The Rare Disease Gazette

Conversations with the world's experts about rare disease

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CRAFTING PUBLIC NARRATIVE

FONDATION IPSEN
BookLab

Editorial

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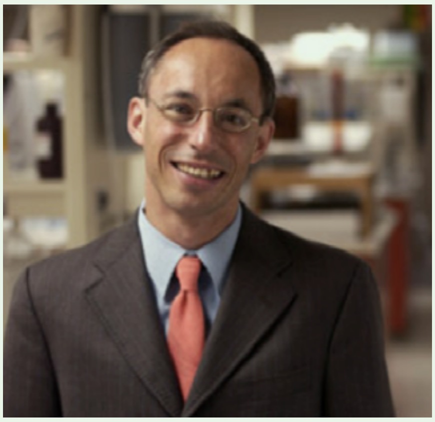
Rare Disease Detection: Rare But Not Alone



The plight of patients with rare diseases is a critical unmet need of patients in healthcare. The statistics are frightening; there are 7000 rare diseases in the world that affect 350,000,000 people. One in eleven Americans has a rare disease. Three-quarters of patients with rare diseases are children and only half of patients receive an accurate diagnosis. The average delay for a patient to receive a diagnosis with a rare disease is 1 1/2 years. It is deeply concerning that one in four patients with a rare disease waits four years for an accurate diagnosis. There is an urgent need to communicate knowledge and expertise in the field of rare disease detection.

The journal *Science*, (American Association for the Advancement of Science) in collaboration with Fondation Ipsen delivers international science webinars for the general public.

In 2022, these webinars focused on building solutions to improve the detection of rare diseases. *The Rare Disease Gazette* is a magazine that broadcasts these discussions.

James Levine

FONDATION IPSEN

DON'T MISS!

The Conversation

Experts of the month: Erika Berg, Ph.D, hosts a conversation with world's experts about Advocacy in rare disease: Crafting the Public Narrative

The Conversation

Experts of the month

Mary Dunkle *(National Organization for Rare Disorders, Quincy, MA)*
Erika Gebel Berg, Ph.D. *(Science/AAAS, Washington, DC; moderator)*
Anne Rancourt *(National Institutes of Health, Bethesda, MD)*
Sparsh Shah *(Musician, motivational speaker, philanthropist, and patient advocate, Iselin, NJ)*

Erika Berg (*host*):
Hello everyone and welcome to our second webinar in the 2023 Science Series on advocacy in rare disease, entitled Crafting the Narrative. *I am Erika Berg, Director and Senior Editor for Custom Publishing at* Science, *and I will be the moderator for this discussion. Today, we are going to discuss the stories we tell when it comes to rare diseases and how advocates can use words to raise awareness, provide education, build relationships, and lobby for change.*

Sparsh Shah:
It is an honor to be here among you all. My name is Sparsh Shah. I am 20 years old. I am a singer, rapper, songwriter, music producer, inspirational speaker, Guinness World Record Holder, and philanthropist, who also has osteogenesis imperfecta type VIII.

Mary Dunkle:
I am a senior advisor to the National Organization for Rare Disorders, or NORD. I have been with NORD since 1999. I originally joined as senior director of communications and for many years oversaw NORD's communications, website, publications, etc. I am now focusing on NORD's educational outreach.

Anne Rancourt:
I am the communications director at the National Institute on Drug Abuse, part of the National Institutes of Health, where I have worked for more than a decade on women's health, HIV, and drug use and addiction issues.

Erika Berg (*host*):
We will start off by talking about language. Sparsh, should we be using the term "rare disease"?

Sparsh Shah:
I think, as with anything to do with language, it has to do with context. Rare disease is no exception, especially because this topic means different things to different people. It means different things to scientists, to patients, and to communities. I feel like most times that we use the term "rare diseases", we use it in a scientific context. With that context in mind, I feel like rare disease is entirely appropriate to use because it is a rare condition and many rare diseases do leave us with some sort of functional impairment, be it physical or neurological, maybe something in between those lines, or both. The only thing I would say about the use of the term "rare disease" would be that it is probably just not best to use it anywhere where it could make someone feel like they are less than someone else just because they have a rare disease.

