

Structure, Function, Integration.

Journal of the
Dr. Ida Rolf Institute®

November 2023

Structural Integration: The People, the Profession

Dr. Ida P. Rolf (1896-1979) pioneered the profession of structural integration, which is now a global profession with a dozen different international schools. In this issue, we feature articles from three of them.

If I Only Knew

One person's story about being diagnosed with muscular dystrophy and how structural integration sessions have supported their embodiment.

Let's Talk About Inclusive Somatics Education

Rolfer® Tristan Koepke discusses the intersection between the Rolfin® Principles of Intervention and somatics education that has global, inclusive, and antiracist perspectives.

Also in this issue

Dr. Tina Wang talks about fascial science, and we remember Dr. Hans Flury.





Dan Somers



Amy Shinneman

If I Only Knew

When My Diagnosis Set Me Free

By Dan Somers, Certified Advanced Rolfer® and Amy Shinneman, 2023 National Ambassador for the Muscular Dystrophy Association (MDA)

ABSTRACT *Advanced Rolfer® Dan Somers interviews his client, Amy Shinneman, who is the 2023 National Ambassador for the Muscular Dystrophy Association (MDA), about her life with a type of muscular dystrophy called Bethlem myopathy and how Roling® Structural Integration sessions have supported her body to be strong and balanced. They discuss the complex path to receiving the correct diagnosis, her triumphs in building the life and family that she desires, and her struggles when facing systemic ableism found throughout society.*

Dan Somers: Hi Amy, let's introduce you to our readers of *Structure, Function, Integration*. I have had the pleasure of working with you for nearly twenty years, and I find your story to be so compelling that I believe it can teach love and understanding to all who hear it.

Amy Shinneman: Thank you, Dan, for inviting me to share my passion for spreading the word about people who live with muscular dystrophy. Do you want me to start from the very beginning?

DS: Yes, I think it's relevant that yours was a congenital condition, you came into this life with this particular body story, and it's all you've ever known.

AS: I would agree. Well, I'm forty-nine years old. My journey with the disability started when I was about seventeen months old. My parents noticed that I wasn't walking yet, and I would pull up on things but not let go. They took me to my pediatrician out of precaution. They knew my sister had started walking much earlier than that, and they were just trying to get insight. They probably thought they were going to hear something like, "Oh, she will be fine. It's just a simple delay. All kids walk in different time frames."

They heard, "This isn't good." Things developed rapidly, and I was sent to a neurologist. My parents were told all

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sorts of things, from I wouldn’t live very long to all sorts of the scariest things a parent could possibly hear. That started the journey to a diagnosis.

It was a forty-four-year journey to getting that diagnosis. During that time, my parents took me all over. I went to the Mayo Clinic many times. There are some of the best doctors in the world there, and they could never pinpoint a definitive determination. They thought it looked like a lot of different things. At the time, despite all their testing and their intelligence, I was not able to get a definitive diagnosis early in my life.

So, for my parents, that was difficult because it was scary, not knowing what was going to happen to their child. The stress took a toll on our family unit. I have a sister, and she’s two years older than me. It was hard on her, too. I’m sure she has her own side of that story. My parents were trying to work and take me to all these appointments; I was having surgeries on my feet and my ankles. Now, as a parent myself, I can sort of understand what that might have been like for them, although not fully because I don’t have that experience with my own children.

It was difficult for me because I felt like I didn’t fully know who I was. That was a really hard thing as a young girl to put into words. I didn’t even know how to put that into words. I just knew that I didn’t feel complete, and I didn’t feel like I really belonged anywhere. I would go to school, and I wasn’t like anyone else at school. There was no one that walked like me.

I walk with a pretty significant limp, sort of a sway. So, my disability is very visibly noticeable. School was difficult for me. Kids would say, “What’s wrong with

you?” So, growing up, I just felt like, *gosh, there’s something really wrong with me*, even though I was living my life and I was adapting to the world. The world doesn’t adapt to people living with disabilities; you have to find your way and make your own way to do things that everyone else is doing.

People would ask me what was causing all my difficulties, and I wouldn’t have an answer because I didn’t know. Over time, that manifested in a severe lack of self-confidence, never being sure of myself, and constantly living in comparison with my able-bodied peers. Ableism¹ takes a toll over time. It turned into depression – many years of depression and really dark thoughts. I struggled throughout my high school and college years to have true connection to anyone who could relate with me, where I could feel understood. I had a lot of awesome family and friends that would listen anytime I wanted to talk about my struggles, but as you probably understand, when you are dealing with something, you really want somebody to be able to connect on that inner level. I felt like I was starving for that connection.

