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Kevin Gregory: Hello and welcome to this latest edition of the HD insights podcast. I'm Kevin Gregory, director of education, communications and outreach with the Huntington study group. On this episode of the HD insights podcast, we spoke with Ken Serbin. Now, many of you may not recognize Ken Serbin by his legal name, but you may be more familiar with his work under his pseudonym Gene Veritas. I met with Ken in Sacramento recently at our annual meeting HSG 2019 and we covered a number of topics including how he came up with the pseudonym Gene Veritas, how he decided to start his blog and what prompted him to kind of finally come public about who he was and who this Gene Veritas had been writing this blog all along. So please sit back, relax and enjoy this episode of the HD insights podcast.

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Kevin Gregory: Ken, thank you for joining us on the HD insights podcast. It's a pleasure to be speaking with you here as part of HSG 2019 in Sacramento.

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Ken Serbin: Well, thank you Kevin for the invitation to be a part of this broadcast and it's an honor to attend really what's going to be my first HSG conference. Many years ago there was one in San Diego that I kind of partially attended, but that was kind of before these things were more open to the HD families. So it really is an honor to be here today talking to you and supporting our community.

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Kevin Gregory: Our pleasure, and that's actually a good place for us to start. So I know you're going to be, you know, participating in the, in the family day session, you know, what about the, you know, the HSG meeting kind of drew you to, to, you know, to want to come and to be part of that.

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Ken Serbin: Well, I think the fact that the HSG is compared to, let's say HDSA is not as well known in the HD community. I think as a blogger and as someone who, if I'm lucky, will get to someday write a history of the Huntington's movement because I am a professional historian. That's my job, my day job as it were. I think that it's really important to get the word out there about what HSG is doing and to realize that it is an important part of the history of the search for Huntington's therapies. I also think that HSG is something that I just haven't had time to research as a blogger.

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Ken Serbin: As you know, and people in the community, you know, there are so many strands to the HD story. It's getting to be a bigger story, a more complex story. HSG is one series of strands in that story, which I just haven't had time to look at and so, but it's such a critical part of the story that I really did want to come here and learn

[00:04:30] more about the HSG, which is why I interviewed Dr Andrew Fagan and I hope to on family day also interview Dr Ira Charleson about the history of the HSG.

Kevin Gregory: Two very good people to talk to. Absolutely let's talk a little bit about your role as a blogger. What have you found to be, you know, the most interesting thing about that? Like when you got into to starting your blog, where has it taken you that maybe you didn't expect to starting out?

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Ken Serbin: That's a great question. One that I haven't thought a lot about, but I think the blog started as a way for me to start getting the word out there about HD. But that's kind of a very strange statement that I'm making because for many years I did the blog using a pseudonym. It was, it's kind of a contradiction in terms, I'm trying to get the word out there about HD, but at the same time, I'm not even revealing who I am. I began the blog using the pseudonym Gene Veritas, which means the truth and my genes. Gene of course, means genes and Veritas is the Latin word for truth. Veritas also happens to be part of the motto of Yale university, which I was lucky to attend as an undergraduate Lux and Veritas, light and truth. So whenever I used the name gene Veritas, I'm reminded of my Alma mater, which I love.

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Ken Serbin: Like everybody loves their Alma mater. But I mainly chose it because of that, that aspect of it being the truth in my genes. And so I was in for many years what I call the lonely, the terrible and lonely HD closet like so many of us in this community have been, and so the blog began as a way for me to I think, start expressing myself about my fears about HD. My mother was, had declined dramatically at that point. I started the blog in January of 2005 my mother died just a year after that in February of 2006 in fact, the first year I didn't write a lot in the blog. Actually the first couple of years because my mother died and it was very difficult for me to do anything regarding Huntington's disease and it was like as I described in one of my articles looking into to a genetic mirror, looking at my mom and seeing what could be me because I know I knew that I had inherited the genetic defect from my mother.

