

**October 16, 2019**

*Welcome to WoW – the Woman of the Week podcast series by PharmaVOICE. This episode was made possible by a generous sponsorship by Purohit Navigation. For more information visit [PurohitNavigation.com](http://PurohitNavigation.com).*

*In this episode, Taren Grom, Editor-in-Chief of PharmaVOICE Magazine meets with Dr. Gwen Nichols, Chief Medical Officer, Leukemia and Lymphoma Society.*

**Taren:** Dr. Nichols, welcome to the PharmaVOICE WoW podcast program.

**Dr. Nichols:** Thank you, Taren.

**Taren:** I would love if you could talk to us about the mission of the Leukemia and Lymphoma Society, also known as LLS, as you are the chief medical officer.

**Dr. Nichols:** The Leukemia and Lymphoma Society is an organization that's been around for 70 years and our mission is to help patients with blood cancers. Now not everyone knows what the blood cancers are, but they include a host of different diseases including leukemias, lymphomas, myeloma, myelodysplastic syndromes, and a large number of less frequent but equally important malignancies that involve the blood. Our goal is to find cures and to help patients get the best possible treatments for these diseases.

**Taren:** And how many people does the society count as members?

**Dr. Nichols:** Well, it isn't really a membership, and I think that that's – the LLS or the Leukemia and Lymphoma Society makes it sound like it's a club, when it's a club that no one would really want to belong to if they had a choice. These are people who have either themselves have a blood cancer or people who care about them or for them. But we serve thousands and thousands of patients each year, along with doing millions and I think somewhere in the \$50 to \$60 million worth of research each year. So it's a very broad mission that we have, and we're there not only to serve the patients and the doctors and nurses, but also the caregivers, the people who care for folks who have these diseases to get them information and to give them support.

**Taren:** Excellent. In terms of that R&D, do you also work with the pharmaceutical or biotechnology companies that are investigating new treatments?

**Dr. Nichols:** Absolutely. So this is one large portion of what we do. So we consider the pharmaceutical industry, and particularly the R&D part of the pharmaceutical industry, partners in quite a lot of this. One of the evidence of that is that when we look over the last three years at all the drugs that have been approved by the FDA for the blood cancers, and there are over 50 new agents over the last three years that have been approved for treatment of patients, when we

look at those we can trace back all – about 45 out of the 50 that LLS research supported some portion of the discovery or the clinical trials that led to the approval of that agent and oftentimes that can be researched where we started – we supported a scientist 15 or 20 years before the agent got approved. So it's a long discovery and development period, but we see ourselves as a really important piece of that continuum to get those drugs to the pharmaceutical manufacturers to be able to develop them fully and get them to patients.

**Taren:** That's an incredible track record. What a statistic. To what do you ascribe that success rate to?

**Dr. Nichols:** Well, the research that we support is not just me and the chief scientific officer picking out our favorite grants, and unfortunately that is sometimes how research get supported. What happens at LLS is that we vet each grant with about 20 experts in the field. And because we've supported their institutions and the researchers themselves over the years, they do this for us for free and they come and we read these grants and we sit around the table and we discuss and rank them so that we can choose the best of the best.

So the people who donate the dollars that go to this research can feel comfortable that we are doing what is really cutting edge and what is really exciting because we know a lot of research doesn't immediately give you results, and so you have to have a long-term picture. And I think our track record is because we take that long-term view and we try – we can support things that maybe the government and the NCI funded grants are a little more conservative because they're using taxpayer dollars. And so we can be a little bit more cutting edge because the donors expect that and they know that what we do is actually leading to results.

So we have a really good track record because we really spend the time and care to go over the grants with a fine tooth comb.

**Taren:** That's amazing. Congratulations to you and your team. You've been chief medical officer of the organization for just about three years now. What has been one of the most surprising things you've learned in your role?

