Episode 58- Wrapping Up 2025 with Ira and Lily

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Mindy Henderson: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest family of content. I'm your host, Mindy Henderson. Together we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them. We are here for you to educate and inform, to demystify, to inspire and to entertain. We are here shining a light on all that makes you, you. Whether you are one of us, love someone who is or are on another journey altogether, thanks for joining. Now let's get started.

Welcome, everyone, to a very special end-of-year episode with the Quest Podcast. As we close out another remarkable year, I wanted to take a moment to reflect, to celebrate, and to look ahead. Who better to do that with than our incredible MDA national ambassadors. Joining me today are two people who have spoken with their hearts and moved mountains all year long. Ira Walker, who is wrapping up his second year as a national ambassador, and Lily Sander, who just completed her first year and will be continuing to represent MDA into 2026. These two have been busy speaking and sharing their stories to empower our community, and I can't wait for you to hear their reflections, favorite memories and hopes for the future. Let's jump right in. Welcome to you both.

Ira Walker: Thank you for having us.

Lily Sander: Thank you so much, Mindy. It's amazing to be here.

Mindy Henderson: Absolutely. I'm so glad you all are here. I've got 93 questions for the both of you. I'm so excited to hear more about your year and what comes next for both of you, so let's just start with some reflection. It's been an amazing year I know for both of you. Can you each tell me maybe what one moment or event is from this past year as national ambassadors that stand out as unforgettable for you? Let's start with you, Lily. Ladies first.

Lily Sander: As national ambassadors, we get to do a lot of cool things, speak at various events and engage with the community in very meaningful ways. It's hard to pick out just one moment that is especially meaningful, but I would definitely say that the small moments of connections with patients and parents of patients always really strike me as this is why we do the work that we do. We represent this community and we make these connections that really uplift us as national ambassadors, and it truly is in the small moments of connection for me.

Mindy Henderson: I love that. I love that. What about you, Ira?

Ira Walker: Absolutely. I completely agree with what Lily just stated. It is the small moments of connection that truly make it remarkable and are those really remarkable moments. For me personally, earlier this year, I had the opportunity to spend the day down in South Florida with Chris Lewis at a film screening. Now, for those who don't know, Chris is the son of the great Jerry Lewis. It was a truly amazing opportunity to be in the presence of the son whose father is one of the early pioneers of awareness for MDA and the face of the telethons to help to raise millions for MDA. Now, although I never got to meet Jerry before his passing, sharing a moment with his son was significantly meaningful to me and an opportunity that I took to thank Jerry and his family for the hope and future that they helped to shepherd for many in the neuromuscular community. Again, this was truly an unforgettable occasion.

Mindy Henderson: Yeah. You actually wrote a beautiful blog. You've both written beautiful blogs for us over the course of the year, and I know that you wrote about that experience. People can look at the blog and see more about that interaction, but I know that it was special to you and their family really has done a lot for MDA just to make it the namesake that it is. I think we're all really grateful to him. You both talk about connection, and for me also as a member of the neuromuscular community, I struggle every time I try to find the words to describe this community and how we come together and work together and help each other even from afar. It's something that's so special. I love that both of you honed in on that in your answers. Ira, as you wrap up your second year, how do you feel you've grown? You are spectacular. I've loved every interaction I've had with you and watching you work over the last couple of years. But whether personally or as an advocate, how do you feel like you've grown over the last couple of years?

Ira Walker: Well, first and foremost, thank you for those kudos and those kind words. Being the adult national ambassador has been the gift of a lifetime and something that I will always cherish. Being in the spotlight and being the face of an organization truly means the world to me. But truth be told, it wasn't something that I saw it after or ever thought that would be a reality for me. See, I believe that it's a true testament and a sign that you're doing the right thing in life when an opportunity like being the base of an organization comes knocking at your door when you least expect it. See, I've grown exponentially as a man because of this opportunity in the way of leadership, and I hope that I've been able to positively advocate for our community demonstrating that even with neuromuscular conditions, one can truly live and thrive in a value-add society.