Erika Berg (*host*):
Thank you. Mary or Anne, any additional comment on that?

Mary Dunkle:
Yes, I have a couple of thoughts. I think it is a really interesting question. You never want to imply that these diseases are inconsequential because they are rare. We have used slogans and campaigns over the years, such as, "Everyone knows someone with a rare disease,", because when you think of rare, it is easy to think, "Oh, that is something that hardly ever happens and it happens to somebody else, so it is sad, but it is not going to affect me." We have struggled against that and had numerous ongoing campaigns over the years.

Sparsh mentioned the scientific context and I think there is a practical reason why we would have to use something like the word "rare". This year, we are celebrating the 40th anniversary of the Orphan Drug Act, which has been incredibly impactful and important for this community. The patient advocates who founded NORD worked very hard to get this piece of legislation passed by Congress. It was signed by President Reagan in 1983 and provides financial incentives that have been incredibly important in encouraging research and development of treatments for these diseases. So, for the purpose of that legislation and to qualify for the incentives, a disease must be believed to affect fewer than 200,000 Americans.

Erika Berg (*host*):
Anne, I imagine that you think a lot about language in your line of work. Could you talk about how you decide how to describe a particular condition at the Drug and Substance Abuse Agency?

Anne Rancourt:
I think that these types of conversations are really happening across diseases and conditions. They are very often brought about by the patient community and their loved ones - people who, for many years, have had labels applied to them, scientific or medical or policy gatekeepers. Now we are in a period where we are really questioning that and in many cases, revising them to be more reflective of a person with lived experiences and perspective. I think that it is a wonderful, valuable, and important conversation worth having. The thing that I try to keep in mind as names change and issues arise, is to always keep an open mind. Language is ever evolving, in culture and across cultures.

> ***"Language is ever evolving, in culture and across cultures."***

So, as we make changes to the language that we use, it is a good opportunity to be open and reflective on the changes behind it. What is the emotion, what is the reasoning, what is the scientific accuracy behind the changing name? How can that conversation about the name itself inform the science, inform the conversation, inform policy? It can be an issue that opens up a broader conversation with a lot of benefits.

Erika Berg (*host*):
A related term that is sometimes used would be "disability". Sparsh, do you have any thoughts on whether we should be using the term "disability" when it is applied in the rare disease space?

Sparsh Shah:
Again, context is emperor. The way that I have heard this term being used in general, is like a label that has been applied to us, as Ms. Anne so beautifully said. However, the good thing is that people in marginalized groups have an amazing ability to take the labels that society places on them and then own them. For example, the LGBTQ+ community adopted the word "queer", or the Christian community adapted the word "Christian". These were all derogatory labels, and we took them and made them our own. In the same way, when you look at the very word "disabled", it is "dis-abled". It implies that, because of our functional impairments, there is something about us that makes us less than people who don't have a disability.

> ***"People in marginalized groups have an amazing ability to take the labels that society places on them and then own them."***

As a philanthropist, and through the music that I make and the speeches that I give, that is something that I really try to tell people, to break that stigma surrounding that word. I have been super blessed to be able to do all the different things that I mentioned in my introduction. It is a huge blessing to be able to live the life that I live. I really feel like this is something that I also evolved in learning. I used to tell people that God closed the door on my ability to walk, but then he opened the door to my voice for me to be able to speak and sing and all these things.

Around 2020, I was doing this scholarship essay for Lyme Connect. They were asking me about what my viewpoint is about disability. During that deep reflective period, I came to realize: is the reason I am really saying that "one door closed and one door open" because that is how I feel about myself, or is it just because it is the best way to explain my situation to people who live in a world that wasn't originally built for us? If this world was built for us, I feel like a lot more people would see it as, the way I see it: God never closed a door on me by giving me this condition. Science or nature never gave me a bad hand by giving me this genetic mutation. It is a window. It is not a door. I just started to realize that. Now, all you must do is open the window and go out. That is what I am doing.

Erika Berg (*host*):
Mary, NORD is an umbrella organization that partners with a variety of smaller patient advocacy groups. How do communication approaches differ for an umbrella organization that is considering many different rare diseases versus a patient advocacy group that may be targeted on a single rare disease?

