

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 healthcare [00:00:30] 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 the HD Insights Podcast. Thank you for joining me today. As always, I'm Kevin Gregory, director of education, communications, [00:01:00] and outreach at the Huntington Study Group and your host for this program.

Kevin Gregory: On this episode, we are privileged to speak with Chandler Swope from the Huntington's Disease Youth Organization, or as they're more commonly known, HDYO. Chandler has been the director of youth services for the past six years and has helped spearhead a number of key initiatives aimed at helping young people deal with the impact of Huntington's disease.

Kevin Gregory: She's a dedicated and compassionate advocate for families and has experience with helping young people address [00:01:30] family trauma and crisis. I thought it would be helpful to bring Chandler onto the podcast as we all continue to navigate these uncharted waters and uncertain times brought on by COVID-19.

Kevin Gregory: She shares her perspectives on helping people cope with stress and strategies to still feel a sense of connection despite the limitations of social distancing. Plus, we get to learn more about her background and work with HDYO. Without further delay, here's my conversation with Chandler Swope.

Kevin Gregory: [00:02:00] Well, Chandler, thank you so much for joining us on this episode of the HD Insights Podcast.

Chandler Swope: Yeah. Not a problem at all. Happy to be here.

Kevin Gregory: Before we get started, I know there's a lot we want to cover in a little bit talking about the impact of everything to do with the coronavirus and the impact that it's had on people's lives, but I did want to start a little bit more about your background. You started with HDYO in 2014. [00:02:30] Can you tell the audience a little bit, how did that opportunity come about for you?

Chandler Swope: Actually, it's sort of one of those normal, everything sort of fell into place. I was currently looking to transition in work. At that time, I was running the Domestic Violence Hotline for the city of Washington, D.C. managing that program and working with families in a safe house, and it was just sort of time for a career change, time to do something new.

Chandler Swope: It was [00:03:00] actually a mentor of mine who came across the job posting before I had seen it and felt that it would be a good fit. I knew a little bit about

HD, but I came in very honest with the team at HDYO to say I didn't know much about it, but I did know young people and families. That's where all my previous work had been.

Chandler Swope: When I spoke with Matt back in the beginning, what really drew me to the position was just Matt's own story of creating HDYO and how [00:03:30] he used the impact of HD to do more or look to help others in the same situation. That something empowering young people and helping young people find their voice and their own strength in challenges is something that has always been very important to me.

Chandler Swope: Being part of a team that that really was the core of the mission and the core of who HDYO was, on top of just professionally being able to help develop [00:04:00] something from the ground up, it really sort of just, everything aligned at the right time, and so that was something I was very excited about.

Kevin Gregory: You really led the way with getting a number of the youth initiatives in place for HDYO. Can you tell us about some of those that have been implemented and what the journey was like getting those started up?

Chandler Swope: Yeah. [00:04:30] When we brought this all together back in 2014, the goal was really to launch a professional youth service. Originally, we focused on the Mid-Atlantic region, Maryland, D.C., Virginia, although that's a pretty big geographical area when you look at it all, working to have specific support for young people.

Chandler Swope: To do that, it was working with the local clinics, the centers of excellence, and working in partnership with [00:05:00] all those that were already centers of excellence, so HDSA, [inaudible 00:05:03] HD patients, some of the smaller neurologists in the area, to get families to know about the program, but also to change the mindset, that young people are part of this conversation. Young people have needs of their own that maybe they're not talking to their families about or how to get young people the right information, so spent a lot of those early months ...

Chandler Swope: Well, what we first did, and [00:05:30] I think one thing that I really appreciate, is even though I had been a social worker for many, many years, they took me back to the beginning. I spent the first few months really learning about HD, so not just reading everything I could on our website and other websites, learning all the different nonprofits and groups that were working in the HD space, learning about what was currently going on, what had come before all of it, and speaking with some of the top names [00:06:00] in research and science and treatment and Mary Edmondson and folks like that to really understand it from all sides of HD. Not just one person's experience, but really trying to get a sense of what is impacting young people in HD families.