Connecting the Data Points

AS: I volunteered at a muscular dystrophy summer camp when I was in high school because I had a neurologist at the time who thought I would be a good fit to be a camp counselor there. A lot of times when I was growing up, doctors would say, “Well, it could be muscular dystrophy, but it doesn’t really look like any of these types.” So, I went to that camp, and that was the first time that I felt like I was around people who understood me. At that time, I didn’t know I had muscular dystrophy, but I thought, “Gosh, these

people are so similar to me.” It was a great week of connecting.

When I came back from camp, life went on because I was still very much on the search for a diagnosis. I made it through college, and I got married. My husband took over that baton from my parents of continuing the diagnosis search with me, and all that involved financially and emotionally. It’s a lot. It’s exhausting on many different levels. Then I ended up having two children who, I wasn’t sure if they would have my same diagnosis because I didn’t really know what that was. Luckily, they don’t. They’re both very athletic. I’m very happy that they don’t have muscular dystrophy, but I also knew that if they did, they would be okay, just like I was.

Years went by with my kids. Then finally, when I was forty-four, my neurologist came in and tossed these genetic tests on the counter, and he said, “Hey, would you be interested in doing these and see if we can finally get some answers for you?” I don’t even know that he finished talking before I was like, “Yes. Absolutely. Of course.”

He didn’t think that I had muscular dystrophy. He was *convinced* that wasn’t it. He was trying to do a genetic test on something totally not neuromuscular related. It turned out that he ordered the genetic neuromuscular panel in error, and he’s not someone who’s known for making mistakes, ever.

That’s how my diagnosis finally showed up. An unintended set of tests revealed the truth. I get emotional every time I talk about it. The way it happened, the mistake that revealed the answer. If he hadn’t made that mistake, I probably would still be searching. I don’t know.



Amy Shinneman: It was a forty-four-year journey to getting [my] diagnosis. (Photo by Victor Aheiev on iStock.)

AS: The world doesn't adapt to people living with disabilities; you have to find your way and make your own way to do things that everyone else is doing.

I got my testing back, and it was a disease-causing variant, as they say on those genetic tests. My doctor was still not convinced. He needed more. He wanted my parents to be tested. I was fortunate that they're both still living and agreed. That round of testing came back with the same indicators: I have a type of muscular dystrophy called Bethlem myopathy. The results were conclusive. It is what it is.

My life, from the very moment that I got the phone call from my geneticist telling me that they knew what it was, my life changed instantly. It was in that moment that I felt like, at forty-four, I finally fully

knew who I was – a person living with muscular dystrophy. I hear people with disabilities say a lot, "My disability doesn't define me," and I understand what they're saying. It doesn't stop them from doing things and living their life.

But for me, while I might agree somewhat with that statement, I feel like muscular dystrophy is just as much a part of me as my brown hair or my brown eyes. It's just me, and what you get when you get me includes my disability. You get my muscular dystrophy along with many other different things.

From that point on, I immediately took off. I didn't have to waste all that time

and energy searching – it had been all-consuming. Aside from raising my kids, understanding my body was my number one goal. When you don't know, you want to know. If you think about it, if you go to the doctor and you have an illness, and then they tell you it's a virus where nothing can be done. It's a vague answer and when you're feeling so sick, it can be frustrating not to be offered help. That can be really frustrating for a couple of weeks while dealing with that illness. This, for me, was forty-four years of not having answers.

There were many different times when I was misdiagnosed, all those ups and downs of thinking I had finally found answers, only to be let down later. That happened countless times throughout all those years. My heart goes out to anyone searching for any sort of medical diagnosis, for sure.

DS: That is interesting to me. Even your neurologist who ultimately helped you get your answer, initially he too had resistance to the diagnosis for some reason. Do you know what that might have been about? Was there another diagnosis he was expecting?

AS: I think that the doctor who did my genetic testing, he had other patients with the Bethlem myopathy type of muscular dystrophy and I didn't look like those patients exactly. That was throwing him off.

