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, and I'm Kevin Gregory, Director of Education, Communication [00:01:00] and Outreach with the Huntington Study Group and your host for this program. On this episode, we caught up with Dr. Lauren Byrne. Dr. Byrne gave a platform presentation at the Huntington Study Group's annual meeting back in November on some exciting biomarker research she's been involved in. Her work on the HD-CSF study has been evaluating mutant huntingtin in neurofilament light. That research has now gone to peer review and well, she'll do a much better job of telling you about the importance of their research than I could ever hope to do.

Kevin Gregory: The [00:01:30] other wonderful part of our conversation was about Dr. Byrne's personal connection to the HD community. Coming from an HD family, she has channeled that motivation to fight the disease into a successful and growing career in HD research at University College London working with and further inspired by some prominent names in the field. Dr. Byrne is also an involved advocate in HD in her local community and more recently, in joining the board of the Huntington's Disease Youth Organization or HDYO. So without [00:02:00] further delay, here's my conversation with Dr. Lauren Byrne.

Kevin Gregory: Well Dr. Byrne, thank you for joining on us on the HD Insights Podcast for this episode today.

Dr. Lauren Byrn...: Yeah, thanks for having me. I'm delighted to be here.

Kevin Gregory: First of all, congratulations on recently passing your PhD defense back in January. And so let's start there, can you put that accomplishment into perspective for our audience? [00:02:30] How much does that mean to you personally?

Dr. Lauren Byrn...: It's a huge thing, particularly... So I'm from a HD family, which some people don't know, some people do. I'm quite open about it. But it was one thing I wrote down to myself whenever I was going through genetic testing, that I was going to work... it was one of my reasons for getting tested, is because I wanted to get into HD research. So [00:03:00] it was quite a climactic moment from 2014 when I got tested to getting through to the other side and being Dr. Byrne. So it's a long process, a lot of sweat and tears go into doing a PhD and there's definitely low points. But it's an amazing achievement and I'm very proud of the work [00:03:30] that I was able to achieve.

Kevin Gregory: You mention your family, and so you have a very personal connection to Huntington's Disease. Can you tell us a little bit about that and your background and how much of that has really driven you in your career pursuits?

Dr. Lauren Byrn...: Sure. So I'm from a HD family based in Northern Ireland and my dad has Huntington's Disease. But he's [00:04:00] from a family of eight, so there's been quite a few of them that have had the genes. I've known about it the most part of my life. My granny had it and passed away before I was born. And I had an aunt and uncle who had passed away from it but I grew up around them when they were still in wheelchairs and suffering from it. So it's always been a part of my life and [00:04:30] I'm one of the lucky ones, I think, that my parents were very open with me about it. My mom was quite involved in some of the associations and quite well informed for that time. So it was never treated as such a scary thing.

Dr. Lauren Byrn...: And it wasn't until late teens where I started hearing about people that were advocating for HD and having [00:05:00] been tested, I think, because previously, in my family, there wasn't a lot of encouragement to get tested at the time. We all lived very hopeful and positively but there wasn't really much point to get tested definitely back in Ireland anyway. There's not much specialist care or treatments or anything like that. So that was kind of the mentality for my family. But [00:05:30] I remember a few points in my life seeing talks from different advocates like Sarah Winckless, who's an Olympic athlete based in the UK who has the gene. Charles Sabine, who's a very well known HD advocate. People that were deciding to face HD in a very direct way.

Dr. Lauren Byrn...: And at that time I was very interested in biology and [00:06:00] science and started going that way with my academic pursuits. So I decided to do biology for my undergraduate degree in university with not really the intent in getting involved in Huntington's Disease research but it just progressed that way. It was, every opportunity I had to do a project that was related to Huntington's [00:06:30] I did. Around my third year in university I discovered Dr. Jeff Carroll, who is a very well known gene carrier who is also a scientist. He's one of the co-founders of HDBuzz. I reached out to him at the time and wrote him a few very embarrassing long essays of trying to get some support from [00:07:00] another person who's from a HD family that was interested in research and doing HD research. And that was before I was considering to get tested. And as that went along I became more sure I wanted to get tested, as I wanted to do HD research.

Dr. Lauren Byrn...: So that's that transition in my life towards ending university and making those career decisions [00:07:30] lead me to getting tested. And then once I tested negative, I started my master's degree at UCL and joined Sarah Tabrizi's team where I was able to do my first project in Huntington's disease research.