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Ken Serbin: The blog was a way, it was a catharsis. It was a way for me to get those feelings out there, share those feelings. I started making friendships through the blog and people started making comments on the blog. There were people in the HD community who were getting emails from the blog. It was, it's funny, in the early years I sent it out over Yahoo and Yahoo would allow you to send out just X number of emails per hour or something like that. So I actually became the pioneer in the San Diego chapter of the Huntington's disease society of America for using an email service. We first used tele contact, and then later we moved to constant contact. But that all happened because I had to find a way to send out my blog without it being marked as spam and but out it also being something that I had to spend several hours just to send out the email.

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Ken Serbin: I built up the email list over the years. And so I've made friendships through email. I guess that's one of, and through the blog, I guess that's one of the unexpected things that occurred, is that I would build some very strong relationships through

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[00:09:30] the blog. I think that I didn't anticipate with the blog that I'd be covering such a wide variety of things. We were talking again about the many strands of the HD story. I ended up writing about so many different topics in the blog, very sensitive issues, things like abortion and the fact that people like my wife and I did had our daughter tested in the womb and luckily she tested negative in the womb and it was a very difficult moment for us of course. But that led me to think about what other people are doing with respect to family planning.

Ken Serbin: [00:10:00] Luckily today there's preimplantation genetic diagnosis, which is still has risks and still for some people that's ethically may be questionable. I mean there's a lot of debate about these kinds of things. As I'd like to say, we in the HD community, we have been moral pioneers. That's a phrase I borrowed from someone else. But we're moral pioneers because we're having to deal with these kinds of issues. Things like genetic testing, we were one of the first wave of people to go through genetic testing in the 90s my mom in 95 was genetically tested for HD. She certainly [00:11:00] was one of the most, one of the first people you know to be tested for for HD and just two years after the test was developed in '93 and I was tested in '99 still in that kind of first wave of testing where the 100% genetic test was available.

Ken Serbin: [00:11:30] And so dealing in the blog with just a variety of issues. There was one article I wrote that had a huge impact about an HD man in West Virginia who was arrested by the police, detained by the police, and he was a, because of his involuntary movements, they thought he was drunk, they thought he was on drugs, they thought he was resisting arrest and the poor guy was being held down and the officers are just have their knees on his back. Someone caught this on video, it went viral and I wrote about it in my blog and the man is saying, I can't breathe. I can't breathe and can hear in the audio of the video. He's saying I can't breathe. They're very insensitively ... it's really interesting because in the black lives matter movement, you know you've got these horrible situations where people are, are, are killed, you know, by officers who are using excessive force and are using some kind of hold or whatever on people.

[00:12:30] Ken Serbin: Here's an example of a guy who, you know, it was not an instance of racism, but an instance of a misunderstanding about a genetic disease and just one reason why we need to make HD more known to avoid situations like this. Another thing that blog led me into in my advocacy, led me into was precisely to interview a policeman, a Sheriff's officer in San Diego about a program called take me home, [00:13:00] which many departments around the country have this program whereby they have a database of individuals who have Alzheimer's or Huntington's or different kinds of conditions. If these people are seeing wandering or the, if they're gone missing, the police then know to go out and get them. So there's a protocol for helping these people. The blog took me into just many different directions and the science also, it became a way for me to try to translate the science into [00:13:30] understandable language.

Ken Serbin: I think I know that's one of the goals now of the HSG cause Dr Fagan was telling me

[00:14:00] about that in my interview that I did with him today that there there's so much out there with the science and so one of my, one of my goals has been to try to really get that into understandable language so that the community can ... first of all, grasp what the scientists are doing and second of all, have hope. Have hope because if you don't talk about what the scientists are doing, where's the hope going to come from?

Narrator: We'll return to the interview on the HD insights podcast in a moment. We hope that you're enjoying this episode as a nonprofit organization. The Huntington study group relies on the generous support from the community and listeners like you to continue bringing you in depth content on HD, like this podcast series. If you like what you're hearing and are interested in supporting HD insights through a grant or donation, please contact us through our email address [info@hsglimited.org](mailto:info@hsglimited.org) or by calling toll free at 1-(800)-487-7671 we greatly appreciate your support. Now back to our episode.

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Kevin Gregory: you talked about the blog being you know, cathartic for you and the fact that you know, initially you started under the Jean Veritas student pseudonym. What was it that prompted you to reveal your identity as Gene Veritas? You know, Ken Serbin is Gene Veritas.

