

Speaker 1: The HD Insights Podcast is brought to you by the Huntington Study Group. The Huntington Study Group is a nonprofit research organization dedicated to conducting clinical research in HD, and providing critical training on HD to [00:00:30] healthcare professionals. Funding for this podcast is made possible through the generous support of listeners like you and sponsorship grants from organizations like Genentech, Teva Pharmaceuticals, Neurocrine Biosciences, Vaccinex, and Wave Life Sciences.

Kevin Gregory: Hello, and welcome to another episode of the HD Insights Podcast. As always, I'm Kevin Gregory, Director of Education, [00:01:00] Communication and Outreach at the Huntington Study Group, and your host for this program. We're pleased to bring you this podcast as the first one we've recorded amidst the full outbreak of the COVID-19 virus. We realize this is a challenging time for everyone, so we hope to continue providing regular podcast releases as an alternative for our audience. Even if it's only a 30 to 60 minute break from all that's going on, [00:01:30] maybe that'll be helpful for you. And to the extent we have guests that can help provide perspectives to the HD community for dealing with this type of unprecedented crisis, well perhaps that can be helpful too.

Kevin Gregory: On this episode, we spoke with Dr. Mary Edmondson. Dr. Edmondson currently serves as chair of the HSG Provider Education Committee, but her role in HD advocacy, particularly in the North Carolina region, spans several decades. For [00:02:00] helping with the beginnings of her local HDSA chapter to starting up HD Reach, Dr. Edmondson's family connection and her personal experiences really helped shape her drive to serve the community. She's certified in internal medicine and psychiatry, which really makes her uniquely qualified to manage the psychiatric, behavioral, and medical complications of Huntington Disease and, I believe, to lend her thoughts on mentally [00:02:30] dealing with the current added complication of the health crisis that is manifesting with this coronavirus. It's a conversation I thoroughly enjoyed and I think you'll enjoy hearing Dr. Edmondson tell her story. So now, here's our conversation with Dr. Mary Edmondson.

Kevin Gregory: Dr. Edmondson, thank you for joining the podcast today. These are some surreal times, but appreciate you coming on and [00:03:00] hopefully we have a really nice discussion to get people's minds off of the world around them and learn more about you and what you're doing in the realm of Huntington's disease.

Speaker 1: Yeah, it was my pleasure. I'm happy to be here today.

Kevin Gregory: Dr. Edmondson, so just for background, why don't we start with your involvement and how you got started in Huntington's disease. What specifically is your connection to HD and [00:03:30] what got you started out in to your current role?

Dr. Mary Edmond...: When I was a junior in college I got a package of materials from my brother one day. As I opened it, all these pamphlets spilled out from the Committee to Combat Huntington's disease, which is the predecessor organization of the Huntington's disease Society of America. I sat down, it was a rainy day, Saturday, [00:04:00] and I just sat down and read them all. And as I did, I realized that my dad absolutely had Huntington's and likely had had it for 10 years, which explained years of job losses and movement from one part of the country to the other, and just that downward drift that people who have mental or cognitive or even physical impairments, what they experience [00:04:30] as they go through the early stages of the disease when you don't know exactly what's going on. That became my journey, my lifelong journey really, to understand what Huntington's is and to get my head sort of inside the insides of neurons, and inside the brain, and inside families, and all those other aspects of Huntington's that are so important.

Dr. Mary Edmond...: My first trip was to the stacks, [00:05:00] the library where I was going to school. I pulled out a whole bunch of ancient neurology texts and they described the worst version of Huntington's I could have humanly imagined, which was violence, and divorce, and hypersexuality, and compulsive gambling, just your worst nightmare of what... At that time in my life [00:05:30] and I was 21, 22 years old, it was in my very naïve understanding of the world, it was craziness. But it didn't match what I understood about my dad at all. My dad wasn't like that at all. He had moments where he became very irritable and unreasonable and that he needed help in a way that did not make any [00:06:00] sense to me. And he had gait problems and other things that made him look drunk, so there was a lot of embarrassment as a teenager. But he was never like that. He never demonstrated what, like I said in my naïve mind, was insanity. So I'm like well okay if this is what's down the road, I guess I better go figure this out a little bit more.

Dr. Mary Edmond...: So [00:06:30] I started going to see human beings. I went to see doctors. The first person I went to go see was his doctor who wouldn't talk to me based on patient-physician privilege. Multiple members of my siblings kind of got the same reaction. He said, "I can't tell you whether your dad has Huntington's disease or not, but you don't have anything to worry about because it's X-linked recessive," meaning it would [00:07:00] just be, or Y-linked recessive, which means it would just affect men, which was completely untrue of course.

Dr. Mary Edmond...: And then I went to go see a really nice neurologist in private practice who examined me. A very kind guy examined me and told me that I didn't have any signs of Huntington's disease and he knew that because my eyebrows were plucked too perfectly. Just saying I had never plucked my eyebrows a day in my [00:07:30] life by that point, so as much as I appreciated his kindness, I also knew he didn't exactly know what he was talking about.

