellowship in Seattle at the Children's Hospital and the Fred Hutchinson Cancer Research Center, my director was looking for ways to fund a fellow. Basically, he said, "Oh, there's that scholarship from the hemophilia community. You'll just have to do hemophilia clinic and go to summer camp every year. It's no big deal, but that way we'll pay for you."

Well, that was the start of a lifelong commitment to hemophilia. Those wonderful men with hemophilia knew exactly what they were

 doi:10.1002/ajh.24316

doing when they started funding fellows. I credit them for the fact that I care so deeply for patients with hemophilia and have had the good fortune to work in hemophilia from that first day of my fellowship. And so it's my longstanding commitment to them to always care for patients with hemophilia, and it's a great honor to do so.

Dr. Hsieh: *Do you think you are better equipped because you are a woman to take care of those with chronic bleeding disorders?*

Dr. Nugent: I don't think being a woman makes me any more skilled at taking care of patients with bleeding disorders, but I do care a lot for my patients and their families. But I've worked with wonderful mentors and colleagues who are men and who do a wonderful job as well.

Dr. Hsieh: *What advice do you have for choosing a specialty?*

Dr. Nugent: I definitely use the same phrase for all of our fellows and people asking me about the choice of hematology focus, and that is, "Choose a specialty that you don't mind coming in on the weekends and working late on a holiday." That it should be a passion for you, that you love it. The work is going to be hard, so it better be something that you really like. It will be a heavy burden for you if you choose something just for the money or just because it's popular now. In 20 years, it should be the same dedication to leave home and see someone in the middle of the night; it takes much more energy and drive at that age, so it better be something that you really believe in. That's the most important thing.

Dr. Hsieh: *How do you encourage young female physicians to explore the area of hemostasis?*

Dr. Nugent: I encourage people to look at hemostasis/hematology because it's an area that impacts all subspecialties; there isn't a patient in our hospital on whom we don't consult on at some point. So if you're curious and you love medicine in general, it's a great opportunity.

In hematology, we have a lot of diseases that are monogenic, like hemophilia, sickle cell, and so on. Almost all of our primary blood disorders are genetically based. So, for people who are curious about molecular biology, genetic disorders, and looking to the future, hematology is a good choice.

Hematology and hemostasis are areas where you can be very, very gratified by being a consultant and running an outpatient service. If you're focusing on women who want to have a career and reasonable hours, it's a great opportunity to interface with patients with chronic complex disease. If you do a good job, they don't go into the hospital very frequently, and that's a very rewarding way to approach long-term care. Hemostasis/thrombosis is certainly an excellent area to keep yourself intellectually active, stay involved in genomics, ask a lot of interesting questions, and yet have some balance in your life.

Dr. Hsieh: *What should women do to rise to leadership positions in medicine?*

Dr. Nugent: I think that women should do the same thing that men should do, and this is the other phrase I tell everybody: "Just show up." If you're interested in leadership, you can't sit in your office and wait for someone to call you to be the leader. You have to start getting involved in your areas of interest. If it's teaching and fellowship, you need to go to those committee meetings and start taking active participation. Pretty soon, people notice that you're there. They start asking you to be on more committees, and eventually you're leading one of those groups.

The second thing is, don't ask to be a leader if you're not organized and able to do it. It requires organization and follow through. You have to learn how to follow through and meet your goals, and help other people on your committees to do the same. I find that being a good leader means that you know how to delegate well. You need to quickly identify people's strengths and interests. Let them do the work that they are there [to do] and interested in doing. So you have to have good people skills, you need to organize your team, you have to organize your office, and you have to set really strict deadlines for yourself.

I think women have an advantage in leadership positions in that they're multitaskers and they're very good and efficient with their time management, particularly if they have children. The gift is learning how to organize other people's time and make sure that everybody comes up with their deliverables or project goals on schedule. It is most satisfying to see your team achieve their goals and get the accolades they deserve.

Dr. Hsieh: *Is finding a mentor important for women who are interested in pursuing an academic career?*

Dr. Nugent: I think having a mentor is important, but it's not always the same mentor throughout your career. More than having one mentor drive you through your career, listen to the people who are around you. Listen to your friends, the people who are there for you. But as far as guiding you through your career, everybody benefits from feedback and guidance in navigating the hurdles of the current professional stage that they're in.

Then again, if I had listened to my mentor when I started in fellowship, I would not be here... At that time, everybody said there will be no jobs at all in hematology/oncology in pediatrics; he said, "We're training way too many people, and there are no positions." There will always be opinions when there are no data... If you are doing what truly is your passion, keep going. There may be fewer opportunities than you had hoped, but if that's your goal, you need to keep going.

So, find a good thoughtful mentor that cares about you and your career, take all advice with a grain of salt, choose multiple mentors along the way, and don't forget to listen to friends and family. They're probably your best mentors.

Dr. Hsieh: *How does the mentor/mentee relationship work?*

Dr. Nugent: I think it's good to hear yourself verbalize what you think you want to do. And sometimes when you actually verbalize it and get feedback from someone else, you realize that there may be areas that you've neglected to consider, or you've chosen a path for which you're not completely suited. A mentor is best at helping you identify where you're really at. Not so much in telling you what to do, but just helping you identify where you are and where you need to go.

Dr. Hsieh's Perspective

I first met Dr. Nugent as a fourth-year medical student rotating in hematology. I was immediately impressed by her passion for hematology and the depth of her knowledge. I still recall her impromptu teaching sessions during rounds, elaborating on bleeding disorders like von Willebrand disease and platelet dysfunction. Dr. Nugent's enthusiasm for both teaching and clinical work was a key factor in my own choice of specialty.

Dr. Nugent leads by example and consistently makes time for people, whether it is a researcher interested in collaborating with her or a team member needing her advice. She is committed to her faculty's growth, and never misses an opportunity to connect them to other experts in the field. For example, Dr. Nugent introduced me to various hematologists specializing in factor XIII deficiency and thrombocytopenia, and has enabled me to pursue partnerships in this area. Dr. Nugent has been mentoring me not just in my career as a hematologist but also in my position as Director of Ambulatory Hematology at our hospital. Dr. Nugent is a strong advocate for women doctors, beginning with her experience in medical school and continuing to our current hospital. She is also not afraid to stand up for her values at the administration level and even at the political level, where Dr. Nugent often lobbies for pediatric issues that she cares about. One piece of advice from Dr. Nugent that has always stuck with me was that half the battle is just showing up. I am trying to practice that in my career by using my own voice to improve patient care.

Donna DiMichele, MD

Interviewed by Suchitra Acharya, MD

Donna DiMichele, MD

Biography. Dr. Donna DiMichele is Deputy Director of the Division of Blood Diseases and Resources at the National Heart, Lung, and Blood Institute (NHLBI), National Institutes of Health (NIH). Until her departure in 2010, she was Attending Physician, Medical Director of the Regional Comprehensive Hemophilia Diagnostic & Treatment Center, Professor in the Departments of Pediatrics and Public Health, and Director of the Special Coagulation Research Laboratory at the Weill Cornell Medical College of Cornell University. Dr. DiMichele specializes in pediatric hematology, and has had a clinical, training, and research career focused on pediatric hemostasis and thrombosis, and most specifically, hemophilia and its complications, and rare bleeding disorders [37].

Over the course of her career, Dr. DiMichele has served as Co-PI [Principle Investigator] of the International Immune Tolerance Study [38], Co-Chair of the UDC [Universal Data Collection] Working Party on Rare Bleeding and Clotting Disorders, and the PI of both the US and International Severe Hemophilia in Females studies [39]. She has also served on the factor VIII (FVIII)/factor IX (FIX) Subcommittee of the International Society on Thrombosis and Haemostasis (ISTH) as Co-Chair (1997-2000 and 2003-2004) and Chair (2000-2003); between 2012 and 2015, Dr. DiMichele chaired an international project group of the FVIII/FIX Subcommittee that focused on optimizing pre-licensure clinical trials for new products in hemophilia. She continues to actively participate in multiple ISTH subcommittee project groups. In her current position at NHLBI, Dr. DiMichele works within and outside the organization to enhance and communicate the scientific vision and capability of the Division of Blood Diseases and Resources.

In addition, Dr. DiMichele has authored or co-authored more than 120 articles, abstracts, and book chapters in the field of hemophilia. She is a member of several professional societies, including the Hemostasis & Thrombosis Research Society (HTRS), ISTH, and the American Society of Hematology (ASH).

Dr. DiMichele received her medical education at McGill University in Montreal, Canada (1978). She then went on to complete a residency in pediatrics and a fellowship in Pediatric Hematology and Oncology at the University of Colorado Health Sciences Center (Aurora, CO), and a research fellowship in hematology at New England Medical Center Hospital, Tufts University School of Medicine (Boston, MA).

Q&A

Dr. Suchitra Acharya: I think one of the things everyone is curious about is why you went into medicine and why did you choose hematology as a specialty.

Dr. Donna DiMichele: To be honest, I had really wanted to be a journalist. I loved writing and I was determined to be a journalist well into my later years in high school, even to the point of exploring university programs in journalism. But I was also part of an early career-streaming experiment in our Catholic school system in which STEM [science, technology, engineering, and math] sciences were taught in an all-female environment—by women to other young women. Within the biological sciences program, we were taught health science and, once exposed, I was hooked. Consequently, by the end of high school, I had made up my mind that I was going to go into medicine.

After that, my career pathway was pretty well defined by a succession of opportunities. Prior to beginning the medicine program, I had taken a child developmental psychology course, which ensured that I was to become a pediatrician. Then, in the second year of medical school, I did a hematology elective that really interested and excited me. After medical school and a rotating internship, I went to the University of Colorado for training in pediatrics. There, I met Dr. Bill Hathaway, the person who enticed and encouraged me (and many others) to pursue a career dedicated to hemostasis and thrombosis and, particularly, hemophilia. Once I got exposed to that area of clinical medicine and research, my career path was well defined. At that point I was so committed to pediatric hematology and hemostasis that, instead of attending a standard general pediatric continuity clinic as part of my training, I spent my time in a general hematology continuity clinic, thereby acquiring lots of exposure to hematology even before I applied for fellowship training.

