Dr. Leon Dure: 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 professionals. Funding [00:00:30] 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, uniCare, Vast Annex 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, communication and outreach at the Huntington Study Group. [00:01:00] Today, we have a special edition of our program for you. We're pleased to turn over this conversation to Dr. Daniel Claassen, chief editor of the HD Insights Magazine, who you met on our very first podcast episode. Dr. Claassen will serve as guest hosts as he speaks with Dr. Ira Shoulson about his perspectives from the research project in Venezuela in the early 1990s, that ultimately led to the discovery of the HD gene. Dr. Shoulson has had a prominent role in HD research throughout the years. He's a co- [00:01:30] founder of the Huntington Study Group and was part of the team that developed the Unified Huntington's Disease Rating Scale or UHDRS.

This is also the first episode among others plan that takes a deeper dive into some of the disparities that impact access to quality HD care. In this instance, for the people in this area of Venezuela, the geographic and severe socioeconomic disparities that isolated them from the rest of the country. So without further delay, here's Dr. Claassen's conversation [00:02:00] with Dr. Ira Shoulson.

Dr. Daniel Claa...: Well, hello everyone. It's Daniel Claassen editor of HD Insights. It's good to be with you again on this podcast. I'm grateful to Kevin, who's given me the opportunity to lead this podcast, and we're really fortunate today to be joined by Ira Shoulson who all of you know, he really is one of the pioneers in Huntington's disease research, especially [00:02:30] with the Huntington Study Group and even broader efforts like the Parkinson Study Group. And today's podcast we're really going to spend some time looking back on what I'm calling the Venezuela Project. I think a lot of us have been reminded of this work through some recent media coverage and just remembering HD as we discovered that the gene.

And I realized that personally, [00:03:00] I don't really know much about the Venezuela experience. I mean, I've read about it. I've seen some papers, which talk about how the gene was discovered, but I thought it'd be great to get some insights from someone who was actually there to tell us what it was like and hopefully encourage us to think about ways that as neurologist or a scientist we can help those who are underprivileged, who don't have access to care as we look at our current [00:03:30] state. So Ira thank you so much for joining us today.

Dr. Ira Shoulso...: Sure. Glad to be here. Thank you.

Dr. Daniel Claa...: So I guess we'll just start off, Ira by just asking you how'd you get involved with the Venezuela Project?

Dr. Ira Shoulso...: So I'll tell you this, obviously from my perspective, I was one of many, I wouldn't consider myself a bit player, but I don't think I was [00:04:00] part of the key leadership that said I was part of the Venezuela Project yearly, usually during February from 1980 through 1994. I think I probably went back one year after that, but so I had a good run on that with an incredible team, both on the ground, in this field work and also back home in the laboratories in [00:04:30] Boston and in Indiana. So, my role starts in 1972. I was a resident in internal medicine at the University of Rochester. And so my first patient there really by chance and was captivated from bio. And I had no training in neurology. I was just training [00:05:00] in internal medicine and that same year in 1972, unbeknownst to me, there was a physician in Venezuela whose name is Americo Negretti who had been following patients with Huntington's disease in Venezuela, in that State of Zulia.

And he presented in 1972, which was the centenary [00:05:30] of Huntington's description. In 1872 there was a meeting in Ohio. I wasn't there to know about it, but he presented a video of patients as part of that. And I think as George Huntington himself said, it was kind of a curiosity and it kind of lay there for a number of years flash forward through [00:06:00] completing my residency, going to the NIH and working in what became the institute in neurological diseases with Tom Chase and seeing 250 Huntington's patients in a period of two years. And in fact carrying on clinical research, that was my entree into clinical research. It was mostly [00:06:30] in patients with neurodegenerative diseases, Huntington's, Parkinson's, dystonia other diseases. So by the time I completed my training at the NIH, I was fairly well steeped in clinical research and these neurodegenerative diseases.

And then in 1975, went back to Rochester at the university and completed a residency in neurology. [00:07:00] And by that time I was actually doing a clinical trial in Huntington's disease and as part of being a junior faculty member, I began to develop ties, some of which had their origin at NIH because by seeing all these Huntington's patients, I got to meet Marjorie Guthrie many times and Nancy Wexler many times. [00:07:30] So that was one part of it. The other thing was that I became colleagues and friends with Ann Young and Jack Penny who had at that time moved to the University of Michigan from San Francisco. And so there was a little bit of a critical mass of colleagues interested in Huntington's disease. [00:08:00] By 1980, I had become part as first as a guest and then as a member of what's called the research group on Huntington chorea.

