

Speaker 1 ([00:00](#)):

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Kevin Gregory (host) ([00:49](#)):

Hello and welcome to the HD Insights Podcast. Thank you for joining me today. As always, I'm Kevin Gregory, director of education, communication and outreach at the Huntington Study Group. On this episode, I spoke with Katie Jackson, president and CEO of Help 4 HD, a grassroots patient advocacy organization and a nonprofit. Katie's personal story is one of determination and hope that has helped drive the impact that Help 4 HD provides. Her story made for a powerfully moving conversation that we're so incredibly fortunate to be able to share with you. And after that, Katie also talked more about upcoming Help 4 HD events, such as their virtual hype sessions in July and August and the training resources they provide to aid first responders or law enforcement who may encounter someone with HD. So without further delay, here's my conversation with Katie Jackson. Katie, thank you so much for joining us on the HD Insights Podcast. I'm sorry, we haven't been able to have you on sooner, but it's a pleasure to talk with you and really a privilege to have you on with us.

Katie Jackson ([01:56](#)):

Well, thank you so much for having me and I'm looking forward to it.

Kevin Gregory (host) ([02:00](#)):

Awesome. Well, let's start with your story. I mean, you have a very compelling story and I know a lot of people are familiar with the work that Help 4 HD does, but your story in particular, you have a unique story as far as how you got involved with this and your family connection to Huntington disease. Let's start there. Tell us about what your experience was with HD, how you learned about it, how you really initially got involved in this whole community.

Katie Jackson ([02:40](#)):

Yeah, so I've known my husband my whole life. We met when we were very young. We lived in the East Bay area of California and my best friend and his best friend were cousins. So it automatically kind of brought our group together. That was back when you would like run around all night and play and you were safe. So that's what we did and we became best of friends. And we started dating in college and we had our first baby Madison when we were very young and then we got married and then we had Cooper soon after. And he was a sheriff for Sacramento County and I was working as a hairstylist at the time and we received a call that his biological father had passed away. And he was estranged from his father.

Katie Jackson ([03:32](#)):

He hadn't seen his father since he was six years old was the last time they had actually been in contact with each other and it was quite a horrible experience. His mother had to actually call the sheriff and find my husband who was stolen kind of. And once that happened, my mother-in-law instantly moved up to Northern California to get away kind of and start a new life. And so she did with my husband and

his brother at the time, that's from a different father and that's when we met in the Bay area when we were young. And so we got a ... So back story, we got a call from a family member. They somehow found us through another family member that his father had passed away. And he had to sign papers at the funeral home and my husband was actually very uncomfortable with that, that he was next to kin.

Katie Jackson ([04:26](#)):

So we drove to the funeral home and we found out through obviously documents and talking to the people there that his father died of something called Huntington's disease. So we came home and of course I did the worst possible thing I could have done is I went on Google and started searching. And I was terrified because at that point, I realized not only my husband was at risk, but we also now had children at risk if my husband, in fact tested positive. My husband right off the bat wanted to be tested. So he did, he went right off. We went to our primary care doctor. Our primary care doctor typed in with looking, searching for the code to test for Huntington's because he had never tested anyone before.

Katie Jackson ([05:08](#)):

We didn't go through genetic counseling. We didn't do any of that. He typed a code in, he sent us down to the lab which was down the hall and my husband's blood was drawn. So it was literally that fast of a process. And with no real safeguards in place, nothing, we just went in. A couple of days later, I think it was probably around seven or eight days later, my husband was at a funeral of a fallen officer. And I got the call from the doctor that his test results were in and he signed that they could give me the results. I don't remember him doing that, but I guess he did because they told me that he had tested positive for Huntington's disease with a CAG count of 49. And most listeners in on this show would know that's a very high CAG, not juvenile, but very high.

Katie Jackson ([05:59](#)):

And I actually didn't know that at the time, it was just a number to me. But I had to go pick them up from a funeral to tell him that he in fact had test positive for Huntington's disease. Most people know I'm kind of a fighter and feisty. My brother has cystic fibrosis. I know how to fight. I watched my mother and my father do it their whole life. So I instantly got on the phone and started calling around. And we ended up with a neurologist at first, it was a horrible experience. He told my husband he was going to die. There's nothing they could do for him, go home, live life the best you can and call us when you get some depression. It was terrible. Luckily, I wasn't going to take that for an answer. I actually had some words leaving that office.

