

- Narrator: The HD Insights podcast is brought to you by the Huntington Study Group. The Huntington Study Group is a non-profit research organization dedicated to conducting clinical research in HD, and providing critical training on HD to [00:00:30] healthcare professionals.
- Narrator: Funding for this podcast is made possible through the generous support of listeners like you, and sponsorship grants from organizations like Genentech, Teva Pharmaceutical, Neurocrine Biosciences, Vasonex, and WAVE Life Sciences.
- Kevin Gregory: Hello and welcome again to the HD Insights podcast. I'm Kevin Gregory, Director of Education, Communications and Outreach [00:01:00] with the Huntington Study Group. On this episode, we spoke with Cat Martin, Executive Director at the Huntington's Disease Youth Organization or as most people are more familiar with HDYO.
- Kevin Gregory: I had the pleasure of sitting down with Cat to talk about the challenges facing youth that are impacted by HD, whether it's serving as primary care giver, whether it's being at risk for Huntington's disease itself. Cat does a great job on [00:01:30] drawing from her own experiences, serving as a primary care giver in a family that has dealt with Huntington's disease. She talks extensively about her experience with her hometown and how it really came together as a village to be the foundation of her future work, her future involvement with the Scottish Huntington's Association, as well [00:02:00] as her current role with HDYO.
- Kevin Gregory: I think you'll absolutely love this episode, so please sit back, relax, and enjoy our conversation with Cat Martin.
- Kevin Gregory: Well, Cat, thank you for joining us on this episode of the HD Insights podcast. I know I was hoping to speak with you in person at the HSG 2019 in Sacramento, but I think you and I were pretty tied up meeting with folks and enjoying that conference. [00:02:30] But again, thank you for calling in and having this chance to connect after that meeting.
- Cat Martin: Thank you so much for inviting me. It was an amazing meeting, especially for HDYO. HSG was so kind to us, in terms of giving us quite a big platform at this year's conference, which means that we were incredibly busy between workshops, and the booths, and just catching up with lots of really important insights that were going on. [00:03:00] So yeah, it's been a really good conference and really busy, which is a good sign, but then it stops you getting to do things like this, so I'm really glad we could do it by phone.
- Kevin Gregory: Absolutely. Let's start out, I want to talk a little bit about your background, and where you came from, and how you got to this point. Let's start at the beginning. You come from a Huntington's disease family. Can you talk a little bit about the impact that HD has had on your family?

Cat Martin: [00:03:30] Yeah. I always think I'm one of the lucky ones. I grew up with HD, I don't know a life without HD. The year I was born, my grandmother was diagnosed symptomatic with Huntington's. Previous to her being diagnosed, her sister had been diagnosed. That led to a realization that my great-grandmother had been misdiagnosed. [00:04:00] So, we grew up with it, but I'm incredibly lucky to have two quite forward-thinking parents, who valued trust and honesty to be able to deal with Huntington's. They never lied to us about Huntington's, so we grew up always knowing about it. We knew the name of it. At that point in time, it was still Huntington's chorea.

Cat Martin: We were involved in lots of aspects of [00:04:30] my gran's care, so conversations with people about what Huntington's was and as a family, we learned together. What that led to was really seeing Huntington's as something that everybody had. I grew up in a very small village in Scotland and more than one person in the village had Huntington's because we were a big family. We weren't the typical isolated nobody [00:05:00] knows what it is family. We were, "Oh, this is something that's in the village." There's only 370 people in the village and maybe 10% of the village are impacted by this because they're family members, so we were lucky.

Cat Martin: But mom and dad made sure that we were always told what was going on, the whole age and stage appropriate conversations with us about Huntington's. But they also gave us [00:05:30] access to specialist teams, should we need it, so I've got really clear memories of being in my grandmother's house when I was probably about seven or eight, and the geneticist actually being in the house doing skin and blood samples of family members, and talking about Huntington's. It all seemed like a party in my young age, but that was how we treated it.

Cat Martin: As we grew up [00:06:00] and we learned more about it, and my family became more involved in raising awareness of Huntington's, and the village joined in with the awareness, and fundraising, it just became part of life. It became part of what happened when you grew up, really.

Cat Martin: I think I was about 15 the first time I went into the genetics clinic and started asking questions, learned about my own risk, what that meant, and that [00:06:30] coincided with my grandmother passing away, and my mom becoming symptomatic. That transition is always difficult for anybody, and when you're 15, and hormonal, and you've just lost your grandmother who was a hero in your eyes, your mom then going down the same path is always hard. I was really informed for my age. I was really informed about what this meant, and I had access to really good people to be able to see that.

Cat Martin: [00:07:00] As a family, we spoke about it really openly. My mom and dad knew because they took me to the genetics clinic, while they sat in the waiting room, and allowed me to have those private conversations, and ask the questions that

I didn't want to ask in front of mom and dad. I didn't want to feel guilty at them feeling guilty.

