The Rare Disease Gazette

Conversations with the world's experts about rare disease

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WORKPLACE WINS

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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.

The Rare Disease Gazette is a magazine that broadcasts these discussions.

James Levine

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DON'T MISS!

The Conversation

Experts of the month: Erika Berg, Ph.D, hosts a conversation with world's experts about rare disease: Workplace wins: Finding a fulfilling career and overcoming stigma in rare disease.

The Conversation

Experts of the month

Elizabeth Caldwell, B.S.
(Clemson University, Clemson, SC)
Dan Jacobs
(American Chef, Entrepreneur, and Advocate, Milwaukee, WI)
Ashley Shew, Ph.D.
(Virginia Tech, Blacksburg, VA)
Bonnielin Swenor, Ph.D., M.P.H.
(Johns Hopkins, Baltimore, MD)

Erika Gebel Berg, Ph.D.
(Science/AAAS, Washington, DC; moderator)

> ***"Nothing about us without us." I think if you let us in the room where decisions are made, we can really inform things. This is something that I am constantly trying to prove: that my experience is invaluable in a lot of spaces, whether it be research, policy, or patient care.***
>
> **– Elizabeth Caldwell**

Erika Berg (*host*):
For many, a career can contribute significantly to a sense of self and purpose. People with rare diseases are no different, yet ignorance, stigma, and accessibility issues can present obstacles to a fulfilling work life. Today we are talking to some amazing people who have successfully navigated the complexities of working in a lab, a university, and even a reality cooking competition, all while living with a rare disease. I would now like to take the opportunity to welcome our panel today.

Elizabeth Caldwell:
My name is Elizabeth Caldwell and I am currently a senior genetics major at Clemson University. My story with rare disease and disability started seven years ago, when I was diagnosed with a disability. At the time, it was considered a rare disease and it really impacted the way that I viewed research and the world in general. I later learned that it is more prevalent than originally believed and it is actually just severely underdiagnosed and understudied. This experience has significantly shaped the way that I view the world and has also influenced my passions and interests.

Bonnielin Swenor:
I am the founder and director of the Johns Hopkins Disability Health Research Center and the endowed professor of disability health and justice at Johns Hopkins. My relationship with rare disease is that I have a rare retinal condition which started when I was 25 years old, as I was applying to graduate school. That experience shaped my research career and really informs the work that I do as a researcher and that my center does. The work we do involves using data to advance equity for people with all types of disabilities, including people with rare diseases. It really focuses on making workplaces, including science and research workplaces, more inclusive for people with disabilities.

Ashley Shew:
I am an associate professor at Virginia Tech and I do humanities-based research on science and technology. History and philosophy of technology are my research areas, and their interface with biotech, in particular. I am multiply disabled from what is considered a rare cancer, but once you have a cancer, you meet a lot of people with that type of cancer through social media and other sources. So I do not think of it as particularly rare anymore but I have the long-term effects and I have had two recurrences of that cancer. So navigating many of the workplace issues faced by people with rare diseases is something I have found myself thinking about, perhaps along with them, more than I expected to at the outset of my career.

> ***"I think the main reason why I went on Top Chef was to inspire people with disabilities to do things that they think is out of their comfort zone."***

Dan Jacobs:
My name is Daniel Jacobs. I am the chef-owner of DanDan and EsterEv Restaurants in Milwaukee, Wisconsin. I am a James Beard finalist for Best Chef Midwest. I was also the runner-up on the most recent season (Season 21) of Top Chef. I was diagnosed in 2016 with a rare neuromuscular disease called Kennedy's disease. Kennedy's disease is very similar to amyotrophic lateral sclerosis (ALS) and is a degenerative disease. While working in the restaurants, I have noticed, in the last five or six years, how my body has changed and how I need to adapt. I think the main reason why I went on Top Chef was to inspire people with disabilities to do things that they think is out of their comfort zone. Also, to help them realize that just because someone tells you no, it does not mean you have to take no for an answer.

Erika Berg (*host*):
I am going to put the first question to Elizabeth, but I am hoping we can go around and get each one of you to weigh in, as each of you has a pretty great job from what I am hearing. Elizabeth, can you tell us about how you ended up in your current role?

Elizabeth Caldwell:
I guess my main role right now would be a student at my university. In that role specifically, I am most involved with the undergraduate research component at Clemson. I am very thankful that I have had the opportunity while at Clemson to partake in multiple different research opportunities, all of which have actually in-

cluded rare disease because I have pursued those, both at Clemson and also at St. Jude Children's Research Hospital. I have been able to really enter the lab and see science through the lens of having a disability while also serving a community that I personally relate to.