And there was a meeting in 1980 that the young Turks that included myself and Young and Nancy Wexler attended [00:08:30] the meeting. And of course we

knew one another, but Nancy was very interested in this population in Venezuela. In fact, in 1979, the year before she went down to Venezuela with Tom Chase, who was my mentor at NIH with the ostensible goal of, is this really look like Huntington disease that we see in the U.S.? And [00:09:00] in fact, brought back more videos and it was compelling not just from the video, but also from the experience that Tom Chase and Nancy conveyed that this look like Huntington's disease as we know it. And so that was really the genesis of my involvement in the project. And there was a lot of skepticism by the established people in those [00:09:30] research group about whether this is Huntington's, is it really worth pursuing, but of course, Nancy having important aspirations and being the stubborn person to meet those aspirations decided to go back.

So in 1980, that was the first contact that I had along with Anne Young, Jack Penny and a pediatric [00:10:00] neurologist called Bob Snodgrass that we went down to Venezuela for two weeks to kind of see this firsthand. So it's kind of a long preface to getting involved, but it happened kind of gradually, incrementally over about eight year period before we got involved and we had a taste of Huntington's disease. [00:10:30] All of us were trained clinically or self-trained in movement disorders. So we went down to see for ourselves. So I'll stop there as far as the history goes and maybe just pause to see if you had any other further questions to your first point.

Dr. Daniel Claa...: No, that's really a great summary. [00:11:00] It's interesting to hear that people were skeptical that this was HD. Did I hear that correctly? Or they're more skeptical that the phenotype was different from the phenotype they typically see in their clinics?

Dr. Ira Shoulso...: I would say both. They were skeptical as to whether this was HD. Of course, we had no gene tests or anything like that to [00:11:30] know it from a genetic point of view, but at least from a phenotypic point of view, there was a lot of skepticism. Also, from the video, there were a lot of young people with Huntington disease, and of course we, at the time associated Huntington's disease with something that has onset in mid adulthood, and the video included individuals with chorea and dystonia and even some [00:12:00] Parkinsonian features who are younger in adolescents and even in childhood. So there might've been some of the justifiable skepticism about it. Then there was skepticism as to that this is just a curiosity or something that has research implications.

Dr. Daniel Claa...: That's really interesting. When the case is presented, were they typically presented with [00:12:30] like family tree history as well? Or is it mostly the clinical phenomenology that was presented?

Dr. Ira Shoulso...: No, it was mostly the clinical phenomenology. We had really no sense of the pedigree or pedigrees that in the family histories that were going on. We knew certainly anecdotally that this was occurring in families in an autosomal [00:13:00] dominant fashion. I'll be able to share with you some interesting

stories about that, but no, this was all clinical information that was presented to researchers and that research group that at the time met in Europe, I think it was in Oxford, in England. They weren't all clinicians, there were a few clinicians, [00:13:30] some of them were researchers like epidemiologist, geneticists, cetera, who were really not that interested in the phenotype as clinicians might be.

Dr. Daniel Claa...: That's really fascinating. So I guess the idea from 1980 on is that there began to be a regular trip. [00:14:00] Is that how I understand it? Like in February, there'd be a regular cohort of folks that would go down there?

Dr. Ira Shoulso...: Absolutely. Well, Nancy went down for the last week in January through February into March. So she really camped out there, but we had these two to three week trips that we would overlap a little bit and Young would go down. I would kind of join that. Jack Penny would [00:14:30] come down, Bob would come down. So the clinicians came down over that entire period of time. And to give you a little color as to what this is like just coming down, our main mode of transportation was an airline called Pan Am. And we all get down to Miami, take the flight from Miami to Maracaibo and make our [00:15:00] way to the hotel, which was our headquarters and get oriented with Nancy. And I'd say there were three key parts of that work that went on, especially in the beginning, as it evolved over time.

One was the cultural adaptation. Not that we adapt it [00:15:30] so much, but the culture they're adapted to us. Number two was the importance of the family history in developing the pedigrees. And number three was the quality control. So the first part on the cultural one was the important, critical step, really rate-limiting clinical step early on, are we to be trusted? Unfortunately, Nancy [00:16:00] of course has this remarkable ability to engage people. And she used it effectively, first in 1979 when she went down there and there were several groups to become a culture at it, with one was the government because this is a research study. By the way, behind the scenes, this whole thing was sponsored [00:16:30] in part by the Hereditary Disease Foundation and also the NIH and Nancy herself was a program officer at NIH and Carl Leventhal, who was a colleague, and I think her supervisor really enabled this research grant to take place.