Cat Martin: Yeah, slightly different experience of Huntington's than most people because I didn't have that isolation and [00:07:30] I didn't have that fear factor, which is what's driving me and has driven me ever since, is that there is a positive way to grow up with Huntington's if all the systems are in place to help support a whole family, rather than just a single individual.

Kevin Gregory: Right. What do you think it is about your parents? I think that's probably less common, especially, when you're talking maybe about a decade ago, where parents [00:08:00] really want to encourage that learning about the disease, and what inevitably is going to happen as a result. What is it about your parents that you think made them open to really encouraging you to pursue that knowledge?

Cat Martin: First of all, thank you for thinking it was only a decade ago when it was 30 years ago. My parents were ... I don't really know how to describe it but they just trusted us. [00:08:30] Throughout this whole Huntington's journey, they considered us part of their team. Decisions that were being made in the house, regardless of Huntington's, was made as a family. They knew what to tell us and always had this policy, "If you have any questions, if you're worried about something, we'll always listen." [00:09:00] It was just something that they wanted to speak about.

Cat Martin: For my mom, I think she had grown up with my gran, who didn't want to speak about it, who didn't want anybody to know about it, and this wasn't how she felt about it. She didn't think we should be ashamed of, she didn't think we should hide from it. She wanted and valued the support of people. I think for her, it was really important that support started within the house.

Cat Martin: [00:09:30] Dad is quite progressive anyway, so his whole thing was, "We do this together as a family, so that involves the kids as much as it involves the husband and wife. We need to do it together, so they need to be informed. We need to make children not scared of death but if they've got questions, that we can answer them together."

Kevin Gregory: I guess it's a good mistake on my part. I was thinking back to [00:10:00] when you first spoke in Dresden, so that's why I said a decade. I totally understand your perspective on that. You mentioned the 30 years ago, so your family was involved in helping start or initiate some of the advocacy there in Scotland. What did that take? What was the result of those efforts?

Cat Martin: [00:10:30] If we go back even further, around about 1983-1984, I was part of the genome sequencing work that was done with Dr. Wexler and all of that, trying to find the gene, if you like. There was samples collected from families all over the world and my family were one of those families. It was led by an

amazing doctor from the genetics department called Dr. [00:11:00] [ME 00:11:00]. Dr. ME had come to my grand's house and basically, whoever from the family was available was called to my grand's house to come meet her and talk to her. She basically, gave us our first link to Huntington's, even though at that point in time, we'd known about it for about six or seven years.

Cat Martin: She was just so good at just finding a way to connect with families and understanding that the genetics [00:11:30] clinic was the possibly not the best place to do that. She spoke to us all, and she did skin samples, and blood samples, and things, and I have this really clear memory of two iceboxes, a red and a blue one, that were collecting these samples to be taken away, that we didn't know, at that point in time, what they were being taken away to do, and how important that was going to be for getting to where we are [00:12:00] today.

Cat Martin: That started things. Then that led to conversations between the adults in the family going, "There must be more of us out there. There must be more families out there and we need to talk to one another because we need to learn about this together." At that point in time, there was a UK-wide support group that was called Combat, at that point in time. We had [00:12:30] a couple of meetings but what was happening was that a lot of the funding and things that were raised, all the fundraising was going to a central port, and it wasn't coming back to Scotland.

Cat Martin: The families worked for a few years, to look at, "What is it that we want to do?" Well, 30 years ago this month, they established the first HD Service in Scotland. That was November 19 [00:13:00] of '89. It was the birth of the Scottish Huntington's Association. One of the big decisions, at that point in time, was that the running of this organization will always come down to the views of families, so families will always be at the heart of that.

Kevin Gregory: How much has that association grown in that time, since 1989? I imagine there are only a handful of families. What [00:13:30] growth have you witnessed personally over those years?

Cat Martin: It is unbelievable really, to see the journey that we've taken in 30 years. In 30 years we have gone from a handful of families sitting around the office table in a backstreet in Glasgow, to supporting 1,100 HD patients and their whole family across Scotland. We have nine specialist centers. We have [00:14:00] dedicated youth work service, that's nationwide. We have a financial wellbeing service. We have a catered service, as well as all the centralized running of the organization teams as well.

Cat Martin: It's a pretty big enterprise now. We always say we support between 97 and 99% of HD families in Scotland because we support everybody that we know of, but there [00:14:30] is still places where this is heading. Every family in Scotland has access to our service. By that, I mean there is a service regardless of where you

in that family. If you're a patient, there's a nurse-led service. If you're a caregiver, there is a caregiving service. If you are a young person, there is a youth work service. If you are looking to do any sort of insurance [00:15:00] or financial planning, at any point in your life, there's a financial wellbeing service to support that. It looks after the whole family.