**Dr. Nichols:** Well, because I came to LLS as a scientist and as a doctor, as a hematologist-oncologist I primarily knew the Leukemia and Lymphoma Society for the research and the research grants that understandably the scientific community holds in really high esteem. Getting one of these grants is a real career starter for a young physician or a young scientist, and so I knew that part of LLS. I knew LLS did some education. I had booklets in my office when I was practicing for patients with a lot of good information about their diseases that they could take home and read, but what I really didn't gather from that is just how much else LLS does to help patients. There are videos and podcasts and support groups. We have clinical trial navigation. We have information specialists who are masters level healthcare workers who will answer a free 800-number and answer questions, help you find financial support, social support and we have local chapters that also have that connection to patients.

For instance, we have a wonderful program where we can find another person who's gone through the same treatment or the same disease who's willing to talk to a newly diagnosed patient. And as much as having doctors and nurses can be helpful, having someone who's been through it and can be really practical about how to help you can mean a world of difference for patients.

And so all of these kind of quiet ways that LLS helps patients and provides financial support and the emotional support – I feel ashamed that as a practicing doctor, I didn't know how broad the portfolio is. So it's something that I feel really surprised about and feel really – I feel pressed to make sure more people know about it and take advantage of it because I think it's an – all the cures – I say this to often – but all the cures in the world that we discover – and I'm a scientist – that we discover are meaningless if they don't actually get to the patients.

If they get stalled as a publication on a shelf somewhere, that's great for the researcher and it's great for their institution and it's great for medical science, but it's really not great for the patients today who need that information and need to be able to access those treatments. So I think that what we do after we find these great scientific discoveries is equally as important as doing this really cutting edge science.

**Taren:** That's excellent. Let's talk a little bit about some of the other programs that LLS has, one of which I think is called Cures and Care for Children with Cancer. Talk to me about that one.

**Dr. Nichols:** This is something I feel really passionate about, and I probably should preface this with the idea that I also did a 10-year stint at Roche Pharmaceuticals doing translational research. So I helped put newly scientific developed drugs into clinical trials for the first time in humans and in that capacity, I had the opportunity to see several new agents that had promising potential for pediatric diseases, in particular pediatric leukemias, but also pediatric sarcomas. Because I knew the pediatricians were interested and wanted to get some of these early molecules, I really pitched that hard to the company and I went to the pediatric ODAC, which is the advisory committee of the FDA for pediatrics and talked to them about how we might move some of these exciting agents earlier into pediatrics. I went to the European Medicines Agency and did the same thing. But in the end – and this is not just Roche, so I don't want this to be construed as a criticism of one company; it is across the board, a problem that because pediatric cancers are rare (thankfully), the business case will never be positive for developing a drug in pediatrics alone. So pharma companies wait until they're sure they have another market before they – and this is again, a generalization, but for the most part, they want to be sure that they can make back the investment it would take to do the trial.

And so if you have a choice of a big indication like breast cancer or lung cancer, that's always going to win over pediatric cancer. I was so shocked and frustrated at that as a parent, as a human being that we couldn't change that system that I said if I ever had the opportunity I would try and change it. And coming to the Leukemia and Lymphoma Society, I had that opportunity to try and change the way we think about doing the business of clinical trial development.

The Children's Initiative is a recognition that it can't just be done with more regulations. To our government's credit, they have tried a lot of ways to try and encourage pediatric development, but it can't just – we can't just say bad pharma company isn't doing it and we can't just say make more regulations and we can't say why aren't the pediatricians doing this. Everyone needs to have a vested interest and we have to understand what the roadblocks are for each of the partners so that we can try and alleviate those roadblocks.

And that's what the Children's Initiative is; we're trying to do research that is targeted towards finding the biology of children's cancers, particularly blood cancers and leukemias are the most or first or second most common cancer in children and blood cancers represent about 40% of childhood cancers. So it's a large percentage that fall under our aegis. And so we want to do the research, but we also want to change the clinical trial paradigms.