Dr. Acharya: Was there a specific moment when you decided to focus on the field of coagulation disorders? Maybe a specific patient you took care of when you decided that you really wanted to be in the field of hemostasis and thrombosis?

Dr. DiMichele: Well, unlike many fellowship colleagues who chose to be oncologists for such reasons, I never had a friend, family member, or a patient in medical school who was afflicted by a disorder of hemostasis and thrombosis. However, during residency, I had tremendous exposure to hematology in general, and hemostasis in particular because of Dr. Bill Hathaway, a definitive pioneer in pediatric hemostasis and the Comprehensive Hemophilia Treatment Center at the University of Colorado, which was one of the first in the country. The intellectual stimulation I received from coagulation science and medicine during my clinical training was highly influential in guiding my career.

Dr. Acharya: As a woman, did you feel challenged taking care of these patients?

Dr. DiMichele: I was in a medical school class in which only 19% of us were women—that's certainly not what medical school classes look like nowadays! But, as a woman, I don't recall ever spontaneously feeling or being made to feel any different than the majority of other students who were men. Furthermore, through multiple internships, residency, and fellowship, I was never aware of any difference in attitudes or opportunities between me and my male counterparts. The only time I began to experience the glass ceiling was as I moved ahead academically in the university environment. Only then did I understand the glass ceilings that women were coming up against repeatedly and that there weren't many role models for women in strong leadership positions. But even then, I was lucky. As a young faculty member, I got the opportunity to work with Dr. Margaret Hilgartner, a true pioneering woman in our field, and to meet some

 doi:10.1002/ajh.24316

other very strong and influential women in the field, including Drs. Carol Kasper, Elaine Eyster, and Jeanne Lusher. And with time, many of my closest colleagues and collaborators were female contemporaries and former trainees whom I continue to admire greatly. So in summary, I think that any challenges I may have had were offset by the fortunate positive experiences that I had in my professional life.

Dr. Acharya: *Do you think you were better equipped as a woman to take care of people with bleeding disorders?*

Dr. DiMichele: I think that the care of individuals with bleeding disorders requires that we build long-term relationships with our patients, engage them as partners in their health care, and care for their medical issues within the context of the lives they lead and the limitations we must learn to accommodate. This type of care is best delivered with an approach characterized by no-nonsense toughness tempered by an abundance of patience, empathy, and compassion. To that end, I believe this is a clinical practice well-suited to women, but by no means exclusively so. In my experience, both men and women can do this extremely well.

Dr. Acharya: *Do you have any advice for the younger female generation in terms of choosing a specialty, and specifically for choosing hemostasis and thrombosis? For me, I didn't ever think I was going into hemostasis, but it just so happened that you were around and with all your teaching, your encouragement, and your role modeling, that's what I wanted to do*.

Dr. DiMichele: Well thank you. I think we all desperately need to enthusiastically communicate our intellectual curiosity, our passion for the science, and our profound interest in the clinical problems associated with these disorders to all trainees because, as we know, our field is in desperate need of new generations of individuals, both men and women, who can get excited about a clinical and/or research career in hemostasis and thrombosis.

I think that encouraging individuals to make their careers in this field requires their early exposure to the discipline. And by early exposure, I mean very early in their medical education. We need to go into the first-year classes, bring patients with us, and teach medical students about hemophilia and other coagulation disorders—what it's like to have a coagulation disorder, what the science is all about, how the field is scientifically advancing, and how the science is translating to clinical care at a relatively high speed. We have an absolutely exciting story to tell! In contrast to oncology, for example, influential, spontaneous, unscripted exposure to this field is very unlikely to happen. So, I think that it is incumbent on those of us in this field, and a very important responsibility we all bear, to convey our excitement and passion about this particular area of hematological science to trainees at all levels. The way I would approach both women and men would be identical. There is plenty of room for people with a wide variety of interests—basic science, translational science, clinical science—the field really is ripe with opportunities across the scientific pathway! And so I believe that women and men should be strongly encouraged to enter the field because there's a lot of work to be done and more than enough work for everyone.

Dr. Acharya: *I agree completely. What do you think are the challenges that women face in rising to leadership positions in medicine? And what advice do you have for younger female physicians who are interested in these kinds of leadership positions?*

Dr. DiMichele: Neither acquiring leadership skills nor getting into leadership positions happen naturally. Leadership is not a right of academic advancement nor is it a given. Therefore, I think that it's very important when working with women whose voices are not naturally heard, to help them find their voice… to help women recognize that they have a valuable point of view, even when that point of view may not be the majority or mainstream point of view. Understanding and working to get beyond that phenomenon can sometimes be a challenge for women. By nature, women tend to be more collaborative, willing to work in teams, and more willing to work without recognition. However, an overly generous spirit can often be the downfall of women who could otherwise be rising, and who are very capable of rising, into leadership positions. Women can bring unique skills to the leadership table, but they don't always get the opportunity to do so. Consequently, the whole paradigm of a woman's place in medicine, in academia, and in our field really needs to be revisited. As a start, I believe women need early, specific, and targeted leadership training in finding their voice, successfully navigating group dynamics and overcoming the particular leadership challenges they face throughout their careers.

Dr. Acharya: *Absolutely. We all understand that it's important for everyone, man or woman, to find a mentor if you're considering pursuing an academic career. How would you say the mentor/mentee relationship helps, and what would be the best time to find a mentor?*

Dr. DiMichele: Well, the earlier the better. I think role models are very important, but role models and mentors are different. I believe that to function as an effective mentor means to thoroughly understand an individual—her/his specific attributes and challenges, as well as aspirations and goals—and to use that knowledge and your experience to guide the mentee toward their goals, teaching them some clinical medicine, science, and pragmatics along the way. Mentorship goes beyond teaching someone the trade or the academic ropes—it is tailored to the individual, very personal and, frequently, a lifelong undertaking.

That said, mentee lives and careers are very complex and getting more difficult to navigate. Consequently, individuals may sometimes need more than a single or lifelong mentor. Different mentors may be required for different stages in a mentee's life or career. Furthermore, due to the complexity of an academic career [nowadays], oftentimes a team approach to mentorship can bring multiple points of view and multiple areas of expertise to the table. That's particularly true for women. Men fall into their mentorship relationships a lot more easily than women do. Women need to understand that it's not organic, and that acquiring the right mentorship is something that needs to be pursued actively. I also don't believe that women should be looking exclusively for female mentors. Women need to actively seek out mentors of either sex who will help them understand where they want to go, and who will then actively identify and spearhead the mentorship team that will get them there.

I also believe that women need to be very proactive about talking to women in academia within the field, and outside their own field, to get a sense of what the challenges are and what they need to learn. And no one should be ashamed of having those conversations; I think that they really are part and parcel of what every woman needs to succeed. And by succeeding, I mean doing whatever they want to do, whether that's clinical practice or being the dean of a medical school.

Dr. Acharya: *I completely agree with what you're saying. But it's not just work all the time–how do you achieve a work/life balance and what do you pursue when you're not practicing medicine?*

Dr. DiMichele: Well, you know that I've been quite bad at it, really… but you are never too old to keep trying to do it better! Work has always been important to me—actually more of a passion and dedication than a job. That attitude, combined with the academic demands of clinical care, teaching, research, and administration, can create a monster that is difficult to contain! That said, it is really important to make time for the pursuits that balance and ground you, and bring you back to a place of calm and centeredness. For me, that has included regular Pilates sessions, yoga, international travel, spending time with good friends and family, and making time to pursue my interests in the arts—the opera, the theater, and especially the ballet. Early on, I recognized the importance of exercise and I have tried to make time for it. And I've always had a love for horses. I rode a little bit as a child and have recently decided to take lessons

again. I'm really loving the time I spend around these animals! As I've found a bit more time and my life has become a little more balanced, I'm beginning to pursue many hobbies and dreams that I had on hold for many years.

Dr. Acharya: *That's wonderful. So one last question: What do you see in your career moving forward? After all the struggles, after all the challenges you have faced to be where you've reached, what do you envision for yourself?*

Dr. DiMichele: When I was living in Colorado, one of my pastimes was to go to the mountains to hike the 14,000-foot peaks. Hiking these mountains proved to be a lesson in life itself, for just when you thought you were approaching the top, you found that you were actually only on a ridge, still staring up at the peak. So has it been with my recent shift in career. Although I may have once felt at the top of my game, as I move through the next stages of my career and look at where I am now, I recognize that there is so much more to learn, to work on, and to accomplish—whether it is developing the science or encouraging young people to come into it. So I can't really think of retiring anytime soon—there's too much left to do!

Dr. Acharya's Perspective

I had the distinct pleasure of working with Dr. Donna DiMichele, as her mentee during my fellowship and post-fellowship years, and I think she is aptly included in this supplement of the *American Journal of Hematology* dedicated to women leaders in hematology. During the second year of my fellowship, I had decided to pursue hematology as a career, but this choice was not clear until I was taught by Dr. DiMichele, who sparked an interest in me to pursue hemostasis and thrombosis. Dr. DiMichele was fortunate to have been exposed to hemostasis and thrombosis since the time of her residency, which explains the depth of her knowledge in this field, and her passion to move the field forward and train the next generation of physicians. Dr. DiMichele has been a pioneer in the field of inhibitor development in hemophilia by her efforts to understand risk factors, as well as prevention and treatment options for this debilitating complication. This work culminated in Dr. DiMichele's design for an international study—the International Immune Tolerance Study—which, in those days, was one of the few international studies that successfully recruited patients with a rare disorder such as hemophilia [38]. During my fellowship years, under Dr. DiMichele's guidance and mentorship, we established the North American Rare Bleeding Disorder Registry to gain insights into disorders occurring at a frequency of 1 in half a million to 1 in 3 million individuals [37], and we are now embarking on an international collaboration. Under Dr. DiMichele's mentorship, I was able to demonstrate the cost-effectiveness and user-friendliness of ultrasonography for the diagnosis of hemophilic joint disease [40] and demonstrate a role for neo-angiogenesis in its pathophysiology [41]; currently, I am working to establish these tools to optimize management of hemophilic joint disease. She has imparted her passion for the field of hemostasis to all her trainees in the field, including myself, and I am truly grateful for that. Her dedication, passion, and enthusiasm for clinical care and teaching are infectious, and I am glad that I caught that "bug." Apart from fellows, Dr. DiMichele has also mentored and played an active role in directing the careers of medical students and residents, many of whom have gone on to pursue careers in the field of hemostasis and thrombosis, attesting to her strong desire to train the next generation of clinicians and researchers in this field [42]. Having moved from clinical care to the NIH, Dr. DiMichele has been working to create strategies and funding lines for hemostasis research to address many unanswered questions in this field. I think we are all truly fortunate to have a hematologist of her caliber at the NIH who will be a relentless advocate for the bleeding disorder community in the age of shrinking funding. In Dr. DiMichele's own words, "there is too much left to do."