Kevin Gregory: Yeah, that's amazing and that's great to see too. Your family certainly had a part of that and definitely need to be applauded for the work and dedication that's helped it grow to this point.

Kevin Gregory: I want to-

Cat Martin: I think it [00:15:30] always comes back to families ... The thing with the Scottish Huntington's Association is that it started with families but even to this day, the board of directors are made up with at least 50% families, and only a family member can hold the chair position within that board because the final nail should always lie with a family member. They view the family should always be first and foremost.

Cat Martin: [00:16:00] That's not to say we don't have phenomenal staff team, we absolutely do. But Scotland is the only place in the world that has a national care framework that brings together every aspect of health, social, and community care for Huntington's, those impacted by Huntington's, the whole spectrum, which is an amazing feat that was done but it was sponsored by the Scottish government. It's not being looked at with other neurological [00:16:30] conditions.

Cat Martin: We're groundbreaking in what we've done, so it's been an amazing journey and it's been a journey which they've kept quite quiet about just how much they have achieved. They don't sing their praises enough, as far as I'm concerned.

Kevin Gregory: Yeah, I agree. That's certainly been one of the topics of interest that we've talked about on other episodes of the podcast, which is establishing or trying to establish that multidisciplinary [00:17:00] care team for patients because it really does cut across not just the care that you get from a neurologist or physician, but you have to take into account, "How do I plan the finances for my family? How do I plan for these things?" That you take for granted in a normal healthy situation.

Cat Martin: Completely. I think that's what makes us really unique [00:17:30] but also, why the support has just continued to grow, and the secrecy levels have continued to die because we've built up to be so supportive, that people feel empowered to actually speak out about what is going on, that they never feel judged about their decision-making, regardless of what that decision is: Whether to test, not to test, have kids, to not have kids, to speak openly, or [00:18:00] to just acknowledge that it's there.

Cat Martin: It's non-judgemental, but they have a support team that know when they go to an HD clinic, they don't need to start by, "Let's Google Huntington's disease, so the doctors are on the same page as us." Every single member of that HD team is absolutely informed about the impact of the disease on family life, as much as the diagnostics and symptoms management.

Cat Martin: We have a [00:18:30] university post-grad certification in Huntington's disease management for health and social care providers, and we've got the accredited nursing home training pack, which means that any nurse in our care, whom take in Huntington's patients, sign out to learn how to managed HD patients and to improve care.

Cat Martin: All of these things have meant that we're covered in all aspects of the disease, and that links it back [00:19:00] into that national care framework being implemented and giving that clear pathway, so that families don't need to go in and start by saying, "Shall we Google this together to find out what it is?"

Kevin Gregory: Right. That's great. Hopefully, this hopes get the word out, and the message out, and other locations, other countries can hopefully get back to you and pick your brain on, "How do we establish that elsewhere and make that a best practice model for [00:19:30] families around the world?"

Cat Martin: Absolutely.

Kevin Gregory: Cat, I want to follow down that path. We're talking about care and again, the impact on youth. In the article in the HD Insights Edition, you talked about being, essentially, 14-years-old, 15-years-old, and having to become the primary care giver. Like you just said a few minutes ago, while still dealing with all of those [00:20:00] typical teenager things, going to school, balancing friendships, and relationships, and everything else that goes along with that age. Can you describe what was the day-to-day like for you? What were the rough patches? What were the moments where things really brought things into perspective for you?

Cat Martin: I think the rough part didn't come until I was older because [00:20:30] that whole village mentality of we all supported one another. For mom's care, in the beginning, she was very independent. She was very independent the whole time, actually. But mom had lots of people who would look out for her, and help out, and support her being independent. If she wanted to go to something in the village, she didn't need a caregiver to go with her because she had 60 caregivers who were [00:21:00] there, and just continued to see her as the person she had always been, which was lovely.

Cat Martin: But as her health diminished and we needed extra support, it was actually fighting with the health and social care teams that was the most stressful. That's why I'm so passionate about the national care framework because that was probably our biggest battle, was just getting people to understand the

complexity [00:21:30] of the disease and the need for care, not to be static. It needed to be dynamic and it needed to be ever changing. They were the stress points.

Cat Martin: I was lucky, again there, because between my dad, and my sister and I, we would have turnabout of who was having the breakdown that day, so that when one had the breakdown, the other one picked up the slack, and the other one had to deal with whatever else was going on. We just continued to work as a team. [00:22:00] We always played to our strengths. We didn't try to do everything. We played to our strengths. My strengths leaned more in the personal care aspect of looking after mom, whereas my sister was so good at the paperwork and making sure that what needed to be done through the official channels were getting done.