Kevin Gregory: You also have a very active role in the HD community through local and national advocacy to an extent. Can you [00:08:00] talk about some of responsibilities that you currently have and some of those roles that you're currently serving in?

Dr. Lauren Byrn...: Sure. I have definitely taken an attitude of getting involved in as much as I can and probably too much in some cases. But in the last couple years I've taken more roles in charities, including a local family association for Huntington's called The Huntington's Disease Association Northern [00:08:30] Ireland. I joined their board of trustees a couple of years ago as it's quite a personal interest of mine is developing the access to research and more specialist care in Ireland as there isn't a lot going on despite efforts over many years.

Dr. Lauren Byrn...: As of, my family are still back in Northern Ireland, and there's, at this point in time, [00:09:00] very little hope that they'll have access to clinical trials or even Enroll-HD. Then, last year, I've always been a big fan of the Huntington's Disease Youth Organization because I really believe in what they stand for and empowering and educating the younger generation impacted by HD to really take charge of their own destiny, and [00:09:30] how they deal with HD.

Dr. Lauren Byrn...: So, I was, I think it was in the HDSA convention last year, I found myself surrounded by several board members at the time. I didn't realize I was being invited to join the board, and since then we had our first face-to-face board meeting at HSG in Sacramento, the annual meeting, which just led to a whole, very exciting [00:10:00] restructuring for the HD Youth Organization. So I'm now going to be co-chair of a newly-formed research committee. And then other activities that I've been involved with is more awareness and communicating the current research to family members, as well some projects with Roche and Genentech. So [00:10:30] I try and do my bit.

Kevin Gregory: Who were some of the other people that have really inspired you or that you've looked to as mentors? I know you mentioned Jeff Carroll, when you first got involved, and then when you were in school, started working with Sarah Tabrizi.

Dr. Lauren Byrn...: Well, yeah. I think probably Sarah Tabrizi was one of the first people, particularly scientifically, who [00:11:00] was inspirational. I was in another university, Imperial College London, based in London in the UK, and I was trying to reach out to people to do some work experience and I learned about what kind of Huntington's disease research was happening that I might be able to get involved with. And that's how I found out about Sarah Tabriz and was immediately in awe of her as a strong woman who's leading [00:11:30] the field and the particular focus that her team has in the clinical and observational side of things.

Dr. Lauren Byrn...: For me, a lot of my research focuses on the clinical aspect and how we can advance therapeutic development in HD, so I was really interested in what she was doing. So when I was in my final year of university, I knew I wanted [00:12:00] to go to UCL and, if I could, get into the group as a foot in the door. And I did, luckily enough, although at that stage she didn't know who I was, so I've had to work a few years before she knew who I was. And at that stage, I had that I had the opportunity to meet Ed Wild, who has been my boss for the last

five [00:12:30] years. I knew of him before, as most family members do who know about HDBuzz.

Dr. Lauren Byrn...: And I'd watch a lot of his and Jeff's videos online, so when I first introduced myself to him and volunteered to learn more about his research, it was in a secret, meeting a personal celebrity or HD rockstar, [00:13:00] although I can't tell him that now, don't know if he can listen to this. Yeah, and then I think the more I've gotten into the HD field, it's just full of so many inspirational people. I've made so many friends, and it was incredible to find out that there's so much more people from HD families involved in the field than I [00:13:30] recently knew, all with their own passions and areas of research that they're interested in or other aspects of making the HD community better.

Kevin Gregory: That's a good point to follow up on, and I wanted to ask you, coming from an HD family, you bring what seems like a fairly unique experience to the research field. Was there anything that surprised you [00:14:00] when you first got into research, in terms of the perspective of scientists or other professionals that maybe didn't have that personal type of family experience that you had, that you've been able to help connect to those two points of view? The family perspective and the scientific perspective?

Dr. Lauren Byrn...: Actually, in a way, I was more pleasantly surprised at how well everyone understood [00:14:30] it. Coming from an HD family back in Ireland, where the average clinical care team or doctor or social worker has never encountered someone with Huntington's disease or knows very little about the actual needs of a HD patient, you get a little skeptical about professionals. And then I entered the actual HD specialists' field and [00:15:00] was pretty much blown away, particularly at UCL, the specialists multidisciplinary team that they have there are really amazing and I don't think the patients in London and around London realize how lucky they are to have such a devoted service.