Bonnielin Swenor:
I got into this job really because of my lived experience. My journey with disability began right as I was applying to graduate school, and that changed the direction of my research. Going through graduate training and public health, while entering into this community of people with disabilities and rare diseases and learning about it in a very different way, was very informative and pivotal. It made me realize that we need to change the narrative of how we are training, researching, and including (or not including) people with these lived experiences as experts, and make research careers more inclusive. That really shaped the work that I am doing.

> ***"I think people in the rare disease community, in particular, do not know what is out there and do not necessarily think of themselves as disabled from the outset."***

Ashley Shew:
I do feel like some of us who are in some of these careers, considering the academic job market, get here by luck somehow. It is not that we are not also talented, but talent is not always enough in a lot of circumstances and is not even what is looked for in others. So I am very lucky to be where I am and I get to work with so many graduate students and undergraduate students at Virginia Tech through our disability alliance and caucus. I became disabled after receiving my cancer diagnosis when I was 30, so I was already in a particular career path. I knew that I needed to find other disabled people. I think people in the rare disease community, in particular, do not know what is out there and do not necessarily think of themselves as disabled from the outset. We ended up forming this disability alliance and caucus. There was interest from some staff members and a number of undergraduate students to organize these things. It has shifted a lot of the ways in which I pursue my own research and how I think about my own classes, in terms of universal design for learning and how to accommodate really unusual situations. It has made me a more creative and better teacher. Regarding the topics I research, I do not think that every disabled person has to research disability, but there is the sense in which the research questions I am really interested in have shifted to more disability-oriented topics, in concert with larger questions about human existence and technology.

Erika Berg (*host*):
Dan, maybe you can tell us about how you entered the kitchen, and then what brought you to your restaurants and then Top Chef.

> ***"I realized that I needed to do more than just cooking. I am not a researcher, and I do not pretend to be, but what I can do is raise money for researchers."***

Dan Jacobs:
I think it is a very long road that actually brought me to working in kitchens. At a very young age, I found that I really loved cooking and I could make a career out of it and I think that is a truly special thing. I think people spend their whole lives looking for something like that. I figured it out when I was about 19 years old, so I have been cooking for 27 years professionally. I worked for over 15 years in Chicago, and then my wife Kate and I moved to Milwaukee about 13 years ago. We opened up DanDan eight years ago in July and EsterEv shortly thereafter in November. In the same year that we opened DanDan, I was diagnosed with Kennedy's disease. I think when you have a rare disease and there is no cure or no magic bullet, you kind of have this moment of denial. I remember the first time my doctor at the University of Chicago told me what I was diagnosed with, I did not really think much of it. The second time I went there, I just assumed that I was going to get a pill that would make everything fine. When you come to that realization that this is not the case, it changes things. I realized that I needed to do more than just cooking. I am not a researcher, and I do not pretend to be, but what I can do is raise money for researchers. So that was where the next path led me. Over the last six years, we have raised over $100,000 for Kennedy's disease research through the Kennedy's Disease Association (KDA) which has been very fulfilling. Also, as you move along, you shift into different roles. I always say that if I am cooking on the line, something has gone horribly wrong. We have really failed at our jobs. I think I have definitely transitioned into more of a mentorship role and R&D position in the restaurants. I have also been able to work in advocacy at our state, local and federal levels, working with groups like the Independent Restaurants Association, No Kid hungry, and World Central Kitchen, just to name some of the big ones. But it has been a long and strange road. Top Chef was something that I had always wanted to do and had thought that I would be really good at. Turns out I was! It was incredibly challenging, but also incredibly rewarding. I am just lucky enough to still be able to do all the things I do.

Erika Berg (*host*):
Ashley, what challenges have you faced in achieving your career goals and how have you navigated those hurdles?

> ***"Luckily, as I work for a university that is a state university, I have pretty good insurance compared to many. I think that is where a lot of people with rare diseases and disabilities really struggle. Remaining constantly employed, when your body is inconstant, is really a challenge."***

Ashley Shew:
I think about what it means to get treatment and deal with fatigue. It is the ho-hum boring things that have impacted my career in significant ways, such as being out on medical leave, getting treatment, facing uncertainty, the scan schedules and having to cope with a lot of unknowns. When people ask, "What is your five year plan for your career?" I think, "I am trying not to die." It is not that exciting. I am going to do a lot of things, but it is also my experiences that have made me like my work. I think my work is fun and good. I enjoy the collaborations that I

have going on, but being so sick and having navigated some weird career related things has also helped me prioritize other areas of my life.