Mary Dunkle:
We always defer to the disease-specific organizations as the experts on their diseases. We frequently get, for instance, media inquiries seeking medical experts to speak on certain diseases or certain topics that are in the news, and we always go first to the disease-specific groups to see if one of their medical advisors would want to respond. I think there is a wonderful and unique role for umbrella organizations. I should also mention that there are organizations like NORD around the world too, and we work with them. Our role is to help to amplify the voices of the individual disease-specific patient groups by bringing them together, helping them to see our common ground, our shared interests across the spectrum of topics in public policy, research, and education. How can we work together to educate the public, medical professionals, medical students, about particular rare diseases, and rare diseases in general?

> ***"Our role [at NORD] is to help to amplify the voices of the individual disease-specific patient groups by bringing them together, helping them to see our common ground, our shared interests across the spectrum of topics in public policy, research, and education."***

There are many aspects of living with a rare disease that have many commonalities across the spectrum of diseases. NORD's slogan is "Alone we are rare, together we are strong." We try to help the people in all the individual groups find that shared experience together and figure out how best to work together. We also provide a platform to amplify their voices, and even tools like a Facebook group where the leaders of the individual patient organizations can share their experiences, ask questions of each other, figure out best practices or best ways to address certain things. I think it is a nice mix of these in many individual disease-specific groups that are doing fantastic work on behalf of their communities. Through NORD, they can come together and figure out how best to work together. Beyond that, we work closely with EURORDIS, an organization like NORD in Europe. We also helped form an organization in Australia years ago, so many other umbrella groups exist around the world.

Erika Berg (*host*):
Anne, what communication tools have you used which have worked best when applied to influential groups and high level decision makers? How can we communicate with those groups most effectively?

Anne Rancourt:
There has been so much conversation in the past 20 years about what can be done on social media and using digital tools, and all of that is incredible. I think it democratized a lot of communications, outreach, and sharing of stories which are incredibly powerful. When it comes to reaching influential groups, I think it is gone out of vogue to talk about the role of mainstream media as a really powerful communications tool, but at the end of the day, it really remains incredibly important.

Working with large media outlets, such as the New York Times, the Washington Post, the Associated Press, or broadcast news, remains essential to reaching huge groups of millions of people with one story. Working with reporters who are amazing at storytelling, at researching these extremely complex areas of disease and of science, and teasing apart those stories and the issues that matter there, is incredibly rewarding and can have a huge impact in reaching organizations and people who are really working at a high level in terms of national or state-wide reach. Getting into the daily paper really draws attention, gets an issue noticed, and can be an important first step toward a conversation on disease issues that might not have been urgently on the radar before.

> ***“Getting into the daily paper really draws attention, gets an issue noticed, and can be an important first step toward a conversation on disease issues that might not have been urgently on the radar before.”***

Sparsh Shah:
As a musician and speaker trying to develop his craft, mainstream media is definitely one of the best tools that we can use to share our story. Thinking back to times when I was covered quite a lot by mainstream media, for example, for my cover of Eminem’s Not Afraid, one of the main angles for press to grab on with this story was the fact that yes, it was a viral cover, but it is also a viral cover by a 12-year-old who has osteogenesis imperfecta. As a patient, I could take this one of two ways. I could either say, “Ugh, why are people trying to grab onto the disability side of things all the time?” , or, I could decide “okay, this is great”.

Honestly, it is a privilege for me to be disabled, because it brought me to a much higher place in my career. I was also able to use my contact with mainstream media and all the stories that people were telling about me to say, first of all, “Yes, this is what I have, this is my condition”, and bring awareness about OI. Second, it enabled me to clearly say, “No, this is not about pity or sympathy. This is about looking at me not for what I look like, but for what I can do and what I can bring to the world.” I think that kind of talent, that kind of ability might perhaps be a little harder to find in people with rare disease, or it may be a little easier in some cases, but no matter what, if we can find the hidden gems in everyone and polish that coal into diamond, then it doesn’t matter whether you have a rare disease or whether you are disabled. You can make an impact on the world, and that is what makes you uniquely you and that is why you belong here and you are worth it.