What I've come to realize since being diagnosed and getting into this community with other people who have Bethlem myopathy is that it's very different for a lot of us. But we also have similarities. It is interesting to see the

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many differences within that diagnosis. This Behlem myopathy group that I'm involved with has hundreds of people living with this disease even though it is considered a rare type of muscular dystrophy. It is common for people in this group to mention that it seems doctors don't know that much about this type of muscular dystrophy, and it can seem like they're not willing to listen, take the time, or hear this feedback.

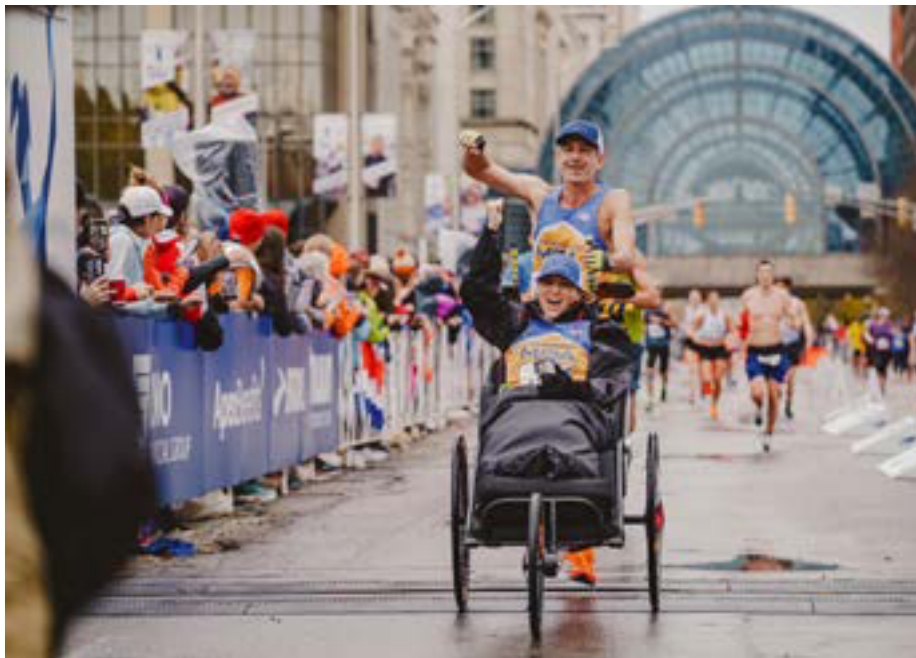
I had many great doctors that helped me immensely throughout the years with different things. I think there's sometimes an ego thing that can get in the way where each doctor wanted to be the one that diagnosed me, so they would rush into these diagnoses. And I would get so excited, especially as I got older. I would research whatever they told me, and I could sort of convince myself, "Yeah, I do fit into that," even though I really didn't. But I would almost convince myself that was it because I wanted it so badly to be it, and I wanted to move on from the searching and live my life. Not knowing was really holding me back.

DS: There's something in the desire to get the diagnosis; you've found something like home. I don't want to put words in your mouth, but it seems like a place of belonging.

AS: It's funny that you said that exact phrase. I recorded a video of myself the day I got the diagnosis, and I will probably never share that with anybody. In that video I said, "This feels like home. I feel like I'm finally home." It's interesting that you said that.

There was a time when I was angry that I didn't have a diagnosis. I was mad at everything in the world. I was a very negative person. Not always, but a lot in my head. I was super negative to myself. I write this blog called *Humbly Courageous*² where I detail what life was like growing up with a disability and what life has been like now, it documents my journey to the diagnosis. What I've discovered through writing that blog and reliving all these moments is that it wasn't all for nothing. It wasn't a waste of time. It was the way that my story was supposed to go for whatever reason, and it taught me so many different things, so many great things.

When I look at it like that, I feel this gratitude for the path I was on. If I could change it, I wouldn't want to be disabled because things are physically so difficult,



Amy and her husband complete a road race. Photo courtesy of Amy Shinneman.

and I do want to do stuff physically that everyone else is doing. But I've come to a point now where I'm almost able to see it as a gift, seeing the world through this lens.

When I started to see it in that light, this changed me from the inside out. It's been really awesome for me. It helps me to be able to live with this disability and live well. Part of my journey is being the 2023 National Ambassador for the Muscular Dystrophy Association (MDA). We're fighting for treatments and cures because a lot of types of muscular dystrophy that are life-threatening, and a lot of people never have the opportunity to be able to walk, ever. I'm so fortunate that I'm still walking a lot of the time. There are times when I use a wheelchair or my scooter.