Katie Jackson ([06:46](#)):

I think back today about how young and feisty I was. We wouldn't have been invited back to that office even if we liked the neurologist after I was done, but we did end up finding an amazing, amazing place that we got to call home. And that was, we found the HDSA center of excellence at UC Davis, California. And from the second I called and got Terry Tempkin on the phone, I instantly felt like I found a place where I was going to find support and that's exactly what we got. The second we were there, I loved the UC Davis team. I owe them so much and they will always have a special place with me for all that they did for us for so many years up until my husband's final days. So my husband did pass away on August 25th after a very long battle with HD.

Katie Jackson ([07:42](#)):

But one thing I will say is right off the bat, UC Davis got us involved in research and I am so thankful for that. Really on our first appointment, Dr. Wheelock and Terry Tempkin started talking to us about clinical trials. They were talking to us about CoQ10. They were talking to us about creatine and some observational studies at that time and right away, they got us involved in research. And I think that's so important to get involved right away if you can, because it really did give us a little power in a very powerless situation that we were living in. So we instantly, he was enrolled in a clinical trial within the first two weeks of us going to UC Davis for the first time. So he was involved in seven clinical trials and studies. My children have been involved in observational studies at Iowa, which I'm a huge supporter of that. Study in that team, they're amazing.

Katie Jackson ([08:42](#)):

So we have been kind of a research focused family from the very beginning and it's helped us. I think it really truly helped us come together and fight as much as we could. We actually took it a step further. We got really involved. I remember the day that I found out that children could get Huntington's disease. I didn't realize there was a juvenile form of Huntington and it terrified me even more having children at risk and I decided that I really wanted to fight for the children. Something really touched me about the children more than anything. And I got to meet a couple of children with juvenile Huntington's disease at a couple of conferences that I attended and I instantly became friends and loved them and wanted to fight for them.

Katie Jackson ([09:29](#)):

So we actually hosted the first ever juvenile Huntington's disease walk specifically for juvenile Huntington's disease in 2015. And that helped to fund the UC Davis lab bench under the amazing Dr. Jen Knowlton and Kyle Fink who everyone knows that they started doing juvenile Huntington's disease research at UC Davis. And then we went and talked to the FDA. My husband was an amazing voice. We went and talked to government agencies. We spoke in front of CIRM the day Dr. Jen Knowlton got her amazing grant to start pre-cell. That trial obviously didn't go through to the end, but what they found out through that trial and all that they learned, and all we were involved. My husband was actually patient number one in that trial in pre-cell and we talked to CIRM and fought for that funding.

Katie Jackson ([10:27](#)):

And I know the research behind that is what got that grant because Jen Knowlton and her team are brilliant and that's what got that grant. But I do have to say that standing up and using your voice as an HD family and telling your story is so important. And we learned that when we talked to CIRM. My husband got up and talked about how he's going to miss soccer games with my daughter, and he's going to miss my daughter's graduation from high school, which he did. My daughter graduated this year. How he's going to miss weddings and how he wanted to fight to be able to be a part of his children's life and to fight for his children's life. And that touched, we looked up and the whole entire room were crying. These are scientific investigators and peer review teams, and they are bawling. And telling that story brought a human component to that room that was so important in making that decision to fund that incredibly important science.

Katie Jackson ([11:23](#)):

And then we learned that again when we flew to the FDA and we told the FDA our story, and I was very honored to be patient one on panel one during that Paducah meeting. And I was able to tell our story and really articulate the urgent need for new therapies and treatments. And I think that's the strongest

thing I can say to the HD community is whenever we talk is we need to use our voice and we need to tell our stories because that is truly where impact lies. No one knows what it's like to live with HD except for us. No one knows what it's like to have a child at risk and look them in the eyes and feel the fear that you fear except for us. So we are the storytellers because it's our story. And we need people to understand, so we continue to get funding and we continue to get help and finding a possible therapy or treatment for our families in the future.

Kevin Gregory (host) ([12:18](#)):

Absolutely. I mean, you are a tireless fighter in this effort. I have to ask you, is that what has given you strength to persevere? Have there been moments where you felt overwhelmed from initially learning about your husband's diagnosis? Was there any point in time where you just felt kind of a drift and not knowing what to do? Or did you just really channel that drive into steering you in a direction and moving forward with this?

Katie Jackson ([12:52](#)):

Yeah, yeah. That's a really good question. And I went through it at the end of my husband's life. I fought so hard for Mike and Mike wasn't my husband, he was my best friend. And we had been best friends since we were kids. And I mean, he was my husband, but above that, he was my best friend and we had fought together for so long. And when he was put on hospice, I remember calling my ... I'm very lucky that I have a tribe behind me. I have tons of HD friends and that I call my HD family that I can call on any time, day or night. And I remember calling them and just bawling and crying and saying, "I feel so defeated." I lost because this had become, my whole identity was to fight for him and to save him and I felt like I was defeated.