Dr. Mary Edmond...: And the third person that I went to was an academician who did my genogram and examined me with a much more, like a motor disorder exam. And she said,

"Well, I don't see any signs of Huntington's disease, so what can I do for you?" And it wasn't like, "What can I do for you?" You know how people lean into that [00:08:00] question, "What can I do for you?" It was more like, "I don't have anything to offer for you so what do you expect me to do about this?" And so I was really disappointed in what I'd got from humans who I thought would know more than me.

Dr. Mary Edmond...: So I went back to those pamphlets from the Committee to Combat Huntington's disease and I realized that this woman by the name of Marjorie Guthrie ran the organization. And I thought, "Well what have I got to lose by writing her? She's likely [00:08:30] not going to write me back, but really what have I got to lose by dropping her a letter?" So I did and I told her that I was a junior in college and that I just found out my dad had Huntington's, and that I couldn't find what I thought was accurate information and I was struggling with planning my life, and did she have any ideas? And I shortly learned that Marjorie Guthrie was not the kind of woman that you would just say, "What should I do?" [00:09:00] Because she would give you something to do.

Dr. Mary Edmond...: So what she suggested was that we form the first meeting of patients in North Carolina. We had a couple of conversations about what I needed to do in order to make that meeting happen. And so my first stop in that endeavor was to go to the Chair of Neurology in the school that I was going to. [00:09:30] I started my elevator speech and he stopped me immediately and he said, "Look, I know you are at risk for Huntington's disease, and I'm really sorry about that, but there's nothing I can do to help you, there's nothing I can do to help anybody who has Huntington's disease. And quite frankly, what I think you're doing is unethical, because you're going to bring all these people together, and they're all going to talk and they're going to get in touch with this whole experience of what their family's going through, and it's [00:10:00] going to be like ripping a scab off somebody's pain and being absolutely unable to do anything about it. So I really don't think you should do this meeting at all," which was really startling to me.

Dr. Mary Edmond...: It actually really made me mad, but that has become in a way my gold standard question. If I do this, am I really doing something substantive for people with [00:10:30] Huntington's disease or really something substantial for my own family? So even though it was unpleasant and it made me mad, I did learn something from it. And I actually learned something from every one of those people that I went to go see about the fact that you can be a very compassionate listener, but if you don't know the facts you're not helping somebody. And if you disseminate [00:11:00] bad information, that's kind of even worse. And if you tell somebody there's literally nothing they can do about a disease or a problem of any type in their life, there's always choices to be made. There's always choices to be made in life.

Dr. Mary Edmond...: So from those early encounters that I had with people, I formed some really pivotal opinions about Huntington's, [00:11:30] one of which is that there's a

real big difference between trying to cure a disease and trying to treat a disease. I sort of right from the start made the decision that I wanted to be on the treatment side, whether there was a cure or not.

Dr. Mary Edmond...: So anyway, back to the Marjorie Guthrie thing. I ended up finding one of my professors, my professor in the chemistry department, who was interested in helping. So he went to the Belk [00:12:00] Foundation and raised the money that we needed for the meeting. We found a guy who was doing research at Duke and so he set up the location. My friends and colleagues in sort of the pre-med group there all got together with me and we put together all the pamphlets and we did all the marketing, all of that.

Dr. Mary Edmond...: So In March or April of 1981, we had 100 [00:12:30] people at Duke. It was the first meeting ever of people and it was so incredibly eye-opening. It was eye-opening for all of us that attended it and it was the pivotal moment for my family, meaning it was the first time we openly started talking about Huntington's disease. We weren't talking about dad, we were talking about Huntington's disease, and it formed this beautiful bridge between the fear and [00:13:00] secrets in my family to a point where we had something to talk about that was kind of close to what was wrong with dad, but it wasn't exactly talking about dad. So it was, I think, a really good way to sort of break the secrets in my family. Fortunately, my mother met a woman there whose husband had Huntington's and they became lifelong friends and supported each other for decades. So it was wonderful.

Dr. Mary Edmond...: [00:13:30] So the people that came to that meeting include Marjorie and Ira Shoulson who was a young investigator from your town, from Rochester, and George Paulson from Ohio State, and Nancy Wexler who got off an airplane from Venezuela to be at our meeting. So she was real excited about what she had seen there. She was young, she was beautiful, she [00:14:00] was openly at risk, and really was a model of how I could choose to live my own life, that maybe I had more to contribute than I thought I did.

Dr. Mary Edmond...: Anyway, so really the most difficult thing I had to do was decide whether or not to go to medical school because I know that the decisions that physicians have [00:14:30] to [inaudible 00:14:31] make are often... They have implications for patients, they can be unsafe decisions. You can give people unwise advice. But most of all, if I did something that was procedural in nature, because I hadn't decided what I wanted to do yet, if I wanted to be a surgeon or a GP, or I wanted to be an obstetrician I would also have technical skills that would require my hands. I [00:15:00] think that most of the people during my 35 years ago when we all went to med school, we all felt like we had a societal responsibility for the public health of the people that we took care of, so I was very worried about whether or not it was fair for me to go to med school. That was the crux of my personal ethical dilemma, and Marjorie knew that.