So we were coming down there and under the auspices of the U.S. we call it the U.S. Venezuela Huntington's [00:17:00] Disease Research Study. So one is who are these researchers? And so dealing with the government and getting their trust and support, which by the way, compared to nowadays was relatively easy. There were very good political and organizational relationships already established, but that was still an important thing. The second piece was just the [00:17:30] community around us, that we were in a kind of an upscale community in Maracaibo at a hotel that turned out to be very important because we were able to use that as a base, but of course you're isolated in a hotel. And the third and most important part was meeting the Huntington's

community. There was a small suburb of Maracaibo called San Francisco, [00:18:00] not to be confused with San Francisco in the U.S and all these barrios, these little neighborhoods around there. There was a small barrios called San Luis, and we would go out there every day, probably get there about eight or nine in the morning and stay there until about 11:00 [00:18:30] PM. So it was pretty grueling days.

Dr. Daniel Claa...: Wow. And so did you have a translator? You were talking about the family history, I guess that must have been challenging to elicit. I'm just imagining myself going down.

Dr. Ira Shoulso...: Yeah. All of us had a little broken Spanish. Nancy was more fluent in Spanish than any of the gringos who went there. And [00:19:00] so that was a benefit, but we hooked up with the medical community there, every little barrios had a clinician, they were not neurologist at all. They were medical doctors or medical nurses, and they served as translators. And we did have from the U.S. some geneticists who went down there. One was Coracioni Konsetago who [00:19:30] was a geneticists who spoke fluent Spanish. And she was very helpful and a researcher and the other was Fidela Gomez, who actually was a colleague of my wife's. They were both nurses at the Washington Medical Center, and she was from Canary Islands in Argentina. [00:20:00] So we brought down two people who turned out to be really very important in terms of connecting. Over the course of time, we learn at least street Spanish.

First thing I learned was how to do a neurologic examination, at least a motor examination in Spanish, how to order food, enough Spanish so I could engage [00:20:30] with patients, but certainly early on people like Fidela Gomez turned out to be really critical in terms of the Spanish part, but they brought more to it than that. They had really good clinical and warmth and empathy for what we're dealing with.

Dr. Leon Dure: We'll return to the interview on the HD Insights [00:21:00] Podcasts 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. [00:21:30] org, or by calling toll free at +1 800-487-7671. We greatly appreciate your support. And now back to our episode.

Dr. Daniel Claa...: I just wanted to circle back a little bit on the phenotype. We think of Huntington's now, we talked about the cognitive and emotional and motor symptoms. [00:22:00] Did you get a sense that there were... And we talked about the motor phenotype and the cognitive and psychiatric symptoms particularly, was that an appreciated aspect of the pathology of back then?

Dr. Ira Shoulso...: Yeah. I didn't know it was appreciated. Besides motor abnormalities, there were cognitive and behavioral problems too. The most striking thing in the first day and this persisted for the next 10 years is how much [00:22:30] this is all, like the differences were minor and really not of any consequence. So the motor part was there. The cognitive part one could even without being fluent in Spanish to appreciate that. And the behavioral features ranging from depression to Frank psychosis were also very evident. You didn't have to be that adapted [00:23:00] at appreciating that even without fluency in the language.

Dr. Daniel Claa...: Yeah. So, I guess from this, is it fair to say that things like the UHDRS, motor exam and such, does this have its genesis in those trips?

Dr. Ira Shoulso...: Yeah. Had its genesis in, [00:23:30] after I think it was... So we were there in 1980, we came down and then we published Anne Young, myself, Jack Penny, the group published the paper, I think it was called... A neurology Huntington's disease in Venezuela. And in it, we developed a motor scoring system, one to four in terms of [00:24:00] chorea, rigidity, whatever and we applied it. By that time we had collected motor examinations on hundreds of patients. So it was a really rich sample. So we published that. That was actually the former runner of what later became the motor section of the UHDRS for better or worse because I think there's still a problem with the... But [00:24:30] at least the motor part had its genesis definitely in Venezuela.

