**SEASON TWO: Episode 35**

Lisa Goldman & Tori Tomalia: The Ros1ders Lung Cancer Patients Turned Precision Medicine Advocates

April 29, 2020

Karan Cushman: Welcome to the [*The Precision Medicine Podcast*](https://www.interventioninsights.com/precisionmedicinepodcast), sponsored by Trapelo. This is the podcast where experts come to discuss the problems oncologists, reference labs and payers face as precision medicine grows, and consider solutions for advancing the quality of patient-centered cancer care. Be sure to subscribe at precisionmedicinepodcast.com to get the latest episodes delivered straight to your inbox.

Jerome Madison: Welcome to the Precision Medicine Podcast. I'm Jerome Madison, Vice President at Trapelo. And today we have two of the founders of the ROS1ders, an international support group. The ROS1ders is an international support and patient advocacy group for patients and caregivers dealing with all types of ROS1-positive cancers. Lisa and Tori, thank you for being a guest on the podcast.

Lisa Goldman: Thanks. Thanks for having us.

Jerome Madison: Lisa, tell us about the ROS1ders and how the organization got started.

Lisa Goldman: So, the ROS1ders is a group for people with ROS1-positive cancer. So, ROS1 is a genomic marker that's most commonly tested for in lung cancer but has been found in at least a dozen different types of cancers. So, we're actually agnostic as to the origin, but we are just due to the status of testing today, primarily lung cancer patients. But we have a variety of patients in our group. And as you said, we're international, so we have patients from all over the world. Although, since we started in the US, we are primarily made up of US patients right now.

Lisa Goldman: We advocate and support for folks with ROS1 positive cancer. So right now, there is about two FDA-approved targeted therapies to treat ROS1-positive cancer. But there are a number of other therapies in clinical trials and developments that are unique to folks with ROS1-positive cancer. So, our group is there to educate and support people, get them the right information and treatments, and hopefully stimulate the development of more treatments for this type of cancer.

Jerome Madison: Fantastic. Tori, how did the organization kind of form? How'd you guys come together?

Tori Tomalia: Well, I feel like it came out of a conversation between Janet, Lisa, and I. I think it was the two of you sat down with one of the doctors, Dr. Camidge and said, if we're going to make sure ROS1 has a lot of treatment options, what do we do? And he sort of summed it up with, you'll need funding and a critical mass of people. So, we said, well, we can do that. And so that's how we sort of decided we needed to gather this rare mutation, people with this rare mutation, and then somehow raise some money to fund research. So that's what we focused on.

Jerome Madison: Yeah. With the podcast, the feedback that we get is the patient stories of those who have walked the path of the patient are most compelling. They're inspirational for other patients as well as the healthcare providers. Lisa, would you mind sharing, and Tori, share your story of the experience of being diagnosed, and then using the precision medicine approach to find that you are ROS1-positive? What was that like and what's happened since that time?

Lisa Goldman: So, my diagnosis was, like many especially ROS1 positive patients, out of the blue because I had no risk factors for lung cancer. So, I just had a persistent cough that I thought was a typical cold and kept going back to the doctor. And the doctor kind of dismissed it and gave me allergy meds because she thought she'd take a shot at that even though I had no history of allergies, then she took a shot at antibiotics and asthma inhalers even though I had no history of asthma. Finally, it got so bad that I went to the ER over Christmas break because I, well, that was more of a health care issue. My health care HMO required me to either go to an HR or see someone only in network.

Lisa Goldman: So anyway, I was at the ER, they did an X-ray, saw that my lungs were all clouded over. Told me I had pneumonia but that I should get a CT when I got home. So again, with that misdiagnosis, I went home thinking I had pneumonia but needed a CT. Went to see a pulmonologist and then things accelerated quickly. So, after months of misdiagnosis, I got the CT, and within a week, I was getting a biopsy and diagnosed with lung cancer at age 41. I just turned 41. The lucky part of this story is, I live in the Bay Area, and I was fortunate to be at community hospital, so I wasn't at one of the university centers, research centers around here. But I was at a community hospital that was quite sophisticated. As of January 1, I was biopsied and diagnosed on January 10.