Chandler Swope: From there, then working with families to sort of change the narrative. I think if you speak with anybody in HD community, whether it's a doctor or a genetic [00:06:30] counselor or a social worker, we hear a lot about the stigma of HD and this history of secrecy and how to have these tough conversations, and so having that conversation with parents about how do we then change the narrative for young people.

Chandler Swope: One of the things I always ask families is, for parents or grandparents, is, "How did you learn about HD?" A lot of times the stories aren't great. It was either a secret [00:07:00] or it was suddenly. It came as a surprise or there had been sort of different stories floating in the family, and families hold on to that.

Chandler Swope: What we wanted to help do is change that narrative. Some of the bad things that can happen when learning about HD, we can change that by giving, empowering families to take control of that discussion, making sure that when they go to talk to their children, they have the right resources, because there are resources now.

Chandler Swope: [00:07:30] A generation ago, there wasn't websites that were particularly appropriate for children. There weren't different information for children, teens, and young adults because, again, where they are developmentally and educationally different. Really making sure that families knew all of this existed, that was really what I came on board to do.

Chandler Swope: Then, one of our goals was to have a camp. Camps have been running in Europe, [00:08:00] either country-specific or with multiple countries, since, I believe, 2011, but it maybe have been 2009. I don't remember the exact year, but for quite a while. We wanted to create that experience for young people in North America. There had been some localized camps and different events through different chapters or groups, but we really wanted to bring camp to North America.

Chandler Swope: In 2015, we hosted our first camp, and that was sort of a [00:08:30] big undertaking of mine. That's been a project that I've now been working on for five years. We worked in partnership with the Huntington Society in Canada and HDSA here in the U.S. We bring staff from both of those agencies as well as we have a core group of volunteers that have been wonderful enough to come back.

Chandler Swope: We host about 45 to 55 young people every year, and we spend four to five days talking about HD, talking about testing [00:09:00] and genetic counseling and grief and loss and care-taking as well as just being able to provide opportunities for professional support with social workers and other professionals at the camp, peer support, and just time to sort of relax and be a young person because, again, we know that the responsibilities for many young people in HD families are different than their peers. We also just want time to go swimming and rock climbing and be able to sort of goof off a [00:09:30] little

bit because not everyone has that luxury at home, just depending on what their family situation is.

Kevin Gregory: What surprised you the most after you first got engaged with youth and families in HDYO? I know you mentioned when you first started with HDYO, they kind of took you back to the beginning and gave you the overview and the training on the disease itself. But when you first started interacting with these folks, was there anything that caught you by [00:10:00] surprise or that you felt that you weren't really prepared to see in person?

Chandler Swope: I think the biggest thing is really the resilience in the community. As a social worker, we learn a lot about meeting families where they are, and there's all this information about how to help people sort of come out of situations, but if you talk to any social worker, there's many times where you sort of feel like the [00:10:30] burden is put on you. You're supposed to come in and fix things.

Chandler Swope: Really, whereas a social worker, you're taught to work alongside and be there to support whoever you're working with in achieving those goals, the HD community, they embody that. They are right at your side. They're not asking you to do it for them. They're asking for support. They are pushing back against the things that may be barriers, but they're figuring out ways to overcome [00:11:00] them.

Chandler Swope: I think from the outside, when you talk to somebody who's never heard of HD or you talk about what HD is, that sort of immediate reaction is, oh, my gosh, that's terrible and how could you? I can't even imagine. But when you talk to the families, even in the hardest days, they're willing to fight. They're willing to give more. They're willing to participate in research. They're willing to start something locally to raise awareness, to raise funds, to give back. [00:11:30] It very much is as much as we know about it, it can really tear families apart in ways.

Chandler Swope: One of the quotes that I heard from actually someone on our team at HDYO is as much as HD has taken away from her, HD has brought her so much more. I think that holds true for so many families in this community because there is this bonding feature about HD. When we have camp, by the time we make it to the actual camp facility [00:12:00] after usually some hours in the airport and about an hour or so on a bus, these young people have shared bits and pieces of their story that they may have not shared with anybody even in their closest circles, because they know that when they share that piece, somebody will understand it to some degree and somebody will empathize with it and not sort of feel sympathy for them.