We used a scale that Tom Chase and I had devolved in NIH that Anne and Jack refined and applied it. We were doing the standard "rudimentary" motor examination on everybody who we met. So that was one of the jobs of the clinicians that [00:25:00] we didn't have a patient who we didn't examine in a systematic fashion at least circa 1980s.

Dr. Daniel Claa...: Yeah. So how did you record this information? I assume you had case report forms that were handwritten and probably it was pretty massive in terms of the paperwork.

Dr. Ira Shoulso...: Yeah, the paperwork was... So I was saying that there are three things. One was the [00:25:30] cultural part. Two is the pedigrees and that turned out of course, to be important. Talk about paper, we would develop these pedigrees. We had a computer... When I say we developed the pedigrees, that was really one of another major contribution from Nancy and the group back home, Mike Conneely at Indiana University. And so we used a computer program to draw the pedigrees and we put [00:26:00] them up in the hotel room, on the wall and pretty soon we had to get a suite to do that because his pedigree was so massive.

So if you talk about paper, that was really the key part of a paper production. We also had a lot of paper on these forms and as we started getting biological samples paper on that. So the third part of that after the pedigrees was the quality control. [00:26:30] And so just in a nutshell, there's no question about

Nancy's leadership and inspiration on this project and especially on the second part, developing the pedigrees through really step-by-step tracing from the history, putting things together. People had different names and they all have the same family names. So it wasn't like what we're accustomed to now.

[00:27:00] The quality control was interesting because at the end of the day, Jack Penny and I took it upon ourselves to ensure, and this sounds like a minor thing and probably the greatest contribution that Jack and I made, to be sure that the name and the code we gave to people match the motor examination and importantly the blood sample. So [00:27:30] that's what we would do. It was a very matriarchal-led project by Nancy, Anne, et cetera. So the boys kind of withdrew in the evening to make sure that everything was tidied up and match. So that kind of gives you a sense about how we were dealing with paperwork.

Dr. Daniel Claa...: Yeah. Therapeutically what was offered to [00:28:00] these patients at this time? Were antipsychotics used?

Dr. Ira Shoulso...: We occasionally used antipsychotics mostly in the form of halopedirol at the time that was available, not a lot of medications available. Most of our therapeutics was treating... My internal medicine background was helpful as was... They had a Bob Snodgrass [00:28:30] who was also fluent in Spanish, and we would be treating diarrhea, insect bites, a whole variety of things. So most of the treatment and occasionally bacterial infections. So most of the treatments were for day-to-day types of problems that people encounter in that environment. And these were not medications we brought with us.

These were medications [00:29:00] we tried to secure through the physicians in the community who'd actually oversee in large part the administration and follow up with the patients, but that was it. Medications I'd say played a relatively minor role in terms of Huntington's disease, but a major role in terms of securing this trust that we were people down [00:29:30] to helping. And of course, many of those interventions like antibiotics and antiparasitic treatments turned out to be very important.

Dr. Daniel Claa...: Yeah. Maybe my perception of this is incorrect, so I'd appreciate you correcting it, but I get the sense that this community was somewhat ostracized from society. Is that a correct assumption or [00:30:00] is that not the way it really was?

Dr. Ira Shoulso...: Yeah. They were ostracized in two ways. One, socioeconomically, these were poor people. So to that extent, you see that worldwide, but they also had what people described as Elmo the disease and the chorea in the community was evident as was the gait disorders that go along with it. And [00:30:30] there was an assumption that a lot of these people were drunk, by the way a few of them were, some of them were fishermen and they'd go out all day on Lake Maracaibo, but then come back and celebrate the catch at the time. So there was a mixture of things, but this was a group that was viewed as a relatively

poor and relatively sick from Elmo, [00:31:00] whatever that notion was. There are certainly, except for people like the Americo Negretti, and others [inaudible 00:31:10] was another one who were clinician, epidemiologists at the time. There was really no appreciation that this was Huntington's chorea.

Dr. Daniel Claa...: Yeah. And we talked a lot about now, at least in our clinic about caregiving and the stress of [00:31:30] caregiving. Were you able to appreciate that aspect when you took care of these folks? Did you see families really suffer as a unit through this disease?