Katie Jackson ([13:40](#)):

I had lost the battle and that's the most amazing thing about our community is we can pull each other back in and say, "No, this fight was meant to be. This is what we've learned." And Terry Tempkin, Katrina Hamill, Sharon Thomason and Vicky Owen, I mean, I could go on and on with the names of my friends that brought me back and said, "You know, this is this wasn't about ... you're not defeated and you still have a fight ahead of you." And I did take a little bit of a break and I had to take care of Mike. I was there three days a week caring for him all day and then my mother-in-law was there two days a week. He got really sleepy at the end so two days a week, we let him sleep because us being there was pretty overwhelming for him.

Katie Jackson ([14:26](#)):

But so I took a lot of time off just to focus on him at the end of his life. And then when he passed, I took a little bit of a break to grieve a little, little break. And then I looked at my children and they're at risk and so the fight continues on. So now I'm fueled by them and I can't watch them go through what their father had to go through. So I will fight with my last breath to make sure that that doesn't happen. And so now I'm refueled again with now just a different focus.

Kevin Gregory (host) ([15:05](#)):

Talk about that. I mean, I know, you know any parent would happily give their own life for their child. So what has it been like for them? How have they grown up? I know you mentioned your daughter just graduated. What has it been like for her and the conversations you've had and how you said they've been involved with observational studies now. What has been the impact on their lives growing up?

Katie Jackson ([15:33](#)):

Well, I think we have the typical HD story, right? I talked to friends all around and we've all kind of go through this same process that my kids obviously are very scared of Huntington's disease. They know they're at risk and they saw that what their father went through. They were involved in everything. And I was very, I think one thing that is the most important is never to lie to your kids. And I was given that advice very early on in our HD journey by some HD friends of mine, caregiver friends of mine that don't lie to your children because at the very end, they're going to need to trust you because you're going to be giving them some really hard information and they need to know you're telling them the truth.

Katie Jackson ([16:17](#)):

And I took that advice and I lived by that advice, and that was very helpful. I never have lied to my children about Huntington's disease. They've always known they'd been at risk. It was very age appropriate talks that we had. I've had talks with my children about guilt and grief and I've had talks with my children about hospice and what that means and what kind of life is about when you're living in an HD family. And I've talked to my kids about IVF PDG, we've talked about how they can't have children without a science being involved in how I will support and pay for that. But this is the end of the line. This is our HD journey is done. I will make sure that in our family, but for now, yeah, we've been very open. So I think being very open and talking about it, but it has impacted their lives.

Katie Jackson ([17:04](#)):

I think the worst part was when Mike was still at home and we were dealing with a lot of falls. I had come home from the grocery store one day and he was basically drowning in the pool. I had walked out just in time and I pulled him out of the pool. He had decided to go swimming, which I don't know why he did, but he decided he wanted to go swimming and my kids witnessed this. My kids had witnessed cracked tiles on the floor from him falling, holding the wall, toilet brought up from him rocking back and forth on it and then doing the chamber or whatever. So they witnessed a lot of really hard things in the home before we placed him. And my son went into an IEP. I thought for sure he had juvenile Huntington's disease.

Katie Jackson ([17:50](#)):

He went all the way back in school. He actually has now gone, he doesn't even have an IEP now. He had so much anxiety and fear. He couldn't focus on school so he dropped back like grade levels and he wouldn't even, he didn't want anything to do with school because he wanted to be with his dad. He wanted to watch his daddy. He was constantly scared. My oldest daughter was having panic attacks. I had to put her Apple watch on her and watch her heartbeat race because she was constantly nervous about what was going on with her dad. So once we placed Mike, things got better as far as the kids were concerned because they weren't constantly living in fear on what would happen to their dad in the home in front of them.

Katie Jackson ([18:39](#)):

And Mike actually got a little bit better, believe it or not. The house was overwhelming for him. We had three very young kids. They were in theater, they were in soccer, they were in school, they were in all these different activities and he was overwhelmed by all that. And when we were able to, when we finally found a place, we placed him in a beautiful facility on a lake and he had a lake view and a balcony going up to look at the water and we would sit there and we would tell stories and we would laugh and we would watch movies together. Like I said, we were there three days a week and that really helps the

kids, I think, not living in that constant fear and just being able to go enjoy their dad for the last couple years.