Luckily, as I work for a university that is a state university, I have pretty good insurance compared to many. I think that is where a lot of people with rare diseases and disabilities really struggle. Remaining constantly employed, when your body is inconstant, is really a challenge. And I have been insulated in many ways because of the career that I have chosen. I also know of people who choose to work for large state universities in different staff roles because the insurance is better than what they might get at smaller institutions or a private college atmosphere. There are some strategic decisions that I hate that we must make about healthcare. However, those are decisions that people with rare diseases have to consider carefully, especially because a treatment can involve many unknowns. It is often unclear how it will go or how it will affect you, which makes having something more dependable, in terms of work, all the more important. I hate that that is often a choice we have to make. In terms of my own career goals I have been very lucky for the insulation that has allowed me to continue to exist in a job as I continue to exist as a human being.

> ***"I think part of it was just getting over that hurdle of asking for help, which can be a big mental block for people with disabilities."***

Dan Jacobs:
I feel like because of my role as a chef-owner, I am a bit insulated as well. I am lucky enough to have these great teams that are willing to pick up where I cannot. I think that is a beautiful thing about the environment that we have been able to create at the restaurant. It is a very team oriented environment. But it is tough. What I do is extremely physical and I deal with fatigue. I deal with the inability to carry things up and down stairs. I think part of it was just getting over that hurdle of asking for help, which can be a big mental block for people with disabilities. Sometimes you want to do everything and prove that you can do everything, but not at the risk of injuring yourself or those around you. Sometimes you just have to ask for the help. I think we have been really lucky in that way, by having great people around us to lean on.

Bonnielin Swenor:
I would say that I have certainly chosen a path to do work in making STEM, science and research more inclusive for people with disabilities, but in many ways I had to, in order to have a job that I wanted. I think that even now, for people with rare diseases or disabilities, we often have to take that on ourselves. And that is on top of everything else we do. I sometimes think, "What could I do with my research if I just did my research?" But that is just not possible because there are so many aspects, from the environment, to the tools we use, to the stigma, to the bias, that if I did not push back against those things, I would have been pushed out a long time ago. So that work is constant.

Elizabeth Caldwell:
Continuing on Bonnie's point, one thing that I always emphasize to people is that my job is being a student. I am aspiring to a career in medicine and policy. I am a friend, a daughter, and all of those roles. But no matter what, I have to be an advocate. That is a role that, unfortunately, almost everyone with a disability has to take on, whether they want to or not. I think it should take a smaller village to help uplift everyone because our community is dealing with health challenges as well as trying to maintain these other roles. That means we are less physically capable than some people to advocate for ourselves, but we have to. I think that, as a society, we need to realize that we should uplift those voices, to help remove some of that burden because at some point, we need to be able to fill our other roles in order to feel the most amount of satisfaction. I love being an advocate, but it is because I choose to be an advocate. Some people do not want that life, but they are forced into it. So I think that is something that a lot of people need to keep in mind when it comes to people with disabilities having careers: we have to advocate for ourselves, but having someone step in as an advocate could be very meaningful.

Erika Berg (*host*):
Let us now talk about stigma. Elizabeth, can you talk about a time when you have experienced stigma and how you dealt with that?

> ***"People have now made assumptions that I am not capable of doing certain things or that I am not able to succeed because of my disability. People are able to make those snap judgments before they have even met me."***

Elizabeth Caldwell:
It pretty much started the day that I was diagnosed, I think. It started when I came to school with this large diagnosis of a disability, at the end of middle school. I went to a small kindergarten through grade 12 school, so most of my grade had known me since I was six years old, and I said to them, "I have a disability and it explains what I have been going through." It was almost as if that could not be true. The replies were, "You are so young. We know you. You are so normal. You are active. You are able to play sports. How could you possibly be disabled?" I think that there is so much stigma around the typical vision of a disability, but equally stigma around moving away from that original typical image. I have received a lot of pushback about the validity of my disability and my diagnosis, as I do not look the part.

Now, since coming to college, my disability has progressed and I have started to use a cane full-time, which has shown people that I do need help and accommodations, and that has been helpful. However, the stigma has now shifted. People have now made assumptions that I am not capable of doing certain things or that I am not able to succeed because of my disability. People are able to make those snap judgments before they have even met me. I always like to say that people see my cane before they see me, and I think that is a big thing that we need to change. If we could just stop assuming things about people, whether it is about disabilities or any other identity, we could really open the door to better conversations that could truly improve the lives of people with disabilities.

Dan Jacobs:
I really feel the same way because my disability does not outwardly show, as I hide my braces. I wear baggy pants so that my braces fit underneath them because I do not want to have that discussion. I do not

want to have to constantly be informing people. I do have a disabled sticker on my truck, and I will park in a disabled spot. A couple of times now I have had people questioning me as to whether or not I am actually disabled. I should not have to have that discussion. I should not have to explain myself to anybody. I also use a cane and when people do not see me using a cane, they assume that I am fine. In reality, it is just that I am having a good day as opposed to a day where I actually need to use my cane. I agree with everything everyone is saying here. It is tough and I wish it were simpler.