Dr. Mary Edmond...: [00:15:30] We had all this informational stuff in the morning and then the afternoon was more for questions and answers. And at one point, George Paulson posed this question to the audience. He said, "So, this pre-med society from this obscure school in North Carolina that nobody's ever heard of really, has worked all these months to bring all of us here to talk about a very rare disease. [00:16:00] Don't you think that it's likely that one of these pre-med students is at risk for Huntington's disease?" Mind you, I'd been very quiet about my personal life at that point. I was still not ready to talk to my colleagues about it. So I'm like up in the top of the theater just trying to hide because I was leading this thing and my friends were kind of looking at me. So [00:16:30] he said, "I sit on an admissions committee at Ohio State, and we get lots and lots of applications from very qualified people. If you knew somebody who was at risk who's applying for medical school, would you pass them by because of that? Would you take a risk on that student? What would we do?"

Dr. Mary Edmond...: Ira said probably the most important thing and [00:17:00] the most difficult thing anybody has ever said around me. He said, "Yep, it's true that somebody who's at risk for Huntington's disease could have a foreshortened career, but isn't it equally true that the very experience of being at risk and the very experience of becoming kind of a patient early in your life, knowing that you had this health related risk, and maybe even health related symptoms, maybe the experience of that [00:17:30] would allow that person to become an even better physician than they would otherwise, and that they would be able to contribute more in a shortened career than many people contribute in a real long career."

Dr. Mary Edmond...: That was just the permission that I needed. It was a bunch of very prominent healthcare providers and investigators who basically [00:18:00] gave me permission to lead a responsible life, a life of my choosing. And I know how incredibly fortunate I was to have had that experience really early in my life because not everybody who's at risk gets permission to lead a responsible life, and certainly very few people meet Ira Shoulson and Nancy Wexler and people of that caliber in one day. [00:18:30] And Marjorie taught me how important advocacy was and Ira set the bar very high for me to work hard in my career.

Dr. Mary Edmond...: So that's how I got started. It's a long story, but I think its importance is a couple of things. One is that those first interactions with those four physicians, each one of them taught me something that I've carried through in my career. She can have the best bedside [00:19:00] manner in the world and still be just sort of an average doctor. And you can have all the knowledge in the world and not be a good communicator and still be an average doctor. You can have all the empathy in the world and it's just nothing more than what you would get from your next door neighbor. We should focus on a combination of all of those things as healthcare providers, and most specifically for people who care for Huntington's [00:19:30] families. And having somebody believe in me that, even though I was facing down a horrible enemy, that I could still contribute and be part of my community and society and part of the medical field.

Dr. Mary Edmond...: Those are the little nuggets of things that I think formed my early opinions and insights [00:20:00] into Huntington's. And I think my career as an internist, which is what I did for the first 10 years of my career, and then as a psychiatrist ever since then, every time I have seen a patient with something, I've looked for what I could learn from that patient, and that family, and my colleagues about how to take care of Huntington's patients better. Fortunately, [00:20:30] after doing my psychiatry residency at Duke, I reconnected with Ira and the Huntington Study Group and just knew that was sort of going to be my professional people, and have greatly enjoyed the people that I've learned and worked with through the Huntington Study Group since then. So long story, but there's a few lesson in there.

Kevin Gregory: [00:21:00] It's a great story and I think it's really impactful from the standpoint of you using those first four physicians that you encountered as motivation rather than being set back by it or just feeling defeated by it. I think hearing the story about that powerhouse group of people that came down to the first [00:21:30] group meeting that you had in North Carolina really couldn't have been better timed for you. The other thing, Dr. Edmondson, that I kind of wanted to lead into and I think this was a fantastic context for it, is you then went on to, and you're still doing a lot of work in the advocacy field. So your next step kind of was working to form HD Reach, correct?

Dr. Mary Edmond...: [00:22:00] Actually, the first thing I did was my brother and I started a chapter of HDSA in 1997. I think that's when we got our charter. When CHDI was formed, one of their grant recipients was Don Lo, he's a neurobiologist from Duke. Now he's at the NIH. He and I got to know each other and we had lunch together periodically. [00:22:30] He had just gone to one of their meetings and he came back and he said, "You know Mary, we don't need to raise money for research anymore. They have more money than... We have hit the jackpot with this organization. We don't need to raise money for basic science research anymore. What do you think we should do?"

Dr. Mary Edmond...: And I said, "So I've thought about some of the limitations of our [00:23:00] particular chapter." One of them was that we didn't have a Center of Excellence. We had one person, Francis Walker who did work at Bowman-Gray at Wake Forest, but there was no Center of Excellence, there weren't social workers, there weren't physical therapists, there were no psychiatrists, no psychologists. [00:23:30] There were people around the state that did things but there was no actual center that had everything, but we had all the pieces. We had a genetic counselor, we had two neurologists, I'm a psychiatrist. And the big thing we thought was missing was a social worker. So we go together with the chapter and we got together with all of the medical leaders around the state, Don Lo and I did. And we got [00:24:00] together with... We asked some family members who were real prominent to join that meeting, it was about 10 people.