Dr. Lauren Byrn...: And, at least in our team at UCL, everyone's so... [00:15:30] I think the patients and family members are at the forefront of everything we do, which, from talking to colleagues outside of HD or researchers, I think, the HD is quite a unique field. Probably because of the family aspect and the collaborative nature that's been driven probably historically by, really back from Nancy Wexler, and the [00:16:00] forces from families driving researchers to work together for the ultimate benefit of patients, rather than their own careers. So that was the biggest thing to learn, and I was surprised to find out that. I'm definitely biased, but...

Dr. Lauren Byrn...: I think, in terms of what I've done to help other researchers understand it, I don't know. [00:16:30] I'm just always there to answer, I'm very open about it with anybody I work with. When I first joined the group, I did a kind of introduction to my family and my experience, and I've always had an open door, in terms of asking about that. But for me, even personally, it's been great to be surrounded by people that get it.

Dr. Lauren Byrn...: Professionally, [00:17:00] I always have people I can ask about my own family, now, without feeling I'm burdening them, which was a bit of revelation when I first joined the research field where, before, you don't really talk openly with friends that don't really understand Huntington's disease and you tend to deal with things on your own, whereas [00:17:30] now, I have people I can talk to about it.

Speaker 1: We'll return to the interview on the HD Insights Podcast in a moment. We hope that you're enjoying this episode. As a 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.

Speaker 1: If you like what you're hearing [00:18:00] 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 1-800-487-7671. We greatly appreciate your support, and now, back to our episode.

Kevin Gregory: Dr. [00:18:30] Byrne, I'd like to switch gears now and talk about some of the recent research that you've been involved with. You mentioned being at the Huntington Study Group's annual meeting back in November, and at that meeting, you presented a platform discussion on a promising biofluid biomarker. And, as I understand it, that same research has now moved into the pre-print process and is undergoing peer review. Let's start there with, what was the background [00:19:00] behind how that project initially came about or was proposed?

Dr. Lauren Byrn...: Sure. So, the research is based on something we call biofluid biomarkers, and biomarkers are just things that we can measure in humans in different ways, whether it's a blood test or a urine sample or even a brain scan, and they can tell us about how [00:19:30] someone's disease is progressing or whether to treat someone with a certain drug or et cetera. So that's the foundation of what we're trying to work at UCL at the HD center, for the reason that we need better tools to run clinical trials and to tell us whether a drug is working and also when to start treating once we do eventually have [00:20:00] disease-modifying therapy for HD.

Dr. Lauren Byrn...: So this project was in a disease cohort called HD-CSF. CSF stands for cerebrospinal fluid, which is just the fluid that bathes the brain, it's in our spinal cord. And the reason it's such a useful sample to look at is, in HD specifically, because we know that Huntington's disease is a brain disease. And this, CSF [00:20:30] or spinal fluid, bathes the brain and happens to be enriched for all these proteins that are specific to brain health and processes, so it's a good resource to collect. Something that's been happening a lot in the HD field, if anybody takes part in HDClarity, a lot of that is to collect these biofluids of CSF and blood for these purposes.

Dr. Lauren Byrn...: HD-CSF was a study [00:21:00] designed by Ed Wild, my boss, and it's a single site study, based in London, of 80 participants. These are people with Huntington's disease with symptoms, as well as those who carry the gene for Huntington's disease but don't have symptoms, as well as healthy controls to compare with. And the 80 participants were followed for two years, so it's the first [00:21:30] CSF collection, or large CSF collection, to have what we call longitudinal sampling, or samples over time.

Dr. Lauren Byrn...: And previously, we've had a lot of progress with new biomarkers or potential biomarkers in CSF and in blood. One that people might have heard a bit more about because of the huntingtin lowering trials is CSF [00:22:00] levels of mutant huntingtin protein. As you know, huntingtin protein is the protein that is damaged in people that have the gene that causes Huntington's disease, the mutation causes a mutated form of the protein that is toxic to brain cells.

Dr. Lauren Byrn...: A few years ago, back in 2015, scientists, including Ed and colleagues, [00:22:30] developed a way to measure this protein which is at really low concentrations in spinal fluids, which has allowed us to show that these new drugs are being tested in trials are doing what they were meant to do, and that's to lower the huntingtin protein in and around the brain. So some people heard of about that, we are looking at that protein... this [00:23:00] research, that is hopefully going to be published in the next few months, was looking at that protein in people that have not had any drugs, just to understand how it changes over time.