Cat Martin: At the heart of everything, we just ensured we had fun. If mom wanted to go on holiday with her friends, [00:22:30] then she went on holiday with her friends. If she wanted to have people to the house, she had people to the house. The big thing for her, was that the kids didn't see her, the extended family's younger kids didn't see it as any different, other than Auntie [Christine 00:22:47]. I think that was the biggest thing for her because she just loved kids, and kids loved her. They were a big part of her life. They were always a part of her life that actually brought her a lot of joy and stability, [00:23:00] so if she was having a day where she was feeling sad or she just didn't want to do anything, the kids were really influential in changing that perspective for her.

Cat Martin: That made a difference because she wasn't seen as a Huntington's patient, ever. She was always seen as [Christine 00:23:20]. That made looking after her much easier in one sense, but because it caused her to remain so independent, [00:23:30] it made it so difficult to get her to comply with anything, as well.

Cat Martin: I wouldn't change that. I wouldn't that, to have a compliant patient, just to make it easier to look after because that independence and that spirit of fighting took her the whole way through the disease and she never lost her personality, she never lost her spirits, or her sense [00:24:00] of humor. She was, until the very end, really, really sharp with her come backs. Even when she couldn't speak, she could still write a little bit. She would very clearly tell you if she was not happy about something or if she wanted something.

Cat Martin: I think just being able to, when you were having a bad time, I knew there was always someone at the back of me that would pick me up, [00:24:30] or pick up the slack, to allow me to have a down day, or a time out. That as the big thing that really helped with mom's care. Caring for mom was totally different from caring for my grand or for other family members, because they're all individuals. Grand's personality was very different from my mom's personality. Grand wanted to hide away from it, and mom wanted to stand up to it, and fight it, and never let [00:25:00] it beat her.

Cat Martin: Any advice I would give to anybody, when it comes to caring for a Huntington's patient, is see the person first, and learn who that person is, and what's their joys in life, what's their personality, what makes them smile? Work on that because it will cut your battle in half by learning about the person, and it will also help you understand symptoms, and what symptoms, what personality [00:25:30] a whole lot better.

Kevin Gregory: That's a powerful story. Let me ask you this, when you meet with youth from around the world, or kids, or teenagers that are in a similar position, where they're essentially serving as the primary care giver for a parent. Even though that parent may have doctors supporting but the pressure and the stress [00:26:00] is on a child or a teen, what do you typically see as their biggest stress points? What do they come to you and say, "Cat, I just don't know how to deal with this aspect?"

Cat Martin: For a lot of the young people that we talk to, who are in that sole caregiver role or main caregiver role, the thing is that they have nobody [00:26:30] to hand that off to. The diminished label of self care that they have, that just keeps diminishing, they keep taking away self care, and they don't think anybody can do it as good as them, so they're holding on to that role as caregiver so tightly because nobody else has done it or they've tried to get other people to help them, and they've done something wrong, which could have caused harm [00:27:00] or it just could have made their life more difficult.

Cat Martin: We talk about this a lot with young people, where we talk about, "Let's find out what we actually need help with, and start small in building it up." The future planning stuff is really important in that. If we wait until there's a crisis, then we've got to be reactive but if we plan, we can be proactive.

Cat Martin: One of the big points of being proactive is that we then plan to do self [00:27:30] care much more regularly. Self care is the only way to care for anybody. If you don't care for yourself first, you'll never be able to sustain care for another person, especially somebody with Huntington's.

Cat Martin: That is about looking at what do you need help with, and if that is that you're not ready to let someone else come in and do personal care or something with your loved one, then can one of your friends or somebody who is saying to [00:28:00] you on a daily basis, "What can I do to help?" Give them something that would help you like, "If you're going to the shop, can you bring me some bread, and some milk, and some thing, and some that?" Get them doing that. They will be happy to do it. They're offering but make sure it's something that's helpful to you. If it's not going to be helpful, then that's fine. Or it could just be saying, "I need 10 minutes where I'm going to run at you about how rubbish things are at the minute. I don't need you to provide me with answers, I [00:28:30] just need you to listen and sit next to me while I do it or sit on the phone with me while I do it."