Dr. Mary Edmond...: Don and I asked the question again, "What should we do?" And everybody said, "Well we need a Center of Excellence in our state, even if all it is, is virtual. We need to have a way to tie all these professionals together. We need a way [00:24:30] that a patient or a family, there's going to be somebody on the other end of a phone call Monday through Friday. And we need to have social workers who understand mental health to help us triage those people so they get to the right place at the right time." HD Reach was primarily formed around that concept, that we wanted to create a network of providers and resources for Huntington's families in our state [00:25:00] where we could streamline how they got services, we could streamline their referrals, and that we could assist the people that we referred patients to by collecting a lot of basic data, sort of the basic database on each patient so they wouldn't have to work quite as hard to gather all that information ahead of time. That was really the premise behind HD Reach.

Dr. Mary Edmond...: [00:25:30] We were formed in May of 2009, so 10 years ago. We hired our first social worker I think in April, Sarah Dawson, and basically gave Sarah the freedom to create, knowing that our vision was, letting her create what she felt what was needed to be done. Sarah had come from [inaudible 00:25:57] and had been a person who was on the front [00:26:00] end of when people came in, meaning she did their initial assessment and triaged them. So she was really the perfect person to do it. Our support group loved her and she just did a phenomenal job and turned what was just an idea into a real reality.

Dr. Mary Edmond...: So then we thought, okay so we pulled this off in Raleigh, the RTP area. How are we going to scale this? And I'll tell you, great ideas are only great [00:26:30] ideas until you can scale them. It's so hard to do it because every community is so different. But that's basically what we've been trying to do for the past 10 years, is to figure out how to scale those services and get them so that there's somebody someone can talk to within an hour drive all across the state. We really haven't found the perfect scalable model yet, but we [00:27:00] keep trying. We recently hired a new executive director who's got just tons of energy and very wise. I'm very hopeful that she's going to figure that out. I think it's going to involve technology and other things like that.

Dr. Mary Edmond...: In the past 10 years the healthcare community itself is dynamic. Our original genetic counselor left and went into industry [00:27:30] work. And Dr. Walker who's just recently retired. And we've got new people that are coming in to the field both at Wake Forest and in Charlotte. Probably the biggest thing that we've learned is that we really need to have sort of a physician champion in every region. It doesn't do any good to say, "Let me help you," when you have no resources. So [00:28:00] that's what we're doing now, is in conjunction with the HSG, we're planning how we're going to reach people over the next two to three years so that our manpower and our advocacy community both with the chapter and with all of the providers, does really create that network. And that when, when not [00:28:30] if, but when there's a positive trial that comes by

that our community will be prepared to help them get where they need [inaudible 00:28:42].

Kevin Gregory: That's actually what I was going to ask you too. For any of the members of our listening audience that may be looking to start similar efforts in their areas, what were some of the biggest lessons learned that you've had in trying to scale? You mentioned having a physician advocate in each region. [00:29:00] Is there anything else that people really need to consider or that you were surprised to encounter in the course of trying to set this up?

Dr. Mary Edmond...: It's so much harder than you think it's going to be, so much harder. I think one of the most important things that you can do is give people the information they need at the time they need it. And that information [00:29:30] might be what's the best way to treat anxiety in a premanifest or prodromal person, all the way to, what do I with this when I'm worried about somebody's safety? Although Huntington's is an uncommon disease, it's constellation of a number of problems that other specialties have solved. Gait disturbances have been solved in movement disorder clinics, [00:30:00] or they know the best thing they can do for people that have gait instability, for example. And psychiatrists know a whole lot about how to manage capacity, people's ability to make their own decisions, about depression and suicide, and how you measure and manage people who are aggressive, and how you risk stratify them. In [00:30:30] a somewhat scientific way you can't perfectly predict risk, but there's some guide posts along the way that are really helpful.

Dr. Mary Edmond...: That's going to mean that those providers in those locations are going to have to be educated, and they're going to have to be educated about all aspects of the disease. And then when they're in the middle of the taking care of a patient they need to be able to access that information, which is what you and I kind of are working on. [00:31:00] So, that's one thing.

Dr. Mary Edmond...: The second thing that we learned is that you really need to have a licensed clinical social worker, and that social workers go into social work because they prefer some margin of autonomy. So the medical model of a doctor writing an order [00:31:30] and you have to do it because I wrote that order, that doesn't work with social workers. It's a leadership style that does not work with social workers. It really has to be team-based. There has to be people within their professional Huntington's community, whatever that might be. If they go to the HDSA social workers meeting or they go to the Huntington Study Group and they [00:32:00] meet other social workers from other places around the country, social workers can create their own little network of people that they rely upon for their difficult cases. And those are the people that you email and say, "Hey I'm struggling with this patient. Can you help me figure out what to do?"

Dr. Mary Edmond...: But beyond that, you need to give social workers as much autonomy, just like we gave Sarah free rein to take that idea and create [00:32:30] whatever she

wanted it to be. I think you have to give them the freedom to do their job, and especially not necessarily not in a medical model. That's one of those things I'd have to probably sit down with people individually and discuss what that means, because I don't know that most healthcare providers realize that a mental [00:33:00] health model, which is a biopsychosocial model of how you assess and intervene for patients is different than a medical model. And for the two specialties to be able to communicate, we need to understand that we have a different format about putting people together and we use a very different language. And that's the kind of thing that a group like HD Reach ought to be able to bridge those kinds of communication gaps so [00:33:30] that everybody gets what they need, both from the point of view of a provider and from the point of view of a family.