Dr. Lauren Byrn...: This information is extremely important to the whole therapeutic development in that it tells us how the protein should be changing in normal disease so that if a drug that is successfully slowing [00:23:30] the disease, dying, we'll be able to detect that more accurately. Another protein that we're looking at in this research is a neurofilament light protein. This is a protein that's found in brain cells, and whenever there's brain cell injury, there is a release of that protein into the CSF or spinal fluid, but also we are able to measure it in blood.

Dr. Lauren Byrn...: And [00:24:00] we published that a few years ago, in 2017. This blood test can tell us about how the ongoing damage or health of brain cells in Huntington's disease. So, in this study we compared those two proteins, neurofilament light, or NFL, with mutant huntingtin to compare [00:24:30] their ability to predict clinical change over time or to compare their prognostic abilities. We also showed how those markers change over time, over the course of Huntington's disease, so we look at their what we call longitudinal trajectories.

Dr. Lauren Byrn...: And what we noticed or shown was [00:25:00] that all three of them had very distinct trajectories over time compared to that in controls. And we can see changes in these markers, in those people who have the gene for Huntington's but are yet to have symptoms, and that the changes with time are related to the mutation that causes Huntington's disease. So, those who have higher CAG [00:25:30] repeats tend to have higher increases and earlier increases in the markers.

Dr. Lauren Byrn...: And in terms of their prognostic ability, we found that neurofilament light protein had the strongest ability to detect changes in clinical outcome over time, so a single measurement of this neurofilament light protein projected or was associated with [00:26:00] how much deterioration happened over the two years in clinical outcomes. And we were able to use this data then to do what we call simulate a clinical trial to help or to theorize how we could use these biomarkers in future to run more efficient clinical trials. So biomarkers could eventually be validated [00:26:30] to be used as what we call surrogate endpoints in trials, so a surrogate is something that can represent, it's a surrogate of clinical improvement.

Dr. Lauren Byrn...: So if we can show in a biomarker that a reduction in its level will show clinical improvement in so many months, but you might see a quicker response in a biomarker, it could potentially allows us to run trials over shorter periods of time [00:27:00] or lower numbers of participants. And I think that's it.

Kevin Gregory: When you talk about the prognostic ability of these biomarkers, is it prognostic for onset of symptoms or progression through the disease or did you observe findings for both of those?

Dr. Lauren Byrn...: So it's important, as well, to highlight, here, this is aggregated [00:27:30] data, it's not at the perspective of an individual, so we wouldn't be able to look at someone's neurofilament level and say you're going to have this much brain atrophy in the next two years or... We see statistical associations, and yet with the prognostic, I mean, over various domains of measures that we use to assess Huntington's disease, [00:28:00] so we have clinical measures, and they include aspects of the Unified Huntington's Disease Rating Scale.

Dr. Lauren Byrn...: And we incorporated the new composite score of that which combines four aspects of that, including the functional capacity motor score and two of the cognitive assessments to create one composite score. And these biomarkers had a association with the [00:28:30] decline in that score, as well as the individual components of the UHDRS, as well as brain volume and atrophy.

Kevin Gregory: Can you talk about specifically what participants in the study had to do for this? I know a lot of people are familiar with the Roche trial and the mechanism of delivery through CSF, but not everybody may be familiar [00:29:00] with what that really entails.

Dr. Lauren Byrn...: Sure, so our subjects were absolutely amazing and took part in... so this study was linked to EnrollHD, so a lot of the assessments and clinical aspects of that were very similar to Enroll, and for anyone who's done HDClarity, the collection of spinal fluid is very much the same, but for those who [00:29:30] don't know about lumbar puncture or spinal tap, it's a very common procedure which sounds a lot scarier than it is.

Dr. Lauren Byrn...: I've had one myself after the study, I did it for another study at UCL, called the Young Adult Study, that was led by Sarah Tabrizi. And the [00:30:00] area of the back is very similar where women that are giving birth would have an epidural injection, so it's the lower part of the spine, and basically the reason why they access the spinal fluid from that part of your spine is that there's a canal of space in the spine at that point where the spinal cord ends.

Dr. Lauren Byrn...: I don't know if we're going into too much detail here, [00:30:30] but the spinal cord ends at your belly button. So then below that is just nerves, so there's no risk, or at least very low risk of any serious damage to your nerves or anything like that. Because I think from what I've heard from people that are asking about the procedure, their first questions are, "Can I get paralysis or [00:31:00] long-term damage from this?" But the whole point of doing it in that space is that it's where most of the fluid is and the spinal cord is not there.