Chandler Swope: It really is just the strength of the community because, again, I think so many people [00:12:30] from the outside would just feel defeated thinking about it, but when you talk to the community, they are far from it. If anything, with where we're at right now with potential treatments and trials, they're even

more motivated to sort of keep pushing and keep fighting and keep raising awareness.

Kevin Gregory: You've been doing this now for six years with HDYO. What are some of the lasting personal relationships you've made with people now? [00:13:00] I know the focus is on youth, but as youth get older, do you still maintain those contacts? Are you still engaged with some of those folks that may have been kids when you started, but are now moving on into adulthood?

Chandler Swope: Absolutely. I mean, it makes me realize how old I'm getting, but we do. There are young people that I've worked with since almost year one, and sort of watching them grow and transition and being there to celebrate the great moments in [00:13:30] life and being able to support in the tougher moments. We always joke that even though we have age limits on some of our services, you never really age out of HDYO. What's great is that even if you're not coming to camp anymore, we've had campers come back and volunteer and become a volunteer. We know they've gone on to do things in their local community, to join the local efforts of things.

Chandler Swope: Really being able to see that transition, that even if you're [00:14:00] not a client of HDYO, even if you're not able to come to camp because you've aged out, there's always something we can do. Unfortunately, speaking of coronavirus, we had to postpone our congress, but that, too, was to really ...

Chandler Swope: One of our goals of congress was to engage that sort of young adult cohort of people that don't always have events specifically for them. They're not necessarily seeing clinicians. They may or may not be eligible [00:14:30] for research. They're too old for most camps or events worldwide, no matter where they are. How do we bring them together and give them that same opportunity for support?

Chandler Swope: It's great that we're able to ... Our services go up to 35, so it's a pretty broad age range, but those who sort of age out, if you will, we see them doing amazing things in their local communities, building resources for the families in their area, and being able to stay in touch. [00:15:00] Some people have either joined our board or been able to volunteer with us in other capacities. It's great because you're always able to stay in touch and see how things are going, which is good because you can ... We're here. We're here to help them find the right resources if it's not HDYO in that moment.

Kevin Gregory: I think one of the things that I wanted to mention and get your thoughts on, that I know you've done for the Huntington Study Group specifically around [00:15:30] our annual Family Day gathering, is you come in and you work with the hotel staff in advance to help them prepare for interacting with and understanding people that may be symptomatic or dealing with effects of Huntington's disease.

Kevin Gregory: What have been some of the takeaways that you've had from people that you've had the opportunity to train and give awareness to HD for the first time?

Chandler Swope: [00:16:00] I think it's that age-old ... We sort of tend to assume what people are not willing to do because we often hesitate to ask. It's sort of human nature to not want to ask for help or not want to be a burden on someone. But in speaking with the staff and letting them know somebody may not say this, but they may need X, Y, or Z in this moment, [00:16:30] they have been so appreciative of being able to be of more help to the families that come through.

Chandler Swope: I think they appreciate understanding what's going on because when we don't know what we're looking at, it's human nature to sort of stare and try to make sense of it in our head. They feel more empowered to ask questions, to not be fearful of doing the wrong thing. If anything, I think it provides them the satisfaction [00:17:00] that they're doing more for the people that come in as well as it's helping raise awareness for HD in general.

Chandler Swope: For the families, it makes that day a little bit easier. It gives those caregivers ... If they know that the hotel staff is trained if it's a sit-down meal to ask about allergies, it's one less thing they have to think about while they're there to get support. I think it gives everyone just a greater level of sort of ease and satisfaction in that moment, because I think families sometimes are wary [00:17:30] about big events because you're not in as much control. As well, with HD in particular, I think staff hear the word disease, they think everybody's sick.

Chandler Swope: But we all know that you can't always see Huntington's disease. You can't always understand that an individual is symptomatic or sick because they don't look symptomatic or sick. Helping the hotel workers or people outside the community understand that just broadens our awareness [00:18:00] of how we treat people in day-to-day existence, that we don't always know what's going on with people. If anything, we've just broadened general awareness of thinking about our surroundings on an everyday level.

Kevin Gregory: Yeah. I mean, I've seen that firsthand and just how fantastic your efforts have been in helping just the hotel staff around that particular meeting.