Dr. Mary Edmond...: The third that I think is that... When we started out we were a nonprofit and we got lots of advice about how to be a nonprofit, and a lot of advice about how to present yourself in a way so that people will give you money, which was good and bad advice. [00:34:00] Money is scarce everywhere, and it's going to be even more scarce in the next couple three, four, six months, who knows. And that can either be something that terrifies you as a nonprofit or it challenges you to create things people in for profit spaces wouldn't take the risk on. So if we completely could solve this issue that requires [00:34:30] HD Reach to solve it, if there was a business model for it that could at least break even, you would no longer need a nonprofit and charitable basis. It would be a for profit company. So if you look at it that way, what you have to do is come up with good plans, good solutions that require a little bit of philanthropy and actually [00:35:00] sort of support from multiple different ways. Just like you would diversify your savings account or your IRA, nonprofits have to diversify their income streams as well.

Dr. Mary Edmond...: I think that part of it, the part of the business aspect of running a nonprofit, was incredibly challenging to me but also [00:35:30] extremely helpful. Nonprofits are diff than businesses, and nonprofits are different than health institutions. And in general, what they do is they fill gaps in services for which there is no market. And their job is to create that market so they go out of business. That's what a nonprofit ideally is supposed to do.

Dr. Mary Edmond...: [00:36:00] The beautiful thing is, the first year that we started HD Reach I had panic attacks about how we were going to get money and keep Sarah. I'd go to bed at night, I'm like, "I don't know how to do this. I have no idea how to raise money. What are we going to do?" So the first Christmas we just said, "Well, we're going to send out a Christmas card and we're going to hand write it so that people will actually open our envelopes. And we'll wish them a good Christmas and let them know that we're there for Huntington's families and [00:36:30] to join the effort." And after that, we always kept ahead of our payroll by doing that. The Huntington's community kept us ahead of our payroll. And they did it because I think they were grateful for what we did, and grateful

for the help that we were able to give them, and grateful that we got them where they needed to be at the time they needed it.

Dr. Mary Edmond...: [00:37:00] It was quite a journey for me personally. I found out I was a terrible leader and that I had to change my ways, and that I didn't know how to run accounting. There's a whole of things I learned about running a business that I didn't know before. And I'm really grateful I had that chance. It's a real learning experience.

Dr. Mary Edmond...: So that's what I would tell anybody who wanted to do something similar. But [00:37:30] mostly, just find 10 like-minded people and sit around the kitchen table and decide what you want to do, where you think you can make the biggest difference for the people in your state, and what are the things that really make sense for you? The process I went through to find knowledgeable people who could give me the information I needed to make decisions in my life, I had to go find them. So it was near and dear to my heart to help people find that without as much [00:38:00] trouble as I had to go through. And I never wanted to see anybody go through the prodromal stages of Huntington's that my dad went through that were just horrible to watch for him. I just never wanted to see anybody go through that again, because there was treatment then, there's treatment now. So that people don't suffer as much.

Dr. Mary Edmond...: Even though we wait and we're going to wait for a little while longer I hope, it's only a little while but you never know. The reason [00:38:30] that they test drugs in humans is because we don't know how it's going to work in humans. I think wanting to help people now, wanting to treat people now, looking for way to help people now, that's always going to be necessary. That's sort of my, what's the right word? It's been my cause in my life. And I feel really [00:39:00] fortunate that it came to me. I wouldn't have chosen it, but it certainly came to me.

Speaker 1: We'll return to the interview on the HD Insights Podcast in a moment. We hope that you're enjoying this episode. As a nonprofit organization, the Huntington Study relies on the generous support from the community and listeners like you to continue bringing you in-depth content [00:39:30] on HD, like this podcast series. If you like what you're hearing and are interested in supporting HD Insights through a grant or donation, please contact us through our email address, [info@hsglimited.org](mailto:info@hsglimited.org). Or by calling toll free at 1-800-487-7671. We greatly appreciate your support. And now, back to our episode.

Kevin Gregory: [00:40:00] Dr. Edmondson, one of the things that I want to talk with you about and get your thoughts on, especially in the current environment where we're dealing with the coronavirus or COVID-19. Based on your experience in internal medicine, and psychiatry, and advocacy, I expect that the sense of crisis [00:40:30] for those in the HD community is going to be even further amplified. Not only dealing with HD and the symptoms or the concerns around it, but now you're also talking about a national emergency for different health related

issues. I'd really just like to hear your thoughts on what patients or families can do to help cope with kind of this onslaught of information [00:41:00] or kind of adverse or negative feelings that may be coming out in this type of environment.

Dr. Mary Edmond...: So, two comments. One is I think that many HD caregivers are stretched to their limit already. It's a little bit of a combination of not really wanting help, [00:41:30] but also not being able to find help that makes the role of a caregiver so difficult. So I would say to anybody who is struggling, whether it's a caregiver or somebody that has early Huntington's, or somebody that's at risk, this is a very good time to expand your circle of people that you can talk to on a daily basis and [00:42:00] reach out to if you need help.

