

- Speaker 1: The HD Insights podcast is brought to you by the Huntington Study Group. The Huntington Study Group is a nonprofit research organization dedicated to conducting clinical research in HD and providing critical training on HD to healthcare [00:00:30] professionals. Funding for this podcast is made possible through the generous support of listeners like you and sponsorship grants from organizations like Genentech, Teva Pharmaceuticals, Neurocrine Biosciences, Vaccinex, and Wave Life Sciences.
- Kevin Gregory: Hello and welcome to the HD Insights podcast. Thank you for joining me today as always, I'm Kevin Gregory, director [00:01:00] of education, communication, and outreach at the Huntington Study Group and your host for this program. We've had several guests on the podcast to help provide a sense of connection during the current pandemic and to share strategies that may be helpful for members of the Huntington Disease community.
- Kevin Gregory: Today's episode focuses specifically on stress. Dr. Bruce Compas is a professor of pediatrics and an investigator at Vanderbilt Kennedy Center for Research on Human Development. In November 2019, [00:01:30] Dr. Compas gave a presentation titled, Families Coping with Illness: Implications for Huntington Disease. They covered research into stress, coping, and resilience for families dealing with chronic illnesses. Dr. Compas is a guest I've wanted to have on a podcast ever since, and there may be no better time than now to have him share his insights with you. So without further delay, here's my conversation with Dr. Bruce Compas.
- Kevin Gregory: [00:02:00] Dr. Compas, thank you so much for joining us on this episode of the HD Insights podcast.
- Dr. Bruce Compa...: My pleasure to be here, Kevin.
- Kevin Gregory: Now, one of the things that you talked about back in Sacramento in November at the HSG annual meeting, was the effects of stress, particularly on families facing some form of chronic illness like Huntington's disease. Can you... let's start there? So, everybody experiences [00:02:30] stress, but how is stress different for families that are facing that type of environment, where they're dealing with someone in the family that has this chronic degenerative type of illness?
- Dr. Bruce Compa...: Well, so if we had to cook up the worst toxic brew of stress. So indeed everybody has stress in their lives. It comes in different shapes and sizes. The probably 50 years worth of research, trying to understand how stress affects our mental health and our physical [00:03:00] health, highlights several features that seems to make some kinds of stressors worse than others.
- Dr. Bruce Compa...: One is stress that we can't control. So if there are things that happen to us in our lives, and we don't feel we have control over what caused it and we don't

seem that much control over how to solve it. That is more difficult for us than if there are things that are controllable in our lives. So that's one feature.

Dr. Bruce Compa...: The second is stress that's unpredictable. That we can't tell from one day to the next exactly how it's going to unfold, we can't predict when it's going to [00:03:30] start, we can't predict what's going to stop.

Dr. Bruce Compa...: And the last is interestingly, acute stress is not as difficult for us as chronic stress. So stress that continues, seems unrelenting, goes on day after day. Even if a chronic stress seems to be lower magnitude than an acute stressor, chronic stress is what seems to wear us out.

Dr. Bruce Compa...: And when I think about chronic illnesses that families are faced with, and Huntington's goes right to the top of the list, it fits the bill on all three of those. There's a lot [00:04:00] about Huntington's the patients themselves and their family members can't control. There are features of it that are very hard to predict from one day to the next, one week to the next, one month to the next. And it is chronic. Once it settles in with the family, it's like bad weather coming in from the ocean that just seems to settle in and rain for days and days and days. So those features make Huntington's and other chronic illnesses particularly challenging for families.

Kevin Gregory: So given that then, [00:04:30] in this era of social isolation and restrictions, that call for people to be physically separated. How does that further exacerbate the type of stress that these families may be dealing with?

Dr. Bruce Compa...: Well, so we're always busy trying to understand and be prepared to study the effects of stress of all different types. And our [00:05:00] research team jumped on the COVID pandemic immediately, and we've been gathering information. And it turns out that the COVID-19 stress and the pandemic, hit's on all three of those buttons again. So it came unexpectedly, it feels much of it is uncontrollable, and it's settling in to be a chronic stressor.