> ***“No, this is not about pity or sympathy. This is about looking at me not for what I look like, but for what I can do and what I can bring to the world.”***

Mary Dunkle:
Just one brief follow-up thought. I think having a compelling call to action is always really helpful. We do an annual conference in the fall where we bring together leaders of patient groups, researchers, medical professionals, and government partners from the offices at NIH and FDA that deal specifically with rare diseases and orphan products. Every year, during the period of time leading up to the conference, I get so many inquiries from leaders of patient groups who see this as an opportunity to somehow catch the interest of a researcher, somebody at NIH, or somebody who might become interested in their disease. So, one year, we essentially asked, what would you want to tell the world about your disease in 200 words or less?

We invited people to submit these little vignettes and each one with a photo to go with it. We got wonderful stories and photos from people, and we put them together in a little booklet to hand out at the conference. I submitted an op-ed piece to the Wall Street Journal that they used much to our great delight. These sorts of spontaneous moments do happen, when a researcher hears or reads something like this from one of the patient groups and that light bulb goes off and he or she thinks, “oh, you know, that is similar to this other mechanism of action that I am studying”. Those connections can lead to important work.

Erika Berg (*host*):
Anne, what would you say is the role of storytelling in advocacy and in general with respect to health? We can then talk about rare diseases.

Anne Rancourt:
Stories are so powerful. When you think about the role that storytelling has played throughout human history, it is the stickiest way to get something embedded in someone’s brain. This is how humans have conveyed information for thousands of years. It has been written into songs, it has been written into epic poems - since Homer! This is how we teach our children what we want them to do through nursery rhymes and fairy tales. You really cannot underestimate the power of a good story, a good short to the point story. Having a succinct call to action or take away from it is incredibly valuable.

> ***“Stories are so powerful.”***

I work with a lot of scientists on trying to tell a research story. There is always a push pull between wanting to share a lot of data, a lot of numbers or prevalence data, and the more human side to convey emotion. They are both important. They both serve their own role. I think that when people walk away from a conversation, if they have heard a compelling story, they are going to remember that forever. When you think about some of the most impactful conversations you have had with people, you remember the story that they told. You remember the emotions that were in it and the way that it made you feel and how you related to it. I think that people are often afraid to tell a story. It feels really colorful, imaginative. When you are talking about medicine or about science, you don’t think that it is the place to be imaginative or to use a story. But it absolutely is the place, because it is how people are going to connect and how people are going to take action because they feel compelled based on the emotion that they have experienced from the story. I think that there is also a lesson to be taken from comedians. I always think of comedians when talking about training to tell these stories. Comedians don’t just go out on stage and do a standup routine. They hone it, telling jokes, telling their stories over and over again at comedy clubs until they really have it packaged in exactly the right way so that it hits their audience, and they get the response that they are looking for - in their case, obviously laughter. That is part of storytelling - figuring out what your story is, how you want to tell it, what are the details that people really respond to. Watching your audience as you tell the story and working on it over and over again until you come out with the best way of telling that story and then repeating it over and over again.

> ***“There is always a push pull between wanting to share a lot of data, a lot of numbers or prevalence data, and the more human side to convey emotion.”***

Mary Dunkle:
I agree with everything Anne said, and I wonder how many lives Sparsh has touched with the stories that he has told through his walks and videos. I think with rare diseases, it is even more important

than with other kinds of health-related topics, because there are thousands of these diseases, anywhere from 7 to 10,000 or more, depending on whether you are counting the various subtypes and that sort of thing. Many of them have very strange long names. It is hard for people to remember. They may sound foreign, but having a real person who is living with that disease share his or her story in a positive way on the realities of living with that disease on a daily basis can mobilize people to understand and want to help and support.

I will just add that we also see an incredible bump in traffic on our website or just the general public conversation when a celebrity or some well-known person makes public that he or she is affected by a rare condition. Some months ago, the singer Celine Dion said that she has stiff person syndrome, and that is a condition that you hear very little about. My goodness, we got a huge bump in traffic to our website after she made that announcement. People were going directly to our report on stiff person syndrome. I know that the organization specifically for that community was getting tons of media inquiries because we asked them if they wanted to comment or have one of their medical experts comment and they responded, “It is wonderful, but we are swamped”.