- Cat Martin: And actually, working with anybody to get them to find out, "What is my care needs for myself and what is my care needs of my loved one?" Is a really powerful journey to go on with someone because when you start breaking things down and getting things planned out, it makes it much easier to manage because you then have those people [00:29:00] who are saying to you, "How can I help?"
- Cat Martin: If you've got to, then go and deal with social services or health and social care providers in some way to say, "This is what we need to help care for my person," you've thought about it from a lot of different aspects, and you know what you need then. Whereas when we wait to case this point, it's just, "I need a break! I don't know what that looks like but I know that I need a break. If you look after them, I know [00:29:30] I'm going to pay for this in a week's time because I'm having to fight them to go into care. They're going to hate it the whole time they're there and that's going to be traumatic, so the next time we come home, I'm going to have to deal with the trauma they've had." It just becomes this vicious cycle of, "Nobody can look after them like I do, so I need to do it all."
- Cat Martin: Then you layer on the guilt on top of that, and you can see why the impact of Huntington's is not just symptoms. It's across [00:30:00] the board, psychologically. It really does shake the whole family if we don't draw a line in the sands and say, "Actually, we're going to do this differently."
- Cat Martin: I'm forever grateful to my parents for drawing that line in the sand and saying, "We're going to do this differently," because I wouldn't be the person I am today and I certainly wouldn't be doing the job that I am today, if it wasn't for them drawing that line in the sand and saying, "No, let's do this [00:30:30] differently."
- Kevin Gregory: Yeah, that makes perfect sense. Sometimes the simplest answers, you tend to overlook, where if you don't take care of yourself, you're just not going to be in the position mentally or even physically maybe, to help take care of that loved one. You do have to take that time to put yourself first.
- Cat Martin: Absolutely, yeah. And it doesn't need to be big. A lot [00:31:00] of them are just like, "I just don't have time. I don't have time, Cat." It's like, "Well, do you go to the bathroom?" "Yeah, but I don't get peace to go to the bathroom." This is where we need to start thinking about it. In terms of mental health as a society, we need to start thinking definitely about how we use our time, and can say, "Today, it's only going to be a minute. It's going to be 60 seconds. I'm going to take 60 seconds to sit and just breathe. That's [00:31:30] self care for me today because I can manage a minute. It might be in two days time I'm going to have three minutes. It might be in five days time, that I'm going to have two lots of three minutes."

Cat Martin: When we start to think about self care, definitely, not you need a half day every single week, just have little chunks where we can just recharge, then we will start to build it up definitely, and we will start to look at things differently. [00:32:00] When I say self care to people, they immediately go, "Well, I can't take a day off." It's like, "Okay, let's take a minute off for a 24-hour period. I want you to find a minute. All I want you to do is breathe for that minute. I want you to sit somewhere quiet and just breathe for a minute."

Cat Martin: That's what we need to teach people to do, if they're in that situation where they don't have time. We need to get them to [00:32:30] make time because it's so important to do that recharge. That's why we end up with so many crises because we don't take that time to recharge and have that time out. Even if we only do a minute a day, that minute is what is going to get us through the next 23 hours and 59 minutes.

Narrator: We'll return to the interview on the HD Insights podcast in a moment. [00:33:00] We hope that you're enjoying this episode. As a non-profit organization, the Huntington Study Group relies on the generous support from the community and listeners like you, to continue bringing you in-depth content on HD, like this podcast series.

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Kevin Gregory: Cat, I want to switch directions a little bit with you and talk about the perspective for how people and professionals deal with youth [00:34:00] impacted by HD. You talked about a story in the story here, where you spoke at the World Congress on HD in 2007. My takeaway from that, was that the response was, I'll call it adverse. It was more of a climate of wanting to shield children from that burden of knowledge.

Cat Martin: Yeah.

Kevin Gregory: Why do you think that was the reaction? Beyond as a follow-up, how do you think that's changed [00:34:30] in the time since then?

Cat Martin: At that point in time, it was the reaction because young people were just not included. It was a protective thing. Still, in a lot of places, if you speak to any clinician, you'll hear them say that they're speaking to a family who don't want to tell anybody because they don't want them to have this in their head just yet.

Cat Martin: [00:35:00] That was seen was the right way to do it. It was a protection thing. We didn't have the science that we have now, in terms of neuroscience, and the development of the brain in children, and understanding that actually being

open, and honest, in an age and state appropriate manner is much better than hiding things.

Cat Martin: But in 2007 we had the National Youth Service in Scotland, and we were dealing with a few hundred kids, [00:35:30] who we were speaking to on a regular basis, who were all saying the same thing, "I have somebody to talk to now." The big difference for us was that my experience of being able to talk about it made a huge difference to me but I didn't know it made a difference to me until I spoke to other young people who didn't have that freedom and didn't have that opportunity.

Cat Martin: We were seeing the fruits of our labor in Scotland by these young people. They [00:36:00] were doing self care, they were much more informed and more educated, they were making more informed choices about their future, they weren't doing that, "I turned 18. I must test because it's the only avenue that I have to information." They had other young people that they could talk to, the isolation was being reduced. We had young people who wanted to really go out there, and share [00:36:30] their story, and talk to other people about it.

Cat Martin: I think we were just slightly ahead of the curve when we spoke in Dresden and said, "This is a really good idea," and terrified 90% of the room. They were like, "This is so bad for kids. We've never done this in the past." All that did was spear me on to what we were doing was right. I've never been very [00:37:00] good at being told I'm not allowed to do something, so that just went, "Okay, I'm going to prove you wrong."