Mindy Henderson: Yeah. You guys are both proof positive of that. Your stories are so interesting, and you're both such accomplished people. I absolutely adore both of you. It's been such fun, Ira, over the last couple of years and such a privilege to have you as one of the faces of MDA. Lily, you too. What's something that you've learned from Ira in your first year in the role that you'll carry forward into next year?

Lily Sander: Yeah. Watching Ira has been incredible. Ira, I feel like you're truly a masterclass in charisma and how to engage with people in such a meaningful way. I really value and appreciate how each and every person that he talks to, it's as if he is giving them all of the attention in the world and he is really honed in on exactly what they are saying. With Ira, there's never a thought or moment wasted. I really appreciate that intentionality and it's definitely something that I have learned from and I hope to carry forward. Ira, I just cannot say enough about how just you're so good with people and that's the whole thing about this role is connecting with our community members. I know everyone feels it too, so thank you.

Mindy Henderson: Love it.

Ira Walker: Thanks for the kind words.

Mindy Henderson: Lily, I think you are the most articulate, well-spoken 18-year-old I have ever had the pleasure to know. You are remarkable as well. Ira, you just released a book that I think we should tell the listeners the name of. But before you do that, I've got to steal the note from Lily, and I think that your next book should be called Master Class in Charisma.

Ira Walker: I... Yeah. I just finished publishing my very first novel titled Torn Branches. Let me say it again, Torn Branches, and you can get it on Amazon, Apple, or on Barnesandnoble.com. It's a dream come true to be a published author, and it is just the start of many to come. Now, I will say my next novel is already being written and the title is already set in stone, but for future novels, I do like the titles that you guys have provided. But I really enjoy writing fiction novels, and maybe one day I'll write a nonfiction book maybe telling the story of somebody like Lily or somebody like Mindy who really are champions in our community.

Mindy Henderson: I love that. You're so great, Ira. Let's stay with you for a second, Ira. You've both connected with so many people across the MDA community this year, families, researchers, clinicians, volunteers, advocates. What's something, Ira, maybe in the last two years even, something that's surprised you or maybe inspired you the most about the MDA family?

Ira Walker: Absolutely love this question. I want to first discuss the makeup of our community for just a moment. See, the MDA community is comprised of many brilliant, creative, enterprising individuals. See, we are a community of doctors, lawyers, educators, entertainers, influencers, and leaders of all avenues of society to say the least. We undoubtedly are a value add in our community and the world. See, it doesn't surprise me, but it may surprise some of the breadth and the depth of our community.

Mindy Henderson: Yeah.

Ira Walker: Now, I'm personally inspired by the strong desire that I see from people in our community to drive positive change and help our vibrant community continue to grow. See, I see this passion reflected most recently in the Hill Day gathering, the various fundraising efforts throughout the year and the wide range of awareness opportunities that we offer year-round. We truly are an amazing community of amazing individuals.

Mindy Henderson: So well said. I feel like... I don't know. I'd be curious to know if you both agree with me or disagree with me, but I feel like the disability community, even more broadly than the neuromuscular community, is having a moment. There are so many voices emerging that are really truly forging ahead and working toward progress and bringing attention to this community I feel like than ever before. Maybe it's just because I'm living in this time that I feel this way, but I do really feel like there's a focus on representation in media and entertainment and things like that. I feel like people are hearing things from the disability community that are really going to move the needle. What are y'all's thoughts?

Lily Sander: I definitely agree. I think we've always known our value and have always seen just this vibrancy within our community. But I agree, I definitely think people are starting to catch on to just the amazing, the diversity. Like Ira said, we are an accomplished people.

Mindy Henderson: Yeah.

Lily Sander: I feel like every time I'm talking to someone, I'm just blown away by their endeavors and their careers and in their families and personally. Definitely with social media, I think people are getting a taste of our community and understanding just how beautiful our connection is. I agree, and I think social media has been a big part of that.

Mindy Henderson: I think you're right. That's a really good point. Lily, I know that you've been plugged into the MDA family for a long time, but is there anything this year as an ambassador, as you've gotten even more plugged in that's surprised you?