Cindy Leissinger, MD

Interviewed by Rebecca Kruse-Jarres, MD, MPH

Cindy Leissinger, MD

Biography. Dr. Cindy Leissinger is Professor of Medicine and Clinical Professor of Pediatrics and Pathology, as well as Chief of the Hematology/Oncology Division, at Tulane University (New Orleans, LA). In addition, she serves as Director of the Louisiana Center for Bleeding & Clotting Disorders. Dr. Leissinger's clinical and research interests include inhibitors in hemophilia A [43,44], acquired hemophilia A [45], and other coagulation disorders, such as von Willebrand disease. She has been an active investigator for numerous research studies and Principle Investigator for 2 investigator-initiated, multi-institutional clinical trials of treatments for individuals with hemophilia A and factor VIII inhibitors: the Rituximab for Inhibitors in Congenital Hemophilia (RICH) study [46] and the ProFEIBA study of anti-inhibitor coagulant complex prophylaxis [44].

Dr. Leissinger is a fellow of the American College of Physicians, and a member of the American Society of Hematology (ASH) and the International Society on Thrombosis and Haemostasis (ISTH). She has been a member of the Hemostasis & Thrombosis Research Society (HTRS) since its formation, and has served the society in several leadership roles.

Dr. Leissinger received her medical degree from Tulane University School of Medicine (1979), where she also completed a residency in internal medicine and a clinical fellowship in hematology and medical oncology. In addition, she completed a research fellowship in hematology at the National Institutes of Health (NIH; Bethesda, MD).

Q&A

Dr. Rebecca Kruse-Jarres: *Why did you go into medicine?*

Dr. Cindy Leissinger: I wanted to be a doctor for as long as I can remember. As a little girl, I pretended that my dolls were my patients, and I would take care of them when they were sick. I was undoubtedly influenced by my pediatrician who was a kind and very professional woman, which was really unusual for that time. I think that

 doi:10.1002/ajh.24316

her influence—or just the fact that she was a woman—made it so that I never had any reservations or doubts. It never occurred to me that a girl could not grow up to be a doctor because I had a female physician; I think that was very influential.

Dr. Kruse-Jarres: *Did you feel that there were any challenges for you as a woman, or did you feel like there was anything holding you back because you were a woman as you followed your path?*

Dr. Leissinger: The answer for me is "no." I have to say that I have been very fortunate in my career to have had strong mentors—mostly men—who helped me along the way. I never perceived any obstacles or challenges specifically because I was a woman; if anything, I felt supported. I always had supervisors and colleagues who were very outspoken and believed that women should be given equal opportunities. My experience may not be universal for women of my generation, but I was very fortunate in that way.

Dr. Kruse-Jarres: *Why did you choose hematology?*

Dr. Leissinger: The summer before starting medical school, I had a job working as a phlebotomist in a hospital laboratory. It turned out that the phlebotomy room was right next door to the hematology lab, and I kept drifting over to the hematology lab because I was really curious about what they were doing. There was a very helpful senior technologist [in the hematology lab] who would take time with me; she would stop in the middle of her day and teach me about blood cells, and about looking at blood smears.

Also, in the evenings, there was one physician who would routinely come to the hematology lab and pull all the smears from his patients and look at them one by one. I used to hover around him, and he guessed that I was interested in what he was doing. So, he started to talk to me and found out I was going to medical school. He would take time to answer my questions, and then he let me look under the microscope with him. It was so amazing to me that he could tell so much about his patients, and whether the treatments he was giving were working, just by looking at a slide. At that point, I was hooked.

One of the things I took away from that experience was that it was just those few extra minutes that he spent with me that really made the difference in my career choice. I try to remember that in dealing with young people. It's not always the big lecture or the big pronouncement or some sort of big teaching moment; but, often, it's just spending a few minutes listening and offering just a little bit of your time to a young person that can make all the difference.

Dr. Kruse-Jarres: *What made you focus on the area of coagulation disorders, and what is a specific moment that made you realize that hemostasis and thrombosis was the right area for you?*

Dr. Leissinger: I started out my training in hematology working in the field of immune platelet disorders with Dr. Ray Shulman at the NIH [47]. Dr. Shulman was a wonderful mentor, and I enjoyed working with him. A few years later, I started my own academic career working with platelets and with patients who had platelet disorders [48].

After several years, life intervened when there was a major exodus of hematologists/oncologists who left my institution. For a very short period of time, we were down to two warm bodies in the section of hematology/oncology... and there was a large hemophilia center that needed a doctor. Since the hemophilia center seemed more compatible with my interests than taking care of cancer patients, I stepped in and took over the hemophilia center, and the rest, as they say, is history.

Once I started in the hemophilia center, after a short time, I knew that I had found my career home. That was over 20 years ago; and in all that time, I have never had a moment of regret that I changed courses midstream. Actually, that was something I took away from my first mentor, Dr. Shulman, who used to laugh and say, "Sometimes, you have to switch horses in midstream, but you'll know when it's the right time." And, for me, when that opportunity came, it was the right thing for me to do.

Dr. Kruse-Jarres: *Do you have any advice for younger professionals in choosing a specialty?*

Dr. Leissinger: That's a tough question, and I can only go by my own experience. I think a specialty chooses you; or, at least, that's the way it felt for me. I didn't necessarily set out to spend most of my career doing coagulation and hemophilia, but that's what happened, and it felt right from the start.

I think you just have to listen to your heart, and you have to pursue what you love or what excites you when you find it; and that's the advice that I try to pass on to younger people. Make sure that you're really passionate about, and invested in, what you're doing; if you're not, then you need to keep looking.

Dr. Kruse-Jarres: *You clearly have a passion for hemostasis and thrombosis, how do you encourage young female physicians to explore this area?*

Dr. Leissinger: I think we need to give young people, both women and men, an opportunity to experience our field because they won't necessarily have many opportunities in the normal, day-to-day med school training. That's why I support the various workshops that are offered to trainees; I think our societies like ASH and HTRS are doing a really good job in sponsoring workshops and in sponsoring fellowships. We need to encourage young women to take advantage of those opportunities and give them a chance to learn more about the field.

Dr. Kruse-Jarres: *What do you think women should do to rise to leadership positions in medicine, and what advice do you have for young female physicians who are interested in leadership positions?*

Dr. Leissinger: Work hard and never turn down an opportunity, especially to take the next step in your career, even if it means extra work; and it will almost always mean extra work. You can't be afraid of that. Advancing to leadership is a series of steps; try not to miss an opportunity. Once you do accept the task, be a closer; finish the tasks you take on, do them well, and be confident.

This is something that's really hard for a lot of women, but it's extremely important. Show your chief or your chairperson that you're confident you can do the job or any job they ask you to do. Your boss wants to depend on you, so let them know that you believe you can do the job by what you say, by your body language, and by what you do.

Finally, you have to stand up for yourself. You have to know your value, and you have to make sure that nobody makes you feel inferior or makes you feel less valued than other colleagues.

Dr. Kruse-Jarres: *Do you think that it's important for women who are interested in pursuing an academic career to find a mentor? How does the mentor or mentee relationship help?*

Dr. Leissinger: A mentor is important for any young person interested in an academic career. This question makes me think about what I consider a mentor to be... I think a mentor is a teacher but also a coach. A mentor is a sounding board. Most of all, I think a mentor needs to be your biggest supporter; a mentor needs to help you find your own way.

Besides that, I think a mentor is also very important in helping to introduce you to the larger community, and to a network of colleagues who will be there for you and touch your career throughout your life.

So, I think those are the hallmarks of what a good mentor offers and what a good mentor should do.

Dr. Kruse-Jarres: *When is the best time to find a mentor?*

Dr. Leissinger: I think finding a mentor as early as possible is always good. For most of us, it happens during our training. I would also say be open to mentorship all along the way—I've had several people who have mentored me at different stages of my career, even in later stages. All of those relationships have been very helpful to me; all of those relationships have a very special place in my life, and

those are very special people to me. So, I think the optimum time is early, but whenever mentorship or an opportunity for good mentorship presents itself, we should all take it.

Dr. Kruse-Jarres: *What is it like to be considered a pioneering woman in hematology?*

Dr. Leissinger: I don't think of myself as a pioneering woman, but I was very privileged to know some of the real pioneering woman in hematology, like Dr. Margaret Hilgartner and Dr. Inge-Marie Nilsson. I was trained by a man who worked in Dr. Rosemary Biggs' laboratory at Oxford. Those are the real pioneering women who I look up to; I think those women broke down barriers for the women, like me, who followed.

Dr. Kruse-Jarres: *For the record, you've been a pioneering woman and great mentor in my life. I know you've worked very hard and tirelessly—how have you managed to achieve a work/life balance?*

Dr. Leissinger: There are a couple of aspects to that. As for work itself, if you love your work, then it's not onerous. As the old saying goes, "If you love what you do, you won't work a day in your life." We are all going to spend a great deal of our lives at work, so be sure that while you are there, you enjoy what you do.

Of course, there are times outside of work and, for me, I have a number of things that I'm really interested in outside of work. I love to read, especially history and biographies. I also enjoy outdoor activities, like hiking and birding; those things, for sure, take me out of my workaday world. I think it helps to have things that are quite different or put you in a different kind of landscape from work—it helps you clear your mind and have some downtime, and it is important to do those things.