> ***“Having a real person who is living with that disease share his or her story in a positive way on the realities of living with that disease on a daily basis can mobilize people to understand and want to help and support…We also see an incredible bump in traffic on our website or just the general public conversation when a celebrity or some well-known person makes public that he or she is affected by a rare condition.”***

At our 40th anniversary dinner, at the National Portrait Gallery in Washington, Peter Alexander of NBC News served as MC because his sister has a rare condition known as Usher Syndrome. He has actually done a wonderful job of promoting awareness of that condition. Anytime somebody like that makes some sort of public comment on his or her experiences, it reaches a lot of people and it is very helpful to the community.

Erika Berg (*host*):
In cases where celebrities don’t have a personal connection with rare diseases, how can we influence the influencers, politicians, public figures? How do we raise awareness and influence them to get involved?

Mary Dunkle:
I think collaboration is key. There is a wonderful community of people coming from different perspectives who are interested in rare diseases for various reasons. This includes the leaders of the patient advocacy groups, but also medical professionals. The doctors, who choose to devote their careers to focusing on rare diseases, really are a special breed of people: they are very supportive of patient organizations and patient communities. There have been some wonderful things written and said in presentations in recent years. I am thinking of one doctor in particular at CDC, who has been very active in exploring this idea of rare diseases as a public health concern. Even if we use the word “rare”, we need to get away from this idea that it is just something that happens infrequently to somebody else.

Bringing together this community of people who are either treating patients or doing research in the pharmaceutical industry developing products for rare diseases, enables to show a united front and to work together in getting our messages out there. In my experience, the public officials really want to do a good job. They must work within certain budgets. They have certain limitations and constraints. But if we do our homework, if we pull the community together and make a good case to them, I think they do listen.

> ***“In my experience, the public officials really want to do a good job…. They have certain limitations and constraints. But if we do our homework, if we pull the community together and make a good case to them, I think they do listen.”***

Sparsh Shah:
This makes me think of my work as a philanthropist. I have been blessed to help serve people who are less privileged than me, or just people who just have it worse than I do, especially in infrastructure of socio-economic terms. In the rare disease/disability sector, I am a youth ambassador and advocate for some of these organizations that I work with. One of them is the Voice of Specially Abled People or VOSAP.

I mention them because it goes exactly with this topic. There are three main prongs through which we help elevate the lives of people with disabilities or as we call them, specially-abled people. First, being grassroots, like a mobile app where people can just sign up, volunteer, and use the map we have, to go to any public place and take a picture and rate it for accessibility. The rating is not just in terms of whether the place has ramp for people in wheelchairs, but also whether the elevators have braille on them so blind people can read them, or whether there are people available to help guide people who are hard of hearing, or tour guides.

Second, there is Academia: for example, we have been starting research internships with college students. It is something that I want be a part of one day. I got to speak at one of their summer internship conferences to the students. We do lots of research on every single aspect of the issues surrounding people who are differently abled in terms of policy, data... It is all about data-driven research to go to the top level - that is, politicians or governments. We have been working quite a lot with the government of India and their legislation to change in language regarding people who are differently abled. We are one of the organizations that helped to foster that change in language and in legislation, bringing more accessibility in terms of infrastructure to, for example, government buildings, or changing the word “viklang” to “divyang” in current public discourse in India. Also, we all may have heard of ADA 2.0? That is something that we are also trying to work on recently in America, by talking to legislators about getting that passed because that is going to bring a lot of benefit in terms of government, infrastructure, and everything for people who are differently abled.

Erika Berg (*host*):
Anne, do you have a public campaign advocacy success story from your experience that you could share with us, that we could benefit from hearing about?

Anne Rancourt:
In the spirit of storytelling and the power of stories, one of the most famous stories of advocacy and NIH working together was way before my time, in the late 1980s. It is a story that sticks with us: the story of AIDS activists that came to the NIH campus to protest against policies that were keeping them from getting, lifesaving drugs outside of the auspices of a clinical trial. This was before Instagram, before we were all trying to create these incredible visuals that you could photograph. They held an incredibly visual, theatric, and passionate protest that drew a ton of media attention, but also the attention of NIH leaders, who I think finally resonated with what the advocates were asking for and invited them in and sat down with them. That began a very productive conversation.

