MVI 2996

NULL

MVI 2997

NULL

MVI 2998

Danton- On 1080p quality

Liz- Naomi can you say hello

Naomi- Hello, Hello.

(liz laughter)

MVI 2999

Liz- Naomi. Testing 1, 2, 3

Naomi- Testing 1, 2, 3.

(liz laughter)

MVI 3000

Liz- 3, 2, 1

Danton- Hi.

Naomi- Hi

Danton- Uh. Could you, in your own words, explain what Huntington's Disease is?

Naomi-In my own words, Huntington's Disease is a severe Neurological disorder that normally generally affects people 30-50, in my experience anyway.

Danton-Ok. And what's your experience with Huntington's Disease. How are you connected to it?

Naomi- My late husband passed away from it in March 2007. My son is also at risk for it.

Danton- Okay. This is not going to be on the video, but can you just move the stuff from underneath, so in case you kick it? You can keep recording liz. There we go.

Danton-Um okay. So. This story is about relationship with people with Huntington's. So, um, when in your, uh, relationship with your husband, did you find out?

Naomi- Um. Actually it was almost right after we meet. It was about 2 years after we met, I think. Uh, He was 31 when I meet him. And uh, I'm sorry. He was 31 when I met him, and, uh, my son was, I don't know. My memory was 9 months, but I think it was older than that. It was probably-He was probably closer to 15 months. Something like that. Uh. Um. Of course he was my husband. He had been experiencing just really minor symptoms of what I thought was a ganglion cyst. And uh (clears throat) turned out to be Huntington's. Um. Uh. His mother had it. Um. I-I don't think I was completely prepared for it because I had no idea what the risk factors were. Um. I guess I thought they were really remote. So…

Danton- And- So before you meet him, had you ever heard anything about Huntington's Disease.

Naomi- Nothin' (shakes head no sadly) Never. Never. I didn't know about it. Um. I did more research after we found out and uh. But that was, my goodness. I mean it's over 25 years now, so there wasn't a whole lot of information about Huntington's. Um. Of course there is a lot more now. (Sniffles) Of course you know. You are doing the interviews, so you know that the gene has been identified and so we have this mad dash to search for the cure…hopefully. And um. (Inhales deeply) That's what I know about Huntington's and that's my relationship to it. Uh. I have a lot of extended family members that are either at risk, have been diagnosed, or have the disease.

Danton- Um. Okay. So when you-when you and your husband found out, how did that affect the relationship? What strain did that put on the relationship?

Naomi- Um. Uh. It-

Danton- If any.

Naomi- We were devastated.

Danton- I'm sorry could you re-repeat the question?

Naomi-Yes

Danton- So what strain did it put on the relationship?

Naomi- It put a strain on our relationship. Um. As far as the immediate response or reaction to the diagnosis was, I'm sure, disbelief. Although, um, in my opinion, I think the signs were obvious. There was a lot of symptoms that I had overlooked. I just thought that was his natural ….uh, way. Um. Uh. The strain was that my immediate concern was my son. Uh. Because he was so little, and I knew right then and there that he was at risk. Um. The doctor was not very good about tellin' us the news. In fact, he walked into the room and said, "he has it" and walked out. Um. And that was probably more devastating that even hearing the news. Was kinda like the candor in which the doctor delivered the punch. Um.

Danton- uh-huh.

Naomi- Uh. From there um my husband was first in denial um and then uh. Behavior was a little off a lot. Um. (coughs) he used to send all these little armies out to fight all these battles. You know, he had his thing about keeping his immune system up. And so I really think he believed he could you know get to it that way. And um as we know now, it's a genetic disorder. it has nothing to do with really the immune, you know, not in a cold sorta way. Um so and then further um tried to go to—we had— they did have support groups back then, but at the time (cough) they were really really negative and not really in my opinion, not really good to even, you know it was just kinda like- I dunno, it felt like we were digging our own grave at that time. There wasn't really a whole lot of positive feedback. So that strain continued until we split up. Although we were always amicable or friendly. And my son would go to see him. I pretty much insisted on that. Uh. But I don't think in hindsight that was a bad thing. I think it was a good thing as far as guilt associated with things. I think it was a positive thing. Um.

Danton- Uh. Okay. We're gonna take a pause just for a second. And you have uh some eye makeup. Liz can help you with it.

Naomi- where?