Live Well Here

AS: I very much think it's important to continue to fight for treatments and cures. It would be life-changing for so many people. In the meantime, I don't want to only live for that moment, if that ever happens. I can live in the present and I can live well here. I don't have to live hoping for something that may or may not happen in my lifetime.

Living like that changed a lot of things for me. I'm able to feel joy. Joy and heartache can coexist. They can both just

run alongside of each other. You can feel a lot of joy, but also, things are difficult. I don't want to sugarcoat my daily life. Every morning, I wake up and have to make a decision about whether to lay in bed and wither away or to get up and live my life the best that I can. But I know when I put my feet on the ground that it's going to be a marathon. My day's going to be exhausting and it's going to be a lot of digging deep all day long to get to what I need to do. The change in my mindset has helped that somewhat. When you're grateful for even the smallest things, that really can become your focus, and you don't think about the negative things as much. Those things, the joy, the small bits of gratitude, outweigh some really tough stuff. That is what I have found.

DS: Truly inspirational. Incredible story. Thank you so much for sharing it.

One thing I've always admired about you is the grace with which you take on what comes your way. And there's also this fire in you. I'm so impressed, and astonished, quite frankly, by the marathons you, your husband, and your son have taken on. It appears to be almost metaphorical of your daily life. You have done so much preparation to begin, and then your every day is also like the race with twists, turns, and heartbreak hills followed by fatigue and thoughts of quitting. And somehow, somewhere, a second wind arises, and you push on.

You've handled all that, and risen above it, to then be the National Spokesperson for MDA, which is a huge gift.

Stem Cell Treatment

DS: In addition to your Roling sessions, I know you're involved in different ways of caring for yourself. You've been a pioneer in seeking treatments; can you talk briefly about the stem cell treatment you're going through?

AS: Yes. I do a type of stem cell treatment called *stromal vascular fraction stem cell treatment*³. That means that they take fat from my body, they extract a small amount of fat, and they're able to harvest stem cells from my own body. I personally have had my cells banked, so I only had to do that major extraction once; that's a painful process. Now that they are banked, they're able to grow them from that sample each time I want to take some out. For me, it's a simple intravenous infusion of those cells. I do it every four months. That's what we've found helps me the best.

I met this doctor on a whim. I would call it divine intervention. I was seeing him for something totally different, and he mentioned that he does stem cell treatments. He was going to do a medical procedure on me, and he said, "Do you have any medical issues I need to know about ahead of time?" I said, "Well, I have muscular dystrophy." He said, "Oh, I'm

actually doing stem cell treatments on a young man that has limb-girdle muscular dystrophy."

I didn't think much of it. I didn't know anything about stem cells other than they were considered controversial. He gave me a book to read; there was no pressure at all, and I went on my way. I got home, and I read this book. I couldn't put it down; I read it the whole night, and I was fascinated. There was actually a chapter in the book about a woman who had muscular dystrophy that had been treated with this type of stem cells.

I was still a little leery about it, but after finding out they were stem cells that would come from my own body, I continued to do more research on it and discussed the process with my husband and my family. We felt like there was so little risk involved that the only thing really standing in my way was the cost of it because it's all out of pocket. It's not inexpensive. But we were able to do it, so we wanted to take that chance. I've had seven treatments at this point.

The way it was presented to me was that it wasn't going to cure me. It was a, "Maybe this could help you. Maybe it could slow the progression of your muscular dystrophy." Muscular dystrophy is often a progressive disease. In my case, it's progressing very slowly but definitely progressive. I thought even if I did that treatment, if it slowed it down a little bit more, it would be worth it for my quality

of life. My goal is to continue walking as much as I can.

Now that I've finished the seventh treatment, I think the benefits are small, but they're undeniable. Other people seem to be able to see small changes in me, more than I can feel. Most notably, recently, my husband told me that I had appeared to be in such a bad place before the stem cell treatments. He was worried that I was going to die. He feared waking up and I wouldn't be here anymore. He had never shared that with me, probably because it would have scared me. When he said that, I thought, *I must be doing better for him to feel safe enough to share that now*. That showed me there is something to say about this stem cell stuff.

At this point, I can feel when I'm ready for another treatment. I think the stem cells are supplying something that needs upkeep. I'm at the point where I'll continue with it for now.