Kevin Gregory: There's one other thing I also wanted to follow up with you. We spoke with Cat Martin [00:18:30] before the holidays on one of our earlier episodes and one of the things she brought up was trying to break down the barriers of talking to children about HD and the fact that historically, there's always been this desire to shield and protect children from hearing the truth of it, but that's the opposite position that she's taken and that HDYO has taken, that there's truth to power. [00:19:00] There's a lot of power in knowledge.

Kevin Gregory: Talk about it from your perspective in the states and what you've seen working with families. Is that a challenging thing to get parents to open up to kids about the risks or the issues with Huntington's disease? Or are you seeing that

becoming more and more the norm, that people are readily sharing what they can expect or what the parent may end up going through or what the child may [00:19:30] end up going through?

Chandler Swope: Yeah. No, it's absolutely something that HDYO believes in and pushes for is open and honest communication with, we say young people, but, again, we're talking up into teens and even young adults. I think in some ways, we're seeing a slow shift, but, again, with HD because there is no one family story, there's always families [00:20:00] that you'll run across that still sort of have trouble having that conversation.

Chandler Swope: I think one of the things that I talk with parents about ... Again, this goes back to something I said earlier. When we find families that are very, very hesitant, one of the first questions I ask, like I said, is, "How did you learn about HD?" Often, what we find is their experience of learning about it was traumatic in some way. Either there was a family secret [00:20:30] that they uncovered on their own, they overheard it, something terrible happened, a fall or some other kind of medical emergency. Depending on how old they were, that leaves a lasting impression.

Chandler Swope: Even though it's easy to say, "Well, you have the ability to change that," when somebody's living with that burden, with living with the weight of how things played out for them, it can be really hard [00:21:00] to pull themselves out to sort of see the picture from a different angle. And in all my work, I've worked with families in lots of different situations, we tend to put blinders on. In some ways, we think it's protecting ourselves, but sometimes it keeps us from doing things that may be beneficial not only to ourselves, but to those in our family or those around us.

Chandler Swope: That's one of the conversations I have with parents, and we really have that [00:21:30] conversation of if you have the conversation, if you take control of this, you get to dictate how your family talks about HD, excuse me, how they learn about HD and even where they get information. I tell families never, ever, ever, ever google HD. There's still things you can find that are out of date, are wrong, are inappropriate, because the Internet, you don't need permission to use the Internet or post [00:22:00] things on the Internet. Anybody can get a website if they really want.

Chandler Swope: It's really important to make sure that families have those right resources so they feel confident in having those conversations, as well as the right resources, whether it's a local support group, the HDYO Youth Service. We have support groups on, secret support groups on Facebook for young people and parents that are moderated, so, again, we know that the information's appropriate and correct.

Chandler Swope: Reminding [00:22:30] them that although we think it's important to, we being HDYO, to talk to children, they also know their children best. It is not us coming

in as HDYO "experts" telling them exactly how to do it. It's supporting them in that journey of they know their family. They know their children, and they know how it can work best once we give them some tools. It's really supporting families in that [00:23:00] journey, not telling them this is what you need to do and you need to do it now, because that's not helpful with everything going on.

Chandler Swope: But it's here's some tips, here's some resources. Obviously, we are really lucky to have Dr. Bonnie Hennig-Trestman on our board, who wrote a book on talking to kids, that we can provide them insight and resources on. We are able through our parent group to connect them to other parents to say, "I was terrified, but I talked to my kids and actually, it went really well and now they want to be involved."

Chandler Swope: [00:23:30] I think we see that when we see ... The young people who are very involved in HD community are often the ones who sort of HD has always been a part of their story. It's something that is part of their normal. It's part of their life. They've just adapted, as this is part of what they deal with every day. Everybody has their normal. Everybody has their story.

Chandler Swope: What we try to promote [00:24:00] is HD is part of theirs, but it doesn't define who they are. If it spurs them to get involved, great. If it's a piece of information they have, but they choose to pursue other interests, that's also okay. So, it is. There's no one-size-fits-all version of this conversation, but it's getting to know families. I've spent years sometimes talking with parents before we talk with children or before even I meet the children, even if the parents are talking to them.