Danton- Um Just on the one side Liz.

Liz-Yeah, I think you just got it.

Danton- You got most of it. Just a little bit on that side. It's okay for— now you are rubbing it in too much. Just stop. (Liz comes in to help giggles.) So liz, for the uh- for our interviews maybe we have a box of tissues or something like that ready—

Liz- Yeah that's a good idea.

Danton- … so that people—she's good. (Liz exits as Naomi laughs) Its okay as its through a questions, I just didn't want it to stay there--.

Naomi- no problem.

Danton- …for every question. Uh. (Pause) And just try to keep repeating the question. I know you its hard as you forget it as you're going through, but that's fine. Uh. So what is your—what is your hope for the future of huntington's?

Naomi- My hope for the future of huntington's is that- this is obvious because you're doing this interview- is that there is a cure. Um. Uh. This is gonna sound really crazy but just e-eradicate it completely. (cough) I think it's one of the worst, um, disease that I ever saw. ALS probably topping that, but um (pause) it's just hard to take. Its um, can you give me the questions again because I just lost it.

Danton- That's fine. I'm gonna jump back a second. Um. So you-You had your son already when your found out about this Huntington's, or at least that your husband had it?

Naomi- Well, (pause) I found out um – what's the question?

Danton- Y-you don't have to repeat this question. The Things like this you can just answer.

Naomi- I found out when—when my husband found out he had it. Is that what I'm going for here?

Danton-Just-just-just wait a second and I'll explain what I am trying to say. Um. Your son had it- uh or sorry, your son was already born when- when your husband was diagnosed, correct?

Naomi- Alright, that's what I wanted to go with. (cough) My son was already born when I, when I uh found out this news. Um. Even though I did know of its existence because his mother had it. And at that time, she had been in a nursing home already for probably close to twenty years, um, which was part of the devastating news or me because that's what I foresaw for him. Um and uh, my mother was a nurse and so she knew of the disease and uh when she- She actually knew it before she was married but I guess as mothers do sometimes, they don't tell their- you don't want to hear that? Okay. Anyway, I'm lost again. Sorry.

Danton- I'm sorry. I'm throwing too many things at you. But the-the thing I am trying to get it: just don't pick your finger. I can hear it loud and clear on here. (Liz and Naomi Laugh) Um. It overwhelms-It takes over. I can't even hear what you are saying because it is so loud. Um. (Naomi makes face) That's just how it is on there. It's a very good microphone. Uh. But. What I want you to say I guess is, um I'm sure you don't regret having your son-

Naomi- of course not.

Danton- …but if- if you had known about your options beforehand, what would you have considered before having a child, if you had known about Huntington's. So maybe just say, 'If I had known about Huntingtons before'-

Naomi- Right, I got ya! (pause) If I had known about Huntingtons beforehand, uh there's a few things I would have been more proactive um trying to find out possible ways to find out if the fetus or my child were to carry the disease. Um. I don't know that I every could have ever gone through with getting rid of my child, but uh that's beyond the point. And I also think that things like insurance and disability, I would have done, you know, I probably would have had that information, or had all that done beforehand— better planning for our life. In my case, and I suspect that this in the case for a lot of people. Uh There is not a lot of support, you know. I don't think people know how to deal with this disease. So it causes a huge strange- strain, not only personally but, you know, professionally with people that normally used to visit you or come see you, uh, all of a sudden they scatter. So this happened with my family and this happened with my friends. Very few people stayed around from onset—

MVI 3001

Danton- Really?

MVI 3002

Liz- okay, sorry continue.

Danton- that should not happen on there.

Liz- yeah

Naomi- while the uh-

Danton- so again, hold on, I just wanna—I just wanna take a minute. Um. I am not—the interviewer is not you son.

Naomi- right

Danton- So talk about me in the third person

Naomi- okay

Danton-you can say, ‘my son’

Naomi- Ok

Danton- ‘danton’ you can say anything like that

Naomi- alright

Danton- uh just but don’t- don’t say you’

Naomi- alright

Danton- because it’s not the interviewer, and the people watching it aren’t going to understand what you is.

Naomi- Ok. Where did I say that at?

Danton- this last one, a couple times you said you

Naomi-Ok so, now I don’t know what to do.

Danton- Ok. We’re just going to ask the question again. Just take your time. Its fine.