Lily Sander: I've been able to connect with more people. I wouldn't say I'm surprised, but I'm affirmed of just the connection that we share and the beauty within our people. I've been able to expand my understanding of our community as I've been able to travel and connect with more patients. I think these universal truths that I already held about our community, such as how resilient, beautiful, educated, and I think it was just affirmed honestly with seeing people all over the country. It's very encouraging too to talk to the next generation of kids, especially at Hill Day. I was talking to a ten-year-old boy who was there to advocate for his rights, and he was so excited to quote, "Make the laws better." I'm just enthused by the younger generation stepping forth and making change in our community. I would just say my understanding of how beautiful we are has been affirmed, and I hope that it will continue to be.

Mindy Henderson: That's such a lovely sentiment, and I know who that 10-year-old was that you were talking about. I had the funniest interaction with him. It just made my heart swell. It made me so happy. It was the day everybody was arriving for Hill Day, and I was waiting for an elevator. The doors open and he spotted me. We were getting on different elevators or I was getting on a different elevator than they were on, but he spotted me and he yelled out before the doors could close, "I'm an advocate too!" It was so beautiful. It just made my heart smile. Lily, like you said earlier, talking about the small moments of connection is sometimes the best moments are the little ones. Is there a conversation that maybe stands out or a connection with another ambassador or community member or it may be an MDA staffer that really has touched your heart this year?

Lily Sander: Oh, boy. There are so, so many. I feel like every time I'm at an MDA event or connecting with patients, I'm excited by the future and I see that beauty that we've talked about, but what's really impactful for me is talking to parents who don't have disabilities and connecting with them about their children. I'm taken aback by how resilient these children are, especially when they are so young, taking the world into their hands and using their disabilities to make our laws better, like we talked about. It's really connecting with parents that gives me a different perspective. Obviously, I'm a patient. I don't have that knowledge of raising a child with neuromuscular disease, but it makes me see the beauty in a different way. I would say connecting with parents is just really special, especially when [inaudible 00:17:58] say things like, "Oh, my kid looks up to you," or "Your story has helped us as a family." Those moments are surreal and not something to take for granted.

Mindy Henderson: Yeah. Actually, I just recently... I'm going to make you blush, but I just recently read a draft that you submitted for your next blog where you were giving advice to parents of kids living with neuromuscular disease. It is so wise. It was one of the most wonderful things I've ever read. Knowing that you wrote it from your heart as a young person living with neuromuscular disease, I hope that every parent who's listening will go read it. It should be published by the time this blog goes live, and it's full of such great advice. What about you, Ira? Is there a conversation or a moment that stands out to you?

Ira Walker: Yeah. I had the opportunity to visit the MDA summer camp down here in Florida this year. Now, from the age of six through 21, I attended summer camp up in my home state of Missouri, but this was the first time I visited a summer camp outside of the one from my adolescence. Now, I must say this was a pretty special moment for me, not only to go down memory lane for a minute and see kids having the time of their life at camp like I did some years ago, but this was an opportunity that I had to connect and inspire some kids.

I got to encourage some of the camper's nearing adulthood that their future with their neuromuscular condition is bright, and I got to show them that they truly have a life of independence and happiness ahead of them. I did this by showing off my cool unique vehicle that I drive and describing [inaudible 00:20:06] exciting enterprising life that I have as a professional living the good life down here in South Florida. See, Mindy, that's what makes it all worth it, when you're able to inspire and excite those who may not know that their future is truly bright. It makes it all worth it.

Mindy Henderson: Yeah. Another good point. Everything that you guys say is just gold, but I also went to summer camp and it was an absolutely... It was such a pivotal experience in my life. I went I think from the time I was maybe 10 until I was about 17 or 18, and I feel like the whole trajectory of my life would've been different if I hadn't gone to MDA summer camp because it taught me, yeah, a lot about independence and what the possibilities were for my life. I think one of the things that I didn't have as much of when I was a kid was role models, adults who were living with neuromuscular disease and had fashioned lives for themselves, like what you're talking about, Ira, and could really show tangibles like, yeah, you can drive.

Yeah, you can move to South Florida and whatever you want to do. I think that that's another thing that you both do in your jobs as MDA national ambassadors is serve that role model function for kids who really need those examples of what they can go on and do. Being a national ambassador means being a voice for thousands of people living with neuromuscular disease. How do each of you approach that responsibility? Because I jokingly say jobs, but you're both volunteers. You do this out of the goodness of your heart, and there is a heavy amount of responsibility that comes along with it. How do you approach it and what does representation mean to you? Lily, let's start with you.