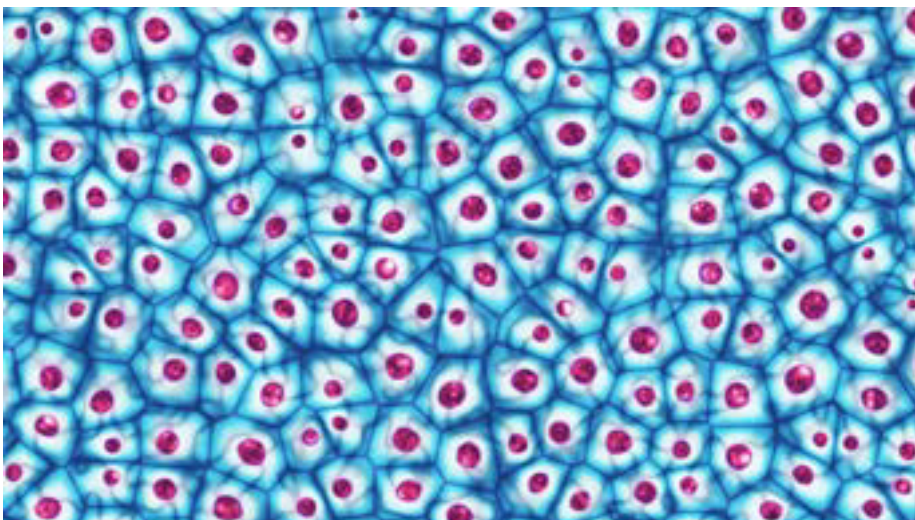
DS: I noticed. Somewhere around your third infusion, I witnessed a different fluidity to your movement, like a lowered level of irritation or inflammation. When we would do passive movement in session, the head of your femur felt happier rolling around in your hip socket. I think I remarked at the time on the change that I felt.

AS: You did. I remember that. I was so encouraged by that because I obviously can't feel the same thing that you are feeling when we're working together. That was very meaningful to me because I got a little insight into what it might be doing inside my body and how it might be slowly changing things. This body of mine has a long timeline of things that need to be reversed, if that is what the treatment is in fact doing. I knew it wasn't going to be a quick fix, but when you told me that, it was great to know it was objectively doing something.

DS: Something new and different was occurring, and it was encouraging.

AS: Yes. Another thing that I deal with is osteoporosis as a secondary condition from the muscular dystrophy, and this leads me to not being able to be as weight-bearing all the time. I don't know if it's a coincidence or what, but I had a very large increase in my bone mass at my last bone density study. The doctor ran back downstairs and checked my results a second time. She was like, "I just couldn't believe my eyes." The people doing the

Three-dimension illustration of embryonic stem cell colony under a microscope. Image by Eduard Muzhevskiy on iStock.



stem cell treatments are starting to do even more research on these protocols and bone density. It's cutting edge, and they're slowly getting into how that could be helpful for people.

DS: Yes. I wish you all the best with that.

AS: Thank you.

Amy's Path with Structural Integration

DS: How did Rolfing® Structural Integration come into your life?

AS: It was around the year 1999 or 2000, and I was living in Memphis, Tennessee. I had a friend who had done this thing called "Rolfing." I had never heard of anything like that. She thought it could help me. At the time, I was fresh out of college, and I was living with my husband, who was my fiancée at the time. We didn't have two cents to rub together. When she told me what it cost, I thought, maybe I'll try that someday. I can't swing it right now. But I was interested.

In the meantime, without me knowing, she talked to her Rolfer and told her about me. The Rolfer offered to do a Ten Series with me free of charge. She knew what medical struggle was like. When my friend told me, I thought it was too generous and that I couldn't do that, I didn't even know her.

DS: Just to be clear, your friend's Rolfer wanted to give you a *pro bono* Ten Series.

AS: Yes, that's right.

DS: That's wonderful.

AS: When my friend called and told me this, I was hesitant. I felt like I couldn't possibly do that. I asked my friend to thank the Rolfer for me, but it was too big an offer for me to accept. When she told the Rolfer my message, the Rolfer said, "No way. Tell her to get in here. Bring her in and let's meet."

DS: I love this story; please continue . . .

AS: So, I met her. There was this immediate connection. She was so kind. She worked alongside her girlfriend, who was a social worker and counselor. So, they did these sessions with me, with both of them in there. I accepted her after I met her. She just insisted. In the back of my mind, I'm like, "I will pay her back for this when I can."

I experienced the Ten Series. I don't know how long that took. I had sessions

AS: Before my Ten Series, my back was very curved out, and there I stood in front of them – I was just so straight. It was very outwardly noticeable and different.