Dr. Bruce Compa...: So now what we've done for families with HD is double dosed. So we have that ongoing stress that was there already from Huntington's disease and the challenges that that presents to families. Layered on [00:05:30] top of that are the challenges that all of us are facing with regard to COVID-19 and everything that comes with it. You can then compound that further, if the COVID-19 stress contributes more to social isolation.

Dr. Bruce Compa...: So I mentioned 50 years or more of research showing what is it about stress that so bad for us, which types of stress are worse? Another important line of work that's been done for about 40 to 50 years, is to understand how our connection to other people and conversely being isolated [00:06:00] from other people can be a source of stress or make us vulnerable to other kinds of stress. Loneliness and social isolation are related to problems in mental health and in physical health. The more cut-off we are from people, the more isolated we are from

people, simple questions about do you feel lonely, are all markers of difficulty in mental and physical health. Even as dramatic as social isolation and loneliness are predictors of risk for cardiovascular disease.

Dr. Bruce Compa...: So if I then [00:06:30] think of Huntington's Disease patients and their families, this is now potentially cutting them off from important sources of contact. I remember a patient recently talking about how important it was to stay connected with their church community and being able to go to services on Sunday and that's taken away. And that's a major source of support in your life and the meaning that it provides. It just has to make the stress of Huntington's even worse.

Kevin Gregory: You touched on two things and I recall you making this [00:07:00] point in your presentation. The tangible effects of stress, there's impacts on your physical health, there's impacts on your mental health. And there's this old adage that you always hear people say, "Well, you're so stressed you're going to make yourself sick." That's that's not necessarily true exactly as stated, correct? It's not that stress makes you sick, but it opens you up to other types of impacts? Is that accurate?

Dr. Bruce Compa...: [00:07:30] Exactly, that's absolutely accurate. So a wonderful stress researcher, Dr. Robert Sapolsky at Stanford University and his mentor, Dr. Bruce McEwen at Rockefeller University, have pointed out for through extensive research that stress directly doesn't make you sick, stress makes it more likely that other things will make you sick. And that's where if we follow this example of the COVID-19, this is a virus, and we need to see what we can do in our bodies to ward off that virus. [00:08:00] Some of that has to do with how our immune system functions, and what stress does is in the short term, a very immediate, acute stressor, it can spike and increase our immune system, but if it lasts very long and even a matter of days, then it kicks the other direction and suppresses immunity. So stress makes us vulnerable psychologically and biologically to other things that are likely to make us sick.

Kevin Gregory: What about mental health? What are some of the other effects or tangible effects that [00:08:30] stress can cause to someone's mental health?

Dr. Bruce Compa...: So the two most prevalent mental health problems. If we look, both the United States and worldwide, are depression and anxiety. I often use the example, when I'm trying to help students understand depression and anxiety, I often refer to a Charles Dickens, a Christmas Carol. And when we think about Christmas Past, Christmas Present, and Christmas Future. Depression is Christmas Past. We've become depressed and sad about things [00:09:00] we've lost, damage that's been done, things that have happened to us. And there's a sense of loss and longing and sadness that goes with that. Anxiety on the other hand, is the ghost of Christmas Future. The things that we don't know, things that are yet to be, the things that scare us, the things that keep us up at night with worries. And stress triggers, both of those. It triggers anxiety, because

many stressors involve a sense of loss and damage and they also present threats and the threats of the things that drive anxiety.

Dr. Bruce Compa...: [00:09:30] And just to make it worse, many times the stressors that we're under are both things that we've lost and worries about the future. So depression is a distinct disorder, brings with it a certain set of symptoms. Anxiety, same thing, different disorder has a certain set of symptoms. But they co-occur, or in medical language they're comorbid with each other. So if I suffer from depression, I'm highly likely to struggle with anxiety and vice versa.

Dr. Bruce Compa...: And stress hits on both of those in terms of mental health, [00:10:00] a good question to ask yourself, as you're feeling highly anxious, as you're feeling sad and down and depressed, what is it that's happening or has happened to you that was difficult or challenging? Because that's probably the main trigger that set those off.

Kevin Gregory: From a measurable, scientific perspective, how do our brains respond to stress? And I guess the other question is, especially for HD families who are already [00:10:30] dealing with a neurodegenerative issue, are there longterm, adverse physical changes in the brain just from stress?