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Ken Serbin: A number of factors. I had discussed for a long time with my wife Regina who's from Brazil by the way. We met in Brazil in 1991 when I was down there doing my PhD research. We met on a blind date on July 5th of 1991 and we've been together since. We got married then in 1992. Virginia has been through all the ups and downs with me over the years regarding a Huntington's disease. She was there when we found out that my mom had been diagnosed. She was there for the genetic testing of course, obviously there for the birth of our daughter Bianca.

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Ken Serbin: We went through all of that together so I had many conversations with her and some of my closest friends and confidants regarding, you know, how should I go public? Should I go public? What are the consequences? That's a conversation that I had over a number of years and the moment came in 2012 hard to believe that's seven years ago this month in fact, it was November of 2012 that I wrote an article in the Chronicle of higher education and that article is still online. People can look it up. It's called Racing Against the Genetic Clock. In that article I went, used my byline, my academic byline, Kenneth P Serbin and the the Chronicle of Higher Education. It's a fairly well known publication, certainly in academia and from time to time reports important news that gets into the mainstream media also. It was quite an impressive vehicle for me to be able to reveal my HD status and I decided to do it because I felt that I was a full professor at my university.

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Ken Serbin: I felt I had greater job security. I felt that with the passage of Obamacare and the end of the prohibition on insurers blocking people from coverage because of preexisting conditions. That also was a huge relief for me because another thing that I had hid all of those years was from my very own health plan, my Huntington

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[00:18:30] status. When you, when you look back on it, it's really, really absurd that I had to go through that and that so many people have had to go through that. The passage of Obamacare, and I will defend virtually to the death this notion of protecting people with preexisting conditions. I mean, and I know the HDSA also defends that, that notion that we need to protect people with preexisting conditions. Not just HD, but any, any condition. I'm willing to debate anybody anytime at any stage on that issue.

[00:19:00] Ken Serbin: I know some people got irritated when I wrote a first wrote a blog article on that. It, the title was "Goodbye Preexisting Conditions." That was before I even had gone public. But, and several people unsubscribed from my blog and they didn't say why, but I could figure out why they probably were upset. People need to understand that this is not a political issue. Right. In the end, we are all susceptible to Huntington's disease for publicans Democrats, socialists, communists, gay, you know, lesbian, black, white, Chinese. I mean, anybody can get Huntington's disease, you know, it's non-discriminatory and in that respect, and so this is something that, for me, it's about all of humanity. I hope that we get to a society where we don't have to worry anymore about these kinds of issues because I know a lot of people are still worried about health coverage and so on and so forth.

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Ken Serbin: There's still a lot of issues. But so the passage of that aspect of Obamacare was very important. Also the passage of the genetic information nondiscrimination act that also played a role. That, it's not clear up to this point to how critical that act has been, but the very fact that it exists and that there was, that there's a law that, that people could appeal to with that name also helped give me courage to go out to become, to go public. Also I think that going back to that original comment I made about the blog, it's kind of a contradiction that I'm trying to get publicity for Huntington's disease, but yet I'm not even using my real name. Like one of our leaders in our local HD community in San Diego said one time at a support group meeting, he said, "If we won't tell our own stories, who, why should anybody care about us?"

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[00:21:30] Ken Serbin: That's really true. I mean that's, I reflected on that. That was one thing that also motivated me. That yes, I really do need to be fully public. We were scared. We were scared because I did, I actually consulted an attorney before I went public before I wrote this article and I made sure I had all my bases covered because I wanted to make sure that if I were discriminated against a legal action could be, take place. I have to say that the reaction from my employer, from my fellow faculty members and other employees at the university was very positive.

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Kevin Gregory: I was going to ask you that. What was the, you know, did you experience any of that or was there any kind of adverse reaction that you know you weren't expecting there?