Dr. Mary Edmond...: All of a sudden, what Huntington's families live with all the time, which is social isolation and to some extent not being fully understood by others, everybody's in the same position now. We are all isolated from each other, at least by six feet. And most of us are staying at home. We're not going out, we're going to the grocery store once a week and [00:42:30] that's it. I've sort of noticed that I've started to grow this little group of people that I call every morning first thing just to see how they're doing, and if they're feeling okay, and what their plans are for the day, are they doing all right. And because nobody's at their job, most of them are at home, and they all answer the phone. We'll have a five or ten minute conversation and all of a sudden the world seems [00:43:00] like it's actually rolling on its axis, because everybody's going through that sense of social isolation now that Huntington's families, especially caregivers and people with mid-stage or more advanced stages of Huntington's live with all the time.

Dr. Mary Edmond...: So I think that's one thing that we need to be mindful of, is to take a few extra minutes to call the people [00:43:30] in our life that matter to us. And for kids to call their parents, their dad, their mom. For parents to call their kids, for brothers to call sisters, and sisters to call brothers, and cousins, and all of that. And your neighbors. Find crafty little ways of saying, "Hello," and, "I know you're alive," kind of things.

Dr. Mary Edmond...: So, that's one thing. The other thing that... [00:44:00] This is my prediction actually and that is that because Huntington's families are so incredibly resilient, they come up with the most amazing solutions to problems sometimes, I suspect that this is going to be just one more thing that they're going to have to be creative about. And that because they've been creative about so many other things that are less worrisome and difficult as the problem of being [00:44:30] in your house all day long, or the problem of worrying about every sniffle and worrying all the time if you have a fever, and the uncertainty of COVID-19 for the rest of the world is the same uncertainty that Huntington's families often live with day by day.

Dr. Mary Edmond...: People at risk understand symptom checking really deeply. So it's [00:45:00] been interesting to me to watch sort of the health behaviors of the people

around me in the way that they're coping with the COVID challenge like cleaning out the grocery store down the way, and not being able to find vitamin C anywhere. People are doing that because they're trying to prepare. They're trying to prepare for the worst so that [00:45:30] they can stop worrying about it. And I think Huntington's families have to do the same thing. They have to prepare the best way that they can and do what they need to do to take care of themselves. And then they just live every day one day at a time. I just think that Huntington's families have to cope with that much earlier in life than other people do. Some people learn when they're a kid that they have to cope with that, as a teenager, as a young adult, long before their parents [00:46:00] would've otherwise get sick.

Dr. Mary Edmond...: I think for Huntington's families it's a really great time to reflect on all the challenges they have met with courage and energy and creativity. Ask themselves, "How did I solve that problem and how could I apply that one to this problem?" And there's some new opportunities that there have been there before. This whole thing of being connected to each other virtually instead of in person is [00:46:30] an advantage right now, I think, for Huntington's families. I would encourage everybody to figure out how to do it, me included.

Kevin Gregory: Absolutely. Appreciate your thoughts and insights on that. Dr. Edmondson, I do want to switch gears a little bit here and talk about your role with the Huntington Study Group and your current service as Chair of the Provider [00:47:00] Education Committee, specifically the CME4HD program that you work on to help provide training to healthcare providers or caregivers. I want to talk about how you first got involved with that, what the motivation is for that, and kind of go from there.

Dr. Mary Edmond...: Sure. Back, [00:47:30] I think it was 2012, our annual meeting was in Seattle. LaVonne Goodman hosted it and she really wanted to have an educational program for local physicians that would grow their population of people who understood something about Huntington's. So within the span of about three months we put together an educational program that sort of talked about the cardinal [00:48:00] symptoms of Huntington's and stages and what kind of treatment you can give and that sort of stuff. It was really well received, and more importantly, the faculty had a great time doing it. So I said, "Well we need to do it again next year." And it just so happened that that next year was going to be in Charlotte, North Carolina.

Dr. Mary Edmond...: So I started early in the year with faculty trying to help them hone down what they really wanted to talk about and how they wanted to present it. Most of the [00:48:30] ways that people presented was the way that they would teach a med school class, frankly. That's the way they were comfortable teaching, and all of our talks were that way. So the next year, I can't remember where we went, but we didn't put as much energy. I think that was Tampa. We didn't put quite as much energy into [inaudible 00:48:54] because there were like 70 people who [00:49:00] showed up for our program because we worked really

hard to market it. So we didn't put quite as much energy into marketing that meeting and I think like 25 people showed up. So it was like, "Okay so that's not going to work. We are going to have to actually work hard on this."

Dr. Mary Edmond...: I gathered the faculty earlier in the year and we had monthly calls. And as a group, we made a decision to do a different presentation style. [00:49:30] And we decided that what we wanted to do was talk about what life was like for someone who was a gene expansion carrier from birth to death. So we talked about kids, we talked about at-risk youth, we talked about premanifest, nonmanifest, prodromal disease. We talked about early Huntington's, mid-Huntington's, late Huntington's and palliative care and end-of-life. [00:50:00] So what we wanted to give people was really the experience of what it's like to live with Huntington's if you're a human being with it. What were the symptoms and what where did that data come from?