> ***"It is about how people react when they have knowledge about your condition, or when they see you acting in ways they do not expect."***

Ashley Shew:
I feel like there is an extra labor in managing all the perceptions of people around you that does not really get unpacked, whether you have an apparent or non-apparent disability. It is about how people react when they have knowledge about your condition, or when they see you acting in ways they do not expect. I do not know that this is necessarily stigma, but it is about dealing with certain perceptions of who you are, where you belong, or what things you are "allowed" to use or not. The way resources for disabled people are policed by non-disabled people, who think they are heroes (but are not), is really ridiculous. I think the Americans with Disabilities Act (ADA) "swagger tags" in your car are an example of that. I have friends who are afraid to use their disability placards because they do not want be assaulted in a parking lot for not looking disabled enough, even though they are in chronic pain or have breathing conditions that make it very difficult to walk long distances. I get a little bit less of that. They eye me weirdly. When I get out of my car and they see that I am an amputee, they leave me alone, which is a delight. I guess it is because I have a heavy object attached to me that I can detach and throw. So I am somewhat more of a threat, and I appreciate that aspect of my life. This managing of other people's perceptions and expectations, whether you are camouflaging in a particular way or not disclosing because you do not want to enter into a conversation, which is none of their business anyway, is tiring. I wish people would let others be, even if they are doing strange things. People know themselves and their bodies better than strangers in a parking lot.

Erika Berg (*host*):
Is there an official name for this type of bias?

Ashley Shew:
It is ableist expectations or ableism.

> ***"When there are barriers that are not being addressed for people with disabilities, the assumption is that it is of course your disability that is holding you back, not the environment and the structures that have kept you out."***

Bonnielin Swenor:
I think in careers, this bias really holds people back. In many jobs, your ability to move forward in your career depends on how others perceive your ability and competence, or on subjective assessments of your success and potential. Academia is a prime example of that and I am a prime example of that. How many talks have you given? How many papers have you published? How many grants have you received? When there are barriers that are not being addressed for people with disabilities, the assumption is that it is of course your disability that is holding you back, not the environment and the structures that have kept you out.

Early in my career, I was kicked off a project because of my disability, as there was concern that I could not see the data. The leader of the project could not understand how I could contribute and thought that I would make too many mistakes. That was a difficult time for me. I was a junior and I was afraid to push back. I knew very well that even if I did push back, it was not and still is not the kind of discrimination that is well understood or accepted by people in power as being real. There are a lot of questions asked and I knew it would just kill my career. So I did not do anything about it and it absolutely impacted my career. It was on a project that was really central to the work I was doing. So, as a result, I shifted gears and started studying something else entirely, because it had major manifestations on what I could and could not do as a researcher, in terms of the grants I could or could not receive. That is actually more common than I think people realize.

Erika Berg (*host*):
Is there a way to respond when you are being clearly pushed aside because of your disability? What should someone do in that situation?

Bonnielin Swenor:
I think now is the moment where this all needs to change. The individual in question was a very successful, very senior, and very influential researcher. As a "nobody", I did not stand a chance to fight that battle. I do not think that has changed much. To be honest, in many institutions and many workplace settings, if someone is bringing in a lot of money or is successful or high profile, it is incredibly hard to fight that and still come out on the other side with opportunities for a career. We need to think carefully, across all career spaces, about what to do when this happens, how to prevent it from happening and how to create opportunities or structures to take the pressure off and offer support. There was no place for me to go to report this, quite honestly. At the time, that would have made sense **and could** have led to meaningful change. Again, I think this is a type of bias and discrimination that is still not being discussed or thought about as real or as happening in our workplaces, and I think that needs to change.

Erika Berg (*host*):
Dan, as you were saying earlier, you have some physical limitations that might interfere with kitchen work, but I am wondering, has stigma entered into your experience in the kitchen or on a cooking reality show? Are there assumptions made about what you can and cannot do that have impacted your work?

> ***"I was lucky enough to be able to make my own path at the restaurant and implement things that would help me as the chef. What I have learned from this experience is to never discount anybody on our team and uplift the people around us. Regardless of where they come from or if they have a disability, we are trying to make our restaurants a better place for people."***

Dan Jacobs:

I was lucky enough to be diagnosed with something when I was already the chef and owner of a restaurant. I think if I had been diagnosed and had started to feel the effects of Kennedy's disease when I was in my twenties then things would have been different. I think I would have had a very similar experience and it would have been very difficult. I do not think people would have understood. The physical limitations would have eventually pushed me into different roles or out of the kitchen, as it is an incredibly physical job. We are talking about being on your feet 12 to 14 hours a day. You are moving a lot and lifting a lot, and on top of that you are adding heat and fire to it all. It is an incredibly physically demanding job and I think it would have been very difficult for me. I was lucky enough to be able to make my own path at the restaurant and implement things that would help me as the chef. What I have learned from this experience is to never discount anybody on our team and uplift the people around us. Regardless of where they come from or if they have a disability, we are trying to make our restaurants a better place for people. Whether it is offering employees health insurance, paid time off, or family leave, we provide it even though we do not get reimbursed for it. I think it is our responsibility to make our restaurant a better place.