Katie Jackson ([19:21](#)):

Obviously the last couple of months were horrific and they actually stopped visiting their dad. It was so bad what my poor husband had to go through to end of life. His end of life was not pleasant at all. But yeah, so it's definitely impacted them, but they are resilient as children are. And they're very strong because they are advocates themselves and they love HDO. They love Kat Martin. They love Chandler. They love their HD community. They're very lucky. They have a lot of people watching over them and calling them and emailing them and actually coming to see them all the time from the HD community. So they're very supported and they're very loved and they're fighters though. They'll continue to fight by my side, but it's definitely had a huge impact in their life.

Kevin Gregory (host) ([20:09](#)):

Well, that's awesome to hear about the resilience and it's a consistent theme that we've heard even on this series about being honest with your kids and don't try and hide the truth from them because they will need to lean on you for advice. Katie, the other thing I want to ask you too, is advice that you can share. You've seen the whole life cycle now. You've experienced it from the caregiver's perspective essentially. What advice would you give people or do you give people now that are in a similar situation? A spouse serving as caregiver or in your case, probably children also helping his caregivers. What are the things that they really have to consider or even start to plan ahead for?

Katie Jackson ([21:01](#)):

Yeah. I think that one is get involved. That's always my biggest thing is get involved and meet your HD community because they are the strongest, most supportive community you will ever meet. You can get on the phone and you don't even have to tell them what's wrong. They know. So I think that's the biggest thing is connect with your HD community and because they are going to be one of your biggest support through this whole process just because they live it and they know what you're going through. I think like I said, getting involved in clinical trials is important because it empowers you and using your voice and tell your story and continue news articles, write letters. Do what ever you can do to tell your story and use your voice. I think as far as your children go, to be honest, be open and always give them a safe place to talk.

Katie Jackson ([21:49](#)):

I know that like I remember my son asking me, "Is dad going to die?" And I had to tell him, "Yes, he's going to die very soon." And so let's talk about that. So always give them a safe place and sometimes your kids may not want it. They may not open that conversation. They're waiting for you to say, "Let's talk about that because they don't want to impact you." They're watching over you too. So always open communication and giving your kids a safe place. I think not lying is very important. I'm so transparent with my children. They know everything. They knew every step I made along the way. And one thing that I think that I advocate for a lot is that everyone in this journey is going to feel guilt about what they have done and decisions they have made.

Katie Jackson ([22:31](#)):

I let my husband or my spouse live too long. I think I killed them too soon with upping the medications. I placed my husband, I shouldn't have. I didn't place my husband and I don't think he got the proper care.

I'm using husband, but you know what I mean in general, because that's obviously my story. But every single person in this HD community I've talked to over the many, many years I've been a leader of Help 4 HD International is the same story is true that everyone walks away feeling guilt and everyone feels guilty about every single decision they make, especially hospice placement, at risk children, lots of guilt with at-risk children. And my answer to that is we're human and we're doing the best we can and Huntington's disease is a very hard, hard journey to navigate, incredibly hard.

Katie Jackson ([23:21](#)):

It's incredibly long and it's a hard road. And I have wives call me upset because they yelled at their husband and they feel so guilty after. You're human, we're human beings. And so just always know you're doing the best you can for your loved one and you're not going to be perfect through this journey. You're not. No one can [inaudible 00:23:42] 20 years and be perfect. You can't. And so if mistakes are made along the way, forgive yourself, because we're all just trying to survive. And no one knows until you've tried to navigate through an HD journey, how incredibly hard it is. It is. And so that is my biggest thing is forgive yourself and know mistakes will be made and that's okay. You're doing the best you can.

Kevin Gregory (host) ([24:10](#)):

Yeah. That's really powerful advice. And I appreciate you being so open about your story and your experiences.

Speaker 1 ([24:21](#)):

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. If you like what you're hearing and are interested in supporting HD Insights through a grant or donation, please contact us through our email address info@hsglimited.org or by calling toll free at +1800-487-7671. We greatly appreciate your support. And now back to our episode.

Kevin Gregory (host) ([25:15](#)):

Katie, I want to switch gears now and talk a little bit with you about Help 4 HD and the work you're doing there. So again, for the people that aren't familiar with the organization, can you tell us a little bit about the mission and goals of Help 4 HD?