Lily Sander: Yeah. I love this question because this is something that I have reflected on a lot in the past year as national ambassador. We're put in these situations where, you're right, we are representing thousands of individuals and our communities are so diverse, so it's important that we represent our community well, but also that we are including everyone in our representation. When I'm going on stage or speaking with donors and clinicians, I remind myself that this isn't about me and truly I envision the families that I am representing, the families that maybe couldn't be here, or maybe they don't know how to access their voice yet. I really try to think of myself as a vessel for representing others, and that's a great way to stay grounded and also to remember the gravity of this position.

Mindy Henderson: Love that. What about you, Ira?

Ira Walker: Yeah. I love this question. I want to first tackle how do I approach the responsibility? When I started my position as adult national ambassador, see, I made a mission and that mission was to encourage, inspire, uplift, and to emulate courage and the spirit of a champion while helping to guide others with neuromuscular conditions to reach for independent self-fulfillment and to be the very best versions of themselves. Now, I believe I'm successful in this mission when I conduct myself in all situations, circumstances and environments with character, moral, fiber, and excellence. Now, you asked about representation. I approach this question by saying this, it takes us all to make the world go around.

Mindy Henderson: Amen.

Ira Walker: Now, this is a philosophical sentiment my father instilled in me from a very young age, and it still rings loudly in my head today as an adult. I do think that everyone in our community brings great value to the table, and I'm hopeful that as national ambassador through the speeches that I provided, the advocacy that I participated in and in my article writing that I've been able to echo this sentiment.

Mindy Henderson: Beautiful. You both each independently gave me goosebumps with your answers. I know though that in your journeys there are silly things and funny things that happen. Is there anything you can regale our audience with that has happened over the course of your journey so far that was maybe the funniest or the most unexpected thing that's happened?

Ira Walker: Listen, and this is a light-hearted... But something that's very near and dear to my heart. Many across the nation aren't familiar with the Ed Morse Automotive Group, but I want to say that the president of that group, Teddy Morse, is a great friend to MDA and to our community. Teddy lives down here in South Florida and hosts an annual golf event, and I've had the opportunity to spend time with Teddy through the golf event and some media interviews that we've shared on behalf of MDA. I want to say this, everyone needs a friend like Teddy. He's an amazing guy and always the life of the party and always keeps it light, keeps it fun, keeps it humorous. When you say fun, excitement or humor, my mind goes straight to our amazing partner and friend, Teddy. It's never a dull moment when Teddy is around, and I just want to personally state in this forum how grateful and thankful we are for Teddy Morse.

Mindy Henderson: I love that. Thank you, Teddy, for everything that you've done. I also want to be your friend. Ira makes you shine. What about you, Lily?

Lily Sander: Yeah. I would like to echo the fact that our roles are serious and there's a lot of time for business, but also MDA staff become like family. Whether we're traveling or having meetings, there's a banter where we're able to connect with each other and be humorous and fun. I would say that that's one of the best parts is just connecting with staff and community members on the human level where we understand that we are all connected by neuromuscular disease, but we can also connect on other things and be humorous and be our full complete selves.

Mindy Henderson: Love it. I love it. Ira, I'm going to try and not get misty when I talk about this, but as you pass the torch, what advice would you give to Lily as she steps into her second year and to MDA ambassadors generally who live all over the country as they share their stories?

Ira Walker: I was hoping you were going to ask me this question. See, Lily is a young woman who has a tremendously bright future ahead of her. She is someone who is going to achieve amazing things, great things in life, reach for heights that some can only dream about, and someone who I am more than confident will be a significant voice and visionary leader no matter where life takes her. Lily, I want to speak to you personally and I want to offer this to you.

No matter where you go, no matter who you are around, no matter what others may say, do or believe, always keep an appetite for doing the right thing. See, what I've learned is that you never know who's watching you in life or who will want to invest in you. But I truly believe this, if you always keep and hold a mindset of doing what is right and ethical, you'll ultimately always win in the long run. I believe this, that life is a long dance, a marathon, if you will. What you across the finish line in first place is courageously doing the right thing. I am amazed by you and I know that you are going to make us proud. We're counting on you. I'm counting on you, and I am excited to see you shine in the future.