Dr. Bruce Compa...: So great question. And boy, has there been a lot of work on that. And work on understanding the role of the brain in managing stress, the effects of stress on the brain has increased exponentially as we've improved our tools to measure how the brain acts. So functional methods to image the brain in real time and what our brains are doing when we're faced [00:11:00] with different kinds of tasks or experiencing different emotions.

Dr. Bruce Compa...: So let's very roughly divide the brain into two sections. One is an emotional part of the brain. It's technically from an evolutionary standpoint, the older part of who we are, and it's the part of the brain that reacts rapidly and automatically to things around us. So our brain is wired to be able to detect things that are threatening, detect things that are arousing emotions, and you don't think yourself into those emotions. [00:11:30] I'm going to click my fingers here they happen automatically. So there's this emotional region of the brain.

Dr. Bruce Compa...: If you look at your brain physically, it's more near the interior portion of the brain. And it's an old brain. It's been part of the mammals for a long, long time. So when we face something that's threatening and scary and frightening, in particular in the brain you have two little almond regions called the amygdala, plural. And they're like the sentries in the brain to tell you something is either really [00:12:00] new and unexpected or frightening and scary. And when the amygdala gets activated to say, "Whoa, that's not good. I'm out walking at night and I heard a noise in the bushes behind me." You don't have to think yourself into being scared and aroused, that happens automatically. Communicates to that executive region of the brain and that's how you then work to either calm yourself down, make a plan of action. When we want to try to think ourselves

out of being anxious, that's where we can think calming thoughts. Think ourselves out of being depressed, where we can try to focus [00:12:30] on positive things, find meaning in situations.

Dr. Bruce Compa...: Stress, affects both of those parts. Stress affects the emotion region of the brain and the executive region of the brain. Unfortunately it affects those two regions in just the way we wouldn't want them to be affected. So what stress does in the emotional region is builds more connections between cells. It amplifies our reactivity. Makes us more hyperreactive, more anxious, more likely to be depressed, that emotion region amps [00:13:00] up. Conversely, what it does in the executive region, the part we need to try to cope with stress, solve problems, manage our emotions, stress doesn't kill brain cells, what it does is decreases the connections between them. So if you could imagine a tree with branches coming out from the tree, the branches are the ends of the neurons in our brain and those branches connect to other neurons. And what stress does is causes those branches to retract, they shrink. And it reduces the connections.

Dr. Bruce Compa...: [00:13:30] So simultaneously stress is taking a complex part of our thinking offline and accentuating that, revving up the emotion part of our brain online. So it's a bad mix. What we know then in addition is that Huntington's affects that executive region of the brain. So with slow, progressive decline in my skills, through things what's called working memory, my ability to keep information in my head and act on it and manipulate it, those skills erode slowly [00:14:00] but surely. And those are the skills that I need to try to manage stress in my life. So stress and Huntington's work together in concert to have adverse effects on those executive regions in the brain.

Kevin Gregory: You also talk in your presentation about the double impact of stress on children. Can you elaborate more on that?

Dr. Bruce Compa...: So it's tough. In particular, when we think about... [00:14:30] We started our research with families with illness, where a family had a mom or a dad who was diagnosed with cancer. And we tried to understand the impact on children and adolescents, boys and girls, in those families. And carried some of those messages forward when we started to work with families with Huntington's.

Dr. Bruce Compa...: So the double piece for Huntington's is that it's sad to watch your parent, lose that person that you've known and loved. They lose parts of their ability to communicate and [00:15:00] be the person that they are. At the same time, you're dealing with your own risk for that disease. So until I have information on my genetic status, I know that I have a 50/50 chance that what I'm seeing is my future. And I really can't imagine a more difficult load then to having to cope with Huntington's Disease in a mom or my dad, at the same time the risk that disease could affect me, and I've got a 50/50 chance that that's what's going to happen.