Naomi- Alright. ask the question again.

Danton- So um before- If you had known before your son was born what sort of options were out there. Or maybe not what sort of options. If you had known before your son was born about huntingtons disease and that your husband had it, what sort of options would you have considered?

Naomi- If I had known about huntingtons disease uh before my son was born, um who knows, I may have taken a- a different path. I may have- um not I may have, I would have uh looked into genetic counseling (a), um finding out if there was any way to figure out if my child was going to have this illness. I would have gotten regular insurance, probably disability insurance and just made a better planning- a better plan for my life. um Because in this particular situation, uh there’s not a lot of support. And once that diagnosis was made, I felt like a lot of people just kinda high-tailed it. I don’t blame anybody for that. I-I think that people, because they don't' understand something or they are ignorant of it. When they don't understand something, a lot of people kinda like run away from it and-or they don't how to deal with and because its somebody that's close to them um maybe it hurts them somehow and so they just don't know how to deal with it. And if that's how they chose to do, so be it. I its just- I guess that because I am personally involved with it just, it matters more to me.

Danton- Okay. So uh this is the probably the final question. We might just randomly talk afterwards but again, what do you think the hope for huntington's is? What do you see--see as the future of huntingtons?

Naomi- The future of huntingtons- I believe that there is- a cure is going to be found. I'm super excited that they have found the gene. They have identified it. That in itself I feel is huge because there're so many other diseases, that is not known. And because that is not known, there grass- it's like a needle in a haystack. Um because this disease is known, it's almost like there is a race out there right now for the first scientist who discovers it. Um an- and really anything that they discover from this point on, in my opinion, is going to be helpful cause it's part of the piece of the puzzle of putting things together and finding out what the causes are and what'll either slow it down or stop it. And then hopefully, you know, um. When I went and talked to the doctor with my son, um you know, the hope was that um that their talking about all kinds of experimental studies and things that they can do now that I didn't even know and in a few short months, uh since the beginning of testing to the end of testing, you know, there's things that I didn't know about. So that is exciting because that information as compared to 25 years ago was basically null and void back then. You knew what the prognosis, if you had a family member, it was just, "and this is why they call it the curse." That's- that's really the long and the short of it, in my opinion.

Danton- okay. And then uh, Could you- could you explain your son getting the test for huntingtons?

Naomi- (deep breathe out) Can I explain my son getting the test for huntington's? Um. Uh. In my experience, most people just don't wanna know. They don't want it. They just don't wanna know. I get that. I don't think I am as brave as my son was. Um. Of course I've lived a lot longer than he has, so un you know, I am in that pain avoidance mode. Um. So the-the testing starting, uh I think, about three months prior. Um He had- he went through counseling and several visits with the doctor to uh find out if he was emotionally and psychologically ready. Uh.. I don't know how they can figure that out, but um (laugh) again I don't think that it would have been my choice. (sniffle) And I'm speaking purely as a mother, because it was an emotionally obviously issue for me. Um So three months out. I think two months out he had bloodwork. And uh again, they kinda leave that in his hands. Uh excuse me, (wipes face) and um—and then when he found out, I was with him. (laughs) The crazy part is, that when he said positive, my son jumped up and thought it was a negative positive, meaning that he was positive he didn't have it, so that kind of threw all of us. And then the devastation I think of realizing (sniffles) um you know, the finality of it. Um, for me, uh, that testing process, I mean I'm grateful uh and I apologize ahead of time but it's an emotional and the cure is what I have to remain focused on, that's about it. (She cries)

Danton- (alright)

(Naomi wipes face)

MVI 3003

NULL

MVI 3004

NULL

MVI 3005

NULL

MVI 3006

(background noise) (CAN BE MUTED IN FUTURE EDITS)

(Lindsay stares concerned and swallows. It's a good emotional and heartfelt shot even though it is quick)

MVI 3007

Danton- Introduce yourself, however whatever what you see fit. If you want to use your name, its fine.

Lindsay- ok and what else?

Danton- maybe as a way to describe how you're connected to HD.

Lindsay- okay. Okay. So just go whenever

Danton-yeah

Lindsay- my name is Lindsay and my father has huntington's disease and I'm at risk.

Danton- Ok. Um. Alright so maybe can you explain more your experience with your father growing up, you know what you saw from when he (she nods) wasn't really, didn't have any symptoms, til later on.

