

Putting Patients First: A Journey to Inclusion in Publishing

Speakers: Dawn Lobban & Sharon Terry

Dawn Lobban (00:00):

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Dawn Lobban (00:23):

My name is Dawn Lobban, I'm head of the Envision The Patient team, a specialist team within Envision Pharma Group, and I'm your guest host for today's episode. Today, we will be discussing patients in publications.

Dawn Lobban (00:34):

I'm delighted to be joined today by Sharon Terry. Sharon is the President and CEO of Genetic Alliance, which works to provide programs, products, and tools for ordinary people to take charge of their health and to further biomedical research.

Dawn Lobban (00:51):

For those of you who attended ISMPP, you'll know that Sharon was also the keynote speaker, and the industry theme was Patients First. She obviously impressed everyone in the audience, including me with her entrepreneurial work as a health advocate and her passion for patient engagement. I'm delighted to welcome you today, Sharon.

Sharon Terry (01:11):

Great, thanks so much, Dawn, I'm delighted to be here.

Dawn Lobban (01:14):

So, Sharon, I understand that despite many very impressive scientific achievements, you weren't initially trained as a scientist. So, I'm wondering if you could just tell us a little bit about how you first became involved in science.

Sharon Terry (01:33):

Yes, thanks so much for the question, that's absolutely right. I, in fact, tried to get out of high school science, I was so science phobic. My two children were diagnosed in 1994 when they were five and seven years old with a rare genetic condition.

Sharon Terry (01:48):

And I was an ordinary mom, in fact, homeschooling my kids and going about the ordinary day, when I learned this and discovered that in fact, nobody knew how to treat

them. And so, threw myself into trying to find a solution for their disease that essentially changed the course of my life and their life for sure.

Dawn Lobban (02:09):

Okay, so obviously, during that process, there would have been a need for you to access information and scientific literature in particular. Can you just give me a sense of what that felt like at the time and how easy that was to do?

Sharon Terry (02:32):

Yeah, so that was in a sense, a lifesaver and also the bane of my existence in the sense that as soon as I realized that the pediatrician and the person who diagnosed them, the dermatologist knew very little about the disease, I thought, "Well, I'm just going to go to a medical library and look it up, and I'm sure the answer will be on the shelf."

Sharon Terry (02:51):

And I first didn't even know how to search medical journals. In those days, in 1994, we're talking about stacks and bound journals and journals that are not yet bound and all that sort of stuff.

Sharon Terry (03:03):

So, I found the papers I could find on PXE. I think I copied about 400 of them because again, nothing's electronic. I brought them home and I literally slept with them because I would fall asleep trying to read them. I discovered that I needed to get some encyclopedias and dictionaries to understand the words in them and so on.

Sharon Terry (03:25):

So, it was a challenge intellectually for sure because of this whole language I didn't know. But perhaps the harder thing for me as I began to acquire the vocabulary was to get a sense of [the data], for example, I decided, "Well, these are all case studies and I don't know anything about case studies versus more population based studies, but I think this isn't exactly an accurate description of the disease."

Sharon Terry (03:47):

I needed to be in the library more and more, and at that time I was living in the Boston area. I would go back to where my kids were born, which was Worcester to the UMass Medical Center, but the trip was an hour. So, I started to try to go to the Countway Library at Harvard, which is a lovely library as you can imagine. And even then, there was a \$25 fee to get in every time. It was very difficult obviously to pay that plus all the charges, 10 cents a page for copying them and so on.

Sharon Terry (04:17):

So, despite having access to world class libraries, really, they were a bit beyond my means. And I did a couple of things. One is I volunteered at the Brigham because if

you're a volunteer, you could get into library for free. And I also discovered that, well, some of this was available online in, I think it was called Grateful Med.

Sharon Terry (04:37):

It was a really primitive search system, but I was delighted by it because I could stay home with the kids and search at night. And what soon happened was I ran into lots and lots of paywalls, of course. I couldn't afford \$40 an article that was even more onerous than going into the library. And I started to do some other things that were probably at the least mischievous.

Sharon Terry (05:03):

I hacked some of the sites so that I could get in and get the articles. I found medical professional friends at the National Audubon where I was a volunteer and got them to give me their password and so on. So, I did a lot to get the articles I needed to begin to understand what was happening in the disease.

Dawn Lobban (05:23):

Wow, okay. So, it sounds like there were a lot of barriers for someone like yourself, and obviously, you were very motivated to overcome those barriers, but it really shouldn't be that hard. And I'm thinking ... Obviously, we're talking about 1994 initially. Have you seen things improve since then? Are you finding this an easier process now?