- Speaker 1: [00:15:30] We'll return to the interview on the HD Insights 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, [00:16:00] 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. Compas, I'd like to switch gears now a little bit. We talked about stress [00:16:30] and the impact and kind of the physical manifestation, I'd like to get a little bit more into coping. You've talked a little bit about some strategies, but what are some of the major guidelines that you see and you like to convey to people in terms of how to deal and cope with stress?
- Dr. Bruce Compa...: So the golden rule of coping turns out to be the serenity prayer. So what I need is the strength [00:17:00] and the skills to control those things in my life that I can control and I need also the ability to accept the things that I can't control and I need to have the wisdom to tell the difference between the two.
- Dr. Bruce Compa...: So a good example of what should I do when I can control it is, I need to be a good problem solver. I need to be able to seek information, learn about a problem, take the information that I've gathered together and make a plan of action. Change things in my life that I can change. And Huntington's often offers [00:17:30] a precious few opportunities for that. But at minimum, we need to be able to make sure we adhere to the regimens that our medical professionals, healthcare professionals lay out for us, that we exercise regularly because that's something I can control and manage and do differently. So do the things that you can control.
- Dr. Bruce Compa...: But then I also need the capacity to say, some of this is out of my control. If I'm a 25 year old and my dad has Huntington's Disease, there's a component of [00:18:00] it where I really need to use acceptance to say, "As much as I would like to stop this from happening to him. And I don't want to see this disease erode this person that I love and care about, it's beyond my control, and I need to come to terms with that."
- Dr. Bruce Compa...: And then I can reappraise it. So reappraisal is trying to find meaning in things, even when they're bad, try to find the silver lining. An example has been through the COVID experience. We're all now in our houses and that's causing stress for a lot of families. [00:18:30] We're living under the same roof, we're getting on each other's nerves. And the simple silver lining is to say, "I never really thought I would have the opportunity at this point in my life to spend this much time with the people that I care about." And it all comes with challenges and difficulties, but the reappraisal piece of it that I can't control, we need to

follow the guidelines and obey social distancing guidelines and rules. Let me see if I can find some meaning in it.

Dr. Bruce Compa...: My daughter and her husband have a new baby. [00:19:00] Their little girl is six months old and they're both trying to work their jobs full time. But as we've talked with them, they've said what a remarkable opportunity it has been. Even with the stress that comes with trying to keep their jobs going and have their new baby home with them, the time they're spending with her is irreplaceable. And had it not been for this crazy experience with social isolation and the quarantine. They wouldn't have gotten that time with her. So we can search for meaning in things that we can't control and try to change [00:19:30] the things we can. Those are truly the fundamental golden rules of coping.

Kevin Gregory: We often on this podcast series we often get into the burden on caregivers and caregiving. Now, there certainly are some amazing benefits to being a caregiver, but what are some of the costs from your perspective in terms of research on stress that we should as an HD community be more in tune [00:20:00] with, do you think?

Dr. Bruce Compa...: Yeah, so, gosh, I can't count how many years ago, but an important study was done to try to understand how stress contributes to depression. And I remember a paper that caught my eye, that the title of it was, The Cost of Caring. And so caring for others, we are social beings, we are connected to other people. I was mentioning that we have parts of our brain that are sort of like sentries and vigilant for seeing sources of threat. We also have [00:20:30] parts of our brain that are truly social. We are hyper-tuned into other people and tuned into people that we love. And the part of us that drives us to take care of people that we love, we would never take that away. We benefit from caring for others. We gain a lot from doing things that are meaningful to others in our lives and that we care for them.

Dr. Bruce Compa...: On the other hand, it can often come with a sense of burden and responsibility, in a couple of ways. One [00:21:00] of the first studies we did with families where a mom or dad had cancer, we wanted to know was that hard for sons and daughters in those families. And we identified that adolescent girls compared to adolescent boys, compared to younger kids, and even compared to older ones seem to be shouldering a huge burden when their moms got sick. And it happened in two ways. They took on many more responsibilities at home than their brothers did. And that practice is not going to surprise a whole lot of folks on the podcast. These girls stepped up. So [00:21:30] it came though with the costs that they were doing these things because they love their moms, they love their families, they were taking on these responsibilities. But they ended up showing much higher rates of anxiety and depression than any of the other groups of young adult, adolescent, or children in those families.