The advocates were, like so many disease advocates, incredibly well versed in science. They were not themselves scientists or having scientific training, but they really wanted to learn, to have that productive conversation. What I think is so interesting about that story is that there was this incredibly pivotal point where there had to be a change from the theatrical protest. Certainly, those continued and needed to happen to continue the pressure, but coming to sit down together in a room and begin that conversation is a really a pivotal point in the process of advocacy. It was important on the government side as well, as they heard that advocacy, were receptive to it and brought it to the table. For AIDS, for HIV, it resulted in a great change to clinical trial policy. People were able to gain access to the medications that could help save their lives.

There was this mutuality to coming to that point and recognizing when it was time to sit down together, how to have that conversation, knowing both sides, so that they continue to each have their own perspectives, their own agenda moving forward. But how can we begin to do this together? There certainly needs to be an openness on both sides to finding that point and knowing that for progress, that point must be realized. So, that is something that I think is a great example to keep in mind. As a public official, that is one of the stories that is very important in our organizational culture at NIH. That was really one of the most impactful times that it became so clear that people with lived experience must be involved in the research process, in setting the agenda, designing the research, and having a voice throughout the process.

> ***“It became so clear that people with lived experience must be involved in the research process, in setting the agenda, designing the research, and having a voice throughout the process.”***

Erika Berg (*host*):
Thank you. Anyone else has a success story they would like to share?

Mary Dunkle:
One that comes to mind is Rare Disease Day. In 2008, I was in Europe for a conference, and I remember coming back to my hotel room that evening and just flipped on the TV and suddenly became aware that there were stories about people with rare diseases on TV. That was amazing to me, so when I got back home to the states, I heard from our friends at EURORDIS, the European umbrella organization. It turned out that it was the first ever Rare Disease Day that they had launched. They did it purely to promote awareness and to educate, and it was a pretty successful first day! They then asked NORD to bring it to the US the next year in 2009, which we did. It takes place on the last day of February each year, because the first one was on February 29th, the rarest day.

It has grown since. I must admit that my initial reaction was, “Well, that is nice, but there are so many awareness days, it passes. I don’t know if we want to add one more.” I kind of reluctantly got dragged into doing it, and it has turned out to be hugely beneficial for the community. It has grown incredibly over the years. If you are anywhere near social media beginning anytime in February and culminating on that last day, you will just see tons of posts, stories, photos, special events taking place, and media stories. NIH hosts a wonderful Rare Disease Day event each year now. NORD creates resources for teachers to use in the classroom and local families who want to educate students can work with their teacher to go into the school on that day. All sorts of things are happening, and it has really been huge.

Sparsh Shah:
I wanted very quickly share a success story. VOSAP has done something really cool during the pandemic in 2020. We called it the Art from Heart contest. I think it ties into what Ms. Mary and Ms. Anne were saying about the colorful theatrical way of telling a story. We had a contest and invited people from all over the world. This was the first international art contest, specifically on the theme of disability. We had people create visual art that deals with the anxieties, hopes, fears or joys of people who are specially abled. I think approximately 53 countries were represented, as well as at least a hundred, or maybe 200 cities all over the world. There were hundreds of artists who applied. I remember when it was time for the annual gala that year, we were declaring all the winners and just looking at the art, it was like, wow. It was so amazing, because a lot of the people submitting art were people with these lived experiences. So, that art flowed straight from their hearts and, being an artist myself, I can relate to that. The power of storytelling is in the places I think that we can least expect it. I think that is where the most powerful stories can be told. It really shows how important it is to get stories from, as John Legend would say, ordinary people living with rare disease or any other health related or any other issue of importance.

Erika Berg (*host*):
Sparsh, what are some best practices for using social media or other engagement tools for raising awareness?

Sparsh Shah:
This is a great question, and to be very honest with you, I feel like this is something that I am still learning, because I am still a growing and developing influencer. I am not just doing this just for advocacy, but also for my career. One, I want to talk about something totally unique. I think one interesting thing that I would love to see more, and I would love to do more as well, as an influencer, is to think from the perspective of modern social media trends, not just specifically in advocacy, but social media trends in general. Think of popular songs on TikTok. Now imagine taking those wildly popular trends or creating those popular trends if you are someone in the music space like me who is trying to make their songs trend worthy, and pairing it with a story that can help advocate for rare disease, pairing it with lived experience.