Sharon Terry (05:51):

Yes, much, much easier. As a result of the kids' diagnosis, I became involved not only in the foundation I founded for their disease PXE International, but also in Genetic Alliance, which I'm now the ... Well, now, for the last 25 years, I've been intensely involved with as President and CEO.

Sharon Terry (06:08):

And what I've found over these years is that society began to understand the importance of these papers. And I think we saw during COVID, even the general public getting it that these papers were critical and also, a trend toward open access.

Sharon Terry (06:25):

And I helped to lead that charge because again, I felt it was really important that we, the public, have access to the papers. I totally understood the journal's needs to have business models, worked with the journals, was the first chair of the PubMed Central Board at the National Library of Medicine.

Sharon Terry (06:45):

And so, really, I sat down with the journal editors and publishers and worked out what ways could we get access and maybe it's a limited kind of access, maybe it's open access, so that now, I can obviously just sit here at my computer and get the papers I need.

Sharon Terry (06:59):

I still bump into paywalls, I still use friends to get the papers for me. And I still speak with the editors and publishers periodically to see what else can we do to make this both sustainable but also, accessible to those who need to read these papers.

Dawn Lobban (07:18):

Okay, great, and I think the move towards open access has been a real game changer for publications and for accessibility of publications. The other area where we have seen a lot of interest in our industry is trying to create more plain language summaries of publications. So, writing in a simpler text to support the manuscript. Is this something that you are familiar with and do you have any thoughts about the value of it?

Sharon Terry (07:52):

Yeah, I think the plain language summaries are fabulous, and the general kinds of concepts and methods and so forth that I need to look at, they're really wonderful for me to get a grasp of what's happening in a particular protocol or project or program.

Sharon Terry (08:10):

It's hard in rare diseases because they're just not written as frequently of course, because it's even rare to get anybody doing research on the disease, let alone doing a plain language summary of something.

Sharon Terry (08:20):

So, a lot of our advocacy groups, myself included, have undertaken writing those summaries and producing them and putting them on our website so that our patients can find the data, the information they need as quickly as they need it and be able to then bring it to their doctor.

Sharon Terry (08:38):

There's a kind of bottom up in rare genetic conditions, I think we're seeing that to some degree in stratified common conditions as well as people start to understand, "Oh, here's a paper about my specific mutation or the group of people that I'm in," then it's very helpful. So, yes, I think overall, that's a fabulous trend and I'm really pleased by it.

Dawn Lobban (08:59):

Great, and obviously, we heard a lot of discussion around plain language summaries at ISMPP how to do them well, where to put them, how to share them, and obviously, the numbers are supporting that. So, I think again, it's been a real game changer in publications in terms of accessibility.

Dawn Lobban (09:18):

And obviously, when we think about open access and we think about plain language summaries, we're thinking about patients and lay audiences as an audience for these publications, which is very important. But also, I was wondering what your thoughts are around including patients in the publications, including their voice as co-authors of publications and the value that that can bring?

Sharon Terry (09:48):

So, very early on, I had the good fortune of working with some investigators who were very generous, I would say, in how they involved me. And so, they certainly involved me in discussions around the research that was happening. And then when it came time to write the papers, I really benefited by being their partner in the process of writing those papers.

Sharon Terry (10:09):

And I think probably, my first two significant publications were: I had discovered the gene working in a lab at Harvard where they lent me bench space, and another team discovered the gene at the same time and I was working with them as well, and so we published back-to-back papers.

Sharon Terry (10:28):

And I published with both teams, and I got to see the process of two different teams working toward a single goal, a journal that accepted both papers at once to give credit essentially to everybody and for me, to have a voice in the publications.

Sharon Terry (10:43):

And over time, (I don't remember how many publications I have now, a couple hundred) I found it obviously a very important way to communicate with the medical community, with the research community and to be able to make a mark in the way that made a difference.

Sharon Terry (10:58):

So, I've worked very hard to include not only myself, but other lay people that could be good voices in the process because I think the patient adds a new perspective and one that we've seen more and more attention for, the FDA itself for example, with patient focused drug development and with real world evidence and so on, is also concerned that people have a voice in the process.

Sharon Terry (11:20):

And I think having people as authors of the papers as well gives credit where credit is due and gives a voice to the very people who these papers are being written ultimately for.

Dawn Lobban (11:33):

One of the things that we hear sometimes when we think about patient involvement as authors of publications is people asking the question, "Do the patients actually want to do this and how do we find them?" So, you mentioned that you encourage some of your patient advocates colleagues to participate as well. What's been your experience in terms of the level of interest and how we can find them?