As far as the show goes, early on they said, "All right, so we are going to run from this spot to another." And they realized that I was not going to do that. Not only could I physically not do that, but I was very adamant about just saying no. It was up to me to make sure that I was vocal about what I can and cannot do and things were adapted. I have nothing bad to say as everybody on the crew and the producers at Top Chef were all about trying to make sure I was comfortable. During Restaurant Wars, they offered me a stool to sit on, but I refused to do it because I wanted to compete as closely as possible to how all the other chefs were competing. I wanted to make sure that I was not given any sort of real special advantage, such as more time or anything like that. I was going to do this on my own. I think that the mental and physical preparation that went along with that, whether it was stretching or getting rest before and after challenges, was really important for me. There was one time where I fell asleep in a folding chair as I was so exhausted. My body said, "You must go to sleep," and completely shut down. Sometimes you have to listen to your body and know what you need.

Erika Berg (*host*):

I would now like to talk about the workplace and what we share with our coworkers and the world. Managing workplace relationships can be challenging for everyone and with a disability it becomes even more challenging. Bonnie, how do you decide what you want to share with coworkers about your condition?

> ***"It is sometimes a surprise to people when I do disclose and I am still shocked by people's responses. I do not know if I will ever get used to the responses that I get. So I think there are days where I simply do not have the emotional energy to manage other people's responses."***

Bonnielin Swenor:

That is a great question. I will first say that I can easily hide my disability. So I have the privilege and the disadvantage, in some ways, of being able to choose what I want to disclose, or not, in many situations. Not in all situations anymore, but in many. I say that because it is oftentimes a privilege to hide it, but it can also be a painful conversation to have, and can come with a lot of pushback when I do disclose. How do I make that decision? Usually it depends on if it is pertinent to what is being discussed, which oftentimes, because of my work, it is. If I think it is going to be helpful to the conversation or the relationship I usually disclose. Usually with students, I am very upfront about it. To be honest, I think at this point, my disability precedes me for better or worse, and usually for the better.

However, there are many occasions when I do not want to have the full-on conversation. I do not feel like answering all the questions that I am going to get. Honestly, in the workplace, it has gotten better, probably because this is my career. It is actually in personal spaces where it is more difficult. For example, as a mom on the playground, I do not want to have that conversation with other moms, every time. It is sometimes a surprise to people when I do disclose and I am still shocked by people's responses. I do not know if I will ever get used to the responses that I get. So I think there are days where I simply do not have the emotional energy to manage other people's responses.

Ashley Shew:

It is too many things to disclose sometimes. I am multiply disabled from chemotherapy. I am a hard-of-hearing, chemo-brained amputee with tinnitus and Crohn's disease. But I am not going to tell people all of that. I think it explains why I ask for particular things. I have also tried to make sure that my advocacy involves things like asking why the elevators are locked every back-to-school night. They know for sure that this event is open to the public. There will be disabled people present. I just want to use the elevator so I can access the same places everyone else can. Everyone else gets to go with their kids happily in all these spaces. Instead, I am watching people in knee braces on the stairs when we have the technology available. It is not even asking them to pay money. I am asking them to flip a switch. I feel like there are so many areas where we actually have things set up in ways that could make spaces more accessible.

I think about Dan having his own kitchen. He can set it up in ways that work for him. We are lucky when we get into positions of power and can control these everyday things that let people see that we can do a good job, when we can use basic technology that has been established for many years. The constant advocacy is ridiculous, and when I have the energy, I am going to advocate for someone else's disability as well. Because I know that we do not all have the energy. We have to pass the baton regularly in order for any of us to survive.