Cat Martin: That led to a whole lot of things. One of the main things was that a translator, a Swedish, Carina, contacted Scottish Huntington's Association and said, "What services are available in Europe for people?" We were like, "Very little." She did [00:37:30] a research project to interview all of the associations in Europe, and came up with only 11 replied, and only there was only two offering any sort of support to young people.

Cat Martin: We started working on a project where there's a European pot of money, where you can apply to do youth exchanges. We got together and decided that we were going to do this youth exchange, where we would do a youth camp, using the [00:38:00] Scottish model of camps, that it would be about education, peer support, as well as having professionals surrounding it to be able to get them somebody to talk to, and talk about research.

Cat Martin: We applied for money. In 2010, we had the first European camp but that came off the back of a whole lot of lobbying, that was done to EHDA and a couple other places to say, "We need to include young people, so let's get young people [00:38:30] to the World Congress in Vancouver." The difference between those two conferences was unbelievable. In 2007 seeing no young people, and in 2009 we had young people who were keynote speakers. They did take us up on it and they did invest, and it was at that point in time.

Cat Martin: The youth camp changed an awful lot because we included countries that didn't have any support. I think [00:39:00] we had eight countries that eventually sent some young people along. One of the young people that came along was Matt Ellison. Matt was one of my young people at the first European Youth Camp. He came back and said, "I have this idea that I've spoke to this guy in America about at Vancouver. We're thinking that we could do this website that teaches young people what Huntington's is, without using [00:39:30] really negative language but that it's in language that they'll understand. What do you think? Do you think you could help us with it?"

Cat Martin: That was the birth of HDYO. It was the start of my involvement in HDYO, was this young person saying, "I have an idea. Would you help us?" Never, at any point in time in that week, did I think that 10 years later I would still be helping with that project and that vision that young people had.

Cat Martin: [00:40:00] The change and the massive change that it has been over the last nine, 10 years, has been led by young people. It's not just been led by me, and Carina, and the team that did that first youth camp. It was young people who were saying, "Thank you for the opportunity. We're going to take it and we're going to run with it." They have. They've lobbied parliaments, they've lobbied associations, [00:40:30] they've badgered people into listening to them. They've been into clinics and said, "You need to listen to what I have to say," and are much more informed.

Cat Martin: We have a generation of young people who are far more educated about what Huntington's is, are being able to articulate very clearly the impact Huntington's has in their life, and they're able to connect with young people around the world and say, "My [00:41:00] story and your story are very similar. We just live in very different places."

Kevin Gregory: I have to image too now, since HDYO almost going on 10 years since that first emerged, you had young people then that were doing that lobbying. Now, those young people have to be adults. What are some of the success stories, where you've seen kids that were involved earlier, now adults out [00:41:30] there helping to push policy or to make changes that help youth going forward?

Cat Martin: It's fascinating some of the stories that we have, of what young people have done by giving them the opportunity to just be here and actually have their story told. Just within Scotland, it's made a massive difference. It was young people that stood in front of the parliament and lobbied for [00:42:00] better care for young people, for part of the national care framework.

Cat Martin: Their stories were really powerful, from young people who have gone into nursing and care professions because they see that as their vacation, and they're so good at it because they've learned a level of empathy that you can not teach. The amount of young people who have gone into the sciences are now involved [00:42:30] in research, and not just Huntington's but using their

personal experiences. Young people who are writing about Huntington's, in a way that we've never had before, sitting on boards of organizations to make a difference to the lives of people who are impacted by Huntington's, to talking to researchers, and sharing their stories on advisory boards.

Cat Martin: It's been overwhelmingly [00:43:00] fast, in terms of the change that's happened. For me, the speed was unbelievable. I can't tell you how quick it felt because we launched in February of 2012 and the next EHDN meeting was in September 2012. The amount of young people who were at that meeting, who were [00:43:30] being supported, who were vocal, who were talking to people, who were part of the audience, who were on the stage doing presentations, who were having their own working groups was night and day to where we were, just in 2007.

Cat Martin: And the attitude to young people being there was absolutely 180 because every single scientist, family member, association member who was there was like, "They [00:44:00] need to be here. They have a place," which was great.

Kevin Gregory: I can hear the excitement in your voice, when you start to talk about the involvement by youth and how that's grown. Where do you see HDYO continuing to evolve, even short-term? Over the next five years, what do you hope to accomplish?

Cat Martin: There's [00:44:30] two main aspects for me, that we need to tackle next. Research is going amazingly fast and we need to change how we work with young people and young adults because predominately, young adults are not seen in clinics and they're certainly, not seen as patients in clinics because they're not patients at that point in time, they're family members.