One of the things we can do, and the plan is called PEDAL, which is Pediatric Acute Leukemia trial, is to think about the child being at the center of the development paradigm and then the drugs being sort of a circle around the child so that the doc can pick the best trial agent for the child to be on. And the current development paradigm – and this is why it's so inefficient – is that the pharmaceutical company says I have drug that we need to test in children and then they screen a lot of children in order to find the ones that would fit for that trial. That's expensive and it wastes children's lives. It's inefficient and it goes against what anybody wants to do. It's not in their best interest and it's not in the kid's best interest, but if we change that around and say we want to find an experimental option that's appropriate for every kid who needs it, we then need to have four or five different potential treatments and pick the best treatment for the kid.

This means that we need pharma partners to sign on to what we call a master trial where they will each have their own separate arm and we will screen children and allot them to the best arm that fits them. Which means that we don't screen 20 children to find one for this trial because that child will have a different trial. So the pharma company only has to pay for the kids that go on their trial. And this changes the whole environment in a way that we think will be much more cost efficient and will help the parents who are looking for trials and are desperately searching. The parents involved in this can take advantage of all of the services that we offer – financial support, travel support, educational support to get the information that they need and to be able to access the trial.

So it's a big undertaking. We are going to have to not only do this in the US, but we're involved in discussions with Canada, the UK, the EU and Australia. So we're really excited that people see the vision of doing better for kids, and we hope that this trial will have its first patient on it in 2020. And if I can make that happen, I will be a very, very happy woman.

**Taren:** That's exciting. Certainly, pediatric trials have always been a challenge as you said, so looking to figure out how to serve these kids who really just don't have any other choices. That's excellent. I look forward to hear how it goes, so we'll have to be back in touch.

**Dr. Nichols:** That would be great. I think we're really gaining momentum, so I'm really starting to – I'm starting to believe. At the beginning, it's a pipedream, but now I see the momentum building and I'm very excited and that our pharmaceutical partners, our pediatric partners, the FDA, the NCI have all been very open and willing to talk about this, and so that gives me a lot of hope.

**Taren:** Because what wouldn't you do to help a kid, right, who's so sick?

**Dr. Nichols:** Right. Right.

**Taren:** That's awesome. Another initiative that you all are working on involves another subset of the population that's been a little bit underserved. Talk to me about Women Curing Cancer.

**Dr. Nichols:** The Women Curing Cancer actually came out of our Washington, D.C. chapter where we have a number of very powerful women, as you know, that are women philanthropists and increasingly – and this doesn't mean that they are women that aren't part of families or women that are part of bigger foundations and organizations, but that increasingly women are investing themselves and donating themselves and choosing charities and their choices may be different than those of men and that's not meant to be a judgment; it's meant to be women should have an equal voice in thinking about how they want the money they've earned to be spent.

We have been framing a way for like-minded women to talk to each other to hear what they think is most exciting and to choose programs within the Leukemia and Lymphoma Society's broad remit, what are the things that you find most appealing to support. And some of the things that we've started to think about are some of our training grants, some of our clinical development grants where we are helping young scientists to stay in the blood cancer business. It is not an easy job to be a laboratory scientist at a university. It's really competitive and financially you have to very quickly be very successful or you're not going to be able to stay employed by the university. It's a hard road, and there are pain points in young investigators' careers, and this is men and women. I think that this resonates with a lot of women who have had careers where they had pain points whether they are in the sciences or otherwise because women naturally, many women have time where they feel biologically they need to have children or to take time off of work. I think that the idea of supporting people's careers during those times where it's really hard to juggle everything you need to juggle as a young person and to stay in the business so we have good doctors and good scientists 20 and 30 years from now resonates with a lot of women who have been successful and that sort of pay it forward idea.

So that's just one area that the Women Curing Cancer had sort of singled in on to be supportive of, and I think that there will be other areas. Obviously, the Children's Initiative is another place that they feel very strongly about trying to help fundraise and support. So this is just in its infancy, but I think it's a really exciting area to think about how we harness the brain power of women who have been successful to invest in things that our future is thinking.