Lindsay- ok. So I was first told about huntingtons disease when I was in sixth grade, so I was about ten or eleven and um my parents sat me down and told me that my dad was sick and that he would probably start changing. And I didn't really notice anything. Um. I was really young and I didn't understand what that all meant. Um. But I think my parents knew that he was symptomatic for a few years before they told my brother and I. Um but Probably when I started noticing changes when I was in eighth grade. My dad had a lot of behavioral changes and psychiatric changes. So there was a lot of bouts with OCD and psychosis. He would constantly check if things were locked. He'd start, um he started packing up for like Armageddon. (laugh) Just buying tons and tons of stuff. Just being really persistent, and getting in your face. If he had a question, he wanted it answered right away. He would lose his temper quite often and it was really scary because my dad was um naturally very subdued and pretty quiet and he'd get in these rages where you could just see these veins popping out of his forehead. Being a kid and not really understanding that it was the disease it was pretty scary sometimes. And then I believe he—we had to get more help when I was in high school, when I was 16 or 17. We had um to look for a facility that could to take care of him because he was engaging in very unsafe behaviors for him. My mom actually passed away when I was 14 and he went through a really bad bout of depression. He started drinking. He convinced himself that alcoholism- or alcohol was you know something good for him because of the disease it wasn't really rational but um he was combining really serious medications with tons of alcohol every day. And we just couldn't prevent him. I mean, my brother and I were so young and we were trying to tell him he couldn't do things so it was a struggle and so we had to get help. And he had been in assisted living and nursing facility ever since then. That was probably twelve years ago.

Danton- Okay. Uh can you maybe explain the family dynamic? Like your brother was how old when um—like how were the two of you, you said your mother passed away when you were fourteen right?

Lindsay- Uh-huh

Danton- So how old were the two of you when your father had to go into assisted living.

Lindsay- I was-- I believe I was 16 um and my brother was 17. We're 15 months apart so um my brother was actually started driving when he was 15 because he was helping my mother out when she was sick and so um he was able to kind of take over the responsibilities of like a normal dad, as far as um you know taking care of me as the younger person. And um, but yeah I mean my dad stayed home. He didn't work for a while. Actually it was really sad. Because He kept on getting laid off, um because of like the behavioral issues. He just wasn't able to work in the right way. He was an actuary so it was a very high critical thinking job. And so our parents tried to find out other ways, once he was more symp-symptomatic to still maintain some form of income. And once he started getting more of the movement symptoms and the chorea, um that sort of caused problems. He was substitute teaching and a lot of the kids were making fun of him because they didn't really understand, you know, what-why he was jerking around or not able to talk properly. And so he eventually just had to stop working and he just sat at home all day and um watched TV and drank alcohol. (laugh) He was very very depressed without my mom.

Danton- I'm sure. Uh. You can stop it for a second.

MVI 3008

Danton- I understand its tough–

Lindsay- even doctors, its really disheartening when even physicians don't really understand. Um. I remember one time, I was by myself and I was in high school. My dad had already gone to bed and I heard this really loud noise. I was in the living room watching tv and I heard just this loud crashing noise in my dad's bedroom. And I knock and I didn't hear anything so I walked in and it was pitch black. And I was, you know, "Dad hello?" And I didn't hear anything so I turned on the light. And he was on the floor with blood all over his head. And the- there was a fan, like a standing, rotating fan, that I think he went to – I don't know what happened but I think he went to try to turn it off and he lost his balance and fell and the blade hit his head. And he was just gushing blood. Soof course I called 911, and I got an ambulance out, and we went to the ER and I was trying to explain to the doctor there like, "he has Huntington disease. That's why he can't talk. You can't really gauge whether he's conscious or not by asking, you know, typical questions.

Danton- Right, right right.

Lindsay- and he just was ignoring me. And kept on saying "oh hes drunk. You don't know. He just drank too much." No he's not. I mean, he's slurring his voice because he can't talk. He physically can't talk. Not because of that. So it's just really frustrating when you can't even get the right support in emergency situations and –

Danton- yea Definitely

Lindsay- …when the people who study diseases can't even understand what's really going on. **It's – It's tough being part of a community of a disease which nobody is aware of.**

Danton- um were gonna do another wave.

Liz- yea?

MVI 3009

Danton- uh. Ok. So another question I guess is, um just in your own words, how would you describe huntington's disease?