Dr. Mary Edmond...: So we held ourselves to a couple of standards. The first year we just did it to see how people liked it. And they really liked that presentation style. The next year what we did is we said, "Okay we're going to go back. We're going to update our slides, but this time [00:50:30] we're going to annotate them with references." So this is just not the world according to Mary, or this is not the world according to Martha, or the world according to Daniel. It's the world according to the Huntington Study Group, and it's the world according to our faculty. A lot of educational programs are not... Like a paper presentation in a journal would be peer reviewed. There'd be three or four people who'd review it and give comments, or maybe even more. [00:51:00] That's how what we believe as fact, we publish it, give our peers a chance to acknowledge or criticize our results. So we wanted our educational program to be not only based in the literature, but also based on good people reviewing our work.

Dr. Mary Edmond...: And so, [00:51:30] we did that one and we recorded it and we put it online. And we challenged every Huntington Study Group and the people who worked at that site to get everybody to take the course online. You know this data probably better than I do, Kevin, but we also offered a scholarship for the person who made the most referrals. [00:52:00] I think the first month we did it there were, am I right, 700 people, or were there 400 people? I don't know, but there were a huge number of people who took the course that first month. And there was a woman in Colombia who asked every one of her colleagues, every single one of them, to take the course. And so she won the prize for the most referrals. So the HSG is proud that we [00:52:30] educated the country of Colombia about Huntington's disease that year.

Dr. Mary Edmond...: The important thing is we had these iterations of the program and we've learned from one year to the next what was a good way to present the information, what holes did we still need to fill, and how could we make it better and better? So what we decided after we did that first one we put online, we decided [00:53:00] we were going to do clinical cases. And this past year was the first time that we did those live. And now we're working with an online case-

based presentation company to help us put our stories about Huntington's by stage, same thing, youth, at-risk people, prodromal, premanifest, [00:53:30] nonmanifest, diagnosis, the motor stages of Huntington's, and then end-of-life or end palliative care. So we're doing it in a case format. We've not worked with a company this professional before and we've never gotten something done this early in the year before, but I think that we're hoping for April or May launch.

Dr. Mary Edmond...: I figured out [00:54:00] a while ago that it doesn't do you any good to have somebody to answer the phone if you can't refer them to somebody. We have to increase the workforce, we just have to. It's estimated that about 70% of people with Huntington's and their families are not seen in Centers of Excellence, either in HSG research site or an HDSA Center of Excellence. And a great many people are cared for by community [00:54:30] neurologists. Very few are cared for by psychiatrists. And about 50% of people are cared for by their primary care physician. We have to find those people where they are. We have to provide them education so they can create, one they can learn, but they can also create their group of four or five or six people that they email and say, "Hey I've got this really tough case. Do you have any ideas?" [00:55:00] So that's what I'm hoping will happen as a consequence of the CME4HD program, is that at some point we'll actually have small groups inside states that can communicate with each other and share their struggles and their successes.

Kevin Gregory: From the in-person trainings that you've done at the HSG annual meeting, what [00:55:30] are some experiences that stand with you from people that maybe that was their very first exposure to anything related to HD through the training? Have there been some light bulb moments that really resonated with you? Or some a-ha reactions? Just things that people were really stunned to learn in that setting?

Dr. Mary Edmond...: There were a couple things. I know the Charlotte [00:56:00] meeting better than I know anything else. For me there were the most a-ha moments in that particular meeting. We recruited our 75 people by getting every physician who had referred to one of the Centers of Excellence, people that both of our neurologists knew by word of mouth, people I knew who had displayed an interest in Huntington's. [00:56:30] Our genetic counselor went to their colleagues. We went to all the medical schools. We created a residency fellowship scholarship so that they could come. And we actually had one professor and four of their med students who came and spent the whole four days with us. Watching them go through it, that was the greatest thing.

Dr. Mary Edmond...: [00:57:00] That meeting, what we did is we spread it across three days. The first two days were half a day each of learning and networking with their colleagues. And then the Saturday has traditionally been family day. And it was almost like they learned all the didactic stuff about Huntington's and had a chance to interface with some of the HSG members and thought [00:57:30] leaders. But on Saturday they saw their real patients.

Dr. Mary Edmond...: We were in this marketing campaign where the guy who was working on it for us managed to get an article in the Charlotte paper like the Tuesday before the meeting. And we had 30 people, 30 families show up to that meeting who had never met another Huntington's family, and had never met a doctor who knew anything about Huntington's disease. [00:58:00] It was amazing to watch them. And all of these people who had come to the meeting, most of whom knew very, very little about Huntington's disease, watched that. They watched those 30 families show up. It was very touching. It was just extremely touching. And also tough because there were a couple people that had to run out of sessions, they [00:58:30] just weren't ready to hear certain things. They also watched us run out after them so we could catch them before they left the building and offer them an opportunity to sort of debrief what they'd heard. So they sort of saw us in action with a few people as well.

Dr. Mary Edmond...: I think that's the incredible part of doing advocacy work. It can be very painful [00:59:00] sometimes, but you also get to see people who for the first time in their life, they need somebody who has experienced many of the same things they have in their life. They feel connected all of a sudden for the first time instead of feeling marginalized and misunderstood. So those were the things that I had tremendous amount [00:59:30] of fun watching that meeting happen. I keep hoping that our in-person program, we can get our schedules such that people will actually attend the family sessions and get credit for. You and I, we've got some work to do on that.