**Taren:** That's exciting as well. This is a great program. A little bit earlier on you talked about some of the different areas in which LLS serves podcasts and some educational materials, and I don't know that everybody understands what the cost of cancer care and the financial burden are on patients and families. So what are you doing to educate the public? I think that if people had a greater awareness around what all of the resources that are needed to solve some of these therapeutic challenges there might be a better acceptance of the pharmaceutical industry which is not doing so well in terms of reputation right now. Tell me what you're doing in terms of education.

**Dr. Nichols:** Well, I think the most important thing that we are doing in our cost of care analysis is to try and change the conversation from just being about the cost of drugs, because obviously that is important. There are challenges – and I know them well having been in the pharma industry with raising prices without a clear indication of why they're being raised other than the business itself. But I think that that's shortsighted, that those conversations need to happen. We need to talk about patent protection and how we work on that. The work we're doing on generics is very important, but it's only a tiny piece of the puzzle. I think many people don't experience the – you experience that your insurance costs a lot of money. You experience high co-pays maybe, but it isn't until you or a loved one has a health crisis that you can really understand how you can go from financially stable to in horrible financial straits in such a short period of time, and it's not just the cost of the drugs and it's not just the cost of insurance; it's the cost of hospitalization. It's the hidden cost within how drugs get administered and it has a lot to do with return of dollars and where they're going and how the middlemen are getting paid. We're really looking into the Medicare reimbursement and some of the out-of-pocket costs for blood cancer patients are extraordinary. They're just extraordinary. It's hard when you are an otherwise healthy person for that to really hit home. But if you think about your mom or your dad suddenly having to come up with \$20,000 a month to pay for their lifesaving medication and another \$10,000 to pay for the infusion center and the insurance premiums and the x-rays and all the other pieces and then the home health aid and the physical therapy... people on a fixed income... even people who have done well and have money in the bank, your retirement can be gone in a blink of an eye.

We have new therapies now that are really, really exciting and can really extend lives and unfortunately, LLS hears because our information resource center gets calls about the cost of care everyday, we hear people who are making decisions about being on the best possible treatment for themselves versus being on a lesser treatment that costs less money and that it doesn't involve using as much resources so that they can leave something for their families. It's heartbreaking, and it's not just one piece.

So we really are trying not to be finger pointing and instead, coming up with very practical things that we can say let's discuss how we do X. And we have a very active policy and advocacy team in Washington and in the States and we have a lot of incredible volunteers who are willing to tell their stories and they go to legislators and say 'here's who I am and here's how much it costs for me to be on this therapy that's saving my life, and here are all the hidden costs that I have associated with this.'

That is very powerful to get everyone at the table to start saying what are the pieces of this that we can address and it can't just be one part. Everybody has got to say I need to put the patient at the center and figure out what we can do to lessen the burden. And it's going to mean a willingness to have less profit for the better of everybody.

**Taren:** Well, that's a big statement, and it'll be interesting to see how that resonates. It's a huge debate so it has enough hope...

**Dr. Nichols:** It is a huge debate and there's a risk, right? There's always a risk being out there and saying we must do something about this would alienate some of the people who help LLS go forward, whether they be donors or they are pharma partners or insurance companies that support us, but I think as human beings we all know we need to try and figure out what we can rationally do that won't bring down any industry but that will help us all do better.

And I think we were very early on willing to step up and say that, and I think it's really important that advocacy organizations feel that the patient is who we're serving, and so we have to say that. We have to be upfront about what we're hearing from patients about how their lives are affected by the fact that our healthcare industry is not yet at a place it should be.

**Taren:** It's brave to have to have those hard conversations, especially with the folks who are supporting you. So again, kudos to you all for taking a stand and looking how to democratize and make equitable healthcare across all sectors. So that's very admirable.