Chandler Swope: It really is, there's [00:24:30] an individualized approach to all of this, but it's, again, making sure families then know where to go with those questions they can't answer or how to connect young people so they're getting the support in the way they need support, which oftentimes is virtual because that's just where most of their lives are at this point.

Kevin Gregory: Chandler, is there a place that people can go to for more information about HDYO [00:25:00] and the type of services that you guys put out?

Chandler Swope: Yep, www.hdyo.org. And that'll have links they can write in questions, which we answer quite quickly. We answer, it's myself or Matt or Cat, and if we don't know the answers, we're reaching out to professionals to make sure we get the right information. Again, I'm not a genetic counselor, so if I get a question about genetic counseling that isn't sort of a basic question I can answer, we take the question, we identify it, we make sure we get a genetic counselor [00:25:30] to get their opinion on that question because that's not my scope of expertise.

Chandler Swope: You can directly connect to me if a family wants some support. It has links to our Facebook groups. It has links to our YouTube channel, which is full of, I think, really great videos, as well as there's a map so they can, if they're anywhere else

in the world, they can connect with their local association and all the different services that are going on in their area.

Speaker 1: [00:26:00] 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 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.

Speaker 1: If you like what you're hearing and are interested in supporting HD [00:26:30] Insights through a grant or donation, please contact us through our email address, info@hsglimited.org or by calling toll-free at 1-800-487-7671. We greatly appreciate your support.

Speaker 1: And now, back to our episode.

Kevin Gregory: Chandler, I'd like to switch gears now to kind of [00:27:00] the major topic of the day in these current times, and that's talking about the coronavirus and COVID-19 and the impact that it's having on everyone, but specifically around what the HD community and families can do in addition to the stresses or the pressures they may already be under.

Kevin Gregory: Just start out from there. From your perspective, what are some of the strategies [00:27:30] that young people from HD families can do to cope with that potentially added stress of everything that they're being bombarded with in the news stream in addition to what they're already dealing with at home?

Chandler Swope: We just sort of had this conversation with young people yesterday. Actually, one of the things that HDYO is doing in response to all this, because a lot of times I meet with individuals locally, face-to-face [00:28:00] ... A lot of events have been canceled in terms of youth retreats in the United States. Our congress was canceled. I think convention is going virtual. A lot of these opportunities that they were looking forward to, to connect with their "HD family," are no longer happening in the way they traditionally happen.

Chandler Swope: One of the things that we've started is these weekly Zoom chats. We just have an open link. It's on our Facebook page for young people, and it's just a time where myself or another HDYO [00:28:30] staff member is available. They can call in and we can talk about HD. We can talk about coronavirus or we can just talk and get that socialization that many people desperately need.

Chandler Swope: I think introverts are thriving in all of this, but the extroverts are really struggling, particularly if we have young people who are in college or out of college and living alone. There may be family members who they can't see because of [00:29:00] concerns for their health. If they have elderly grandparents, they may not be able to go visit them right now because they want to protect their grandparents.

- Chandler Swope: Again, a couple of different groups have put out some really great information on other [inaudible 00:29:16] of larger concern for somebody with HD and coronavirus. I know HDSA sent an email. So did the Huntington Society of Canada. Those are great resources if that's a concern. My understanding is, at least generally speaking, [00:29:30] there's no increased concern unless there were also some other health concerns.
- Chandler Swope: I think the biggest thing that I stressed with young people yesterday is don't stress over what we can't control right now. In these major incidences of uncertainty and fear, it's easy for all of us to get anxious. That goes for, I think, probably everybody across the country and it really is finding the things that you can [00:30:00] control and that you can do something about in this moment.
- Chandler Swope: We don't know how long this is going to go on, so what I even tell people just in my own life is stop stressing about what you don't have, what you can't have right now, and focus on what you do have and you can do. If young people can't go visit a loved one, what can they do? Are virtual chats an option? If they have a loved one in a nursing home, [00:30:30] the nursing home may be overwhelmed right now because their staff might be limited, all these extra precautions people have to take. The staff who may be happy to help facilitate some kind of virtual chat may not have the ability right now.
- Chandler Swope: Can you write letters? Can you create a memory book? That's something we do at camp where it's sort of like a photo album, but also at times, you can have other [00:31:00] families write in memories and stories and different things to help feel connected to a loved one.
- Chandler Swope: Really, I think the biggest message is trying to use mindfulness, if that's what we want to call it, to focus in on what we can control, trying to breathe through the moments where we get anxious about the things that are out of our control because right now there's a lot of uncertainty [00:31:30] and really being diligent and proactive about connecting with others. So many times in our life, we're busy. Things are moving a million miles a minute and you sort of forget to check in with that friend.
- Chandler Swope: For myself, I make lists of people I feel like I need to check in with daily, and that's something I'm doing, just, how are things going? Are you okay? Do you need anything? It's taking the time to schedule those video chats, [00:32:00] to schedule those phone calls. There's all different kinds of ways to do it. I think it's doing the little things.
- Chandler Swope: None of us can do anything big right now and we don't know when that'll change. Sometimes it's the little things and finding those things that keep us all common, whatever that is, if it's reading, finding a new hobby, learning a new skill while we're all sort of trapped in our [00:32:30] houses, but finding ways to find calm in all this uncertainty is key, and that looks a little different for everyone.