Cat Martin: There's a move [00:45:00] that HDYO can really help to get that group into the clinics and actually start being part of that clinical. It's not necessarily seeing all the doctors and doing all the tests, but it is taking part in research and it is being able to learn and to share their stories. Because as treatments evolve and the clinical trials for treatments evolve, young people are going to actually be key to them because we're looking at these [00:45:30] gene modifiers, or gene therapies, or protein lowering treatments that are going to actually be aimed at young people. They're going to be aimed at that presymptomatic group because we've always wanted to ensure that we can keep them as healthy for as long as we can. I can't remember what scientist talked about that golden window, between receiving your test results, and symptom onset, and making that bigger.

Cat Martin: [00:46:00] That's what we want to do but if we wait until we have that, and not engage young people, just know we're going to end up expanding that time before these treatments are available, so we need to start thinking definitely, about how we engage young people and young adults in a clinical process, and what that looks like, and how that needs to change in the clinic.

Cat Martin: That's one of the things, and I'm excited about that because [00:46:30] we're not fighting against a closed door there but we do have some really good learning that we can help with, and that we can start really looking at how we change that practice. It's not to say that current practice is bad, it's just that the current practice doesn't include this population. If they want them in, we need to change the practice slightly to include them. That's one thing that I want to do.

Cat Martin: The other part of it is we need to really [00:47:00] fight the fight for juvenile onset Huntington's and pediatric Huntington's because we're not talking about that enough. And because it's so rare and because it's not very well known, even within the Huntington's community, we need to start fighting that fight more. For us, as HDYO, we want to go and actually find those families, and find where they're getting those treatments, and where they're getting access to [00:47:30] services, and how can we help improve things for them, and how do we link them up to the specialists in the world, the handful of specialists in the world that know this disease and this aspect of the disease, to be able to get a treatment for them?

Cat Martin: That's not just within well-established countries that have really good infrastructure, but it's also in countries where they don't have any infrastructure. How do we make sure that we get to them as well? [00:48:00] And use the networks that we have for supporting young people, not just with Huntington's, but there's networks of supporting young people. How do we use those networks to find these families?

Cat Martin: They're probably the two big newer projects that we're looking at, so this registry of juvenile and pediatric Huntington's, and work with clinics to include young people as part of their clinical model. We'll never do this alone. I think [00:48:30] HDYO has always looked at this as a partnership, as a partnership between us as an organization, and young people, and families, and associations, and science, and clinics. If we collectively work together, our strength is impenetrable. We can solve any problem if we do it together. It's when we get into little silos and don't want to work together, that it becomes much more difficult. [00:49:00] For us, it's about how do we work together to do that? Which is why the importance of having these networks, and being able to come to things like HSG Conferences, and say, "We can help you with that and you can help us with this. Let's see how we work together." It's so important.

Kevin Gregory: Absolutely.

Cat Martin: It's one of the big strains of the Huntington's community, is that everybody is open to that partnership. It is so different from other diseases, [00:49:30] where people can still hide their work. There is an openness to communicate, and to partner, and to do things together. For us, it is about doing things together. It's not about us going in and doing everything or somebody else doing something.

It's about how do we do this together and play to those strengths, so our strength is X, and your strength is Y, but together we're going to solve this? That's what we want to do. We just highlight what young people are telling us, and then [00:50:00] try and move forward with it.

Kevin Gregory: I know we've been privileged at the HSG to work with you and continue to look forward to do so. Cat, before we wrap up, there is one other thing I wanted to give you a chance to talk about, and that's the Inaugural HDYO Young Adult Congress, that I know was recently announced. It's got to be really exciting for you because it's going to be in Glasgow. Do you just want to talk a little [00:50:30] bit about what participants can expect and what to look forward to for that in May next year?

Cat Martin: Absolutely. It's our biggest project yet, so we never do things by half at HDYO. We always say, "Oh, we can do that." Glasgow 2020, the idea came about from, we need to showcase the power of young people and we need to showcase the knowledge of young people, [00:51:00] so why not get everybody in a room, and let their voices be heard, and turn the table on the experience, and say, "You are now going to learn from the audience."

Cat Martin: That's where the idea came from it. It was a bit like saying, we know what happens when we do a camp. The science and research day at camp is probably the busiest and most exciting day for everybody. The questions [00:51:30] that are asked on those days, they're truly ground breaking, in terms of the knowledge that these young people have. They prepare themselves hugely, for coming in and asking these questions. For some of the clinicians and scientists who come along, they get terrified by the questions because they're like, "This is like a job interview. I've had easier job interviews." Or, "My PhD was much easier than talking to you guys."

Cat Martin: [00:52:00] We wanted to do that, but step up a notch and just make sure that, one, young people can get support, and they can get connected to more young people around the world, but we can amplify their voice and say, "You keep telling me that you can't get young people to participate. You've got hundreds of them in a room now. They're telling you that they want to participate. [00:52:30] What are we going to do to change that? How are we doing to allow them to participate? How are we going to empower them to participate?"