Dr. Ira Shoulso...: Yeah. The caregiving was really poignant and just share with an anecdote about that is our Spanish became better and we were able to engage in the families, of course, that the size [00:32:00] of the families was enormous. The average number of children that someone had during this fertile period of 10, 15 years was about seven kids, some 14. So you could actually see as we gathered the pedigrees what the family structured look like, at least in terms of a family history, but most people [00:32:30] live together if not in the same house or shack, but within this biracial. And I was very interested to learn from the families how they took care of each other. The care was remarkably good and very empathetic and supportive. And [00:33:00] I remember asking a family as I got through, I said, "Well, why in families on average, half the people are affected and the other half aren't?"

And I remember the response of one of the unaffected kids and said, "Well, that's that way because we need the healthy people to take care of the sick people." And it just really struck me. Their understanding [00:33:30] of what we know appreciate the level of molecular genetics was the reason that is, was to be able to care for the sick. So [inaudible 00:33:41] you don't know if healthy people that do and it kind of... During the current pan up pandemic that we had you really appreciate that you need healthy taking care of the sick. Unfortunately, this wasn't an infectious, so we had no concerns about that, [00:34:00] but it really hit home on how from a sociocultural point of view, care was really so well established. Now it wasn't care that we know it today, but I would put it as really good care and very caring.

Dr. Daniel Claa...: Yeah. Just following up on that. Genetics, I mean what we know now is much different from what that culture experience. [00:34:30] Do they have an explanation for Elmo? Was there attempt to understand what the reasons for getting sick were, or it just kind of fate?

Dr. Ira Shoulso...: Well, I wouldn't make a distinction between heredity and genetics. They understood that it ran in families, but they didn't understand of course that from a Mandalian point of view about the genetics, except [00:35:00] for some people who had some clinical or academic training down there. So, no, their appreciation was really at the level of care and family unity.

Dr. Daniel Claa...: Yeah. So as the day would go on, would you have folks come to you or did you actually go to their houses? How would you find the patients who [00:35:30] were maybe more impaired than others? And how do you go about getting the community?

Dr. Ira Shoulso...: No, except for the somewhat upscale. And I'd say this relatively speaking neighborhood in which the hotel was, and there were some individuals who were living in the area where there were HD families, but they were relatively small. We'd see them at the hotel and do our [00:36:00] interviews and examinations, 95% of that was home visits and not just in San Luis, but also along, we'd take day trips to other villages along Lake Maracaibo. One Byron Kido is said to have the largest population of Huntington's as far as density in any place [00:36:30] in the world. And then on the Southern tip of Lake Maracaibo there was a community, I'm sure you've seen videos of it, on stilts where people lived on the lake to stay away from the wild animals in the adjacent jungle. And there is a large community down there.

So no, this was home visits and this was truly a field [00:37:00] research project. And we went out as I said, perhaps every morning early and came back sometime after midnight, depending on where we're going. Sometimes we stayed in the community like in Nepal, because there was a long trip from our headquarters in Maracaibo.

Dr. Daniel Claa...: Yeah. What was the comradery like of the group that went? Did you guys become [00:37:30] like I assumed, really close friends and shared a lot of painful, but also probably humorous anecdotes? What was it like over time, did you become really a close knit community academically?

Dr. Ira Shoulso...: Oh yeah. We went on in the ensuing decades to be colleagues and friends. And there was a lot of socialization and [00:38:00] comedic release along the way. So that turned out to be very important and sustaining. And we also, from academically, we published together and just to flash forward to 1993, after the gene was discovered the day establishment of the Huntington Study Group, many other efforts that principally Jack Penny [00:38:30] was instrumental in helping me launch that initiative. So, we went down in 1980 and by '83, largely through the collaboration that was established with Jim Ghazala and Marcy McDonald at Mass General, the linkage for the Huntington's disease was established. So we knew we were [00:39:00] onto something.

Of course, it took another 10 years before the link gene was identified through Marcy and Jim's efforts. So we were part of that ride, not just socially, but in terms of research in academic work. So it became a very cohesive group of friends and colleagues that [00:39:30] was sustained to this day. Of course, Jack Penny passed away prematurely before he could, I mean after I think it was by Huntington Study Group and been going on for about six or seven years when he died and Young and I and Nancy have remained close friends and colleagues.

And [00:40:00] that was a benefit that has endured throughout that time and to this day.

Dr. Daniel Claa...: Yeah. Have you followed up at all with the situation in that region in Venezuela in terms of the clinical care?