Amy Shinneman: [Rolfing work] I felt very different. I still had the weak muscles and all that, but I felt more fluid in my movement. Things got a little easier and that sparked the whole journey into holistic healing. (Photo courtesy of Amy Shinneman and Dan Somers.)

every week or every other week. I don't remember. It was a while ago. During these sessions, I had a lot of emotional stuff surface. She had explained to me before we started that a lot of times, our body can hold memory in our tissues. To me, that sounded sort of out there. I didn't know about that. But I very quickly realized that I would go through all these emotions during this first series.

I hadn't seen my parents for a couple of months at that time. They came to visit me and I don't know if I had completed all ten sessions, but they just stopped dead in their tracks because my body

looked so different. Before my Ten Series, my back was very curved out, and there I stood in front of them – I was just so straight. It was very outwardly noticeable and different.

I felt very different. I still had the weak muscles and all that, but I felt more fluid in my movement. Things got a little easier and that sparked the whole journey into holistic healing. It brought me a little bit out of the medical world where I had all my hopes and dreams that they were going to help me. I had this new thought, "Well, maybe someone else can help me that isn't a doctor. Maybe there are all

According to Talila A. Lewis, social justice engineer, educator, organizer, attorney, and artist:

***Ableism* is “a system of assigning value to people’s bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism.**

This systemic oppression leads to people and society determining people’s value based on their culture, age, language, appearance, religion, birth, or living place, ‘health/wellness’, and/or their ability to satisfactorily re/produce, ‘excel’, and ‘behave’.

You do not have to be disabled to experience ableism” (2022).

these things out there that I can look into that can help me.”

A Roling Ten Series was one of those things. Then I moved back to Indiana in 2001 and I Googled Rolfers in the area. There were two Dans that did Roling and so I picked one, and it was the other Dan, not you. But I think you know the other Dan. Dan was awesome, very kind and wonderful. [Dan Somers: that “other Rolfer” was my original Rolfer named Dan Dyer and he is indeed “kind and wonderful!”] His style was very gentle compared to my first Rolfer, and I felt I had to endure a little bit of that physical discomfort to get the results that I needed or was looking for. That was when I contacted you and we met. Do you know what year that was?

DS: I’m thinking 2003 – does that sound right?

AS: I know it was a long time ago, longer than I realized it had been. It is my sense

that each Rolfer has a different kind of touch or way that they do the work. It was a good experience with you as well – and here we are.

DS: I’ve learned so much and continue to learn a lot working with you.

In a very general way, bodyworkers, including Rolfers, are trained to discover patterns of strain, tightness, tension, and contraction in a client’s body and then to soften, release, lengthen, and balance these patterns. We’re kind of good at loosening things. For many people with muscular dystrophy, the tissue can already feel lax, and joints can be hypermobile. I’ve found it’s good to appreciate that shortened or rigid areas might be the compensation for laxity elsewhere in the body and to release areas of contraction can lead to *dis-integration*. What may be most helpful is to balance tissue release with strengthening in an oppositional way.

Do you have a sense with Bethlem myopathy, is there laxity in the major joints of the body? Are hips or sacrum unstable or do you experience instability around the wrists and ankles?

AS: I don’t think Bethlem myopathy has those issues specifically, but it does certainly affect joints, but it’s more so with contractures. I have heard and read comments people have made that there seems to be some overlap with the Ehlers-Danlos Syndrome (see page 6 for a related article). There seems to be a bit of overlap.

I do have a good friend that has Ehlers-Danlos syndrome and we talk a lot about it, and she actually is a massage therapist. She’s expressed that it isn’t as widely known what to do for people that have more loose joints and things like that. But she’s keenly into that because she knows what her own body needs. I

don't think hypotension describes me so much as it might for people who are closely related to Bethlem myopathy and other conditions as well.

DS: That makes sense to me and thank you for that clarification.

Ableism

DS: At the beginning of our conversation, you mentioned that when you were growing up, you felt constantly compared to your able-bodied peers. Now, this has become an essential part of what you do with your advocacy work. I want my colleagues to hear from you about the majority view of ableism and how able-bodied people are the standard against which disabled individuals are considered and judged. It's so deeply baked into the culture. Can you share with us a bit about your advocacy work?