Dr. Lauren Byrn...: And it's done under local anesthetic, like injection when you're at the dentist getting a tooth out or a filling, it's a similar procedure, and that can sting for a few seconds, and then it [00:31:30] should be pain free. I think nine times out of ten, a lumbar puncture is very straightforward. Particularly in research setting, all of our doctors are very specialist and have done hundreds, if not more, lumbar punctures, and all of these doctors are the same doctors in the intrathecal injection trials.

Dr. Lauren Byrn...: So, the difference between a lumbar puncture and [00:32:00] the intrathecal injection in our study and in HDClarity, we have the needle goes in and then we allow the fluid to drip out and we collect it. Whereas in the intrathecal injections that are where the drug would go be injected into the spine, in the trials, they would remove some of the fluid with a syringe [00:32:30] and then inject the fluid with the drug or placebo into the spine.

Kevin Gregory: And that's really great point and I'm glad you mentioned that because to somebody who's not familiar with it, or if you're like me and you have an aversion to needles, something like a lumbar puncture sounds potentially horrifying, but like you said, the these are people that have done hundreds of them and are well trained, [00:33:00] so I appreciate you bringing that up. Dr. Byrne, in terms of this research, were there any findings that really surprised you or any assumptions maybe that you had going in that may not have been reflected in the result?

Dr. Lauren Byrn...: I think the biggest surprise was we thought [00:33:30] mutant huntingtin would have the strongest associations, perhaps, with the clinical manifestations of disease because it's the root cause of it, but as we thought about it more, it makes sense that neurofilaments, which is a marker of the pathology and damage to neurons, which is the precursor to the symptoms, [00:34:00] would be closer associated with those features. Whereas mutant huntingtin is the most upstream event, perhaps, this is obviously more hypothesizing here.

Dr. Lauren Byrn...: I think that was probably one of the most surprising, but that being said, mutant huntingtin is still has a lot of prognostic value compared to other potential biomarkers. [00:34:30] I think the fact that the blood tests of neurofilament has such a strong biomarker for clinical progression is probably the most exciting finding, and maybe surprising, even compared to measuring the same protein in the CSF, which is also great news for patients because it's a blood test rather than having [00:35:00] to go through the lumbar puncture that we just discussed.

Dr. Lauren Byrn...: And it opens a lot of doors for the research that we can do or retrospective research that we can do on this biomarker because a lot of studies that have already happened will have definitely had blood samples. That's something where I'm going with in my future research, in my postdoc, is to try and get as much information on this [00:35:30] neurofilament marker in whatever samples that we have available to us in the HD field, which is quite a bit. We have studies like the [DictHD 00:35:40] and all the TrackHD samples, all these large cohorts of people that have given samples and clinical and MRI information for many years.

Dr. Lauren Byrn...: And I'm sometimes not really understanding why they have to give so much blood or biosamples, what will it be used [00:36:00] for? This was a prime example of something that came when technology advanced, that we were really glad that we could go back to those samples that were collected years ago without really knowing that they would be this useful.

Kevin Gregory: Yeah, that's incredible, I was actually gonna ask you is if this research has brought up any questions or that will spawn future research activity or, as you said, that even the retrospective research [00:36:30] review. Dr. Byrne, in terms of the timeline for publication, I know you alluded to a few months, is there a timeline that you expect for completion of the peer review to occur and your next steps for publication?

Dr. Lauren Byrn...: In the science review gods, we don't make claims of such as that which we can't risk that. [00:37:00] It's all very scary at this stage, once you've sent the baby off to be reviewed, so I am not going to say anything. I think, if people would like to see the data, it's available online on medRxiv, and we can share a link with the podcast and... yeah. It will be announced, I'm sure, with a stream of tweets from Ed Wild when the actual article gets [00:37:30] posted online, so hopefully people will hear about it if and when it does get accepted.

Kevin Gregory: Perfect, we'll definitely will post that link for folks at the end of the podcast. In terms of the the HD-CSF study, are there other any other colleagues that that you wanted to to mention that you know really helped you with the effort or really helped make a difference on it?

Dr. Lauren Byrn...: Yeah, for sure. All [00:38:00] of this work has been a joint effort with my colleague, Filipe Rodrigues, who is a clinical fellow that also works with Ed Wild.

We've worked from the very beginning of the study and he did pretty much all the lumbar punctures, so we've been a double act from start to finish, so it'll be Rodrigues Byrne at [inaudible 00:38:25] 2020, hopefully.