Lindsay- oh that's a tough one. So huntington's disease is a nuero-degenerative disorder that affects your brain cells and eventually kills your brain cells. There's three primary symptoms. One is psychological. The other is behavioral, so peoples personally may tend to change. Um. And then the one that everyone knows of, is the chorea, which is the motion disorder, much like Parkinson's. I've heard huntington's disease as a combination of parkinsons, alzheimers and ALS. So I think that kind of speaks out to people who aren't really familiar with HD that can kind of understand those other diseases. And – and think of it's a concoctions of all three and it's kind of the worst case scenario. (nods)

Danton- Definitely, yes. Um. so your father is still alive, he's in a home now? Where is that?

Lindsay- Yes. He's in Houston. That's where I grew up. was in- in Houston. And I just celebrated his 62nd birthday with him and my uncle and my brother. We all went to Houston. And got to see him on his birthday. Um. At this point, he is, you know, in a bed. Um. He can't talk. He can't really do anything. He just kind of lays in bed all day. He can't even move his head to reposition what he is looking at. He is usually looking over to the left. And um he has to be fed with help from someone who's been trained and been working with him for years. We chose not to do a feeding tube. He just is fed a puree diet. That's basically what he does. He wakes up and eats and hangs out in a chair all day and then he's put back into bed at night. He really has no form of communication or interaction on his side at all at this point. And it's been for- pfft I don't even know, maybe 6 or 7 years. But he hasn't been able to talk for probably over a decade. (nods)

Danton- ok um do- huntingtons affects families,

Lindsay- uhhuh

Danton- It's especially a family uh devastating disease, I guess. So could you maybe describe the larger dynamic? Like outside of your family. Did your fathers siblings have it, you know, what's its doing know with your cousins or things like that.

Lindsay- Yeah. (nods) so um Huntington's disease affects the entire family. And With my family my dad was uh one of 8, 6 siblings, 4 sisters, and then a 10 year gap in age and then the two brothers. And my dad is the oldest of the brothers. Out of the- nobody has been genetically tested at all- um but my dad's mother had huntington's and that was the first time that they knew about huntington's disease. I think before it was just misdiagnosed as something. Um. Something else. But um she was in Houston and there was a doctor in Houston that just luckily came across her and you know she was already in a nursing home then, but he said, I think she has huntingtons and they did some sort of test and confirmed that she had huntingtons. This was before 1995, so I think it was more of a - not a genetic test but more of a symptomatic test. And um. So that kind of helped the family explain a lot but they still didn't really know too much about it. One of the four sisters had huntingtons and the other three as far as we know they don't have it. But they've kind of passed the age where um you know my dad and my aunt got it, started showing symptoms in their late 30s/ early 40s. And my aunts and uncles are well beyond that so we are kind of assuming that they're negative- gene negative. But one of my sisters actually- or one of my aunts passed away from a heart related illness and so she died relatively young. And my cousin and I are pretty close and she talks about how you know she just doesn't know for sure. They thinks she didn't – that she didn't have the gene but they just didn't know for sure. And she has children and she wants to have that piece of mind to know that she didn't pass it along. So shes been thinking about getting tested. She's quite a bit older than me, so shes probably passed that prime time, so just in case, people are still. It's still in your head. Non stop, you're constantly thinking, what if, what if? Um without that 100% certainty of the genetic test. Um. My aunt who had huntingtons disease, she died when I was very young, so I don't – I didn't really get to see-see the symptoms or anything. The only perspective I have is through witnessing my father and my friends in the community and their families. But she had, I believe, 4 sons and 2 of them, so two of my cousins, have- are gene positive. And I believe one of my cousins um had children and I believe one of them is gene positive and some of the other ones are at risk as well.

Danton- um so. We ok—

MVI 3010

Danton- um so. I guess you're- you're aware of the gene breakdown. And I guess, what's the question I am trying to ask? If one parent has it and then you have it, you are likely to get the same C-A-G repeat or higher?

Lindsay- Uhuh. And if your father has it, the chance of your CAG repeats exponentially increasing is a lot higher. For some reason if its passed along from your father then its more of a chance for that to happen then if its passed along to you-by your mother. (nods)

Danton- So now, no one, out of any of those people that found out, they didn't officially find out they had or get the blood test until a doctor said "I think your symptomatic?"