Dr. Bruce Compa...: And we think it happened for two reasons. One, it was beyond what they were developmentally capable of. They weren't prepared as 14 year old and 16 year

old girls to take on that level of responsibility. In addition, it hit at a time, adolescence, [00:22:00] when you're starting to move away from the family, explore and create lots of opportunities and relationships outside your family. You keep your roots and you keep tied to your family, but it's a time to get out into the world. And mom's illness yanked them back in and it cut down their opportunities to be involved in things with their friends, to be involved in things outside the home. So it was both more than they could handle developmentally, but also at a time when they should have been tracking to get involved in other parts of their lives. So [00:22:30] part of the cost of caring is whatever time we spent caring and the benefits that brings there's other things we can't be doing that come with them.

Dr. Bruce Compa...: And then another piece I would add to that is that often caregiving in a chronic illness can feel pretty relentless, just there's no breaks. There's no time off and a powerful, important resource that we need to provide to families of HD patients is the opportunity for respite, for resources, where if I'm a [00:23:00] young adult or an adolescent son or daughter of a parent with Huntington's, or a spouse, I need my time to refresh, recuperate, recharge, and we need to provide resources to families to do that to get that respite.

Kevin Gregory: You also talk about resilience when it comes to coping with stress. Is there a way for people to train themselves to be more resilient when it comes to that?

Dr. Bruce Compa...: Well, so yeah. So boy, there's a lot [00:23:30] written about resilience. It's a fabulous concept. And what it turns out is to say someone's resilient is to find someone who's been exposed to high levels of stress, and yet they don't seem to pay the price. They don't seem to develop significant mental health problems or physical elements. And that's the marker, that person is resilient. The key is how did they get there? And that just brings us right back around to what are the skills they use to cope with that stress and what are the relationships they had in their lives to provide them the [00:24:00] support that they needed to become resilient.

Dr. Bruce Compa...: So the keys to resilience are those golden rules about coping and then sustaining important relationships in our lives. Just because it's fresh in my mind, it was part of the work we do with Dr. Daniel Clawson here at Vanderbilt, in the Center of Excellence for Huntington's Disease. We work on a study with families. And one of the things we do is video record patient's, parents and their adolescent and young adult children talking [00:24:30] about Huntington's Disease. And then we code those conversations and we code emotions and behaviors in the patient and in their adolescent and young adult children.

Dr. Bruce Compa...: And we just analyzed some data to be able to share with Dr. Clawson over the weekend, in fact. And one of the findings was that the number of the CAG repeats, and I'm thinking that most of the audience knows those repeats are the things that indicate the genetic risk you have for [00:25:00] Huntington's, combined with age produces something called the CAP score. So it's the product

of how many repeats you have times how old you are. And that score, as that goes up, that means your disease is probably more advanced. And we took that score and our people who were naively coding these videos, not knowing data about the patient's disease status, the higher the CAG repeat, the more severe the disease, the poorer that patient's communication was with their [00:25:30] son or daughter. And powerful association. So as the disease progresses, those patients were less able to be responsive and listening, communicating clearly, providing a sense of support.

Dr. Bruce Compa...: A real twist for resilience was as that score got higher for a patient indicating more severity, it had the opposite effect in their sons and daughters. That the more severe the disease, the more we saw attentive listening by their sons and daughters, the more we saw them being warm and supportive [00:26:00] and providing supporting good communication to their parents. And as soon as I saw that, I thought of the concept of resilience. That these folks, these sons and daughters were stepping up and working at that communication. And we've controlled for a bunch of other factors, how old was the son or daughter, other things that might feed into that. And it just said they are rallying to the cause with the little footnote that we want to make sure we support them as they do that. Because that says, they're really in there taking care of their parents, working hard to communicate. [00:26:30] But that to me was just such a great example, that as things got harder and harder for the patient, we saw this true stepping up to the plate and being resilient in their sons and daughters. I was so impressed by that.

Kevin Gregory: That's really amazing. Can you talk a little bit more about that research that you're doing, that particular study, is that something that's ongoing? Are there next steps or are you close to wrapping that up?