Ken Serbin: I have not had any adverse reactions to this day. I mean there may be people out

[00:22:30] there saying things, thinking things. I mean I think a lot of HD people wonder about their symptoms and I think maybe more than we HD people. It's the people around us who are probably wondering about our symptoms, but I've never talked to anybody at work about that or it's only in support group do I talk about those kinds of things. But I'm sure that, I sometimes I'm worried now because I'm thinking, well, like if I slip in my use of a word or if I am going to be stumble walking down the hallway or something like that, I sometimes think, "Oh my gosh, am I getting HD?" Then I'm thinking maybe someone else's thinking, "Oh yeah, you know, maybe it's time for him to go on early retirement or something like that." But thank God I'm up to this point considered still presymptomatic.

Ken Serbin: I don't think I've demonstrated any classic symptoms of HD, but still there could be those adverse reactions. But in terms of people discriminating against me, no. Now in terms of my career as an academic, who knows? I mean at this point I don't anticipate moving from San Diego. I'm going to be 60 years old. I'm hoping to finish out my career at the University of San Diego. I'm a, I'm in a profession where I'm very, very fortunate. I recognize being a college professor is a super privileged position because I get to work with young people. I, my mind is constantly stimulated by my academic work, which is great for keeping the mind active. I know there was a study on Alzheimer's patients and people working in academia had a lower incidence of Alzheimer's probably because of their active minds. I'm very fortunate that academia is one of the few professions left where you can make a career at a single institution.

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Ken Serbin: It's like people used to work the entire career at, you know, Republic Steel or GM or something like that, you know. But that doesn't happen anymore. We're all in a very mobile-

Kevin Gregory: It's gotten very rare. Yeah.

Ken Serbin: Very, very rare. So I'm in my 27th year at the university of San Diego and I hope to spend at least another 10 years there working and teaching. I hope to retire before I get HD. It's been very supportive and, but you never know though when somebody out there might be ... so I'm privileged in the sense that I have tenure and I have a relatively amicable work environment. You know, it's not like working at Amazon, you know, or working at a some kind of high pressure bank or law firm or something like that.

Kevin Gregory: Yeah.

Ken Serbin: You know.

Kevin Gregory: Well I imagine too, when, when colleagues of yours first found out, I imagine most of them probably didn't know what Huntington's disease was. So it was an opportunity I assume for them to educate themselves on it and, and help you spread the word.

Ken Serbin: That's a good point. Yes, that's absolutely one of the reasons I wanted to write that article is to raise the profile of HD. I think some people had maybe a vague notion of it, the older people might've heard about Woody Guthrie, but I think yes, the younger people probably don't have as much knowledge of Huntington's and so clearly ... and people, even if they've heard about HD, they really don't know what it's about. So that did provide me with an opportunity to educate people.

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Kevin Gregory: Kind of along those lines, do you find when you're interacting with people in the public, do more people know you as Gene Veritas or as Ken? Like, where is the, is it 50/50 or what would you say is kind of the split is as far as how people recognize you?

Ken Serbin: Yeah. Great, great question. Yeah, well I think in the HD community, I'm definitely known as Gene Veritas. In fact here today a young person came up to me at, I was walking by, I think it when I was walking by to go meet you, she saw me, she was registering there getting in line and she recognized me from the blog and she said, "Oh yeah, I follow you on Facebook." Because I hadn't met her before so, and she said, "You're Gene, right?" So yes, I think I am known more in the HD community as Gene Veritas. I'm happy with that. I'm fine with that. I now put in my blog when I have a photo credit or something like that, I just put in, you know, photo by Gene Veritas, AKA Kenneth B Serbin.

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Ken Serbin: So I use kind of like both interchangeably. I sign my blog, now I used to sign it on the email, just Jean Veritas, but now I also put, you know.

Kevin Gregory: Well I know, I had to make the badges for this year's events. We did exactly that for you. So people will make the connection.

Ken Serbin: Thank you. Thank you, thank you for doing that.

Kevin Gregory: I, you know, personally I think it's, I always thought it was a clever name and I was, I really like the story now, now that I know that that ties into your time at your Alma mater at Yale, that gives it even more meaning. I think it's, it's a really good beacon for people, you know, that are kind of dealing with, you know, going into, you know, do I get tested, am I at risk? You know, am I, you know, pre-symptomatic, do I have symptoms? I think you've been beacon for the community.