Katie Jackson ([25:32](#)):

Yeah, Help 4 HD is kind of become like just our lives. So for those of us who work for it, it's an amazing organization. It's a grassroots organization started by families starting 2010, and it was started by Melissa Biliardi and it started as support groups. And then she went in and she started this radio show to help connect the community and bring information to the community. For the lack of, there was like a big gap obviously in communication, especially for people that weren't near a center of excellence or weren't getting expert care. So she started that and we kind of started as this little organization and now we've grown into a very large organization that has lots of programs and projects, but all of them have been thought up and created and ran by Huntington's disease families.

Katie Jackson ([26:26](#)):

And I think that's kind of special because people always talk about advisory boards and I said, "I have this great advisory board. It's everyone on my board." I can call and say, "What do you think?" Oh, well, my husband, when I did this or my child ... we have mothers that their children have passive JHD on our board. We have at risk that tested negative. And so it's really cool working with families and that holding tight to that grassroots kind of that we started on as families coming together and just trying to fill some of the gaps that exist out there for Huntington's disease.

Katie Jackson ([27:05](#)):

So it started with a radio show and we're really excited. Help 4 HD live is getting a facelift right now, we're going to have new intros and outros and a whole bunch of new kind of topics and different things that this virtual world we're living in has kind of given us some time to do some facelifts on some of our programs. So that's exciting for us. So yeah, it's started with just a radio show and now we have so many projects and programs. I can kind of do a quick overview for you. There's a lot of them, so I won't spend too much detail on them or we'll be here forever.

Kevin Gregory (host) ([27:42](#)):

I definitely did want to ask you, and I'm wondering if this is a focus because of your husband's career and profession, but I know Help 4 HD does a lot of work with first responders and helping train law enforcement officials on Huntington's disease. Can you talk about that a little bit?

Katie Jackson ([28:03](#)):

Yeah, for sure. We actually started that project after Jeffrey Bang, that Jeffrey Bang story kind of went viral and the community was upset and they wanted change. They wanted awareness. They wanted first responders to understand Huntington's better so this didn't happen again, which we obviously know it continues to happen. But we decided at that point that we needed to come together and do something. So we actually fundraised individually to go to the ICP, which is the International Chief of Police meeting. It's an international meeting. There's like 10,000 officers and we had a booth. And we paid, families literally paid from their own pocket to have this booth. And we sat for three days and educated officers about Huntington's disease. I actually didn't attend that first meeting, but the first group of people that attended it, they did an awesome job and it was really cool to have a booth.

Katie Jackson ([29:01](#)):

So we decided at that point, well, let's keep going and let's make this a whole program. So that's when we started Huntington's disease law enforcement and the education in a flash, and it's a flash drive. The flash drive has had publications, brochures explaining Huntington's disease, but it also has videos. And I think this is where it is the most ... where we hope it has the most power is that it's videos of families living with Huntington's disease. So we do have experts speaking on this. Dr. Vicki Wheelock speaks on this video and so Terry Tempkin speaks on the EMT version, but there's a lot of families at different ages, different races, male, female to really show that Huntington's disease is not a one size fits all.

Katie Jackson ([29:50](#)):

They can contact people that are very young or people who are older. It shows the slurred speech. It shows the impaired gait. It shows the symptoms of Huntington's. It shows chorea and what may happen and even shows the cognitive impairment. We actually ask people with Huntington's disease some questions, and we show how long it takes for them to process and be able to answer back. So we definitely did, I think the team did a really good job creating this video because it definitely tells a story.

And then we decided to take it a step further and focus on EMT and firefighters, because they will be the first on the scene that not more law enforcement, but more medical. So we talked about choking, we talked about it's a, we call it a little toolkit for a first responder that comes on an emergency with someone living with Huntington's disease. And remember these people are coming in our home and our loved ones are ... it's going to be a crisis situation a lot of the time, so it's nice to have these tools and these publications.

Katie Jackson ([30:57](#)):

Hopefully we reach them before that happens, but sometimes it's during the crisis. So these are free to the Huntington's community. This flash drive, these publications, this is all sponsored by Teva pharmaceuticals and Griffin foundation. This is free to you. So please let us know. And we always say, teach you law enforcement and your first responders before the crisis happens. So take this information, take it to your local law enforcement, take it to your fire department, take it and teach them and they're very, very appreciative. We hear kind of across the board that they're thankful for this information. And a lot of them want to know where you live in case they do get a call, so they know that someone with Huntington lives in the home and they're going to need more support.