Lily Sander: Thank you so much, Ira. Those words are so kind, and I'm so glad to have someone like you to look up to and to learn from. Thank you.

Mindy Henderson: I want to bottle that moment and package it. Lily, looking ahead now to 2026. First of all, we're thrilled that you're going to stick around and let us be part of your journey for another year, but what are you most excited about now in this second year in your ambassador role?

Lily Sander: Yeah. First of all, I am thrilled to be given the opportunity to complete my second year. I am just honored to be in this position, and that's never lost on me. I guess I'm just excited to enter a year where I know what to expect.

Mindy Henderson: Yeah.

Lily Sander: I feel like this year I've done a lot of learning and understanding my role, so I'm very excited to have a year where I have my bearings and hopefully my impact can go even further. I am so, so overjoyed and so excited for the future, although I'm so sad that Ira will be parting with us in this way. But the thing about our community is that we're always in community with one another, so there never really is truly a good goodbye. He'll be around.

Mindy Henderson: No.

Lily Sander: We are so lucky for. Yeah. I'm just overall very [inaudible 00:31:36] excited.

Mindy Henderson: I love that. Yeah. Ira can run, but he can't hide.

Lily Sander: Yeah. Right.

Mindy Henderson: He's stuck with us.

Lily Sander: Yeah.

Ira Walker: I'll be around. Absolutely.

Mindy Henderson: Perfect. Well, Ira, what are your hopes as you look ahead now with this ambassador journey as you check that off your list of dones? What are your hopes for the MDA community and for your own journey beyond this chapter?

Ira Walker: Absolutely. I hope to continue to discover ways to be a true value add for the neuromuscular community in any way that I can. I am truly proud to have published a novel this year. I know that now that I'm a published writer, one way that I know that I can be a value add is to continuously create more novels. I look forward to creating novels that highlight the strength of those with disabilities and hope that through my writing and many other avenues, I will continue to inspire and continue to shine a light towards hope.

Mindy Henderson: Beautiful. Well, we will look forward to reading those words that you write. A bit of a serious question and maybe the opportunity to pay homage to someone or something that has played a big role in your life, but I'm curious to know who or what keeps you motivated, keeps you showing up, speaking out and spreading hope because there are definitely tough days and sometimes it comes more easily and more naturally. What keeps you going, Ira?

Ira Walker: I really appreciate this question. I was recently asked a very similar question, and I want to share the response that I provided at that time. See, the future of our community is shaped by our youth, those who are coming right now and helping to really mold our community. It's individuals such as Lily who demonstrates their dedication and they have such innovative thinking and a positive contribution to our community that gives us hope and a bright future. The talents and commitments of Lily along with others, emerging ambassadors, play an essential role in sustaining our community. That's what keeps me motivated. That's what keeps me wanting to continuously investing in our community and wanting to constantly write speeches and be involved are those who are coming [inaudible 00:34:47] and those who are wanting to truly be a positive voice in our community.

Mindy Henderson: Yeah. I think it's so, so true. I think we've talked a lot about community in this conversation, and we truly lift together even when we're not in the same room with each other. I feel like we feel each other and the strength of the community when we most need it. I agree. What about you, Lily? What keeps you going?

Lily Sander: Yeah. I would also say people coming after me. I know that sounds a little crazy because I am very young, but seeing just the next generation already coming into themselves. I recently met a four-year-old little girl who has the same diagnosis as me, and that was very impactful to know that her family has more resources than I did at her age. It truly is that I want anyone that comes after me, whether they don't know they have neuromuscular disease currently or they're not born yet. Just having people having the ability to have an easier time to be better connected in community, that's what keeps me going. But as well as making my younger self proud, as cliche as it sounds. I always wanted to do something big for the neuromuscular community as it really served me, especially through MDA camp. That's when I first found my voice. I am always thinking about how can I make her proud and how can I help the people who come after me have an easier time with this journey?