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Ken Serbin: Well, thanks for saying that, Kevin, because they're in the beginning, there was some doubt. I mean, I think one of my confidants thought, well, what does that really mean and what isn't that kind of goofy and awkward that pseudonym. It is an unusual name. But now it actually, it really is a trademark, you know? It does represent those things. You know, it's really not about me. That's the cool thing about a pseudonym and for the HD community, it's really not about me. It's really about the community and what role facing. So thanks for helping me realize that

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that's what it's about.

Kevin Gregory: Absolutely. I do, this has been a great conversation. I do want to ask you one question that I typically ask, you know, anybody on the podcast and, and your perspective is different. I've spoken with, primarily with researchers, so I have their perspective. But from your perspective as someone in the community, in your time learning about Huntington's disease and doing the blog, describe for me your reaction to the evolution in treatments and care, you know, available for people and where you see things going in the near future.

Ken Serbin: Well, I think that in in line with what a lot of the scientists feel, I'm optimistic that there will be Huntington's disease treatments slash therapies of some sort coming in the next five, 10 to 20 years. I think that that's going to happen. I look back at the time when my mom was diagnosed and when my wife and I first started attending support group, I was absolutely forlorn about the fact that there was nothing, there was no hope.

Ken Serbin: There was HDSA, but with not much of a research profile at that time. There was the HDF, Hereditary Disease Foundation, which frankly I didn't know much about at the time. It was not an organization that really publicized greatly what it was doing. Then came along CHDI and I started attending the CHDI conferences and once again, I'm fortunate to be in good circumstances. I'm in San Diego where Ionis pharmaceuticals is located. When I first heard in 2008 that Ionis was partnering with CHDI to do a form of gene silencing, that really, really made me start to feel some hope because HD in the early, for me, the early going, which was the mid to late '90s, the idea of actually altering the genetic workings of this disease, it seemed to science fiction, right?

Ken Serbin: It really did seem like science fiction. Some people did say like, "Oh yeah, maybe in 20 years that'll come up." In fact it is turning out to be about 20 years from the late '90s to the gross trial now. It's coming up to be about 20 years. It's further along I think, than I could have imagined. I think that there are other clinical trials, not just in gene silencing but in other types of therapies that are very helpful. I think that I tell people that you don't, you don't have to fear genetic testing as much as you used to, don't have to fear fear of this disease. Now Charles Sabeen said this at one of the CHDI meetings, you know, we can fear this disease less now because of what the scientists are doing.

Ken Serbin: I agree with Charles on that. On that point. They're really making an effort. We're really making strides. Again, there's no guarantee, there's no guarantee. I do know in the Alzheimer's community that there have been hundreds of clinical trials. None of them have worked in Parkinson's there's been, I don't know what the count is, but there's been many clinical trials in Parkinson's also. So let's hope that HD with its unique, you know, purely genetic cause that this, these treatments will, potential treatments will work. But again, we have to be both optimistic and realistic at the same time.

Kevin Gregory: Well, I think you bring both of those to the field, to families and you know, we appreciate you working on the blog. We look forward to many, many years of continuing to read it as these treatments evolve even further. But in the meantime, Ken or Gene Veritas, thank you again for joining us for the HD Insights podcast.

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Ken Serbin: Thank you very much again Kevin. Again, a pleasure and an honor to be here in Sacramento and you have a wonderful radio voice. You're the perfect person to host this podcast.

Kevin Gregory: Oh well I appreciate it and we hope to keep this going as well. So thank you very much.

Kevin Gregory: [00:35:00] We hope you enjoyed this episode of the HD insights podcast. I certainly enjoyed sitting down with Ken in person and learning more about who he was and how he came to write his blog and the tough decision about coming forward and revealing who Gene Veritas really was. Please stay tuned for the next episode of the HD Insights podcast in a couple of weeks. Until then, thank you for joining us.

Narrator: [00:35:30] 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 content, you can do so by becoming an ongoing sponsor or through a tax deductible donation. To do so, please email us@infoathsglimited.org that's I-N-F-O @hsglimited.org. Or by calling our toll free number at (800) 487-7671 thank you for joining us on the HD Insights podcast from the Huntington study group.

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