For example, I recently released a song called, ‘This Is Me, The Rap Prince.’ The first verse is a mini autobiography. The second verse is my vision statement to the world. In the first song, I am talking about my whole life and how the doctors gave me 48 hours to live. I had 35 to 40 broken bones coming out of the womb - those kinds of things, right? In a sense, I am indirectly telling people about OI and what I go through as a person with OI.

One thing I did, was that I took particular lines, such as "I was bound to die, ain't no lie. Parents cried, life hung, a thread of silk. But I survived that trial, the first of many cases." or "I survived that trial," and the musician in me, was like, "Repeat that." "I survived that and that." Every time, it repeats, it switches images. I just made a bunch of images that tell that story of my life. I haven't seen it yet, but would love to see people using that sound, making the lyrics universal. Now, everyone can use that sound, or that template, to tell their story of the trials that they survived in life, whether they have a rare disease or not.

That can start an even bigger conversation because the whole context of that verse was what made me different and why I almost wasn't here to be here today. That is a very specific example, but I think it would be so cool to continue using popular trends like that or create trends like that, that appeal to the masses in a very natural way.

Anne Rancourt:
I will leave the best practices to Sparsh because I don't think there is anything competing with that. The creativity there is just so wonderful. The greatest part of social media is getting to see that from people. From the boring organizational end, I don't think people usually look to government agencies as the bulwark of creativity on social media or anything, but that is okay. I do think that agencies such as the NIH, and other large organizations, that are on social media but aren't out there doing these creative things and grassroots campaigns, are really open to being a part of the conversation or being involved or helping in some appropriate way for their accounts and for what they represent.

> ***"Agencies such as the NIH, and other large organizations, that are on social media but aren't out there doing these creative things and grassroots campaigns, are really open to being a part of the conversation or being involved or helping in some appropriate way for their accounts and for what they represent."***

At the NIH, it is about communicating the science, that is our mission space. I think that communications offices are often staffed with people who want to be a part of these creative endeavors in the right way, so they are very open to being asked to collaborate or to being approached in some way. So, my advice is to be always never afraid to reach out with an email to communications offices and say, "Hey, I am going to do this. If it is something you would be interested in, let me know, we can discuss." It is not always a fit. Obviously, I can't speak for every communications office if you will hear back or not, but I think, nothing ventured, nothing gained. It is always a really great way to start a relationship or a dialogue about messages where you have a mutual interest.

Mary Dunkle:
Anne was being modest, but I think it has been an incredible help to us to have the information that NIH provides about diseases. I think it would be impossible to overstate the impact of the internet and social media on people with rare diseases. I recall hearing NORD's founder and first president talk about how for many years, when a story would come out, for instance, in Reader's Digest or some widely read publication, and there would just be bags of letters coming into NORD from people across the country who were thrilled to find out that there was an organization that existed that might help them and had no other way to communicate. They were seeking to connect with other people with their disease and that sort of thing.

Obviously, social media has completely changed that. While we always remind people to be careful of the sources to make sure they are getting information from reliable sources, the internet has been truly wonderful in general for those folks. We are often contacted by people who, for instance, have a child who has just been diagnosed with a condition that maybe there are a dozen children around the world known to have the condition, and for them to be able to connect with other families, share information and resources, feel like there is somebody they can talk to and be heard, that is hugely important.

Erika Berg (*host*):
Thank you so much. Unfortunately, we will have to stop there. Many, many thanks to our panelists for being with us today. It has been a delight talking with you all. Goodbye everyone. ■

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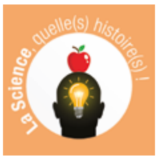

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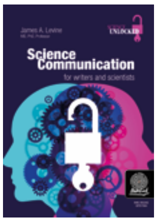

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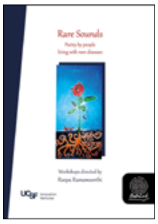

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