Kevin Gregory: What are some of the issues that people have brought to you maybe in the last couple weeks or concerns, or have you been surprised, perhaps? Maybe it's because it's such a resilient group, the HD community, that maybe they're coping better than the rest of the general public has been.

Chandler Swope: [00:33:00] I think that's probably true in some ways because there's so much uncertainty with HD. Uncertainty is something many individuals in the HD community have lived with for a lot of their lives. But I think it is, I think it's the isolation. I think particularly depending on if somebody has a family member in what one might consider the later stages, there's a lot of fear about when this'll end and what [00:33:30] they can do for that loved one.

Chandler Swope: Like I said, there isn't one answer, but it's finding what makes them feel connected, if they can do video chats. Again, it all depends on if they're in a facility, what they can handle right now because I think everyone's a little swamped. And if they can't do it for the loved one, can they give back in some other way that helps them feel fulfilled?

Chandler Swope: I think there's so much goodness going on [00:34:00] in the world with all this sort of bad with coronavirus. You see neighbors helping each other out. You see people finally connecting maybe with their elderly neighbor to go to the grocery store for them because they don't want their elderly neighbor to leave the house. I think that's what we see already in the HD community, always the first ones to help out in a crisis.

Chandler Swope: Again, I think it's trying to find ways to feel connected to [00:34:30] those loved ones if they can't physically connect with them. The hard part is there's so many different pieces of news coming out about this that it's hard to know what's right and what's wrong. It's hard to know what rules we're supposed to be following because, again, looking just across the U.S., every state is in a different place with this. It can be really hard to understand what you can and can't do or what you should and shouldn't do.

Chandler Swope: But within each family, [00:35:00] again, it's going back to what is best for your family. If it means completely self-isolating to protect your family, then that's what's best for you. If it is, again, using different modes of communication because that's what's available right now, it's doing that. It's finding the things that bring a little bit of peace each day because we're all in this together and that goes for everyone in the world right now.

Chandler Swope: [00:35:30] Then, again, really being proactive about that communication because I think day to day, our lives are always so busy we sort of sometimes put those relationships on a back burner of, oh, I'll call them tomorrow, but being really proactive to check in on the people we care about helps all of us. It feels like we're connected. If I'm worried about someone, I not only know that they're safe, but that's going to calm my own anxiety down as well as even if I feel like I'm doing okay in [00:36:00] isolation or quarantine or with less

socialization than normal. It gives you some socialization, even if you didn't know you needed it.

Kevin Gregory: You mentioned that the congress, for obvious reasons, has been postponed to next year. Is there anything, and maybe it's too early to say at this point, but is there anything that HDYO as an organization is looking to implement or do differently during these times to help connect people more frequently?

Chandler Swope: [00:36:30] Like I said, we're opening these weekly Zoom chats. The information's on our Facebook page. They're just open links. Right now, we've got them at twice a week. We did one yesterday, and I had a handful of young people join and it was great. We talked a little bit about what was going on and how people were handling it. They got off talking about tattoos and whatever else, but it was nice to just be able to ...