AS: Certainly. I think a lot of my friends with disabilities would appreciate your way of describing that as deeply baked. That's pretty spot on because that is what it is: deeply baked. Sometimes, when you do this type of work, it's so daunting and it's so discouraging at times because you feel like you're one small person trying to undo what is deeply baked. The thing that I do is try to educate and advocate for, not just for me, but my community. In doing this type of work, I'm able to get outside of myself, and it's not really about me. It's about everyone else I'm trying to help, and I am also in that group.

Working on behalf of this group, what I hear is, that our disabilities teach us perseverance. And that's exactly what is needed to be in that world of advocacy and educating about disabilities because our society is just not designed for people with disabilities. We're still trying to fight for simple things, like accessibility in buildings and restaurants, trying to be able to easily use the restroom, or making sure to have accessible buttons on the outside of bathroom doors. If you're in a wheelchair and you can go into the bathroom by yourself because there is a simple button that opens the door, it's exciting. Whenever I see that, I'm so glad I can get myself into the bathroom on my own. It's still not common; we're still talking about little things like that.

It seems so crazy in this day and age that we're still fighting for things like accessibility to restaurants, theaters, and concert venues, wherever it might be. The

Americans with Disabilities Act⁴ helped to move that along greatly, but there's still so much work to be done, but that's what it takes. It takes people like myself and the many others that do this. It takes longevity and the commitment to wanting this change for the people that come after us. I think that's why it's such a beautiful thing, although it's a difficult thing. But it's beautiful in that I see all these people who are willing to do that, and it's not really just for them. It's for so many other people.

DS: What do you think about this relationship between 'able-bodied people' and 'disabled-bodied people'? There is this idea that the able-bodied person is the normative standard and the disabled-bodied person is somehow less than – that's really problematic.

AS: It is.

DS: If I could say a bit more before you answer. I find that when I'm thinking about the standard of personhood by which things are compared, I think about how you must hold your ground and assert your place as entirely legitimate.

What I see you doing is owning your whole self as – *I am*. And there's some element of swimming upstream with that because the larger culture might have another idea. How do you personally transcend against that larger culture to own yourself and your existence when you've got a bit of societal force pushing against you?

AS: Some days are much easier than others. In doing the advocacy work, it can feel like a force, sometimes like a very large force against us. We're back to the *deeply baked in* idea, the "system of assigning value to people's bodies and minds" that Talia A. Lewis has described (2022), is still being taught. That's what people see when they are in public spaces. People define their worth on physical capabilities. Yet the truth is that everyone struggles with something. I'm not making light of disabilities at all, I would never.

I don't want to sound like I'm speaking for all disabled people either, because I am not. I'm speaking for myself as a woman who has lived her whole life with a disability, and I have my perspective. And I think we have a very long way to go. I can go out to a store today and possibly when I park in the accessible parking spot with my tag clearly displayed, someone might walk up to my window screaming at me because they have judged me on my appearance sitting in my car. These

things happen where someone will decide I don't deserve that parking spot and they feel like telling me all about it. Then that same person, when I do get out of my car and they get the chance to see all of me, they're probably going to switch to seeing me as *lesser than*. Those kinds of interactions are hard to deal with.

Disabilities are a hard thing to live with, and if you get the opinions of other people into your head and their bias, thinking that we are weak or not capable – wears on a person. And it's just not true. We are capable of doing lots of different things. If one good thing has come out of social media, perhaps it would be the connections that are being made between people and the supportive awareness that we are able to share widely with the world. There are a lot of people with disabilities on there who illustrate what our individual lives look like. I feel like that is what we need to do to get to a different place where people with disabilities are seen on an equal level as those people who don't have a disability. There is still a very long way to get there.

DS: There is that. Hopefully, this article will help us practitioners be more sensitive, more informed, and more aware of the capabilities of our clients.

DS: Taking care of yourself is so essential as you do this work on behalf of others – you seem to have a good internal sense of when to come in for a Rolfing session. How do you know when you're ready for a tune-up session?

AS: Usually, it's way after when I should have contacted you. I always wait too long. I start to feel very unbalanced. For me and my body, I tend to stand on my right side because that's my stronger side in many ways. Over time, that gets farther and farther until I feel like I'm going to maybe fall over to the right. But I'll start feeling all the uncomfortable things that happen on my right side. I'll think, *I need to contact Dan. I've got to get in there.*

I've become familiar with that feeling of being unbalanced, now that I've had that opportunity to be balanced out. I crave that feeling that I experience after I see you. I leave there, and I feel better. I'm balanced out again. I wish I could come in more, and I probably should. But I do what I can, regarding time limitations in my life and all that.