Dr. Lauren Byrn...: And the whole UCL [00:38:30] HD team's, a lot of the co-authors on the paper are my colleagues at UCL, we have a fantastic neuroimaging team, including Rachael Scahill and Ellie Johnson who helped analyze all the MRI scans for the study. The nice thing about this study is that it's a resource for the future development of biofluid biomarkers, [00:39:00] so we still have lots of CSF and blood left over and they're continuing to come up with prospective biomarkers to investigate that might be useful in their own rights.

Dr. Lauren Byrn...: And in terms of future work with other colleagues, maybe outside of this, I am hoping to get involved with developing [00:39:30] better Huntington assays. From one thing out of this work, it's made us realize we still need even more sensitive, robust Huntington assays, and assays that can measure different types of huntingtin species of the huntingtin protein to really understand what we're changing and what's going on and what pathology when it comes to huntingtin lowering trials.

Dr. Lauren Byrn...: [00:40:00] And to that, I'm starting to work with Dr. Rachel Harding, who's based in Toronto, to understand how to characterize antibodies, which array the core parts of assays that make them specific to the proteins that we want to measure. I'm working with some colleagues at UBC [inaudible 00:40:28] to look at this protein [00:40:30] neurofilament and also mutant huntingtin in animal models to answer some of those biological questions related to treatment and the changes in these biomarkers in ways that we can't do in humans. So we've been working on a study treating a mice model with HD, with huntingtin lowering agents, to see how this affects the neurofilament and mutant huntingtins. So there's a lot of [00:41:00] work going on, which is exciting.

Kevin Gregory: Well, Dr. Byrne, I know the HD community and the research field is stronger and better for having you in it, so I appreciate the passion that you've you've brought to this, and I also want to thank you for taking time out to speak with us today for the podcast.

Dr. Lauren Byrn...: Yeah. Not a problem, I'm delighted to do it. Sorry if I ramble a bit, I get on a tangent [00:41:30] sometimes and...

Kevin Gregory: No, no, this is perfect it. Again, thank you so much for joining us, and for podcast listeners, I will share that URL that Dr. Byrne mentioned in a moment, but again, in the meantime, I know you're also dealing with a lock down situation in the UK with the COVID 19, so we hope you continue to stay safe and healthy and [00:42:00] that everybody is doing their part to be well and get us through this as quickly as possible.

Dr. Lauren Byrn...: Yeah. And the research, HD research is still happening despite lock down, allowing up to write up and analyze data, so if anybody's worried that it's slowing down research, there's still plenty we can and do well, at home.

Kevin Gregory: I [00:42:30] am extremely thankful to Dr. Byrne for her time on this episode. There's such incredible research being done around the world by passionate and dedicated people. Dr. Byrne's involvement and work is truly a reflection of how driven this community is. If you're interested in reading the pre-print edition of the HD-CSF study, you'll find a web link included in the description for this podcast. There is no charge or subscription needed to view it.

Kevin Gregory: Before wrapping up this episode I want to again take the opportunity to reach [00:43:00] out to our audience about a project that HD Insights, in collaboration with colleagues at Vanderbilt University and Roche Genentech, are embarking upon that aims to shed light on racial, ethnic, economic, and geographic disparities that impact access to quality HD care, education, and community connection. As part of this project, we're reaching out to HD clinicians, advocates, researchers, and study coordinators who might be listening and [00:43:30] interested in sharing their stories and experiences working with diverse populations impacted by HD.

Kevin Gregory: For example, what inequities do you see in your HD practice? What unique challenges have you or the community you serve faced, in particular when it comes to health inequities in outreach, access to care, willingness to engage, and affordability of healthcare?

Kevin Gregory: We would like to select a few stories and individuals to highlight in an article and future podcast with the intention of lending a [00:44:00] greater voice to this experience. If you would like to share a story for consideration, please contact me by email at Kevin.Gregory@HSGLimited.org. While this initial call to action focuses on the researcher and clinician point of view, we recognize the importance of other perspectives to this overall conversation, most notably those of the patients, families, and research participants. Additional efforts [00:44:30] will focus on bringing a spotlight to this group, which, in the end, is the group in most need of the microphone.

Kevin Gregory: 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: We hope you enjoyed this edition of the HD Insights Podcast. Remember to subscribe to this podcast to make sure you [00:45:00] 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. 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 deductible donation. To do so, please email us at info@hsglimited.org. That's

[00:45:30] I-N-F-O at H-S-G limited dot org, or by calling our toll-free number at 1-800-487-7671. Thank you for joining us on the HD Insights podcast from the Huntington Study Group.