Mindy Henderson: Well said. Very well said. I've got two more questions that I want to ask each of you. No pressure, but I feel like there's some really good wisdom coming. Not that there hasn't been. We're almost full up on wisdom here today, but two more questions. First question. As we close out the year, this podcast is our final episode of 2025, what's one word or maybe a short phrase that sums up how you feel about 2025 and... Well, let me leave it there. Let me ask that question first. Lily?

Lily Sander: I would say transformative. Yeah. Just in the way that our community has come together, I feel like every year we get better and we get better at supporting each other and we become better advocates and leaders. But especially this past year as my first year being national ambassador, it's been a transformative experience and has taught me a lot. I think that's where I'll leave 2025.

Mindy Henderson: Amazing. Ira, how about you?

Ira Walker: The best is yet to come, and I think about that from a research and development with the various cures and treatments that are on the horizon for many of the various forms of muscular dystrophy. The best is yet to come.

Mindy Henderson: So well said. Finally then, what is the best piece of advice that each of you have been given by someone in your life that you would like to share with our listeners as we go into 2026? Lily, let's throw that to you first.

Lily Sander: Yeah. My mother always has the best advice. She's the wisest person I know, and she is truly the one that reminds me of the responsibility I have in this role, but also the privilege and to never get too caught up in... We do have a lot of responsibilities, so it can be easy to not see the absolute privilege that this role is and that working with an organization as amazing as MDA is. She's the one that reminds me of my beginnings and gives me insight into my childhood and how to connect with others.

She's also the one that gives me advice on my speeches and my blogs and really coaches me through life generally. She's also the one that told me initially that I am a vessel for thousands of families, and that's something to take seriously and to understand. She always has some tidbit of advice that I'm so grateful to hear. It's just interesting to have her perspective as someone who doesn't have neuromuscular disease. I would definitely [inaudible 00:39:53] anything that my mother tells me.

Mindy Henderson: Wow.

Lily Sander: She's always right. They say that. Right? They say your mother's-

Mindy Henderson: [inaudible 00:40:00]-

Lily Sander: ... always [inaudible 00:40:00]. I think it's true.

Mindy Henderson: It's so true. That's so true. Everyone remember that, your mother is always right. Your mother is fabulous. I've enjoyed getting to know her as well.

Ira Walker: She's a lovely woman, isn't she? She really is.

Mindy Henderson: She really, really is. Ira, I'm going to give you the last word here. What is the best piece of advice anyone's ever given you?

Ira Walker: I've been fortunate that I have been raised by a father who has had a distinguished career of 37 years in law enforcement. It is been a blessing and it's been one of the greatest gifts from God is being raised by somebody in law enforcement. Years ago, my father told me that it would be a mistake not to carry a smile and a spirit of gratefulness during each and every day of life. He followed up and advised that though challenges will present themselves along the way, the reality is that there are many people who would love to be in my position in life. I believe this to be true, and I hope that everyone is listening receives this advice and begins to or continues to approach life by presenting their very, very best because there's always somebody that would love to be in your place in life. No matter the challenges that you're going through, there's always a reason to smile and to be grateful and to be hopeful.

Mindy Henderson: Y'all are so good. I am a little bit sad that our time has come to an end. I could talk to both of you forever. But I just want to thank you one more time for not just this time that you've spent with me today, but for all of the time that you've given to MDA and to our community. Ira, over the last two years. Lily, over this past year and the year to come. We are so grateful for you, and it's truly a privilege to know both of you. You're so special, and so thank you for all you do. I am looking forward to watching both of your journeys continue to unfold in the year to come.

Lily Sander: Thank you.

Mindy Henderson: Thank you, Mindy.

Lily Sander: Thank you. It was great. Amazing conversation. Thank you.

Mindy Henderson: Thank you for listening. For more information about the guests you heard from today, go check them out at mda.org/podcast. To learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved and to subscribe to Quest Magazine or to Quest Newsletter, please go to mda.org/quest. If you enjoyed this episode, we'd be grateful if you'd leave a review. Go ahead and hit that subscribe button so we can keep bringing you great content and maybe share it with a friend or two. Thanks, everyone. Until next time, go be the light we all need in this world.