Lindsay- Um well as far as my father's siblings, that kind of level of the tree, the test wasn't really available. They were quite a bit older already before the genetic tests but some of my cousins and my brother have done the pre-symptom genetic testing- predictive genetic testing- so um on my cousin's level, yes they have but at my uncle and aunts level no. Yea

Danton- so then personally,

Lindsay- Uhuh

Danton- Whats you stance on you personally getting the presymptomatic tests?

Lindsay- Um, this is something that I reevaluate all the time, is doing the predictive genetic testing. At this point, and obviously it's been that way for a while, I've just chosen not to get tested. I'm not saying that I won't ever getting tested. But I don't see myself getting tested in anytime soon. That may change eventually. Um But part of my way to cope it- cope around the disease is to have the hope that I might not have it. I think if I knew, I wouldn't- even thought I would try to live my life the way that I want to- I don't think I could. Just the knowledge of having it and you know, feeling- the feeling of knowing that your eventually going to be a burden on somebody and that's just a little too much for me. If I chose to have child, um I would-I feel like it's my responsibility to um know that and make an active/proactive decision on um you know how I want to go about having a child. I wouldn't want to um do that blindly. At this point I'm not looking to have children. So that's the only- as far as it goes right now- that's the only time that I think I would get tested. But it may change. I'm completely open to my feeling when it comes. But I just I reevaluate it quite often and it's still maintained the same thing, "No" (laugh) I don't think I want to deal with that at this point"

Danton- Uh now as I said, the relationship thing is a big focus of this film—

MVI 3011

Liz- Continue.

Danton- Um. So I guess, just at what point in your life did you realized that if you are going to be dating someone or marrying someone and this burden is there or in the back of your mind. How to you broach that subject with someone, when you are dating. You know, at what point in a relationship do you decide, I can tell this person. How did you go about—I guess the basic questions is, how did you go about dating with this in the back of your head?

Lindsay- Going about dating with Huntingtons Disease in the back of your is a tough thing to decide how to approach it. Um I think in high school when I first started dating it wasn't really an issue because everyone was so close everyone knew about my dad and they may or may not have known that I was at risk, but it was just kind of , it wasn't really hard for me to bring up because it was there and present every day. Um when I went to college, I dunno. I guess I've been pretty open with it. **Just from the beginning, I feel like I want to give the person every opportunity to run away. (laugh) I-I would feel so guilty if someone feel in love with me, and then was kind of introduced this wow life changing thing Okay. It's like, they don't really have a choice. They've invested in- in me and if there in love with me it would sort of be hard for them to make a more logical decision I guess as far as if they want to be a part of this process with me.** Um so I guess I've just always been really open about it. Knowing that I might get really hurt and I might um scare people away. But I just feel like being open and honest is the best thing. I – I mean I wouldn't talk about it on a first date but (laugh) usually you start talking about your family and where your parents are and what they do. I'm just honest and tell them my situation. And just go from there. And if they want to know more and ask questions I'm very open and honest about it.

Danton- cool. Thank you. um I guess with your parents relationship, I know- how- how did- did you see a strain there? They stayed together as far as I understand it.

Lindsay- yeah.

Danton- But what kind of strain did you see if any. Maybe just talk about that.

Lindsay- my parents loved each other. You could definitely tell that they loved each other. They wanted to have children because they knew what happened to my father's mother. And they knew that my dad was at risk. But eventually they decided that they really did wanna have children and they were gonna make that risk together. Um they were a really strong couple but I did notice, even when I was you know so young when my mom was alive that with my dad's behavioral changes I think the one that was the most challenging for her was his obsessive compulsive behaviors. Because she would be working all day, with the stress of trying to support two children, and her husband and she'd open up the door and my dad would just be standing at the front of the door waiting with a list of all the things that he wanted to tell her that day. Or all the things that he needed for her to do. And there was no decompression time there. It was just one thing after another. And I think the stress and his kind of overbearing behaviors got to her a lot. And you could see the, the strain that she was in some times. Um. But it still kills me because even after my mom dies, years later when my dad would be introduced to someone new, if we brought a friend with us to um visit him, the first thing he would say was "my wife and I were married for 27 years." And I mean he- they really did love each other. And he – was that was the one thing that he was the most proud of that he wanted to let everybody know that he met. So it was pretty awesome to hear that from him. But it was also a big downfall in his depression. Um, I think that was the main reason he started um drinking after she died. And I would remember um he'd be watching tv on the couch with and he would just start crying. And you know he missed her and it must have been so scary for him to know that he had two children he could not take care of and there wasn't a lot of support. I mean our uncle was our savior. (noise) He really went in and took care of my father and my brother and i. But it still must have been really scary to see him slowly lose control and know that he's leaving two children behind with no father or mother. So But they did love each other. Despite everything

Danton: that's great, yeah. That's good.