Lisa Goldman: The week prior they had decided to start testing for the ROS1 marker as a matter of course. So, I having no knowledge of lung cancer, no background to know that I should ask for genomic testing, they did it as a matter of course. And so, before I even knew to ask for it, I found out ... I started getting these results, these genomic marker test results back. I had already started chemotherapy right there in the hospital just a day after my biopsy because I was in such bad shape. But I had this information in hand. And so, when chemotherapy stopped being effective for me, we switched over to the targeted therapy.

Jerome Madison: Tori, how about your experience? Can you share a little bit of that with us?

Tori Tomalia: So, it was 2013. I was 37 at the time. It's the same thing. It started with just this bad cough. I was, it's a cold though. It's asthma. And I went through all the asthma inhalers all the same, I mean, it's the same story. And then it was probably January that the cough started. And finally, in May, I got a chest X-ray, a CT scan, and that's when they saw like my whole left lung had this enormous tumor in there. And then when they did more testing, they saw it was all through my bones, in my liver. It was widely metastatic.

Tori Tomalia: So, I started chemotherapy, and at that time, they were only testing for EGFR and ALCF regularly where I was. So, I started on chemo, did six cycles of that. And then in the meantime, I was trying to learn about this horrible thing called lung cancer. That's when I came across Janet, Janet Freeman-Daily, the other founder of the ROS1ders. And so, learning from people like her, I heard there was also this thing called ROS1. And so, I asked my doctor if she could test for that. And long story short, she did, and it came back that I have ROS1. So, at that point, I started cabozantinib. I was on it for four years. And I had four great years and since then I've gone through several others, and I'm in a phase one trial right now, which is kind of working. So, it's become a lot more complicated over the past year or so.

Jerome Madison: Understood. I would…know that your group is such a tremendous resource for patients once they hear your stories and your experiences. How do other ROS1 patients find you and what type of information and support do you offer for them?

Tori Tomalia: Well, sometimes they find us from their doctors, which is pretty exciting that doctors are recommending…they speak to other ROS1 patients as well. But sometimes it's just like a Google search or they read one of our blogs or something. And they say, that's the same mutation I have, I want to find out more.

Lisa Goldman: We have a website, ros1cancer.com, and we have a very active secret…so, it's not public. It comes up if you search it, but you can't see the content until you're approved and admitted to the group. But a very active, robust group on Facebook. So that's where most of our content resides. So, people either do searches on Facebook or Google and find our website or our Facebook group.

Jerome Madison: Yeah. Lisa, in addition to your own stories, are there any success stories that kind of stand out in your mind that you can share?

Lisa Goldman: There are a lot of success stories. I mean, it's hard because we also lose a lot of people. I mean, the reality is people only typically get the genomic testing when they're stage four. So, our entire group is pretty much made of metastatic patients. So, I'm going to qualify that before I go into success stories that this is the population we're dealing with, mostly people in dire straits. But it was just posted in our Facebook group a few hours ago, that we had a patient...I forget what country. Tori, what country was she in? Somewhere in Europe.

Lisa Goldman: Anyway, she's having trouble navigating treatments because there's actually a surprising disparity on treatments that are available depending on what country you live in. And it doesn't matter if it's a western country like Canada or the UK or other you'd think fairly sophisticated countries in Asia or Europe. Some of these countries, you cannot get ahold of even the first-line targeted therapy that I'm on. So, these folks really need help navigating to even learn about what treatments are possibly available and then getting them.

Lisa Goldman: And so, there was a collaboration where there were people pitching in from all over the world to help this patient figure out and educate her doctor on what treatments would be best and how to get them. And she's flying, I believe, to Germany soon to get going on a treatment that will if not save her life then hopefully, drastically shift out her survival date.

Jerome Madison: Yeah. It's incredible to listen how your level of influence has spread all over the world to help people who are seeking the knowledge and information that you bring. I guess you guys were set up for success very early with your vision, because as you mentioned, you engaged Dr. Camidge. I think you guys also connected with Bonnie Addario. How did they help you kind of expand that vision?