Sharon Terry (12:05):

So, there's huge interest and I'm really happy you asked that question because I think we can partner — as I said at ISMPP, the key really is that a society like yours partners with an umbrella organization like mine, I have access to about 2,000 advocacy organizations representing almost 10,000 conditions.

Sharon Terry (12:24):

So, it's pretty robust in the sense of interest, and obviously, there's a lot of interest by the advocates. A lot of times they are like myself, a mom or a dad who has a kid and really wants to push forward the research. So, I think matching that way, I think on the local level, there certainly are people in various communities who have an interest in a particular topic, even geographically based for example, and we can help match with that.

Sharon Terry (12:51):

The other way is we run a website called diseaseinfosearch.org. And on Disease Info Search are all of these advocacy groups and the key contacts for them. So, you don't even have to wait for me to answer an email, which I'm pretty fast at, but instead could search on diseaseinfosearch.org and find an advocate who would be willing to work with you as an author.

Dawn Lobban (13:16):

Wow, okay, that sounds like a fantastic resource, thanks for sharing that. And just thinking back to ... You mentioned the first couple of publications that you got involved in. You've obviously had a lot of experience since then, but can you just think back to that initial experience and explain to us how it felt and maybe some of the barriers because we need to start thinking as an industry on how we can make this process easier for patients to participate?

Sharon Terry (13:50):

Yeah, I think the first barriers I encountered were about language vocabulary, ontologies and so forth. And I began to learn that I didn't have to know all of that, I certainly could ask my very senior co-investigators in various projects to help me understand better.

Sharon Terry (14:10):

So, I think the first may have been on my side in the sense of not having to worry about being proud that I could achieve in this particular way, but instead being able to say, "I

don't understand this paragraph”, or “I don't understand the concept you're trying to get across here”, so that was the first.

Sharon Terry (14:27):

The second was understanding that I as a person with a lived experience (in this case, my kids) have a lot to offer in the sense of understanding the whole picture of the disease rather than just one aspect. And that's always a good thing, I think, for a journal article.

Sharon Terry (14:46):

I remember even way back with the discovery of the gene or the first mouse model that contextualizing this makes a big difference, and so having the people's voice in that article made a difference. And then I think the next thing was really figuring out how are we going to have my contribution and the contribution of people who are living with the condition makes sense to the readership.

Sharon Terry (15:10):

Because while here I am on my side struggling with, well, it's a whole other language I don't know, it's a culture I don't know, it's more formal than I'm used to, it uses passive tense way more than I'm comfortable with and so forth.

Sharon Terry (15:26):

Well, the researchers, the investigators are struggling as much as I am because while they all are ordinary individuals also living with conditions, when they're in their seat writing the papers and so forth, they're not thinking like the lay public.

Sharon Terry (15:39):

And so, that culture exchange was really important at the beginning. And I think I even wrote one paper on what are the elements of my culture and the investigator's culture that we need to consider when we are writing a paper together.

Dawn Lobban (15:53):

Perfect, that sounds like a good article to read. And I think it's really encouraging that we're seeing more article types coming out that help to capture that patient perspective and also, some training courses specifically aimed at patients who want to co-author, so I think that's fantastic.

Dawn Lobban (16:13):

So, we're nearly at time now, Sharon, but do you have any final comments that you would like to share with the audience?

Sharon Terry (16:25):

Yeah, I think I would say that I'm delighted that societies like ISMPP and particularly ISMPP, are coming forward this way with patients at the center. And I said at the meeting that you're taking it quite seriously and not just checking the box, because we've certainly seen a lot of check the box kind of activity as well.

Sharon Terry (16:43):

I really believe that our voice together with the investigator's voices will make a much, much better platform for advancing research. And I think even as investigators and scientists get a better perspective, a better sense of what the public needs, then obviously, there'll be more support for research, more support for this kind of science. And I'm absolutely delighted that we're seeing so many advances in such a short time really.

Dawn Lobban (17:11):

Brilliant, and just to say thank you so much for all the contributions that you personally have made in this field, it's been very inspiring and incredible. So, thank you so much for your time today and for sharing your experiences and your advice. We could keep talking about this for a lot longer but sadly, we have run out of time.

Dawn Lobban (17:31):

So, thanks to everyone for listening to Informed for medical communication professionals, please take a minute to subscribe to the show on your favorite podcast app, you can inform your colleagues and rate our show highly, if you've liked what you've heard today.

Dawn Lobban (17:46):

We hope you may also join us at an upcoming ISMPP U Webinar or even consider becoming a member of our association. If you're interested, just go to ismpp.org where you can learn more. I'm Dawn Lobban, thanks for listening and goodbye.