'---

(STOPPED **DETAILED** TRANSCRIBING AFTER THIS VIDEO. AFTER THAT ONLY VALUABLE QUOTABLE LINES ARE TRANSCRIBED in bold)

'---

MVI 3012

Nick is introduced in this video.

Nick- I do teach about HD and other nuero-degeneritive disorders in class to medical students and undergrads and things like that but honestly I've learned more about it from Lindsay coming in to the relationship.

Nick- Then the decision for her to get tested will be her own decision on her own time.

Lindsay- I was really angry at him actually I was selfish, um, because the thought of losing my one last immediate family member or knowing that I would, I just wasn't ready for that.

Lindsay- He had convinced himself and his wife that he was positive.

Lindsay- Those were the longest three weeks of both of our lives.

Lindsay- Luckily he got tested and he was negative. That was really hard for him to accept actually. He thought they were wrong, that the test must have been wrong. He wanted to do it again. The counselor had to assure him; no you are one of the lucky people. You don't have it. You need to accept that.

Lindsay- You think about it all the time. It can consume you…

MVI 3013

Nick- I can say that the advantages that HD has relative to some other diseases is that it does have an identifiable cause.

Nick- Just live our life.

Lindsay- It's hard for me to talk about that because again it makes it more real, more scary.

Lindsay- I don't really talk too much about about the kind of emotional side of it to Nick.

Nick- the number one that she fear, about having it is becoming a burden and that's sort of a reflection of who she is.

Nick- It has zero um influence on the way I feel about her and you know I knew long before we wound up together that she had it. It just really is a non factor for me.

Lindsay-I could potentially just cause a lot of angst and sorrow in his life. Because you care about the person and you've experienced that and you would never want to put that on somebody else.

MVI 3014

Lindsay- I find myself being one of the people stigmatizing right. I'm avoiding interacting with these people. Um as part of my own coping thing. But I don't really want to do that. How can be active if I'm not really embracing it fully?

(PHOTOGRAPHER at HD persons wedding coincidentally also had HD and was not chosen perhaps because of this. Can I find this guy and try to talk to him?)

(At very end, when I tell her I was tested and it was positive, the look on her pretend stone face and the gulp is great. I can redub the interviewee asking the question later but the reaction is subtle but priceless.)

MVI 3015

NULL

MVI 3016

MOSTLY NULL

MVI 3017

Katie: Huntington's disease is a neurological brain disorder that kills brain cells, and it affects many people and it's genetic.

Kendall: It's a family disease; it's very much a family disease. Um since it is genetic. Kids grow up- Kids typically grow up in a family with a parent with HD and see what their future could be. Because they're at risk. And it also affects multiple people in the families. So it's a really burden- it's a huge burden to a lot of people in our community.

Katie: Since we were young we saw our mother deteriorate. When we were 16 we had to put her in a nursing home.

Kendall: Katie and I both have tested and we're both gene positive. Not symptomatic yet, living every day to the fullest.

MVI 3018

Kendall: I got tested in 1999 prior to me get married. I just wanted to let my husband know what he was getting into. So I'm really glad he's decided to marry me anyway.

Kendall: The best way is to keep living, don't let HD stop me. I ended up getting married. I have three kids and they are at risk. I do struggle with that a little bit.

Kendall: I mostly just didn't want HD to hold me back from anything.

Katie: When I started to thinking about it more I realized that if I got tested at 18 and it was positive my life would probably be over, I probably would have quit college, I just think I could handle it.

Katie: I knew in my heart when I got tested, it was positive.

Katie: I'm not changing my life just because I'm gonna be affected.

MVI 3019

(me off camera- It is interesting the kind of person the disease creates almost because you have to be a certain person to overcome that.)

MVI 3020

(both laughing if I need that clip)

Kendall- It was a big step for him to come into our family from the outside not being grow up in the HD world.