You are scientist and your career has pretty much covered the gamut. You've worked in academia. You've worked at big pharma. You mentioned Roche, and now you're at one of the world's largest voluntary health organizations. So talk to me a little bit about your journey. How did you get from being a bench scientist to being a chief medical officer?

**Dr. Nichols:** Well, it's only with the retro spectroscopy, as they say, that I can look back and actually realize that I always wanted to be a scientist. I think it was my 9<sup>th</sup> grade biology teacher that I just thought was terrific and said biology, that's it for me. When I was in college I had a great mentor in college. I did research in college, and he encouraged me because I wanted to do human-based research to become an MD. I wasn't thinking about that at all. There are no doctors in my family. I wasn't one of those kids who always wanted to be a doctor; I really always wanted to be scientist. But I loved taking care of patients and I found that out when I went to medical school, and so I wanted a career where I could do both, where I could do science and take care of patients. And so academia and doing translational medicine in academia was the choice.

I was at Sloan Kettering and then I was at Columbia, and I only realized now – and this is where the retro spectroscopy comes in – that every 10 years I get an itch that I move. So I did 10 years at Sloan Kettering between my training and being on the leukemia service and then I got offered a laboratory and a chance to teach at Columbia's medical school. So I made the move to Columbia

where I spent 10 years, and then I realized then – I had gotten promoted and I said I was in one of those midlife moments and maybe people who listen to this podcast will recognize themselves in this and I said ‘well, I could either stay at this and get promoted to full professor and be doing the same thing I’m doing or I could try something different.’

And that’s when I just looked into whether what jobs in pharma would be like and the same thing, I did that for 10 years and said by chance got the opportunity passed by me by, of all people, my friend, the LLS chief scientific officer who sent me the job description and I realized when I looked at that, that when I started I got a lot of satisfaction taking care of one patient at a time, but my frustration in doing that was we weren’t changing the science fast enough. So I went to a pharmaceutical company where I thought if I developed some drugs that has the opportunity to change a whole disease and maybe thousands of people’s lives, and I did that and I really enjoyed it. It was incredibly interesting and I learned a lot.

And then I said it still isn’t quite enough. And when I looked at the job description for LLS, I realized I felt badly. I thought maybe I’m just a jack of all trades and master of none that I can’t stay with anything long enough to become the head of it or the chief of it or really the best at that. But then I said no, I think it was all to get to this job where I have the opportunity to change the spectrum of how we treat patients in a much more global sense and change the trajectory in a way that you can’t at one academic institution.

And the other part was that I looked at the job description and said ‘yeah, I can do that. I’ve done that.’ It was very exciting to me to be able to be the chief medical officer and have the ability to think about where we want the research world and the patient care world to go.

**Taren:** That’s awesome. Thank you so much for sharing that. I love it. So you went from one patient to millions of patients.

**Dr. Nichols:** That’s my hope.

**Taren:** That’s fantastic. Along the way, you had to have acquired a number of leadership lessons, things that helped you navigate from one part of your career to the next part of your career. Can you share some of those with us? And what ultimately gave you the courage to step up to be chief?

**Dr. Nichols:** You know it’s an interesting question because I oftentimes I look back and think if I had the confidence I have now when I was in my first job, I might have done things differently and I guess everyone does that that with the tincture of time you hopefully become more confident and have more faith in yourself and your abilities. But part of it also is understanding that collaboration and finding the best in everyone that you truly believe wants to do a good job to help them do that will build you up, it makes the best teamwork and actually gets more done.

I was a lone wolf for a lot of years and I wish that I had learned that lesson earlier that advocating for yourself doesn’t mean talking yourself up and being a sort of – I hear my mother’s voice don’t

boast. It's about finding like-minded people and figuring out how to work together, and I think the more you can help people succeed, the more all of you will succeed. And I think that oftentimes we think if you put your head down and work really hard, you will be rewarded for it. Well, there's a certain amount of that, but it's much better if you all do it as a group and you all put your head down and you do what you're best at and you let somebody else do the stuff that they're best at. And I think if we had more of that in the business world, in the not-for-profit world, in the science world, we would all be happier in our jobs and we'd probably do better.