Katie Jackson ([31:44](#)):

So I always say, "Utilize this program, please. It's free to you and go to your local law enforcement and fire and teach them before the crisis happens." And you'd be shocked, sometimes they'll put it in their advanced officer training for their whole department. And this has happened numerous times that we're in numerous advanced officer trainings for recruits and also their yearly updates. They play this video. We actually have some departments that make it mandatory for them to click and watch this video and the department shows the department that the officer has watched it all the way through. So that's really exciting when that happens for us.

Kevin Gregory (host) ([32:24](#)):

Oh, that's great. I mean, I have to imagine when the officers or first responders see this training for the first time, there's some sort of reflection back on past events wondering, wait a minute, was this situation not what I thought it was at the time? What are some of the stories that you've gotten in reactions like that?

Katie Jackson ([32:46](#)):

Well, we actually get a lot and the one thing that we do get a lot is that they knew as someone that lived with Huntington's disease, for instance, there's one department, she's homeless and they do know that she had something wrong, but she kept saying Huntington's disease and they didn't know what it meant. And so we were able to help support her through education to them that she does have Huntington's disease, and this is how she's going to need different support. And so that was, we always like when we hear that they actually are in contact with someone still and they're able to support them now in the right way. But one thing I want to say that I forgot is that with this whole thing going virtual, our world, typically we do go to law enforcement events every year and we exhibit.

Katie Jackson ([33:36](#)):

This year, we were going to the Sheriff's National Association meeting and we are going to Ohio, and there was a couple other local, a lot of local training we were doing. Those have all being canceled. So we are the kind of people that if we have funds, we're going to call and see if we could switch them over

to something else that will help our community. So we were actually very excited to say that the funds were approved to move elsewhere. So we had to cancel these shows and what we did is we offered two new programs. One was an awareness sticker and these are all free to the community and the sticker can go as a decal for your car, but you can also, a lot of people are putting it on their windows+ in their homes and stuff.

Katie Jackson (34:22):

And the sticker reads individual with Huntington's disease on board. And it says, in case of emergency, please be aware that individual may not be able to speak or articulate pain or injury, may not be aware of the situation, may be resistant to any help, may appear intoxicated. So it just gives a little blurb about Huntington's disease. It's not a lot, but it's enough for the first responder to know that someone's in the car with Huntington's that will need more support or someone's in the home. So these stickers went out to families for free. We sent out hundreds of stickers and we've given people multiples so they can have them on their cars if they had multiple cars and also their home.

Katie Jackson (34:59):

Another thing we launched was our medical ID cards this year and once again, they were completely funded and they're free. And these cards on one side say, I have Huntington's disease. I may appear intoxicated due to my symptoms. I may have all of these symptoms and it talks about movement and care gaits, delayed response, slurred speech, trouble following direction, increased agitation or anxiety. And then it gives us information for the caregiver to be called. And on the back, it does talk about Huntington's disease being a fatal brain disease that impairs thought, the movement behavior. And then it has our website, if they need more information which is all ... our website is full of information for first responders or first responders in general. So those are two programs we have launched this year that are free to the HD community and we send you what you need.

Kevin Gregory (host) (35:51):

That's fantastic. And then you also of course do the weekly radio show. What was that like for you getting involved for the first time? Was that your first experience hosting that kind of live event?

Katie Jackson (36:08):

Well, my first actual go at Help 4 HD live was I was a guest. So I was a guest back in 2012 and I was actually hosted by Melissa Biliardi. So she really set the tone on Help 4 HD live. So going in and being the host of Help 4 HD live was kind of easy because we had been working together with Help 4 HD for so long. And I had been a guest, so I knew what it was like to be a guest and I had done ... But yeah, the first time hosting I guess I would say it's probably a little nerve wracking. I still to this day kind of get sometimes if it's a certain type of show, I'll get a little nervous and then once we start going, we go. But these are live shows that we'll be switching over to a lot of pre-records here soon, but live shows are very intimidating because you sometimes don't know what's going to happen, but yeah, it's been great though.

Katie Jackson (37:05):

I mean, we have had some historic shows. I mean, Nancy Wexler, we've had some, I mean we have almost 500 shows available now because we've been going for so long. We're available on Spotify and iHeartRadio and iTunes and all these different places. And it's great to see that it's a library of information if you go through. It is overwhelming. I tell people when they first go to the radio show

archives, I'm like, "You're going to be a little overwhelmed when you see 500 options for you to listen to, but we've tried really hard to make the titles easy to find if you're looking for something like for cognitive impairment or psychiatric behaviors or suicide or hypersexuality, or any of these topics that you would just type them in and then the show would come up." So they're a little bit easier to search. We try our hardest for that. But if anyone has any questions, if we've done a show on a certain topic, usually we can find it for you because chances are we have.