Dr. Kruse-Jarres' Perspective

How do I summarize the essence of the individual who has paved the road of my career? Let me start by describing what Cindy has contributed to the field and why I believe her to be a pioneering woman. And let me then explain how this is the basis, but does not even scratch the surface, of her being the best mentor I could have ever wished for.

Cindy has made many significant contributions to the field of coagulation, particularly in hemophilia, with an emphasis on patients with inhibitory antibodies. Among a lifelong career that includes numerous clinical research studies dedicated to improvements in this area, Cindy's most widely known accomplishment is arguably the implementation of prophylaxis in hemophilia A patients with inhibitors. This practice that was not routinely employed prior to her investigator-initiated, international, multicenter clinical trial that showed that prophylactic use of activated prothrombin complex concentrates in hemophilia patients with inhibitors significantly reduces bleeding [44]. Results of her study have changed the lives of patients with inhibitors, allowing them to emerge from the shadows to lead more normal and productive lives, similar to their non-inhibitor counterparts who have been on prophylaxis for years. I consider Cindy a pioneering woman, not only because of the research she has conducted and the discoveries she has made, but also because of how she went about it. She started her career with a fellowship at the NIH in 1981, at a time when one could envision few women there. In the late 1980s, she joined Tulane University and became the Director of the Louisiana Comprehensive Care Center a few years later. Almost exclusive of local mentorship, she created one of the largest centers for coagulation in the country. This merely happened because of her pioneering, clear, and resolved vision.

When it comes to my mentoring relationship, I often refer to Cindy as my "academic mom." I would not be where and who I am today without her. I learned to walk and talk academic coagulation medicine because she guided me, because she taught me what I did not know, because she made fun what seemed daunting, because she challenged me where I needed to develop, because she supported me when I needed to get back up from a fall, because she let go when I needed to be independent, and because she is still there when I need her. Mentorship comes in many forms and I feel I hit the jackpot and won the all-inclusive comprehensive package. I got to work with and alongside a superbly intelligent, successful, in many ways, self-made and steadfast woman; someone who has always been selfless in her mentorship—like only a mother could be with her young. This mentorship was never just scientific; it has been academic, about how to be a woman in this environment, about networking and interacting with peers, and largely about life in general.

Barbara A. Konkle, MD

Interviewed by Suman Sood, MD

Barbara A. Konkle, MD

Biography. Dr. Barbara Konkle is Professor of Medicine in the Division of Hematology at the University of Washington School of Medicine in Seattle, WA, and also serves as Director of Clinical and Translational Research, Associate Director of the Washington Center for Bleeding Disorders, and Director of the Hemostasis, Platelet Immunology and Genomics Laboratory at Bloodworks Northwest. Dr. Konkle's interests include clinical and translational research in hemostasis and thrombosis [49], transfusion medicine, sickle cell disease, and evaluation of the impact of ageing-related health risks, particularly cardiovascular disease, on adults with hemophilia [50,51]. She has a long-standing drive to develop better testing for bleeding and clotting disorders, and is involved in clinical trials of new therapies for hemophilia and von Willebrand disease.

Dr. Konkle has been named a top doctor in Seattle and Philadelphia, PA, where she had previously directed the Hemophilia Program at Thomas Jefferson University and the Penn Comprehensive Hemophilia and Thrombosis Program at the University of Pennsylvania. She was previously a Professor of Medicine and of Pathology and Laboratory Medicine at the University of Pennsylvania. Dr. Konkle has held many national positions within her field, including Chairman of the Board of the American Thrombosis and Hemostasis Network (ATHN). She is a founding board member of the Foundation for Women & Girls with Blood Disorders and the Thrombosis and Hemostasis Societies of North America, and serves on the Medical and Scientific Advisory Council (MASAC) of the National

 doi:10.1002/ajh.24316

Hemophilia Foundation (NHF) and on the advisory Council for the National Heart, Lung, and Blood Institute (NHLBI).

Dr. Konkle received her medical degree from Vanderbilt University (1979) and completed a residency in internal medicine at Rush Presbyterian–St. Luke's Medical Center in Chicago (1982). Her fellowship training in hematology/oncology was completed at the University of Michigan (1988). Dr. Konkle is board certified in internal medicine, medical oncology, and hematology.

Q&A

Dr. Suman Sood: Let's start with the basics: Why did you go into medicine? And then why did you choose hematology?

Dr. Barbara A. Konkle: I was a chemistry major as an undergrad and was torn between continuing in chemistry and going to medical school. The personal patient interaction attracted me and that's why I decided to go to medical school.

I decided to train in hematology so I could have a career in coagulation. As an intern, I had several patients with really interesting coagulation disorders and I really loved it. I loved how the clinical and the research laboratories and patient care were so intertwined.

Dr. Sood: What challenges did you face along the way as a woman? Did you ever feel like there were any specific issues or that you were held back because of your gender?

Dr. Konkle: I don't think so. I always felt really supported, particularly by my family. I did well in school and I always felt that I could do whatever I wanted to do. I think that I was of a generation that was accepting of women, versus those a bit older than I. There were occasional comments during medical school that were inappropriate... the assumption that I'd be a pediatrician... being told I was too assertive for a female. There were those things but, in general, I felt supported in what I wanted to do. The women in my medical school class have done lots of things and several have risen to leadership positions, so I don't think we were held back.

Dr. Sood: That's great to hear! Moving on to residency and then to fellowship, it sounds like things continued to go well and you didn't feel like you had limitations in the areas that were open to you.

Dr. Konkle: Yes, I really didn't feel that way. Although, mentorship wasn't really something that was done a lot then. I can recall that I didn't have a single woman who was *the* person that made me feel this was possible. But I really didn't feel like I couldn't do something because I was a woman.

I remember as a fellow, the head of the division thought it was surprisingly convenient that I was having my second child right after my clinical year and before research, and he had no concept that that might be planned. He said, "Wow, that works out really well." So, sometimes things are a little amusing. There was always a bit of cluelessness. There was probably more of that when I was training than now. But in terms of being individually supported by the people who were important to me, I never felt they were not supportive, or that they thought I should do different things because I was a woman.

Dr. Sood: Do you think that there are any particular areas in medicine that still need improvement gender-wise? For example, what we could do to improve the number of women who are rising to become professors in medicine?

Dr. Konkle: I think that there continues to be issues in terms of women being successful in academic medicine. It's a struggle for everyone, both men and women, on how to make everything work. There are likely biases, looking at the numbers... and so to make that better, we need to have more women in roles where they are doing the evaluations.

I think it's getting there, but probably one of my biggest disappointments is from when I was in medical school and thinking about the future—I thought there would be changes such that there would be family-friendly support. What has happened is that, if there are measures taken, they're very much focused on the woman and not the man. While it's nice to have those, as long as the policies are primarily focused on women, it will be the expectation that adjustments due to family commitments are a woman's role and that you could not have another arrangement. I think we perpetuate some of the challenges by instituting policies that don't necessarily help with the flexibility needed to be able to advance.

Dr. Sood: Excellent point that we need family-friendly policies, not female-friendly policies per se.

Dr. Konkle: Right. And, having taught medical students, I see that both male and female medical students want family-friendly policies and want to participate and have a work/life balance, not just female medical students.

Dr. Sood: Switching topics, what achievements are you most proud of throughout your career? Can you describe the most memorable patient or professional highlight?

Dr. Konkle: That's a tough question. I'm probably most proud of developing programs or providing clinical care or clinical research that really improves the lives of our patients. My most memorable experience in that area is probably the patient with a high titer factor inhibitor. We were one of the first to do joint replacement surgery by using rFVIIa; the patient had not been able to walk upstairs directly since he was a teenager and he was able to do that again [52]. When I left the University of Pennsylvania, another patient gave me a photograph on which he had written, "Thank you so much for all you have done that has allowed me to fulfill my dreams." Those accomplishments are so rewarding to me.

Also, taking care of patients with inherited bleeding disorders... you take care of them over a long time and you get to know them well. A challenge and a joy is that you can see both sides, things that don't work and things that work, but it's very rewarding to see the things that really help patients.

Dr. Sood: In your current position, you're both involved in clinical work, continuing to see patients, as well as very involved as the Director of Translational Research, correct?

Dr. Konkle: I am. When I came to Seattle, one of my jobs was to take the basic research that was happening at the Blood Center, now called Bloodworks, and help get that into the clinic. We have been successful in doing that in studies of *N*-acetylcysteine in TTP [thrombotic thrombocytopenic purpura] and sickle cell disease. A lot of what I'm doing now is helping to develop structures to facilitate research, which ultimately will improve patient care.

Other work involves using basic and clinical laboratory resources to develop better testing for coagulation disorders, including bleeding disorders.

Dr. Sood: You've had a very prolific career that has explored a lot of different areas. What more do you hope to achieve before you retire? What do you hope your legacy will be? Is it in developing the structures to facilitate the research and clinical care that you mentioned that will stand for generations to come, or do you have other things in mind?

Dr. Konkle: I think that is an important achievement. There is also our current project, My Life, Our Future, for which we are genotyping patients with hemophilia and developing a research repository [53]. That has been a lot of fun because it takes me back to my earlier career in genetics/genomics, although that field has transformed since I was a fellow, when PCR [polymerase chain reaction] was invented. So instead of circling back, I'm circling forward. I think this project will have incredible impact in the hemophilia community. And it's been a lot of fun to think about those things in more depth again from the scientific standpoint.

I've also been involved nationally with the Foundation for Women & Girls with Blood Disorders, which came out of a need to address issues specific to women with blood disorders. I was involved with Project Red Flag of the NHF and we realized that a lot of the needs of women with other blood disorders were similar to those who were

carriers of hemophilia or who had von Willebrand disease, and that providers of care for these women really could use resources. I think we've been very successful. I am a founding board member for that organization. A recently developed program that's very exciting is facilitating clinics where hematologists, gynecologists, and other providers are seeing patients together. These are mostly programs for adolescent girls, and I think they are making a real impact.

I've also have been very involved, nationally, with ASH [American Society of Hematology] and the NIH [National Institutes of Health] in facilitating careers in hemostasis and thrombosis because we need the next generation of benign hematologists.