Cat Martin: That's what we're going to do at Congress, is to say, "Okay, you want to speak to them, they want to speak to you, let's start having conversations about how we move forward." But also, looking at how do we involve young people, I don't necessarily want to keep having [00:53:00] to do events just for young people, about how to be managed to make it that young people are part of events that happen around the world. There's a track there for them. Let's not patronize them, that it's actually really helpful, not just for the young people but for the teams who are presenting it or who are going to be there, that they need young people to be there, and they value the input into that.

Cat Martin: What [00:53:30] goes in partnership with that is support. We talked about that whole going through that hormonal stage, or those transactions, those early life transitions of I'm leaving school, I'm getting my first job, I'm moving into my first house, or I'm having to choose life insurance and I have no idea what that means. All of these things are happening as our bodies are coming to the end of our hormonal changes in adolescence. [00:54:00] We've just finished a whole pressure time of school. There's always relationship complications that end up breaking our hearts, so all of those life transitions happen while Huntington's is part of it.

Cat Martin: If we want them to take part, we need to support them to take part, and we need to give them the avenues to have that support because they are absolutely entitled to it. We know that if we support young people and we [00:54:30] educate young people, they are much more motivated to be part of the solution. This is just another part of that motivation and that empowerment is to say, "Okay, you want a platform, here you go." The young people who have been involved in our committees to Congress have been really forthright in saying, "We want this. We want to be able to do that. Not only do we want to hear from the world famous people. Who is the young person in the clinic? Who is the young person in the lab that's also taking part in this? What's their motivation to be there?"

Cat Martin: They want to see someone that they can relate to on that stage, as well as having access to that name person as well, who's a [00:55:00] rockstar that they want to see. They're absolutely entitled to it but they want to have someone that they can relate to as well on there. It's a mixture of a whole lot of things, and we're really excited about [00:55:30] just what will happen when we have a couple hundred young people together who are [inaudible 00:55:37] in what they want to do.

Cat Martin: The last time young people got together, they changed the face of Huntington's by just being able to talk to one another. HDYO was born out of that, the increase in services for young people around the world grew dramatically [00:56:00] since 2009, and that was young people that did that. There was all of us professionals who were there engaging and empowering that opportunity, but it was young people who could have that opportunity, and took it forward. It's time to step that volume up again and let's see what they do next. I'm excited to see what they'll do next.

Kevin Gregory: I have no [00:56:30] doubt that it will be a top-notch problem. The reputation of HDYO is amazing in the community. I know the members of your team go all out to make this a meaningful event for youth. We wish you the best of that. We actually look forward to hearing the reports and the outcomes of that Congress.

Cat Martin: We hope to see you there.

Kevin Gregory: Absolutely.

Cat Martin: You're more than welcome.

Kevin Gregory: It would be the perfect time of [00:57:00] year to go, for sure.

Cat Martin: Yes.

Kevin Gregory: Well, Cat-

Cat Martin: Not too much rain but not enough sunshine. But yeah, come on over.

Kevin Gregory: Well, Cat, thanks so much for taking time out of your schedule to speak with us. This has been absolutely great. I think people, adults and youth that listen to this, will come away with a lot of great advice and a lot of exceptional insights to [00:57:30] incorporate into their daily lives.

Kevin Gregory: For me personally, thank you very much for joining us today.

Cat Martin: Thank you so much for the opportunity.

Kevin Gregory: Thank you again for joining us on this episode of HD Insights podcast. That was an absolutely inspiration conversation with Cat Martin. I hope, you all as I did, [00:58:00] appreciate her insights and experience, not only as a caregiver for a family with Huntington's disease, but as an advocate for HD youth, and for youth caregivers, and the amazing work that they've done in Scotland, that she's carried into her work with HDYO. Just a fascinating organization and one [00:58:30] that we're really proud at the HSG to have worked with.

Kevin Gregory: If you do want more information about the Huntington's Disease Youth Organization, I encourage you to go to HDYO.org. You'll find more information there, about not only their organization but also, about the Inaugural HDYO Young Adult Congress that's coming up in Glasgow in May of 2020.

Kevin Gregory: This episode [00:59:00] is our last episode of the 2019 calendar year. We thank you for joining us this year and being part of the HD Insights podcast. We look forward to bringing you many more episodes in 2020. But for the next few weeks, we're going to take a bit of a hiatus for the holiday season. We look to be back with our next episode sometime in mid to late January. Be on the lookout for new episodes starting then.

Narrator: [00:59:30] We hope you enjoyed this edition of the HD Insights podcast. Remember to subscribe to this podcast, to make sure you automatically get the latest episodes to your device. Please rate and review this podcast with your feedback, so we can continue providing the best possible content.

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Narrator: Thank you for joining us on the HD Insights podcast from the Huntington Study Group.