Tori Tomalia: Well, Camidge gave us a very sort of nuts and bolts from the point of view of a researcher who's on the forefront of this kind of research—what they need and how to proceed. And Bonnie has such a robust organization that it helped to guide us, like how to connect to different people, how to find funding and so forth.

Jerome Madison: Yeah. Patient advocacy groups have become a vital resource to accelerate clinical trial awareness and enrollment for patients. And Lisa, I read in a recent article in Nature, I believe it was, about how your organization promoted the ROS1 Cancer Model Project. How are you guys involved with that and how has it helped further discovery for ROS1 patients?

Lisa Goldman: This is probably the thing I'm most proud of. We initially started with a Facebook group just sharing information, but the fact that we've now been pivotal in pushing research and getting patients to donate biospecimens that may actually move the needle forward is groundbreaking and something that I think other genomic-marker patient groups are trying to do in their own ways as well. So, I think it's really shifting how research is done. So, what we did is, as Tori mentioned, Dr. Camidge told us we just needed a critical mass of patients to study and develop cancer models so that we can do valid research.

Lisa Goldman: So, Janet, Tori, and I collected patients, and then we worked with the Bonnie Addario organization, which is now called GO2 Foundation for Lung Cancer. And they helped us put all the pieces together. We had weekly meetings with them, they would reach out to the researchers sometimes or the pharma companies figuring out what we needed to do. And in the end, the project that we launched a couple years ago is a collaboration both with University of Colorado and the researchers there and Champions Oncology, and the researcher that's associated with that is Christine Lovly at Vanderbilt University.

Lisa Goldman: And the way the research works is, anytime a ROS1 patient goes in for an otherwise necessary medical procedure, and there's excess biospecimen that they have to donate, whether it's from a pleural-effusion draining or from a surgical biopsy, they can overnight that biospecimen to one of the labs either at Colorado or Champions. And they will try to make either a PDX or a cancer model for research. And any models that are created are to be shared freely with any other academic researchers and available for a fee to pharma research. So, we've had success greatly expanding the number of ROS1-cancer models available and research is being done. We're waiting anxiously for more treatments and results from that research. But as you know, researches can be time consuming. But we're on the road.

Jerome Madison: For sure. Well, you guys really started this effort, and it involved collaboration from the very beginning. And with collaboration, we move faster. In fact, over the last year, the conferences that I've attended, including the Precision Medicine World Conference in ASCO, one of the central things were about the information patient records being siloed. And many times, providers can't access information, many times patients can't even access their own information. But with the growth of Precision Medicine, there seems to be a sense of urgency to find ways to share information in order to accelerate the learning and tell more patients. And this seemed to be very instinctive for the ROS1ders, because you decided to only work with researchers who would be open to sharing data and allowing you to direct the use of tissue. Tory, why was that important for you guys?

Tori Tomalia: Well, on one level, it's a very sort of blunt answer in that we all have a vested interest in this. We're not trying to further a career or anything like that. We're trying to stay alive. So, the quickest way we can get answers, the better for all of us. I mean, I guess ideologically, I also feel like that it's most important that you do something for the greater good. So, if you can share that information and further everybody with it, I think that's the best way to go.

Lisa Goldman: I'll just jump in and just emphasize also; we are a very small fraction of the overall pie of cancer patients out there. We were only in about 2% of lung cancer patients. And I'm not sure what the percentage is for the other types of cancer out there. But frankly, just as a matter of practical reality, we can't afford to have our biospecimens siloed. There just aren't enough of us. There aren't enough samples that we can have that luxury.

Jerome Madison: Yeah. For those listeners out there who may be patients experiencing these things, Tori and Lisa, both what would be your advice for them? How would you give a word for them to kind of start this journey if they want their tumor to be profiled and they've not had this conversation yet with their doctor or to learn more about it, what would be your advice for them?