So when I'm looking at what will be a legacy, it will be those endeavors.

Dr. Sood: Starting off in the all-male research area of hemophilia and then circling forward towards recognizing the importance of including bleeding disorders with women and girls, it sounds like being a female may have influenced part of your legacy. Do you feel like being female has helped with the care of people with bleeding disorders in other ways as well?

Dr. Konkle: I think it does. Clearly, classic hemophilia is male dominated in terms of patients, but I think it does help being a woman to be able to recognize and talk about women who have mild hemophilia—or even more severe hemophilia—by being carriers of hemophilia, and women with other bleeding disorders. I think that's partly because, maybe not so much now but in the past, male medical students would have no idea, for example, what a normal menstrual cycle was. And so to recognize that heavy menstrual bleeding is a major issue in women with bleeding disorders. . . women can relate to the fact that if you're menstruating 3 out of 4 weeks a month, that's probably not good.

Both men and women have advanced care for women with bleeding disorders, but I think that women can sometimes open the conversation more easily and, therefore, advance this area as important. Women in positions of leadership can speak up and, by doing so, help recognize bleeding disorders in women as an important area of research and clinical care.

Dr. Sood: What are your thoughts, or what have you been working on, towards encouraging all young physicians, particularly young female physicians, to explore the area of coagulation disorders?

Dr. Konkle: I think helping individuals see that there are great career opportunities in benign hematology and that there are mechanisms for support. So, it's making opportunities available through training grants to get funding, providing research opportunities and setting up mentorship programs. I think it's really important to have those formal structures. It's important for trainees and junior faculty to have goals and to have mentors to facilitate achievement of those goals. Otherwise, it gets away from us and, all of a sudden, time has gone by or there are opportunities that have been missed.

Dr. Sood: It sounds like you feel finding a mentor is very important to make sure that goals are achieved. Do you think the gender of the mentor matters? What should trainees be looking for in their mentors?

Dr. Konkle: I think the important thing in picking a mentor is that you can see that they have been helpful to other mentees. That sometimes excludes more junior people and that's not necessarily the right thing either, but it's something to consider. The mentee should pick a mentor who is available, interested, and has the expertise and contacts to help the mentee advance. There are going to be different things that are important depending on the mentee's career plans. And so I think as much as possible, it's important to have goals and look at who would be helpful in terms of achieving those goals. If you're a woman and have challenges like balancing work and family responsibilities, it might be easier with a woman as a mentor. But it may not, so I think it really depends on the situation.

Dr. Sood: On that note, do you have any tips or advice about how you have managed to achieve a work/life balance?

Dr. Konkle: Some days I don't feel like I have [achieved a balance] and I wish I had been able to be a little more directed and say "no" more. Someone said that trainees need to act like they can't hear and their hearing aid is out and only put in their hearing aid at certain times. I think that's really good advice, too. You want to take advantage of opportunities and follow up on them, but you don't want to try to do everything. In terms of goal setting, do what is important to you and important to what you want to achieve.

Having children takes time and it's a wonderful thing for those who want to have children; and it's been a wonderful thing for my husband and me. We have always considered parenting a team effort. There always needs to be time for your children and it doesn't end when they get in school.

At times, I would feel overwhelmed but I would be working and thinking, "Oh, I love this. It's so exciting. I'd love to do this all the time." And then I would go home and it was wonderful. Then I would think, "Oh this is so great. I want to do this all the time." And then I thought, "Well, that's pretty good to have everything in your life be really great."

And so it's just dealing with the challenges of juggling, which is tough. The hardest, physically, is when the kids are young. I remember that I didn't want to miss anything, but I was so tired that I wanted to have the world stop while I went to the moon to rest and sleep for a while. My advice is to try to focus on the most important things and you'll get through it. I know that we worry, or I certainly worried whether my kids were okay. And so just look at them and say, "They're doing okay. Everything is okay. We will be able to get through this."

Dr. Sood: That's a relief to hear from someone with a sense of perspective! Moving on, during your career, you have been involved in all sorts of areas of research, you've been an excellent clinician, you've been an excellent teacher. Do you still think that young physicians entering academics can "have it all," and can do all of those things? Or do you think that it's more important to focus on key goals and perhaps limit ambitions?

Dr. Konkle: Given academic medicine today, it's hard to do everything completely and you have to acknowledge that if you're going to lead a basic research program, you're probably not going to do that much clinical care, which was something that physicians did decades ago. That doesn't mean that you can't be involved in some way, but that in the current environment—leading a research team and writing grants—is incredibly time consuming.

On the clinical side, the structures have become complex and the expectations have also become complex and very focused on clinical revenues. But, for those wanting to pursue clinical research, there are great opportunities today with team science. If you are a clinical researcher, you can be part of a bigger team and be an integral part of that research but still spend time providing clinical care. It takes a little more creativity these days so that is a challenge, but there are incredible possibilities.

Dr. Sood: Do you think ASH and NIH are recognizing that need for team science now, that one person can't do it all anymore?

Dr. *Konkle*: They are recognizing that need; in the NIH's strategic visioning, one of the areas is to teach people how to do team science well. I think that one of the challenges remains in recognition of each individual's input into the science—how do we recognize that and how do departments recognize that in terms of promotion? In some institutions, that recognition is really lagging. It's something that needs to change and probably impacts women. I think women tend to be very good at team science overall; it's a generalization, but women may be a little more collaborative. So if they're not recognized for their contribution, then that is an issue in terms of promotion.

Dr. Sood: What do you think other women should do to rise to leadership positions in medicine, as you have? Do you have any advice, particularly for young female physicians who are interested in moving up the ladder?

 doi:10.1002/ajh.24316

Dr. Konkle: I guess I have a theme: to be focused and have goals. Be selfish about it and say, "I'm going to put time into things where I'm going to be recognized for my contribution. Be strategic and pick areas of research where there's expertise and strong investigators with whom to collaborate. As a junior faculty, I was fortunate to begin a many-year collaboration in heparin-induced thrombocytopenia where my clinical research/clinical laboratory expertise could contribute to basic science discoveries and vice versa.

That doesn't mean that you have to put on blinders and never participate in other academic or clinical activities, but I think you have to look at your goals and determine what you need to best accomplish those goals while enjoying your career.

Dr. Sood: *Finally, how does it feel to be considered a pioneering woman in hematology?*

Dr. Konkle: Well that is a real honor, so thank you.

Dr. Sood's Perspective

I had the honor of first meeting Dr. Barbara Konkle when I joined the University of Pennsylvania as a first-year fellow in hematology/oncology. I knew entering fellowship that I wished to specialize in benign hematology. Barb immediately welcomed me and was very receptive to taking on the role of mentor. She has been an incredible mentor to me over the years, and these days I try to model her behavior as much as possible with my own mentees.

Barb has had a huge impact on my career, both through the opportunities she has opened to me and as a role model. Through my time in her clinic, I learned how to care for persons with complex bleeding and clotting disorders. I still occasionally go back to my notes from her clinic when I need to develop a particularly challenging surgical hemostasis plan! She was always on the lookout for grant opportunities for trainees, including being very involved in establishing a K12 program in clinical benign hematology and helping me to become a scholar. She taught me how to write a grant and, to this date, patiently suggests revisions. She encouraged me to achieve my goals, including obtaining a Master of Science degree in Clinical Epidemiology to help facilitate a career in clinical research. She helped me to attend national meetings and introduced me to other people in the field. During fellowship, she allowed me to lead projects including an analysis of the Universal Data Collection database and exploring von Willebrand disease in pregnancy. Even after I completed fellowship and moved to the University of Michigan, Barb offered me the opportunity to become involved in a national cohort study involving older men with hemophilia, which is leading to many new insights that, I think, have an opportunity to really impact future clinical care.

As a role model, Barb demonstrates both professional and personal success. She is a triple threat—a dedicated clinician, teacher, and scientist. She is hard working and seemingly tireless. With so many men in leadership positions in medicine, it was revelatory to see a well-respected woman sitting at the head of the table. While she was indisputably in charge, she made clinic feel warm and welcoming for staff and patients alike. In research, her excitement when presented with new ideas and challenges was contagious and her door was always open to drop by for a chat. While I was in fellowship, she had three other trainees also interested in coagulation disorders, and the center was a fun, active, and vibrant space under her guidance. Barb excels in helping trainees achieve their potential, and numerous mentees have her to thank for their success over the years.

Personally, in her day-to-day, Barb shows how to achieve work/life balance. She is very involved with her family and is a wonderful and caring mother on top of all of her other identities. Her strong moral conscience, sage wisdom, and often hilarious stories of juggling work with motherhood have been inspirational for me and her other trainees. It is clear from her stories that raising a family takes a village, and having family-friendly (not just female-friendly) policies is key.

Over the years, Dr. Konkle has studied numerous aspects of coagulation disorders, ranging from basic science work with Dr. David Ginsburg during fellowship and as a post-doc on the molecular basis of von Willebrand disease as well as PAI-1 expression, to translational work particularly in the areas of heparin-induced thrombocytopenia and hemophilia gene sequencing in the My Life, Our Future study [53], and finally to clinical research, especially with trials of novel factor replacement therapies and outcomes in patients with hemophilia. She has made numerous contributions to the field in the areas of von Willebrand factor modulation in pregnancy and the postpartum period, prevention of postpartum thrombosis, arising issues with hemophilia and aging [50], and the care of patients with hemophilia and inhibitors [49]. She has received federal funding from the NIH and the Centers for Disease Control and Prevention in many of these areas. Dr. Konkle, herself, mentioned that she feels her biggest contribution is in clinical research that really touches and improves the lives of patients. Her groundbreaking work on using rFVIIa for secondary prophylaxis in patients with hemophilia and inhibitors highlights just one of the trials that has expanded treatment options for our patients with hemophilia [49]. Her work in establishing a prospective cohort of older patients with moderate and severe hemophilia who will be followed to study aspects of cardiovascular disease [51], and in establishing a genotyping and research repository through the My Life, Our Future study [53] are also going to have significant impacts in the future both for patient care and as research platforms. Finally, Barb has worked hard to establish new programs to champion trainees, both male and female, and to develop structures to facilitate research that will ultimately improve patient care.