Kevin Gregory: Well that's really motivational and inspiration to hear you discuss it. Dr. Edmondson, before we wrap you the episode, the last question [01:00:00] that I wanted to ask you is, you've had just an amazing career and it continues with your work today still and on into the future. But I have to ask you, what is the one thing that you identify as the professional accomplishment that you're most proud of?

Dr. Mary Edmond...: I took care of a lady who [01:00:30] came to see me who was just really suffering. She was suicidal, she'd already figured out how to jump out of her window. Her husband was struggling to understand what was wrong with her. She had two small kids at home. I saw her first in the Duke clinic with Burt Scott, and Burt asked us to kind of keep an eye on [01:01:00] her and see what we could do to help her. So I sort of managed her psychiatric meds and when we needed them to help us with motor symptoms, we would collaborate with them. But for the most part we looked after her and the process she went through to get tested for Huntington's.

Dr. Mary Edmond...: The day that she came to get her results, we had her test drawn at Duke, [01:01:30] but she wanted us to tell her the results. So she came to our offices for her result. Burt was great to work with that way because he always wanted what the patient wanted. I really admire that about him. Anyway, so she came in to the office. She was scared like anybody else is on a day they know they're going to get results. I sat down and I told her results and [01:02:00] that she was

a mutation carrier, and that a lot of the symptoms that she was having were because of that. You expect in somebody that's had that many problems to, even before they know their diagnosed, for it to be really difficult, but she was just fantastic with it. And she walked out and she said, "I never dreamed [01:02:30] that hearing that I had Huntington's would be a day where I actually felt better." But she said, "I do, I feel better now."

Dr. Mary Edmond...: That to me is the goal. That is the goal, is for someone to feel so supported and so ready that getting a diagnosis actually is relieving. That the uncertainty is finally over and your deepest fear, whatever it might be, often [01:03:00] is around learning that you have Huntington's and am I going to go off the deep end? How am I going to react? Am I going to lose my sanity just by knowing? I think we know that's not what happens anymore. People do fine with understanding this information if they're ready. Sarah and I helped [01:03:30] her get ready. And Burt and his team helped her get ready so that when she found out, she was really confident she was going to have people help her. And her husband was confident. She was beginning to see Huntington's through a lens that wasn't so depressed, it wasn't so bleak and dismal, and desperate. She saw that she was going to be okay, and that her kids were going to be okay, and her husband was going to be okay. So [01:04:00] it wasn't the horrible moment she thought it was going to be. And in fact, it was relieving.

Dr. Mary Edmond...: That was a real privilege to be there and see that. It was a privilege to see her grow and get better all because it was all her decision. We were just sitting there watching it. How she chose to handle Huntington's was completely her choice and she executed [01:04:30] her choice. I would have to say that was really a highlight for me.

Kevin Gregory: I appreciate you sharing that story, Dr. Edmondson. Just want to thank you for all the years that you've put in and the work you're currently doing to help make a difference for families dealing with HD. Also, just to thank all of the caregivers out there, especially in these [01:05:00] more challenging times than usual. To try and stay motivated and keep it upbeat and focus on the things that need to be done. Most of all, Dr. Edmondson, I want to thank you for joining the podcast today and sharing all of your stories with us.

Dr. Mary Edmond...: Yeah, my pleasure. You don't often get asked about your own story, and a lot of people are reluctant to tell some of their own personal stories, [01:05:30] but I figure that the heart of why people do things is kind of important to know. I have to say that the faculty that I work with and the people that I know in the Huntington Study Group have shared their stories with me about why working with Huntington's families is so important to them. And their stories are incredibly inspiring. They might not come from a Huntington's family, but they [01:06:00] have some collateral experience that they can apply. I actually am amazed by most of them. So thanks for including me in this podcast, it's kind of cool.

Kevin Gregory: We hope you enjoyed our interview with Dr. Mary Edmondson. Again, I can't thank her enough for sharing her story with us and providing some amazing perspectives. These are trying times around the world and hopefully this podcast [01:06:30] provided a brief break from everything. I did want to follow up and provide a website link, though, if you are interested in taking the CME4HD online courses that Dr. Edmondson spoke about. To do so, go to [www.huntingtonstudygroup.org/cme4hd-online](http://www.huntingtonstudygroup.org/cme4hd-online). [01:07:00] There you'll find steps to register. These courses are free to take and healthcare providers can also earn continuing education credits for completing them. If you are a researcher, advocate, or provider working in Huntington disease and have an interesting story or want to share that story, or if you know someone we should profile on a future episode, please feel free to reach out to me at [Kevin.gregory@hsglimited.org](mailto:Kevin.gregory@hsglimited.org). [01:07:30] Let us know what you're working on or how your efforts can help make a difference for those affected by Huntington disease. I can't promise we'll be able to get to all of them, but we want to keep providing as much content as possible as we navigate these complex times.

Kevin Gregory: so until next time on the HD Insights Podcast, again I'm Kevin Gregory. Thank you for spending time with us. Stay safe, be well, look out for each other, [01:08:00] and we look forward to bringing you our next episode.

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