> ***"I think I have proven and they can tell that my relationship with having a disability makes me more motivated in lab. They know that I will do my work well and sometimes even better than my peers who do not have that same motivation."***

Elizabeth Caldwell:
I think in terms of disclosing my disability in my role as an undergraduate researcher, I have thankfully been in spaces where I felt comfortable enough to be very honest with my principal investigators about what I think I can or cannot do. They have all been very understanding. I think I have proven and they can tell that my relationship with having a disability makes me more motivated in lab. They know that I will do my work well and sometimes even better than my peers who do not have that same motivation. I think the difference comes in when you are disclosing to people that you are not going to have an extended relationship with. I think that is what confuses me. When I first came to school with my cane, in every single classroom I entered, I had at least one person ask me why I used the cane. The questions ranged from, "Are you okay?" or "Why are you using a cane?" to more direct ones like, "What's wrong with you?" I love to advocate, but when I cannot even be a normal student and focus in class or when I go to the grocery store, and keep having to answer the question of what exactly is wrong with me, that is where disclosure gets a little awkward. I am just trying to be a normal person and I do not understand why we have normalized asking strangers about their health history, or assuming it is an injury. I am proud of my disability, so I do not try to hide it. What I cannot stand is when I say, "I am actually just disabled," and it is as if I just said I had the plague. Then the person who was sitting next to me in my class, who was a stranger, wants to keep themselves a stranger, because they feel like they just uncovered this landmine. They pull back and they never speak to me again. That is where the biggest problems occur.

Dan Jacobs:
That is sad, but I think I have had similar interactions. What I did on Top Chef was very public and I made that decision. However, people will come up to me and ask me, "How are you doing?" That is always the most loaded question I think somebody could ask me. It is a deeply nuanced question and I do not even know you. So most of the time I say I am fine. But I did the show because I wanted people to be inspired and to realize that we can do more than people think we can. It is something that we somehow learn to deal with, but you are absolutely correct about the stigma. When I tell people I have a rare neuromuscular disease, there is almost a pull away sort of situation where I have felt that same thing, and where I almost feel like saying, "I am not going to sneeze on you, you are not going to catch it." I am sorry that this is happening to you Elizabeth. School should be fun, or at least a little bit.

Erika Berg (*host*):
Thank you for sharing those stories. I would like to shift gears a little and talk about some strategies for success. Elizabeth, what strategies have helped you navigate the lab environment with a disability?

> ***"Seeing two people in a lab who both live with a disability is really empowering. We are both extremely productive, we have a positive attitude about it and we make great strides in what we do because we are both motivated by our own condition."***

Elizabeth Caldwell:
I think first and foremost, the most important thing for me is feeling socially accepted by my principal investigator and my lab mates, because when you feel like you are on a team, it becomes a lot easier to be yourself and advocate for your needs. As I said before, my principal investigators have both been very understanding, and they know my backstory and what I can or cannot do, but it is based on what I say. They do not assume I cannot do certain assays just because I have a disability. I think that is the most important thing: having an employer, a boss, or a principal investigator who will let you tell them what you need rather than making an assumption about what you need.

Having an inclusive lab space is extremely important to me. All of my closest friends are actually in my lab back at Clemson and I made amazing friends at St. Jude as well. They are extremely helpful when I do need an extra hand. Sometimes, when I have a flare-up, I have trouble opening a tube, but I do not feel like I am a burden for asking for help. And having trouble opening a tube does not mean I am not mentally capable of conducting meaningful research. I just need help with the tube. I actually have several lab mates at Clemson who also have disabilities and one of them actually has the exact same condition as I do. Seeing two people in a lab who both live with a disability is really empowering. We are both extremely productive, we have a positive attitude about it and we make great strides in what we do because we are both motivated by our own condition. But that is all to say that the physical lab is not necessarily accessible. When I need to use my wheelchair, I cannot be at the bench with my wheelchair and have to transition to a high-top. Thankfully, I have the physical ability to do that, but I think labs have been designed without inclusivity in mind. I think that is because of the unconscious bias we have that people with disabilities are not going to do basic science research. All of the doors are too heavy and none of the benches would accommodate a wheelchair. There are simply things in the lab that are not accessible. I am not going around and demanding every single lab become the most physically accessible for me, I just think it would be nice if we could start having that in mind when we design spaces for these careers. Because it is almost a subconscious assumption of, "We do not expect you to be in this career, so we will not design it for you." When you want to go into a career, and you look at all these spaces, why would you want to enter into a space that is not made for you? I think that further excludes people with disabilities from STEM and basic science research, because they can see that it is so inaccessible. I think if we can start redesigning things, and once again, my biggest catchphrase is: do not assume anything about us, we will see real change. So many people are inspired by their condition, their rare disease or their disability, and they want to do that research. They want to fill that gap themselves. Patient scientists are needed. We just need to create a space where they can actually do that, and then I think we will surprise everyone with how much work we can actually do.

Erika Berg (*host*):
Bonnie, are these types of issues, like making science STEM careers and lab spaces more accessible, being discussed?