And so I think that my thinking is really about how do you get the most from others and therefore, get the most for yourself.

**Taren:** That's excellent. Speaking of happiness, how do you gauge success for yourself and then how do you celebrate those successes? Women don't tend to, so it's a question that I ask everyone.

**Dr. Nichols:** I gauge success by knowing that what I've done has had an impact. So I go back to my thinking I knew when I was taking care of individual patients that even if I couldn't save a patient's life, that treating them with respect and kindness and helping them through the worst possible time in their lives had great value, and so I knew I was having an impact.

And the same – when you move a drug forward in development and you bring it so that it can get farther along and hopefully help patients and you see patients benefit from that, you know you're having impact.

And it will be the same at LLS that if some of these programs that we now are creating and building move forward to be what I believe they can be, it will be a really amazing impact and for me a very nice career topper to say I can die a happy woman knowing that I did good for human beings.

**Taren:** That's amazing. You've had so many significant milestones in your career, can you pick one wow moment out that changed the trajectory of your career or made you think differently about what you were doing?

**Dr. Nichols:** Well, this is going to perhaps seem like a not wow moment, but for me it really was. So if you can imagine people who go to medical school tend to be rather intense and driven and those who are medical scientists maybe even more so. I spent a lot of time trying to get the next paper written and the next breakthrough in the clinical trials and the next big thing and I had the fortune of being voted by the nurses at Columbia as the Physician of the Year, and I was really honored. I thanked all the nurses.

One of the nurses who I had worked with offered to give a speech about why she voted for me as Physician of the Year, and she told a story that I had to really go back in my head to even remember. But there was a patient whose room I went into who had had diarrhea and during the diarrhea, their IV line popped out and blood went all over the place and the patient got dizzy and

fell to the ground and this all happened as I was walking in the room. So I came into their room and there's blood all over and there are feces all over and the patient is on the ground. So I assessed the patient, I rang the bell and I realized that the patient was incredibly embarrassed and distressed not by the blood, but by the fact that they had lost their feces. This was someone going through chemotherapy and very weak and absolutely shouldn't have been embarrassed, but we're human beings.

And so I started cleaning the patient up, because I knew how unhappy they were and this nurse came in and couldn't believe that I was actually there cleaning the patient. And she said that was her story and her – she said it isn't... you know 'everyone at Columbia is smart. Everyone is a good doctor, but Gwen didn't sit around and wait for somebody else because it wasn't her job. She realized that the patient was in distress and put the patient first.' I did it without even thinking because I cared about the person. So that stuck with me as a young physician and I was so honored – whenever I have a question about something I say what would the patient want me to do, and that helped guide the rest of my career.

**Taren:** Well, that is a wow moment. I have chills. That's amazing, and I would imagine that she had never seen a doctor do that before. So not only did it impact you, it impacted the patient, but it impacted her as well as I'm sure other nurses as well, and hopefully some physicians too who heard that story.

Dr. Nichols, I can't tell you how much I've enjoyed our conversation. It's been fabulous. I look forward to what you do in the future for Cures and Care for Children, Women Curing Cancer and all of the other good things you're doing at LLS. Thank you so much for spending some time with us for our WoW podcast program.

**Dr. Nichols:** Well, thank you Taren, and I would love to give you an update in the future. So thank you so much.

*Thank you for listening to this episode of WoW – the Woman of the Week podcast series. And thanks again to Purohit Navigation for sponsoring this episode. For more information visit [PurohitNavigation.com](http://PurohitNavigation.com).*

*We also encourage you to listen to additional episodes at [PharmaVOICE.com/WoW](http://PharmaVOICE.com/WoW).*