Kevin Gregory (host) ([38:03](#)):

Excellent. And I know you said you're going to pre record it, but will those be released on kind of the same schedule as the recurring live was?

Katie Jackson ([38:12](#)):

Yeah, yeah, absolutely. On Wednesdays. And we definitely want to keep Help 4 HD live on Wednesdays seeing as how we just launched Help 4 HD TV and those launch every Friday.

Kevin Gregory (host) ([38:22](#)):

Awesome. Now the other event that I want to chat with you about, I know you have a HIPE event coming up and you do those periodically throughout the year. So tell our audience a little bit about how those came about, what the focus is on them, and then specifically information about the upcoming event, which I know is because of the current times we're living in is now virtual and accessible from anywhere.

Katie Jackson ([38:51](#)):

Yeah. Yeah. So HIPE is like one of my favorite programs at Help 4 HD. It's highly interactive participant education. That's what that stands for. And what we did is we held our first symposium in 2014 and it was just very science heavy. We had CIRM come out. We had great speakers, Ira Shoulson, we had ... it was amazing, but it was incredibly science heavy. And we realized a lot of science is hard, right? Especially when you are lay, we don't know any, we're not scientists. But we also knew that there is a need for help today that patients come looking for when they go to these conferences. And I know because I went to my first conference looking for help and navigating my journey and the first one that I went to. And so knowing that, we decided, okay, let's make half of the day ran by the patients and caregivers.

Katie Jackson ([39:48](#)):

And a lot of topics that we deal with with Huntington's disease are very hard to talk about, especially with our loved ones sitting right next to us. Topics like depression, suicide, hypersexuality, gastro problems. These are not things that you want to raise your hand during a Q&A and say, "Hey, look, I have a problem with this," and then call your loved one out or calling yourself out. It's really sad and I really take a huge stance on this. The stigmas behind depression, suicide, hypersexuality, hyposexuality. It really frustrates me the stigmas, but they exist. So we have to be sensitive to that. So what we decided to do was de-identify all the questions and that way, no one's put on the spot, no one, and that people feel comfortable asking.

Katie Jackson ([40:35](#)):

So during the HIPE day, we hand out clipboards and the clipboard has just blinds to write a question and some examples of questions on there that have been asked in the past to make people start thinking about it. And then they fold it in half and Katrina Hamill and I, or Sharon Thomason or Vicki Owen, whoever's there at that day, Stacy, we go around, we collect them all. And then a panel of experts sit on a panel with microphones, do not know what is going to be asked of them and they get asked questions. They get asked very hard questions. but it's been really, I think I've learned more at our HIPE days than I've ever learned anywhere else, because questions have been asked that people normally won't ask. And the answers have been really, sometimes the panel kind of looks at each other like, huh, let's really problem solve this. So each question takes a while because the panel actually problem solves all together.

Katie Jackson ([41:31](#)):

One of my questions was really amazing to me that I was like, "Wow, I've never thought about that," is I have a child with JHD and I have a husband with HD, advanced stage HD. And what if there's a fire in my house, what do I do? Because it's just me. Do I get off my child or do I get out my husband or what do I do? I mean, that's a really hard question. Right? And so they talked about different strategies and the big thing was call the fire department. Work out a plan before it happens. And so questions like that have come up and there's always a lot of questions about sexuality which we need to talk about more. There's a lot of questions about gastro stuff, a lot of genetic questions that come up.

Katie Jackson ([42:13](#)):

So moving into, we were scheduled for three HIPE days this year Sacramento, Nebraska and Michigan. And we had to go virtual right off the bat because the week of our California HIPE was the week California shut down. So we had to cancel everything last minute, we canceled on Wednesday, the event was happening Saturday. So we didn't go virtual right away. We waited till Michigan because we were hoping that we could do Sacramento again because that's when things were up in the air and we didn't realize how bad this pandemic was going to become. And so we did Michigan on May 2nd and it was really awesome. We had Terry Tempkin, Dr. Sam Frank and Lisa Mooney from Sacramento on there and it was really cool. We got a ton of questions. The problem was we didn't give ourselves enough time.