Bonnielin Swenor:
We certainly need more discussion, but I would say in the past few years there has been some policy change and conversation in some high levels of federal science policy about the prioritization and the need to prioritize making STEM more inclusive for people with disabilities. That includes the second “M” in STEM, which is sometimes expanded to STEMM, for medicine. This includes the universal design of spaces and places, communication, information, and also addressing the ableism that is often present in STEM. As a scientist that uses data, we need more data to help drive that change. That is also a part of the conversations that are being had so that we know where and when things are working and when they are not. We do not even have that yet. So there is lots of work to do, but progress is happening at a faster pace than ever in my career, which is a good sign.

Erika Berg (*host*):
Sounds like there will be a young army of patient scientists just waiting for this opportunity. Ashley, I was wondering, with your personal experience in academia, and with your teaching responsibilities, if you can talk about your experience and how you have navigated your workspaces and what accommodations and strategies have been helpful for you.

Ashley Shew:
I think this is true for many people, but the official channels are often not very helpful. I work with many other disabled people and my research groups end up being majority disabled spaces, just by happenstance. Usually most of the teams I am on include other disabled people. Now that I sometimes lead projects, it is not that I exclude non-disabled people, but the people who are drawn into the type of research I do are often disabled as well. So I actually hear a lot of stories from other people who are trying to navigate a particular infrastructure. At universities, things are really hard for students who are also researchers. Students have to go through services for students with disabilities. It is called many things, but it is a student office for classroom accommodations. Then, there is a second office for workplace accommodations that faculty and staff use, that often students have not even been told about. Services for students with disabilities only cover classroom and some campus stuff, but they will also refer you out to residence life. So it involves twice the paperwork. Those offices have not talked to each other in decades. It is different paperwork and what they can actually offer at the end of the day that might help is really kind of silly. We therefore go through all of this work to get accommodated and to be included. We need accommodations to be included. These may include a workbench you can work at or, for one of my friends with migraines, a different shade of light bulb and not fluorescent lights. It is usually not very complicated things and people have to fight tooth and nail to get them. Most accommodations cost employers under $500 over the course of the life of the technology we are talking about. It is not like accommodations cost the university that much, yet they still get policed. I am lucky in that my physical disability is a very visible one. So in disability spaces, people can infer why I might be there.

“At some universities, if you are teaching, you have to resubmit paperwork every semester, even though some of our disabilities do not change that much or at all. So it just seems like a never-ending stream of paperwork, which I feel is one of the biggest hurdles of being disabled.”

At one point, we had to shift my teaching online. My university dropped its mask mandate and my classroom was an enclosed space. We had to run really heavy duty air purifiers in the room and I am hard of hearing. My hearing aids really love buzzing sounds and amplify them. So I was just listening to buzzing and my students were talking and I thought, “What is this new hellscape that has been created for me?” Because of this, we actually shifted my class online, but I had to submit recent audiograms to show my level of hearing loss, which I did not think was really relevant. The fact that I use hearing aids was relevant. They do not know what I hear and what the hearing aids are causing to be amplified. I would have liked to have a discussion-based class. They were making it really hard to do so. I shifted online for that one, but I was basically warned that I could not keep asking for online teaching because our provost was pressuring everyone to be in person all the time. They said that they would make this a one-time exception. At some universities, if you are teaching, you have to resubmit paperwork every semester, even though some of our disabilities do not change that much or at all. So it just seems like a never-ending stream of paperwork, which I feel is one of the biggest hurdles of being disabled. That does not even include all the insurance paperwork we have to do. Sometimes people hand me a form for something and I just want to start swearing. It is not at them personally, but none of it needs to be this hard. It is set up in a hostile way because they do not want disabled people there. They want to police us out of spaces. We have to remember that our institutions are ableist. Jay Dolmage has a wonderful book on academic ableism that talks about the history behind it. When we talk about sciences and research in universities, much of it was justified as a way to understand, characterize and segregate people. If we are talking about the era of eugenics and institutionalization, it was always non-disabled people talking about disabled people as objects that needed to be managed or eliminated. In fact, the Americans with Disabilities Act does not specify any specific paperwork you need to complete to get accommodations. It does not say you need a note from your doctor. That is how it has been interpreted in ways that are hostile to disabled people.

Erika Berg (*host*):
Let us now switch gears to the kitchen, which is not that different from a lab. Dan, how have you adapted and prepared that space, especially given the physical demands? And what advice would you give to young chefs with disabilities about creating accessible and supportive spaces?

Dan Jacobs:
Elizabeth touched on this, but I think the biggest thing is having the conversation and bringing the team along with you by explaining to them what you are go-

ing through and what you might need. It sounds really simple, but it is harder than it seems. I am an optimist (I am a lifelong Cubs fan), so I believe people want be good and do the right thing. It is so important to have that conversation with people when you need help. Elizabeth, I really relate to what you said about opening jars. I am constantly asking, "Hey, can you open this for me?"