Dr. Ira Shoulso...: I personally have not. I've not been down to Venezuela since the early 90s. Nancy and [00:40:30] I guess once with... Well, once I joined her, but Nancy has going down from time to time to Venezuela. I think as recently as a couple of years ago, it's become pretty brutal as we know politically and economically. And so their project is we knew it certainly has not been sustained, but Nancy through the Hereditary Disease Foundation has [00:41:00] devoted a lot of effort and established some funding to keep the clinics going down there. But I don't think there what could be, and that's been a great regret that everybody's had, that we weren't able to sustain those. But fortunately Nancy has continued to try and sustain those ties.

Dr. Daniel Claa...: [00:41:30] Yeah. And one of the things that impresses me most and just thinking about this story and hearing your experiences is just the opportunity given by the NIH and Hereditary Disease Foundation to do this. You feel like in 2020, there may be a lot more barriers to going on something like this, is that [inaudible 00:41:54] as you appreciate that now looking back, like this was a great time to do [00:42:00] it and amazing resources?

Dr. Ira Shoulso...: With this pass peer review master now a days, as we know from NIH type of support, and I think that's questionable because this was really more an aspiration, not so much data-driven as a people-driven. And as I said, particularly Nancy Wexler, but that said field [00:42:30] research has become less common, a big ALOS project in Guam. There were other projects, of course on transmissible spongiform encephalopathy is that the NIH was involved in, but these types of large field projects, at least to my knowledge are much less common and would be more challenging for NIH [00:43:00] support.

Dr. Daniel Claa...: Yeah. It's definitely something that I can see. I guess from looking back, what kind of experiences did you take away that you might be able to share with junior investigators or investigators that weren't a part of that just as they apply to their own clinics, their own populations of HD patients that they care for?

Dr. Ira Shoulso...: Yeah. [00:43:30] Well, I'd say first and foremost, you hear this from old folks like me is to each his or her farthest star. If there's something that catches your fancy and commitment, especially in a research collaboration mode, you got to go for it and be prepared for disappointments and setbacks. Of course, other than [00:44:00] this time in February and March, all of us were back doing research, not just on Huntington's disease, but on other neurodegenerative disorders. For me, it was principally Parkinson's disease and the Parkinson Study Group. Anne and Jack were doing a lot of really important research in terms of

describing the circuitry of the basal ganglia and using post-mortem work. So you have to do a lot of things.

[00:44:30] And of course, how many peer reviewed reports have you seen where this is too ambitious? It can't be done. It's scattered. And then the like we didn't know about that time, just kind of head down. So, I think that's an important lesson too that you have to do things that you're capable of doing, but sometimes you have to shoot for your farthest star. [00:45:00] And that's an important lesson. The farthest star is a longterm project. But day-to-day, it's sometimes more difficult to do then, I'm mindful of that.

Dr. Daniel Claa...: Yeah. Well I can't thank you enough for giving us your time. This has been so informative and I've learned so much about this experience. It almost feels like it was there a little bit. [00:45:30] Thanks a lot for joining us today, Ira.

Dr. Ira Shoulso...: You're welcome, Dan.

Kevin Gregory: That concludes this latest episode of the HD Insights Podcast. I want to thank Dr. Claassen for stepping in and facilitating this conversation with Dr. Shoulson. It's extremely interesting and valuable to listen to these two experts discuss one of the seminal events in Huntington's disease research, which has led to the innovative new treatments being brought to clinic today. As I also mentioned, this is [00:46:00] the first of several future episodes that the HD Insights Podcast is putting together 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 are reaching out to HD clinicians, advocates, researchers, and study coordinators who might be listening and interested in sharing their stories and experiences working with diverse populations impacted by HD. For example, [00:46:30] what inequity is 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 and outreach, access to care, willingness to engage and affordability of healthcare.

We'd like to select a few stories and individuals to highlight in an article and future podcast with the intention of learning a greater voice to this experience. If you would like to share a story for consideration, please contact me by email [00:47:00] 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 with the patients, families and research participants. Additional efforts will focus on bringing a spotlight to this group, which in the end is the group in most need of the microphone. Until next time on the HD Insights Podcast, [00:47:30] 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.

Dr. Leon Dure: We hope you enjoyed this edition of the HD Insights Podcast. Remember to subscribe to this podcast to make sure you automatically get the latest episodes to your device. Please rate and review this podcast with your feedback so we can continue providing the [00:48:00] 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 info@hsglimited.org, or by calling our toll free number at +1 800- [00:48:30] 487-7671. Thank you for joining us on the HD Insights Podcast from the Huntington Study Group.