Kevin Gregory: Oh, we're in the middle of the... Well, I don't even know if we're in [00:27:00] the middle of the stream. So we've been at it for a while, excuse me. And we're making lots of progress, but we're trying to understand a number of different pieces of the puzzle. So in Huntington's we know there's cognitive decline. So in our study, we're doing as best we can to measure multiple facets of cognition and executive function and complex thinking skills, both in patients and their offspring and their spouses. And then we're looking at psychological factors, [00:27:30] are they depressed? Are they anxious? How are they coping with stress? And then we do these direct observations, looking at the quality of their communication. And we weave all those pieces together.

Kevin Gregory: And one of the things we've put sort of in the middle of all that is that communication between parents and kids, between spouses and caregivers, and offspring kids in those families. And what we're finding is communication, our ability to be able to talk and support one another, and listen to each other, be responsive and helpful [00:28:00] to each other, that's affected by the cognitive function of the patient, the cognitive function of the sons and the daughters. Then the communication's related to their anxiety and depression.

So all of those pieces of the puzzle, psychological functioning, neurocognitive functioning, and the ability to communicate and relate to each other were all in the mix.

Kevin Gregory: What we hope to take from it as we continue to enroll more families and get more data, is we've done this before [00:28:30] with other groups of families... We'll now know which families seem to be doing well, the resilient ones, which families seem to be struggling, the vulnerable ones. And we'll be able to identify ways to improve cognitive function, coping skills and communication in those vulnerable families to help them become more resilient. So that's the longterm goal, but we didn't want to dive in and try to help HD families, and so we basically let them teach us by observing, by asking lots of questions, [00:29:00] and helping to differentiate families who seem to be again, being resilient as opposed to those who are more vulnerable. So somewhere down the road, we know we're going to have programs that we'll develop and test and then be able to share and disseminate with HD patients and their families.

Kevin Gregory: Well, that's fantastic research that I know a lot of us will look forward to continue to follow. Dr. Compas, I did want to, it's a good segue into your background. So I'm very curious. What was your motivation [00:29:30] for getting into medicine and specifically, how did you find your way into this line of research?

Dr. Bruce Compa...: So some things in life are planful and some things in life are serendipitous, and I'd have to give a strong vote to serendipity on most of the work that I do now, that I've done for many years. So I was drawn to psychology when I was... I started in college as an engineering major and thought that's what I was going to do. The time at which I was in school [00:30:00] there was a poll to say, "Well, what are you doing for the welfare of your fellow people? How are you contributing to people's lives?" And engineers contribute in incredible ways. But my goal was to do something more direct. So I was drawn into psychology and then eventually into clinical psychology, with the motivation of doing things that would be helpful and beneficial to people who are struggling with depression and anxiety.

Dr. Bruce Compa...: And I was studying families around mental health problems. At the time I was at the University of Vermont and sort of a new eager beaver, young assistant professor [00:30:30] and someone came to meet with me and she was working... she has graduated from college, her husband had started medical school and she was working as an office assistant in a cancer clinic at the University of Vermont. And she asked if she could volunteer in our lab to work on things. And I said, "Yeah, we study people who are faced with stress." And she kind of rolled her eyes and said, "You want to see stress. You got to come over to this clinic and see these families who are faced with cancer." So that was my entree into studying chronic illnesses, medical illnesses, physical [00:31:00] illnesses, and how they generate stress.