I think people understand that and they want to help. Some of the things that we have done to make the kitchen a little more accessible include doubling down on slip-resistant surfaces. I fall really easily all on my own and do not need any extra help. So we make it as safe as possible. Having areas where people can work sitting down is also important, because sometimes my legs are just so tired that I need to have a stool or an area where I can sit and prep at the same time. I think the biggest one is having that interaction with people and talking to them about what you are going through. Restaurants are unique places as you have creatives and people who are in it for the love of the game. That makes them special places, where people tend to be a bit more empathetic.

Erika Berg (*host*):

Bonnie, you have been involved in translating research data into policy change. Can you share some examples of how data is being used to drive more inclusive workplace practices or policies for people with disabilities? How are we using that data to help?

"Data is an important lever for change, and it has not been used for people with disabilities enough. We do not have the data infrastructures like we do for other groups that are often excluded, and without data, it is almost as if we do not count."

Bonnielin Swenor:

Well, we certainly need to be doing it more often. I would like to share a story. After the experience I talked about earlier, where I was kicked off the team, it was a pretty low point for me, and I had to grapple with my biggest fear: that people would not want to work with me because of my disability. I was worried I was going to be pushed out of my career. So I did the only thing I knew how to do, which was research. I wanted to find data on how many people with disabilities were working in this field, but despite an extensive search, I could not find anything. Eventually, I filed for a Freedom of Information Act request to get data on people with disabilities who have received funding from the National Institutes of Health (NIH). And as a cathartic act, I published that data. What I learned from that experience was that people pay attention to data. I received some responses and that data, along with other's data, led to several changes in committees, which have brought about ongoing change at the NIH and elsewhere. It really showed me how we need both people's stories as well as quantitative data to demonstrate that including people with disabilities is a priority and is necessary. Like I said before, the data we need is where and when it is working and where and when it is not. Data is an important lever for change, and it has not been used for people with disabilities enough. We do not have the data infrastructures like we do for other groups that are often excluded, and without data, it is almost as if we do not count. We are not included in policies or evidence-based decision-making. That is why it is so important to focus on data. As researchers, we can embrace our love of data to drive change.

Erika Berg (*host*):

Elizabeth, what advocacy issue stands out for you or what is the top priority in your mind for making workplaces more inclusive?

""Nothing about us without us." I think if you let us in the room where decisions are made, we can really inform things. This is something that I am constantly trying to prove: that my experience is invaluable in a lot of spaces, whether it be research, policy, or patient care."

Elizabeth Caldwell:

That is a very big question. I think that there are a lot of things that can be done, but the phrase that has been published everywhere for a lot of different minorities is "Nothing about us without us." I think if you let us in the room where decisions are made, we can really inform things. This is something that I am constantly trying to prove: that my experience is invaluable in a lot of spaces, whether it be research, policy, or patient care. While I do have a disability and it does give me challenges, I think I have an advantage in those experiences as I have actually lived them. I am an expert in that field. It is literally in my genetics, since I have that disability. So if you give us a seat at the table, we can really start making changes that will improve the lives of most people with disabilities. Thankfully, Clemson has given me that space and allowed me to try to make some of those changes, but we need to continue doing that. It should not take a disabled person's motivation to be included. I think institutions should want to do that before someone individually comes and says, "Hey, I want to talk about this. Put me in the conversation, please. I am not being included. I am not being heard." I think taking that initiative, before someone has to experience discrimination to bring it up, would be a good change.

Ashley Shew:

I think it is really important to recognize expertise and to view disabled people as experts with their lived experience of disability, especially in community with one another. I would love to see a world where people believed disabled people without requiring us to justify ourselves or provide a lot of health information, especially in the world of rare diseases. You do not always know how things will unfold. Asking for extra paperwork that explains what is going to happen in the future is not always possible and creates an undue burden in the workplace.

Erika Berg (*host*):

Dan, you have been an advocate for Kennedy's disease. What do you think are the biggest issues? How can professionals with rare diseases use their platforms to advocate for their communities?

Dan Jacobs:

I think I am going to echo a lot of what has already been said. However, I think being in the room to inform the decision makers is really the most important thing. It is also important to realize that your government works for you, and that you work for your workplace. In general, I think people want do the right thing, and I am hoping that, given the opportunity, we can make a lasting change that will allow us all to feel comfortable in our spaces.

> ***"Including us is not a nice thing to do, it improves the work we do. And that is the shift that I think really needs to happen."***

Bonnielin Swenor:
I would just add that I think there has to be this mindset shift. Including us is not a nice thing to do, it improves the work we do. And that is the shift that I think really needs to happen.

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