In summary, having Barb as my mentor has largely made my career in coagulation disorders possible. Her wisdom and example have been a guiding light to me, as well as her numerous other trainees, over the years, and I am delighted to be asked to write this perspective. She has made strong and lasting contributions to the field of coagulation disorders, and has greatly improved the lives of patients with bleeding disorders. We are lucky to have her in this field as a true pioneering woman in hematology.

Amy Shapiro, MD

Interviewed by Jennifer Maahs, MSN, PNP

Amy Shapiro, MD

Biography. Dr. Amy Shapiro is the CEO, Co-Medical Director, and Pediatric Hematologist at the Indiana Hemophilia & Thrombosis Center, Inc (Indianapolis, IN). She co-founded the Indiana Hemophilia & Thrombosis Center in 1999 with Dr. Anne Greist, and it is now one of the largest federally funded hemophilia treatment centers in the United States.

Dr. Shapiro has served on the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) since 1997, and is active in many other medical organizations worldwide. She has been a member of the American Pediatric Society, Society for Pediatric Research since 1999. Dr. Shapiro has served as Co-Chair of the Board of Directors for the American Thrombosis and Hemostasis Network (ATHN), and was an active board member from 2006-2013. She has been a member of the International Society on Thrombosis and Haemostasis (ISTH) since 1991. Over the course of her career, Dr. Shapiro has received many awards for her work, including the W. George Pinnell Award for Outstanding Service from Indiana University and the Distinguished Hoosier Award in 2009 from the state of Indiana. In 2001, she was voted the NHF Physician of the Year.

Dr. Shapiro received her medical degree from the New York University School of Medicine (New York, NY) in 1980. She then completed her pediatric internship and residency, and a pediatric hematology/oncology fellowship at the University of Colorado Health Sciences Center (Aurora, CO). Dr. Shapiro continues to be active in studies to improve the treatment and outcomes for people with bleeding disorders. She has also authored or co-authored over 120 articles/abstracts and 8 textbook chapters in the field of hemophilia [54,55].

Q&A

Ms. Jennifer Maahs: To start out, why did you originally go into medicine?

Dr. Amy Shapiro: When I was 8 years old, I was ill and in the hospital for a period of time. I distinctly remember the physicians taking care of me and speaking to people around me as if I weren't there. I thought, "I may be 8 years old, but I understand what you're saying." I wanted to treat children differently than what I experienced as a child.

Ms. Maahs: So what made you focus specifically on coagulation disorders?

Dr. Shapiro: This was more of a circuitous route. I went to medical school first thinking that I wanted to go into surgery, yet I was more attracted to pediatrics. After I went into pediatrics, I realized that I didn't want to do general pediatrics; I wanted to do subspecialty work, as I was interested in focusing on specific types of disorders. I met Dr. William Hathaway at the University of Colorado; Dr. Hathaway made hematology very interesting, so I decided to pursue pediatric hematology/oncology. I believe I spent the first 6 months in hematology, and Bill was one of my attendings. I liked the idea of taking care of people for a long period of time, not due to an acute illness but rather a chronic disease model; making an impact on their life, seeing children develop over time and what you could do to help them was compelling.

Ms. Maahs: What do you remember about the first hemophilia patient you treated?

Dr. Shapiro: I can't remember who the exact first patient was, as there were many where I trained. Overall, caring for patients was fun. There was a wide range of people from all walks of life. Some children were very serious and studious, exercised a lot, and took incredible care of themselves. I remember a few seemed to get themselves into trouble, one sticking a pinto bean in his ear and nose, and another chasing his brother with scissors resulting in a significant palmar laceration—an interesting group of children doing all sorts of things. So there was just a huge spectrum of different kinds of people, and that was interesting.

Ms. Maahs: Do you feel that early in your career you faced special challenges being a woman in medicine? How has that changed over time, or has it changed over time?

Dr. Shapiro: I think that the environment for women in medicine has certainly changed over the years. It was approximately 36 years ago that I graduated from medical school. When I went to medical school, the class was about 25% women, and I think this percentage was fairly consistent from year to year; not as many women went to medical school as now. I think it was difficult for women to get into medical school at that time. I still recall a bank officer where I got a loan for medical school who told me every year to remember that if I didn't finish medical school, I still had to pay back the money. I thought it odd that he felt he needed to say this every year and wondered if he felt compelled to inform male medical students of this same information. Certainly some specialties were more difficult for women to enter compared to others. Today, the number of men and women in medical schools appears far more evenly distributed. It seems now that women feel that they can become physicians and have careers in medicine without sacrificing their personal life, perhaps the way they felt they did a generation before.

Ms. Maahs: How do you feel you've been able to achieve a work/life balance?

Dr. Shapiro: I think the assumption is that I have achieved a balance, but I am not quite sure that is true. Perhaps my husband, who is also a physician, and children should weigh in on this. My children might say that, in some ways, I was less present when they grew up as compared to my husband; this could be true, as he had less on-call responsibilities, less demands on weekends, and more time after work. Therefore, I think he was present for some events that I wasn't. Overall, I think I have achieved more balance in the latter part of my career. I think I just worked harder at both career and family, and probably slept less.

Ms. Maahs: If you could counsel somebody that's starting out now with a young family, is there any advice you would give them to prepare for achieving that balance?

Dr. Shapiro: I think everyone finds a balance in their own way, and I think each person has different expectations. Some people say they want to practice medicine and go home and not think about work. Other people have different aspirations, they want to achieve other things beyond their daily practice, including participating in research, publications, or work in a certain area. Depending on what each person desires, different stressors may be experienced, each requiring different life adjustments or decisions about what can or cannot be reasonably achieved. I think I have made compromises on both sides. I believe that many women likely feel that they may not be as good as they could potentially be as a professional, parent, or spouse. Everyone makes compromises in life. There are things that each of us thinks we are capable of, but realize the extent of required time and effort, and decide perhaps it is not feasible due to personal commitments of family.

Ms. Maahs: Do you think your gender impacts your approach to caring for patients with hemophilia?

Dr. Shapiro: This question presupposes that there are gender differences in the communication and care of patients; data exist regarding differences in communication styles and resultant patient satisfaction between genders. Women bring a slightly different approach to medicine in comparison to a more conventional model of physician-patient interaction. When I trained in medical school, residency, and fellowship, there were many good examples of male physicians who were compassionate, kind, warm, and communicative in their patient interactions. I tried to take the best examples of physicians I worked with regardless of gender. Personally, I think I am not threatening to patients. Patients likely see a short, friendly woman walk in and feel comfortable—not so scary. Mostly, I think it

 doi:10.1002/ajh.24316

is the personality and attitude and not necessarily your sex. It's what you bring to patient interactions on a personal level that is most important. From my personal experience of being ill and from my communication style, I am not afraid to be honest and engage patients and families on a more personal level, to discuss and explain things; this is the essence of what motivated me to go into medicine.

Ms. Maahs: How many of your male pediatric patients do you think look at you as a mother figure? I've heard some parents say, "When he talks to Dr. Shapiro, she's going to be really mad at him because he's not infusing." They may see you as a little bit of a disciplinarian.

Dr. Shapiro: That is what my children say! I was a disciplinarian at home; my kids say, "Don't use that work voice with me." It is important for children to understand the role that they have in their care and outcomes; they must learn to be active participants, not passive. As a provider or parent, it is your responsibility to help them understand and take responsibility for themselves, to participate in their own care. I do speak to patients on that level. I hope they did not think I was angry at them when they experienced adherence issues, but I certainly did speak to them about their obstacles, and tried to help them understand that it was not really in their best interest or good for them to miss prophylactic infusions [56,57]. Most children rebel against their parents and their authority; oftentimes, it is easier for someone outside the family unit to say, "This is not what you should fight over—choose something else."

Ms. Maahs: How do you feel when you see patients that are now adults that you've taken care of since they were babies?

Dr. Shapiro: I think it's great, amazing. I've seen more than one generation of people for whom I have provided care. In some families, I think I've seen three generations—it is an amazing experience and privilege.

Ms. Maahs: What advice would you give to women for choosing an area of focus in medicine? For example, you have a daughter who's in medical school. What advice do you give her?

Dr. Shapiro: I try not to give my daughter advice about these issues, as I want her to find her own way. Now that my daughter is going through medical school, I think she has a deeper understanding of my life and career, and she asks for advice more than she did before. I think she respects my thoughts and opinions a bit more, and understands where they're coming from. When my daughter was young, she came to hemophilia camp and was there with the campers. She saw that our team was involved in these children's lives for a long time and had an impact on them. As she goes into medicine, she thinks about these experiences in relation to her professional goals; one of the things she has said is that she really liked that my patients seemed to know their physician on a deeper level than many patients might and that the long-term relationship had an impact on their lives.

Ms. Maahs: What path do you recommend women should take who want to go into leadership positions in medicine? Do you have any advice for them?

Dr. Shapiro: One thing I have learned through my work at our center, and from our board of directors and management team, is that there are important skills to master that contribute to the ability to lead well. The training one receives in medicine offers some opportunities to begin to learn leadership, but largely these skills are learned through observation or innately acquired. After medical school, you have internship and residency: as an intern, you are taught by attendings and residents; as a resident, you have an opportunity to lead and to teach; and as an attending, you have the opportunity to teach and lead larger groups. The skills you use are often learned through example. Each person has individual strengths and weaknesses, and as individuals or physicians we are not necessarily best suited or equipped to be leaders. If you truly desire to lead and to have people work together towards goals, you may need to learn a different skill set. You need to learn to engage people's hearts and minds to obtain their best effort and achieve the best results. I would advise anyone who wants a leadership position to look at themselves to determine the balance between their ambitions and their personal skill set. An individual's ability to lead can be improved with guidance and effort; just as we need to temper our interpersonal interactions with patients based upon their capabilities and social/emotional issues, we also must temper our interactions with those we lead in the same manner.

Ms. Maahs: Do you think that finding a mentor is important for women who are interested in a successful career in health care? How does that mentor/mentee relationship help?