Tori Tomalia: Well, if they have ROS1, they can go to our website and there's information right on there, how to engage your doctor and what forms you need fill out and so forth so that their tumor can be used to grow cell lines.

Lisa Goldman: Can you repeat the question? I wasn't quite sure what you were asking me. Is this before or after they're getting tested?

Jerome Madison: Well, before. So before. You guys had an experience where you were making a diagnosed it kind of went down a path. For those patients who are out there and maybe listening to this, what would be your advice to them to seek help or how to communicate with their doctor to have their tumor profile?

Lisa Goldman: Well, my first piece of advice to any cancer patient who comes to me is, demand politely for genomic testing. No matter the type of cancer. Lung cancer, it's getting more routine but not necessarily universally routine to get the genomic testing, so certainly for lung cancer. But even for any type of cancer, that field is evolving so quickly and you never know what they're going to find, and maybe there'll be additional treatments available to you. So, it's absolutely worth it. If you run into any resistance from your doctor or health insurance for getting that test, it's very possible to reach out to companies like FoundationOne directly, and they're very accustomed to helping patients navigate that process in getting tested.

Lisa Goldman: And then my second piece of advice for new patients is once you have results from that, if you come back with any markers for your cancer, even if there aren't any known treatments today, start googling that and try to find what I call, your people. Because the more precise you can be in navigating to other patients and communities that have your specific diagnosis, the better information and guidance you'll get about available treatments, about clinical trials, about side effects from those treatments, all that kind of stuff. The more specific you can get, the more helpful the information will be to you.

Jerome Madison: Absolutely. And for those listening, you can reach out to them and find this information on their website, ros1cancer.com. That's R-O-S, the number, cancer.com. Are there any other social media platforms where patients, healthcare providers or those interested in learning can better connect with you guys?

Tori Tomalia: Yeah. On Twitter we're @ros1cancer as well and same on Instagram.

Lisa Goldman: Instagram we're the @the\_ros1ders. Yeah. So, you can reach out either those places. All three founders also have personal blogs and you can find us there as well.

Jerome Madison: I think it's fascinating when you go to the ROS1 Cancer website. You guys have the video where it is superheroes, and what you're doing for ROS1 patients out there is super heroic. So, I'll get you out of here on this question. What is your superpower? Because you all are painted in the video as superheroes? What is your superpower and what do you want your legacy to be?

Tori Tomalia:

I guess from the big sense I want to know that I've done something good in the world, through both my family and then through the greater things like ROS1, that have made people's lives a little better.

Lisa Goldman: Yeah, absolutely. I agree with Tori. When you're handed something as difficult as a metastatic cancer diagnosis, it can be overwhelming. So, I take a lot of comfort and pride in the fact that we have managed to create something positive out of this. And create a community that supports each other and helps people live longer, and hopefully accelerating research that will have ripples, not just for ROSS1 positive cancer patients, but all other types of genomic marker groups that are also pushing for their own research. I don't know what my superpower would be.

Jerome Madison: Well, as if you can only pick one superpower. I know, Tori and Lisa, your superpower that's in effect right now is really expanding the vision of what we can all accomplish through having faith in making a difference. So, thank you for that.

Lisa Goldman: Thank you.

Jerome Madison: Lisa Goldman, Tori Tomalia, two of the founders of the ROS1ders here on the Precision Medicine Podcast. Thank you for joining us.

Tori Tomalia: Thanks.

Jerome Madison: Thanks for Having us.

Karan Cushman: You've been listening to the Precision Medicine Podcast sponsored by Trapelo. Trapelo is the first clinical decision support tool to align the interests of oncologist, labs and payers to give patients the best chance at beating cancer. To learn more visit, gettrapelo.com. To subscribe to the podcast or download transcripts of any episode, visit precisionmedicinepodcast.com. We invite you to join the conversation on social media. You can find us on Twitter @PMPbyTrapelo or on LinkedIn at the Intervention Insights company page. If you know someone who would enjoy the Precision Medicine Podcast, please share it. They'll thank you, and so will we. We hope you'll tune in for the next episode.