- Dr. Bruce Compa...: So it started then with families where a mom or dad suffers from cancer, that then led to another very high risk group, which was families in which a mom or dad suffers from depression. I did all that work started that work in Vermont. And Vermont is a lovely place, it's a beautiful place, it's all those gorgeous scenes you've seen in the fall with the trees turning color and the beautiful mountains and skiing in the winter, but it's a hard place to get work done because there's hardly [00:31:30] anybody that lives there. Total population in Vermont is 500,000.
- Dr. Bruce Compa...: So I was able to take a position at Vanderbilt University. And then that really changed my career in dramatic ways to then be able to work, not only with families where parents struggled with problems, but able to then work with families with children who are ill. So since coming to Vanderbilt, we've worked with families where children are diagnosed with cancer, specific studies with children with brain tumors, children with sickle cell disease, congenital heart disease, hemophilia, [00:32:00] a whole host of experiences. And what's carried me through all of that and has been the motivator is to first understand how do these illnesses affect families, how do they try to cope with it, and then not just to observe... and a lot of research has done to observe and document problems. And doesn't take that next step to say, how are we going to fix that problem?
- Dr. Bruce Compa...: So our group, my colleagues and I have been absolutely committed to understanding a problem first, in order to [00:32:30] then turn that into ways to try to help families. And probably our greatest success so far is the program to help families where a mom or dad suffers from depression, a serious mental health problem, could we build resilience in children in those families? And we have good success by working with parents to help build strong parenting skills, to be there for their children, even if they're struggling with depression and teach kids how to cope with the stress of what mom or dad's depression does to mom or dad and what it does to the family.
- Dr. Bruce Compa...: [00:33:00] So that then put me in a position to be sort of open to things. I was working with a colleague here in pediatric neurology who worked with kids, with congenital heart disease and sickle cell disease. And she mentioned in passing that a colleague of hers, Dr. Clawson, and asked her, "Do you know anybody who studies stress and families and helps families to cope with that? Because we've got a lot of that and Huntington's." And Laurie said, "Yeah, you should talk to this guy." And [00:33:30] to paraphrase some old film, a Tom cruise movie from long ago, Daniel and his team had me at hello. There was something remarkably compelling about what families are faced with in Huntington's, the stories that we see of resilience and the stories we see of vulnerability, where we want to be able to strengthen that.
- Dr. Bruce Compa...: So Huntington's went from... I said this at the meeting in November, Huntington's went from not on the list of things we studied, on the list of things we study, [00:34:00] top of the list of things we study. Most complicated, most

challenging, but I see it as potentially the most rewarding thing we're going to do in our work.

Kevin Gregory: Well, Dr. Compas, we're certainly thrilled to have you in the mix and helping out with any research in this area on HD and really appreciate your dedication and just really fortunate that that connection came to be. Especially now in this time [00:34:30] like you said, there's a lot of additional factors that are going to be impacting people and how they deal with stress. And it was fantastic having you on and being able to chat with you. So I just want to thank you so much for your time today.

Dr. Bruce Compa...: And thank you. I appreciate that comment about... that hopefully we have something to bring to the HD community, but I'll tell you it's a two way street Kevin, and I think I and my team have benefited just as much from [00:35:00] the opportunity to work with these families, as we hope our work can benefit these families. So it's really an important part of work, an important part of life right now. And we're glad to be a part of it.

Kevin Gregory: I hope you enjoyed my conversation with Dr. Compas. Stress impacts us all, especially in these uncharted times with the COVID-19 pandemic and varying levels of social distancing in place. That stress can be magnified for HD families and caregivers, [00:35:30] which makes the research and science behind it all the more important to understand. Again, my thanks to Dr. Bruce Compas for sharing his insights on stress, coping, and resilience.

Kevin Gregory: Before wrapping up this episode, I want to reach out to our audience about a project that HD Insights in collaboration with colleagues at Vanderbilt 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, [00:36:00] education, and community connection. As part of this project, we're seeking stories from the HD scientific community that can help bring this important topic to life. This is a call out to clinicians, advocates, researchers, and study coordinators who might be interested in sharing their stories and experiences working with diverse populations impacted by HD.

Kevin Gregory: For example, what does diversity mean to you in your HD practice? What unique challenges have you or the community [00:36:30] you serve faced, in particular when it comes to diversity, health inequities, or related issues? We would like to select a few stories and individuals to highlight in an article and future podcast with the intention of lending a greater voice to this experience.

Kevin Gregory: If you'd like to share a story for consideration, please contact me by email that's kevin.gregory@hsglimited.org. While this first call to action [00:37:00] focuses on the researcher and clinician point of view, we recognize the importance of other perspectives to this overall conversation. Most notably, those of 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.

Kevin Gregory: So 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, [00:37:30] and we look forward to bringing you our next episode.

Speaker 1: We hope you enjoyed this edition of the HD Insights podcast. Remember to subscribe to this podcast, to make sure you automatically get the latest episodes to your device. Please rate and review this podcast 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 [00:38:00] 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 I-N-F-O@hsglimited.org, or by calling our toll free number at 1-800-487-7671. Thank you for joining us on the HD [00:38:30] Insights podcast from the Huntington Study Group.