Dr. Shapiro: I think having a good example of a quality that you want to emulate in life is important; this is something a good mentor can give you. There are many other advantages to good mentorship in terms of ability to conduct research, publications, and patient care. When I think back to my mentor, Dr. Bill Hathaway, I remember admiring his disciplined thought process, his approach to problem-solving, his method for self-learning, and his dedication to patient care and the center he created. He is an amazing teacher. This skill set is tremendous and I admire him for all these qualities.

Ms. Maahs: You said you consider Dr. Bill [Hathaway] your mentor. How do you think he shaped your career?

Dr. Shapiro: I believe that without Dr. Hathaway, I would not have pursued a career in hemostasis/thrombosis. Dr. Hathaway shaped my vision of hemophilia comprehensive care, how to approach patients from a multidisciplinary standpoint, and the importance and value of each team member.

Ms. Maahs: When you think back on relationships with colleagues that you've met over the years, what has that meant to you?

Dr. Shapiro: I think of my relationships with colleagues as a privilege in my career. As the field in which we work is smaller than others, you have the ability to meet people and develop relationships that are collegial, collaborative, and at times blossom into friendships. You can work with people and remain friends for years. You can meet and work with colleagues from all over the country and the world; this has been an amazing opportunity for me. I have friends from fellowship, and I've developed colleagues and friends from around the country and the world; it is interesting and an honor to be able speak to colleagues from different places, explore their practices and interests, discuss their research and potential areas for collaboration, and also learn about different cultures. I don't think there is anything more I could have wanted from my career than this.

Ms. Maahs: What do you consider your biggest accomplishment in your career so far?

Dr. Shapiro: I believe that the development of our treatment center, The Indiana Hemophilia & Thrombosis Center, is my greatest accomplishment. The group of care providers that we have assembled, the dedication they have to patient care, the desire to place the patient first and to achieve excellence is extraordinary. I don't hear our staff say, "I can't do that, I won't do that, it costs too much." When I hear one of them say "That's not good enough. We need to do something more," it makes me proud to know that we have care providers who have truly embraced the concept of great care. To have our care providers sit together to discuss mechanisms in which to do something better, to ask how we can put in more effort or resources to achieve a better outcome, is gratifying [58].

Ms. Maahs: Please share about your first meeting with the Amish. I think that's interesting.

Dr. Shapiro: In approximately 1988, I had a collaborative project with the Mayo Clinic to perform genetic analysis of the factor IX gene in patients and carriers of hemophilia B [59]. I sent letters out to as many patients as I could find and discussed the study with the Indiana Hemophilia Foundation, so they could inform patients and

families as well. One family that responded was Amish and they came to the center in Indianapolis to participate. At the time of their visit I was on the oncology inpatient service and couldn't get off the floor, so I sent our hemophilia nurse to meet them. She called me and said "There are 17 Amish people here, what am I supposed to do?" I replied that "You should see them, discuss the project, and obtain consent and the needed samples."

There were no Amish where I grew up, studied, or trained. I did not understand the impediments or the issues they faced in terms of their health care. I realized after a few interactions that they did not have health insurance, they didn't drive, and most of the community lived 3 hours away from our center. The magnitude of their issues became apparent. In the end, I wrote to the family that had participated in this study and asked if I could come to them and meet other individuals from their community who were affected with hemophilia to discuss their care and issues. I wanted to identify their issues with access to health care, and to determine how these might be overcome. We held the first meeting with their affected community members in a family's home. I remember walking into their home and the women were all in the kitchen glancing at me sideways and the men were assembled in the living room, sitting on benches against the wall, their hats on their heads looking down at the floor. I walked in and thought "Oh my, this is not the friendliest room I've ever walked into." I pulled up a table and chair and pulled out a data collection form I had put together and asked who wanted to speak to me first. The men pushed one member forward at me, saying that "Richard should go first." It turns out that Richard was somewhat of the curmudgeon of the group, so the group wanted to see how I could do with Richard.

I started talking to Richard about his issues with hemophilia and how he treated bleeding episodes. Richard became more animated talking about how he had to go to the ER to get treated, how much dental care cost him because of bleeding and re-bleeding. He didn't know what product the ER gave him, if the dose was correct, how to calculate a dose, or about adjunctive therapies, such as antifibrinolytics. He became emotional as he talked about how much a simple dental extraction had cost him and the burden it placed on him, his family, and his community. No one had educated them before about their disorder, or gave them the knowledge they required to manage or be a partner in management of their hemophilia. I told him that he needed to know more about hemophilia than his doctor; in fact, I thought that for the most part he should be able to take care of himself. At this point, all the men began to inch forward towards our table to hear and participate in our discussion. I asked if they wanted to learn to calculate a dose and learn self-infusion. There was uniform agreement and enthusiasm. I got out a little calculator and I showed them how many units each of them should receive for different kinds of bleeding episodes. I brought out the kits I had put together for venipuncture, if required, and told them "You men are farmers, you do lots of things for your animals, and of course you can learn to self-infuse." I told them to look at their arms and said that these were the best veins I had ever seen! So we sat around the table, each one learning to perform venipuncture. There was enthusiasm, comradery, and excitement.

I had an extraordinary visit. I got everyone's name and address, listed their issues, and left them with information and a beginning sense of empowerment. The next hurdle was to determine how to get them access to replacement therapy, as they had limited income and resources. As a group, they do not want to waste financial resources and did not want to personally purchase product they might not use or need. I had to develop a system that could work for their community, which meant that I subsequently had to work with their community leaders (bishops) and get their approval for whatever system I developed. The community does not like charity from the outside and developing programs that would make replacement therapy available yet avoiding cultural issues was difficult. The community was also somewhat suspicious of me as they felt I must have wanted something from them in exchange for the help I was providing. It took time to develop a trusting relationship and for them to believe that what I truly wanted was for them to receive good care. In the end, we worked together to develop a program that worked for them and achieved access to home infusion therapy. Their barriers to care were overcome and their care equalized. These programs continue and have become enhanced over time. Our center has developed a real partnership with their community where we have been able to work with them to develop other systems of care to address dental needs, the needs of other rare genetic disorders prevalent in their community, and methods to address the financial burden of medical care for the whole community. What starts with one chance encounter, one patient, can turn into something beautiful.

Ms. Maahs: What type of legacy do you want to leave at the end of your career?

Dr. Shapiro: I want to leave our center knowing that it goes forward with the same mission and commitment to the *patients* we serve; I want our center to have the leadership it deserves with people equipped to provide this leadership, people who have a desire to keep us at the forefront of care, education, program development, and clinical research.

Ms. Maahs' Perspective

I first met Amy 22 years ago. I was looking for a part-time nursing position as I pursued my Pediatric Nurse Practitioner degree. At that time, I knew very little about Dr. Shapiro and even less about hemophilia. I had heard that Dr. Shapiro was demanding and had very high expectations. As the hours met my schedule, I accepted the position.

My on-the-job training included working with Amy in the triage, evaluation, and treatment of pediatric patients with bleeding disorders. As our work relationship developed, I learned that the label of "demanding" did not mean she was impossible to work with, but rather she felt every patient deserved the best care possible. I learned that even the most complex problem could be solved with desire and perseverance. I witnessed the result of these efforts in her patient relationships. Amy was truly their champion and their dedication to her was unparalleled. I learned how to listen carefully to patients, develop a plan of care, and work to overcome obstacles to achieve the desired outcome. One example that comes to mind was a young patient who moved back to Indiana after a few years of living in another state. Despite multiple attempts to get the patient back into clinic, we were unsuccessful. The family lived 3 hours away and experienced a variety of social and economic issues creating obstacles to attending scheduled appointments. Instead of trying to schedule another appointment, Amy drove to see the family. She met with them, discussed the importance of the child's medical care, and ultimately succeeded in connecting the family back to the center. The compassion and concern she showed this family had a tremendous impact on everyone involved. The day she dedicated to this patient's visit was worth much more than the 8 hours expended.

There have been many times over the years when Amy has come up with an idea and my first thought was "Are you serious? This will be impossible!" But as I have continued to work with her, I find that these thoughts now rarely occur. I may still think some of her ideas are overly ambitious, but very few are impossible. When our treatment center moved from a university setting to an independent nonprofit program, it was not easy. We knew from experience that our patients did not get the care and attention they needed in a larger university setting. We knew we could improve the care delivery

 doi:10.1002/ajh.24316

system if we were an independent, agile organization. We were honored that almost all of the patients were so dedicated to the physicians and Hemophilia Treatment Center (HTC) staff that they followed us to our new location. Amy's drive and absolute resolve have paved the way to our HTC's success.

As I reflect on the past 22 years, there are a few things of which I am certain. Amy's mentorship has shown me that striving for optimal care for patients should be the first priority of any provider. The assumption that something is difficult or impossible is not a sufficient reason not to try. Goals should be established and pursued no matter how difficult or time-intensive. Lastly, I feel I am a better provider and person because of her guidance.

Acknowledgments

Publication of this supplement was made possible by Novo Nordisk Inc. Editorial assistance was provided by Bo Choi, PhD, of MedErgy.