DS: Amy, you have a very full life with your family and your MDA National Ambassador commitments and I'm



Dan Somers: Hopefully, this article will help us practitioners be more sensitive, more informed, and more aware of the capabilities of our clients. (Photo by Rawpixel on iStock).

delighted whenever you come in. Is there anything else you would like people to know about MDA and any other aspects of the work that we do together?

AS: Yes, another thing that Rolfing work has helped me do is to be able to connect my mind and my body, if that makes sense, and to be able to understand what is going on within my body, and how that's connected to my emotional state. Rolfing interventions can be very physical, of course, but in my experience, it has been mentally helpful to me, to be able to make those connections.

I think before I had Rolfing sessions, there was this big disconnect, and I don't really know how to explain it other than to say that it felt like it all became one afterward. There was new compassion for myself that connected me. Before then, I had my mind and then there was my body, it seemed to be two different things. When I did the Rolfing sessions, I was able to understand myself better and how things worked. Having someone take the time to explain it to me made such a huge difference in my life.

I want to tell people that Rolfing Structural Integration can help you feel better and more balanced physically, and also mentally. It helps release some of that junk that you might be holding onto, all those negative emotions that need to be released. That was the beginning of my healing up until this point.

To the Rolfers

AS: Let me say to your colleagues, if you're working with someone who has a disability, don't be afraid to ask them things you don't know. I'm always glad to help educate whoever's working with me or on my body. I'm glad when those questions are asked because, a lot of times, you can't know everything about every type of disability. I never look down on a practitioner for not knowing, but I really respect someone when they ask me questions about what I know about my body. That's helpful in getting the overall outcome that we both want.

DS: That is hugely important. Well said.

AS: Thank you for this opportunity, Dan, to spread awareness. And to talk about your work and how it has helped me. And I hope it helps someone try this modality who's never heard of this work.

DS: We are really so thankful as well that you made time for us.

Endnotes

1. According to the Merriam-Webster.com dictionary, *ableism* is discrimination or prejudice against individuals with disabilities (2023). According to Talila A. Lewis, social justice engineer, educator, organizer, attorney, and artist, ableism is "a system of assigning value to people's bodies and minds based on

societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth, or living place, 'health/wellness', and/or their ability to satisfactorily re/produce, 'excel', and 'behave'. You do not have to be disabled to experience ableism" (2022).

2. Amy's blog about her experience with Bethlem myopathy, which is a type of muscular dystrophy, can be found at <https://www.humblycourageous.com>.

3. "Stromal Vascular Fraction (SVF) is a heterogeneous collection of cells contained within adipose tissue that is traditionally isolated using enzymes such as collagenase. With the removal of adipose cells, connective tissue and [sic] blood from lipoaspirate, comes the SVF, a mix including mesenchymal stem cells, endothelial precursor cells, T regulatory cells, macrophages, [and] smooth muscle cells" (170, Nguyen et al. 2016). The stem cells, in particular, are the treatment that shows promise in regenerative medicine (Yao et al. 2017).

4. For more information about the Americans with Disabilities Act, see <https://www.ada.gov/>.

Amy Shinneman lives in the greater Indianapolis area with her husband, Jamie, and teenage sons, Luke and Jack. Shinneman lives with a type of muscular dystrophy that is called Bethlem myopathy and was diagnosed when she was forty-four years of age, even though she had symptoms of the disease in early childhood. Shinneman enjoys painting, cooking, baking, reading, and exercising. She completed the New York City Marathon in November 2021. You can read more on her blog, "Humbly Courageous." <https://www.humblycourageous.com>.

Dan Somers has a master's degree in social work from Indiana University (2009), he is an Certified Advanced Rolfer®, a certified craniosacral therapist, and a certified visceral manipulation therapist. Somers is also a graduate of the Hakomi Institute. Somers is a Indiana State Licensed Social Worker (LSW), Licensed Acupuncture Detox Specialist (LADS), Licensed Addictions Counselor (LAC), and Licensed Massage Therapist (LMT).

He is also a certified sex therapist and educator and currently sits on the Board of Directors of the Dr. Ida Rolf Institute®.

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neuromuscular disease; muscular dystrophy; congenital condition; adaptation; ableism; stem cell treatment; structural integration; balance; case study. ■