Chandler Swope: We used Zoom, so we had video, and it was nice to just see people [00:37:00] and kind of check in and have those moments of this is how I'm doing. It doesn't always have to focus on coronavirus or HD, but just bring back that connection because so many of these young people know each other whether they've actually met in person or through all these virtual ways that we have. We'll be hosting that twice a week.

Chandler Swope: Again, we are looking to see what we can do this year because our congress is now postponed to March of 2021. [00:37:30] I know I've been speaking with Jennifer Simpson at HDSA, who runs all their youth programming, about what we can do for young people right now with postponement or events being made virtual. I think as we figure out what might work best, we'll keep posting things.

Chandler Swope: I always encourage those young people, this is what I want, reach out to us because if we can help implement something or [00:38:00] create something, we want to hear what the community needs and that's how we develop a lot of our programs and services. It's hearing what folks need or want and seeing if we're the right person to make that happen.

Chandler Swope: I think the weekly chats will be a big help, and they're very informal, which I find young people tend to like, so they can pop on if they want. They don't need to register. If they remember, they remember. If they forget ... I'm always available individually. [00:38:30] If a young person does want to talk, my information's all online. Again, as long as they call and I'm not busy, I will answer my phone and we can chat. We can set up video chats.

Chandler Swope: HDYO is lucky in the fact that a lot of our work is virtual and was before this, so we're continuing those services. We will set up virtual chats with folks. We have our Facebook support group going. We'll have these Zoom chats. And we're looking just for more opportunities for [00:39:00] young people to connect during this time because we know that HD can be isolating as it is, so we want to

make sure that we're providing opportunities for connection and support during all of this.

Kevin Gregory: You mentioned HDYO is largely virtual anyway. I was going to ask you how are you and your colleagues getting along in this and dealing with this?

Chandler Swope: Again, because we're spread out all of the world, we obviously do a lot of our work virtually. [00:39:30] The biggest change for me is that we've suspended meeting with families and young people in person, again, to stop the spread and flatten the curve and all those phrases we're hearing.

Chandler Swope: I think for some families, that's a little bit of a change, although, again, when I check in with young people that have come to camp in the past, we do that via phone or Skype or whatever virtual platform that we're using. We're really lucky in the fact that it doesn't [00:40:00] change too much of our day-to-day. We're still able to do a lot of the work that we do.

Chandler Swope: We're still looking at the future and what programs we want in the future and what we can do to continue to have young people included in the HD community and services geared toward them. If anything, we're plugging away. It was a letdown for us to have to postpone congress, but it was obviously the right move and we will have just as an amazing, [00:40:30] if not even bigger, event in March. We've got basically all our speakers confirmed to come for next year, so, if anything, it'll just be even more excitement built up because we've had to wait a little bit longer for it.

Chandler Swope: But it's something, having this event in person is really important to us. That in-person support for young people and young adults is so vital, and so it's something that we are committed to and we are raring to go for [00:41:00] 2021. In the meantime, we're just trying to make it a point to keep checking in with each other, because, again, all of us are spread out, so what we're allowed to do just even within the confines of our own city is different, first the shelter in place and that sort of stuff.

Chandler Swope: I feel very fortunate that I am able to still work through this because we know it's impacted a lot of families and individuals with businesses shutting down, [00:41:30] so I just personally feel very fortunate. We want to just be able to do what we can in this time to support families that we work with.

Kevin Gregory: Well, I'm really appreciative of the dedication and the passion that everybody brings to HDYO and I really appreciate your insights and thoughts that you were able to convey with our audience.

Kevin Gregory: Chandler, before we wrap up, there were a couple questions, [00:42:00] a couple of other questions I want to ask you about your career and personal. First is, is there one specific person that you really would identify as a mentor

that has really guided you down this path and really helped you evolve into the person you've become today?

Chandler Swope: Oh, man. Wow. You just threw that one at the end, huh? I mean, there's so many people. [00:42:30] Within the HD community, there are so many people I look to when I have questions. I mean, not just on my own team, I mean Cat, Matt, Bonnie, BJ, they're all people that have really helped guide me, and I think made me feel really confident in my abilities to work in the community.