References

1. Kasper CK, Dietrich SL, Rapaport SI. Hemophilia prophylaxis with factor VIII concentrate. Arch Intern Med 1970;125:1004–1009.
2. Kasper CK, Aledort L, Aronson D, et al. Proceedings: A more uniform measurement of factor VIII inhibitors. Thromb Diath Haemorrh 1975;34:612
3. Kasper CK, Pool JG. Letter: Measurement of mild factor VIII inhibitors in Bethesda units. Thromb Diath Haemorrh 1975;34:875–876.
4. Kasper CK. Desmopressin acetate (DDAVP). Good news. JAMA 1984;251:2564–2565.
5. Kasper CK. In vivo recovery and early half-life of infused factor VIII in haemophilia A. Haemophilia 1995;1:14–16.
6. Lusher JM, Shapiro SS, Palascak JE, et al. Efficacy of prothrombin-complex concentrates in hemophiliacs with antibodies to factor VIII. A Multicenter Therapeutic Trial. N Engl J Med 1980;303:421–425.
7. Lusher J, Ingerslev J, Roberts H, Hedner U. Clinical experience with recombinant factor VIIa. Blood Coagul Fibrinolysis 1998;9:119–128.
8. Lusher JM, Roberts HR, Davignon G, et al. A randomized, double-blind comparison of two dosage levels of recombinant factor VIIa in the treatment of joint, muscle and mucocutaneous haemorrhages in persons with haemophilia A and B, with and without inhibitors. rFVIIa Study Group. Haemophilia 1998;4:790–798.
9. Lusher JM, Shuster J, Evans RK, Poulik MD. Antibody nature of an AHG (factor 8) inhibitor. J Pediatr 1968;72:325–331.
10. Lusher JM, Zuelzer WW, Evans RK. Hemophilia A in chromosomal female subjects. J Pediatr 1969;74:265–271.
11. Kulkarni R, Lusher J. Perinatal management of newborns with haemophilia. Br J Haematol 2001;112:264–274.
12. Kulkarni R, Lusher JM. Intracranial and extracranial hemorrhages in newborns with hemophilia: a review of the literature. J Pediatr Hematol Oncol 1999;21:289–295.
13. Kulkarni R, Ponder KP, James AH, et al. Unresolved issues in diagnosis and management of inherited bleeding disorders in the perinatal period: a White Paper of the Perinatal Task Force of the Medical and Scientific Advisory Council of the National Hemophilia Foundation, USA. Haemophilia 2006;12:205–211.
14. Kulkarni R, Soucie JM, Lusher J, et al. Sites of initial bleeding episodes, mode of delivery and age of diagnosis in babies with haemophilia diagnosed before the age of 2 years: a report from The Centers for Disease Control and Prevention's (CDC) Universal Data Collection (UDC) project. Haemophilia 2009;15:1281–1290.
15. Kulkarni R. Improving care and treatment options for women and girls with bleeding disorders. Eur J Haematol 2015;95 Suppl 81:2–10.
16. Kulkarni R, Mauser-Bunschoten EP, Stedman C, Street A. Medical co-morbidities and practice. Haemophilia 2014;20 Suppl 4:130–136.
17. Goldenberg NA, Hathaway WE, Jacobson L, Manco-Johnson MJ. A new global assay of coagulation and fibrinolysis. Thromb Res 2005;116:345–356.
18. Manco-Johnson MJ, Abshire TC, Shapiro AD, et al. Prophylaxis versus episodic treatment to prevent joint disease in boys with severe hemophilia. N Engl J Med 2007;357:535–544.
19. Manco-Johnson MJ, Nuss R, Lear J, et al. 32P radiosynoviorthesis in children with hemophilia. J Pediatr Hematol Oncol 2002;24:534–539.
20. Goldenberg NA, Knapp-Clevenger R, Manco-Johnson MJ. Elevated plasma factor VIII and D-dimer levels as predictors of poor outcomes of thrombosis in children. N Engl J Med 2004;351:1081–1088.
21. Ragni MV, Moore CG, Soadwa K, et al. Impact of HIV on liver fibrosis in men with hepatitis C infection and haemophilia. Haemophilia 2011;17:103–111.
22. Ragni MV, Devera ME, Roland ME, et al. Liver transplant outcomes in HIV+ haemophilic men. Haemophilia 2013;19:134–140.
23. Ragni MV, Belle SH. Impact of human immunodeficiency virus infection on progression to end-stage liver disease in individuals with hemophilia and hepatitis C virus infection. J Infect Dis 2001;183:1112–1115.
24. Bontempo FA, Lewis JH, Gorenc TJ, et al. Liver transplantation in hemophilia A. Blood 1987;69:1721–1724.
25. Ragni MV, Bontempo FA, Hassett AC. von Willebrand disease and bleeding in women. Haemophilia 1999;5:313–317.
26. Gill JC, Wilson AD, Endres-Brooks J, Montgomery RR. Loss of the largest von Willebrand factor multimers from the plasma of patients with congenital cardiac defects. Blood 1986;67:758–761.
27. Gill JC, Menitove JE, Wheeler D, et al. Generalized lymphadenopathy and T cell abnormalities in hemophilia A. J Pediatr 1983;103:18–22.
28. Gill JC, Shapiro A, Valentino LA, et al. von Willebrand factor/factor VIII concentrate (Humate-P) for management of elective surgery in adults and children with von Willebrand disease. Haemophilia 2011;17:895–905.
29. Gill JC, Castaman G, Windyga J, et al. Hemostatic efficacy, safety, and pharmacokinetics of a recombinant von Willebrand factor in severe von Willebrand disease. Blood 2015;126:2038–2046.
30. Gill JC, Endres-Brooks J, Bauer PJ, et al. The effect of ABO blood group on the diagnosis of von Willebrand disease. Blood 1987;69:1691–1695.
31. Montgomery RR, Gill JC. Interactions between von Willebrand factor and factor VIII: where did they first meet. J Pediatr Hematol Oncol 2000;22:269–275.
32. Flood VH, Gill JC, Friedman KD, et al. Von Willebrand disease in the United States: A perspective from Wisconsin. Semin Thromb Hemost 2011;37:528–534.
33. Inbal A, Oldenburg J, Carcao M, et al. Recombinant factor XIII: A safe and novel treatment for congenital factor XIII deficiency. Blood 2012;119:5111–5117.
34. Kritzik M, Savage B, Nugent DJ, et al. Nucleotide polymorphisms in the alpha2 gene define multiple alleles that are associated with differences in platelet alpha2 beta1 density. Blood 1998;92:2382–2388.
35. Nugent D, McMillan R, Nichol JL, Slichter SJ. Pathogenesis of chronic immune thrombocytopenia: increased platelet destruction and/or decreased platelet production. Br J Haematol 2009;146:585–596.
36. Hsieh L, Nugent D. Factor XIII deficiency. Haemophilia 2008;14:1190–1200.
37. Acharya SS, Coughlin A, DiMichele DM. Rare Bleeding Disorder Registry: deficiencies of factors II, V, VII, X, XIII, fibrinogen and dysfibrinogenemias. J Thromb Haemost 2004;2:248–256.
38. Hay CR, DiMichele DM. The principal results of the International Immune Tolerance Study: a randomized dose comparison. Blood 2012;119:1335–1344.
39. DiMichele DM, Gibb C, Lefkowitz JM, et al. Severe and moderate haemophilia A and B in US females. Haemophilia 2014;20:e136–e143.
40. Acharya SS, Schloss R, Dyke JP, et al. Power Doppler sonography in the diagnosis of hemophilic synovitis —A promising tool. J Thromb Haemost 2008;6:2055–2061.
41. Acharya SS, Kaplan RN, Macdonald D, et al. Neoangiogenesis contributes to the development of hemophilic synovitis. Blood 2011;117:2484–2493.
42. Greene LA, Goldenberg NA, Simpson ML, et al. Use of global assays to understand clinical phenotype in congenital factor VII deficiency. Haemophilia 2013;19:765–772.
43. Leissinger CA. Prevention of bleeds in hemophilia patients with inhibitors: Emerging data and clinical direction. Am J Hematol 2004;77:187–193.
44. Leissinger C, Gringeri A, Antmen B, et al. Anti-inhibitor coagulant complex prophylaxis in hemophilia with inhibitors. N Engl J Med 2011;365:1684–1692.
45. Kruse-Jarres R, Fang J, Leissinger CA, Ganapamo F. Reduced production of IFN-gamma and LT-alpha is associated with successful prednisone therapy in patients with acquired hemophilia A: A pilot study. Thromb Res 2011;128:e86–e90.
46. Leissinger C, Josephson CD, Granger S, et al. Rituximab for treatment of inhibitors in haemophilia A. A phase II study. Thromb Haemost 2014;112:445–458.
47. Hotchkiss AJ, Leissinger CA, Smith ME, et al. Evaluation by quantitative acid elution and radioimmunoassay of multiple classes of immunoglobulins and serum albumin associated with platelets in idiopathic thrombocytopenic purpura. Blood 1986;67:1126–1131.
48. Leissinger CA. Platelet kinetics in immune thrombocytopenic purpura and human immunodeficiency virus thrombocytopenia. Curr Opin Hematol 2001;8:299–305.
49. Konkle BA, Ebbesen LS, Erhardtsen E, et al. Randomized, prospective clinical trial of recombinant factor VIIa for secondary prophylaxis in hemophilia patients with inhibitors. J Thromb Haemost 2007;5:1904–1913.
50. Konkle BA, Kessler C, Aledort L, et al. Emerging clinical concerns in the ageing haemophilia patient. Haemophilia 2009;15:1197–1209.
51. Sood SL, Cheng D, Shapiro AD, et al. A cross-sectional analysis of cardiovascular disease in the hemophilia population. Blood 2014;124:2836
52. Konkle BA, Nelson C, Forsyth A, Hume E. Approaches to successful total knee arthroplasty in haemophilia A patients with inhibitors. Haemophilia 2002;8:706–710.
53. National Hemophilia Foundation. My Life, Our Future. http://www.mylifeourfuture.org/. Accessed January 11, 2016.
54. Shapiro AD, Gilchrist GS, Hoots WK, et al. Prospective, randomised trial of two doses of rFVIIa (NovoSeven) in haemophilia patients with inhibitors undergoing surgery. Thromb Haemost 1998;80:773–778.
55. Palla R, Peyvandi F, Shapiro AD. Rare bleeding disorders: Diagnosis and treatment. Blood 2015;125:2052–2061.

56. Duncan N, Kronenberger W, Roberson C, Shapiro A. VERITAS-Pro: A new measure of adherence to prophylactic regimens in haemophilia. Haemophilia 2010;16:247–255.
57. Duncan NA, Kronenberger WG, Roberson CP, Shapiro AD. VERITAS-PRN: A new measure of adherence to episodic treatment regimens in haemophilia. Haemophilia 2010;16:47–53.
58. Duncan N, Roberson C, Lail A, et al. A haemophilia disease management programme targeting cost and utilization of specialty pharmaceuticals. Haemophilia 2014;20:519–526.
59. Sharathkumar A, Hardesty B, Greist A, et al. Variability in bleeding phenotype in Amish carriers of haemophilia B with the 31008 C–>T mutation. Haemophilia 2009;15:91–100.

 doi:10.1002/ajh.24316