Katie Jackson ([43:08](#)):

So we didn't get to all the questions that were submitted by the community. We had hundreds of people register, of course, because now we're virtual, more people can attend, which is exciting. That's one good thing that has come out of it, but we did notice that because we are virtual, we didn't want it to become kind of stale to do three HIPEs and possibly get the same type of questions would become, we didn't want the community ... We want to give the community something they need and something new, especially with everyone doing virtual conferencing now, it's kind of becoming a little bit hard. So what we did is we decided to put an emphasis on each HIPE day from here on out, we only have two left. So July 11th we'll be hosting, the UC Davis team has agreed to come on with us, which is awesome, on July 11th.

Katie Jackson ([43:57](#)):

So they are going to make up the Sacramento day that was canceled for us. So it'll be Dr. Vicki Wheelock, Terry Tempkin will be on there, Mara who is an amazing genetic counselor, Lisa who's an amazing social worker. So they're all coming on and we will run HIPE a half an hour longer and the focus will be on genetics. So anything about testing at risk, life planning, family planning, now having a virtual

world, what are we looking at genetic counseling virtually. Mara is going to answer all those questions for us. What does testing look like now? Are we going to do virtual genetic counseling and swab in the mouth and send it off?

Katie Jackson ([44:34](#)):

What's going to happen now that our world's changing? And so we already have around 13 questions that have been submitted and we just opened the portal and they are really good questions. So we will be focusing a lot of that on July 11th. And then August 15th, we will be doing it again with Dr. Amy Hallam and a couple people that are coming on that one. Janell Hogan, who's amazing and they will be focusing on caregiving. So that will be the focus for the August HIPE.

Kevin Gregory (host) ([45:05](#)):

Awesome. So where can people go to register for that?

Katie Jackson ([45:08](#)):

So you could just register July is already up on the website www.help4hd.org and you can register right there on the site and then as well as when you register for that, if you want to submit an anonymous question at the end of your ... once you register, you're going to get a thank you note and it'll have a link on there that you can go and submit your anonymous question. So that's kind of how that works.

Kevin Gregory (host) ([45:34](#)):

Well, excellent. And I highly encourage everybody to check out the website. If you can attend the event, if you're available by all means, absolutely sign up. Katie, this has been fantastic. I've really enjoyed having you on the episode today.

Katie Jackson ([45:51](#)):

Thank you for having us. And if anyone needs any support, please let us know. We are always open for any families that have new ideas or anything. Our families [inaudible 00:46:01], please contact us. We work together. Anything to support our community, that is our number one goal until a cure is found, until new therapies and treatments are found is support. So we have our relief fund, we've supported people through COVID, we've supported people through natural disasters. We've sent out thousands and thousands and thousands of dollars to support families. We have tons of publications. If you need awareness, we have life interrupted one, life interrupted two. We have books published. We have anything that you need that will help support your families. And like I said, if you have any ideas, please contact us. We are always open for new ideas and anything to help our community.

Kevin Gregory (host) ([46:44](#)):

Absolutely. And I just, I really have to end our conversation together by saying, certainly the best of all worlds would have been your husband didn't have HD, everything goes on as normal, but on the flip side, the HD community has really gotten a strong, powerful, driven advocate that I think has made the world a better place for everybody else that is going to have to deal and battle with the disease going forward. So thank you so much for your commitment and your dedication and really making your husband's legacy something that will live on for years and decades to come.

Katie Jackson ([47:28](#)):

Oh, thank you so much, Kevin. That means a lot to me. And before we go, I just, a huge shout out to Help 4 HD team. I mean, these people work endless. Vicki, Owen and, and Katrina Hamill and Michael Sabato and Terry Tempkin, all of our people at Help 4 HD running these programs, Sharon Thomason. I mean, they work with so much passion and so much love and I'm very, very lucky to work daily with these amazing people that all have the same mission. So a huge, huge shout out to all of them because none of this would happen without them having to deal with me as being a crazy leader and sometimes bringing me back in line. No, but they're a great team and I love all of them. So we are very lucky to all work together to make a difference.

Kevin Gregory (host) ([48:22](#)):

Well, that does it for this episode of the HD Insights Podcast. Katie does such an amazing job sharing her experiences in a way that really resonates and motivates. And I hope you found that informative in a way that also motivates you to help make a difference in the lives of people impacted by Huntington disease. Katie mentioned a number of events and resources that Help 4 HD provide. So I just want to remind the audience of that website address again. It's www.help4hd.org, that's www.help, the number four, hd.org. Until next time on the HD Insights Podcast, I'm Kevin Gregory. Thank you for spending time with us, stay safe, be well, look out for each other and we look forward to bringing you our next episode.

Speaker 1 ([49:14](#)):

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