Chandler Swope: But I am just lucky to be in a place where I get to work with some of the greatest minds in the HD community. I always [00:43:00] joke with [inaudible 00:43:01] any time I get to do work with her because she wins all these awards, Person of the Year at that, and just being able to know that I can call her when I have a question is pretty amazing on my end.

Chandler Swope: But even coming into this, my mentor, her name's Laura [Losner 00:43:18]/ I have worked with her on and off for, I think, a decade now in different capacities and she's just someone I always look to for guidance, whether it's career advice or [00:43:30] social work advice, but we've become friends over the years. I think back just all the different pieces of advice she's given me over the year or two, take chances on career moves and to just sort of open myself to different opportunities.

Chandler Swope: I think a lot of people when I joined HDYO, it was small. We were only a couple of years off the ground. Most people get a little nervous with that. It was a pilot program, so didn't know how long [00:44:00] it was going to last, but I got to say, "I told you so," in the long run, which is one of my favorite things to say to people when they have doubts about things that I feel very strongly about.

Chandler Swope: I'm really lucky that I have been really fortunate to just work and know some really amazing people since starting HDYO and before that, that I've helped ensure that I'm supported as I sort of make my own journey through life.

Kevin Gregory: [00:44:30] Oh, that's awesome. Then, last question. What would you consider as your proudest professional accomplishment?

Chandler Swope: I think that would have to be camp at this point. It's funny, I don't think I do anything more than actually get it off the ground, the actual logistics, make sure flights are booked. Try not to mess them up because the magic that happens is with the volunteers and the campers.

Chandler Swope: I think [00:45:00] really my role is facilitating the fact that making it happen each time. It's hard to explain to anybody who hasn't been, what happens at camp, but watching these kids literally ... They hate when I call them kids because some of them are over 18, but these young people transform in the matter of days. You'll have someone come in, arms crossed, eyes down, one-word answers and by the end of the camp, they're the one hugging everyone,

grabbing [00:45:30] everyone for the group photo, posting everything, sort of the ring leader of everything.

Chandler Swope: Watching that transformation brings so much joy, I think, to anybody who gets to witness it. It's hard to talk about if you haven't seen it, but I think being able to facilitate that moment for, I don't even know how many kids now, so many young people, I think that's probably ... If [00:46:00] I had to leave one legacy at the end of all of this, that's the one I'd like to be remembered for.

Kevin Gregory: Well, Chandler, thank you so much again for joining us. I really appreciate having you on, and I think families and young people will enjoy listening to what you had to say on this episode.

Chandler Swope: Absolutely. No, thank you guys for always having us. HDYO loves HSG. We love our partnership [00:46:30] with you guys. We love being able to continue working with you guys, and so we're looking forward to as soon as we can all reconnect in person again. If there are any families who listen to this, they need some support, they can go to hdyo.org or they can email me and it's just chandler@hdyo.org.

Kevin Gregory: That concludes my interview with Chandler Swope. If you're feeling overwhelmed by the news stream or isolated because of social [00:47:00] distancing, there are little things you can do to help take control of your situation. And if you're a young person impacted by HD and have questions that you might want to ask in a more private setting or know someone who could benefit from their programs, then I strongly encourage you reach out to HDYO.

Kevin Gregory: My thanks once again to Chandler for joining us today. Again, I want to make a pitch or a plea, if you will, for guests on future podcast episodes. If you're a researcher, advocate, [00:47:30] or provider working in Huntington disease and have an interesting story that you want to share, or if you know someone you think we should profile in a future episode, please feel free to reach out to me at Kevin.gregory@hsglimited.org. Let us know what you're working on or how your efforts can help make a difference for those affected by Huntington disease. If you enjoyed these interviews, we'd certainly love to put out more episodes during this time so that you have more to listen to.

Kevin Gregory: [00:48:00] Until next time on the HD Insights Podcast, I'm Kevin Gregory. Thank you for spending your time with us. As always, stay safe, be well, look out for each other, and we look forward to bringing you our next episode.

Speaker 1: 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 [00:48:30] with your feedback so we can continue providing the best possible content. If you are interested in providing financial support for the work needed to produce this content, you can do so by becoming an ongoing sponsor or through a tax-

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Speaker 1: Thank you for joining us on the HD Insights Podcast from the Huntington Study Group.