Kendall- At least my spouse kinda knows that hes gonna have something to deal with going into that. So maybe where ahead of the game there.

Kendall- At least my spouse kinda knows that hes gonna have something to deal with going into that. So maybe where ahead of the game there.

Kendall- I think there is good promising treatment. I think they'll be a treatment and hopeful a cure by the time they are older.

Katie- Every time I've gone on dates, it's always the question of when do you introduce--, when do you talk about it, when do you introduce it. When should you even let them know. Do you let them know at first. But why?

Katie- If anything is going to go forward, you need to be honest.

Katie- You wouldn't think it would be a hard topic but its- sometimes it starts to be a hard topic to talk about a lot.

MVI 3021

Katie- You could look at like two different ways. You can give up or you can just go on living.

Katie- You can't give up. You have to live.

MVI 3022

(Good info but not good quotes)

MVI 3023

Katie- The more people that know about the disease, the better.

(Good info but not good quotes)

(Baseball story with dad and kids thinking he was drunk. Who is that drunk guy?)

MVI 3024

(Go info but not good quotes)

MVI 3025

(Good info but not good quotes)

MVI 3026

(Good info but not good quotes)

MVI 3027

(Good info but not good quotes)

Billie- He's a workaholic. We all have that in us. And He's not a good caretaker. Just out of self-preservation. I can't really be the sick. Because he's not a good nurse.

Jo-

MVI 3028

(Good info but not good quotes)

MVI 3029

(Good info but not good quotes)

MVI 3030

(Good info but not good quotes)

Billie- They don't really say what it is. They don't really tell you that there's a psychotic part of this that tears families apart.

Billie- Nobody wanted to get tested and nobody wants to think about it.

Billie- Yep. You better face it and then see what you can do about it.

MVI 3031

(Good info but not good quotes)

Jo?- A little concerned that if she does become symptomatic, how am I actually going to take care of her? Or will I take care of here? I think I will. I have confidence I will.

MVI 3032

NULL

MVI 3033

NULL

MVI 3034

(Good info but not good quotes)

MVI 3035

(Good info but not good quotes)

MVI 3036

(Bad info and no good quotes)

MVI 3037

(Bad info and no good quotes)

MVI 3038

(Bad info and no good quotes)

MVI 3039

(Good info but not good quotes)

Mom- It's a little different than alzheimers in that the person stays aware of their current surroundings and understands what's happening around them unlike alzheimers where they don't know that.

Rob-It's a genetic disease that starts with the brain, and it's a den- diagnosed, you can be diagnosed with it.

MVI 3040

Rob- My mom died quite a few years ago of it. She took her own life. At that point, with no medicine, it was quite common with HD patients.

Mom- He has another daughter who has chosen not to get tested at this point time. She's married with children. So it has a little different impact than it did for his oldest daughter. She's single. And that's been difficult as well because she's dealing with a lot of this on her own.

MVI 3041

Mom- He had gotten into a car accident and the officer accused him of being drunk. And he remembered that woody Guthrie was frequently accused of being drunk when he wasn't. And so he called me up and said, I need to get tested and find out if I have huntington's.

MVI 3042

(Good info but not good quotes)

MVI 3043

Rob- I had I had known quite a while because I was 12 when my mom told me she had the HD and that I have a gene that I might have it. So that left me with a lot of years to do it. When I decided to have a kid, I you know I said. I have a counselor. You know you have a lot of life to live. You might not get it. He counseled me to go ahead and get it.

MVI 3044

(Good info but not good quotes)

Mom- And then probably the most important thing that we've learned in our lives and living with huntington's is to not do it alone. So To-to share our journey with those that are around us that are important to us. To be open about what's hard and whats-what's not working right now. Because by doing that, there is a gift in it, both for the people who are a part of your lives to participate in that journey with you and learn what's truly important in life. And there is a gift in it; there's been many gifts in it for us. We've been blessed beyond what we ever dreamed or imagined or expected. The depth and quality of our life has improved since robs diagnosis because were really focusing on what's important about each day. And trying to live life.

MVI 3045

(Good info but not good quotes)

MVI 3046

NULL

MVI 3047

NULL

MVI 3048

Guy?- I won’t forget that day. Him and my mom had went and came back home that day. And I’ve never seen my dad cried. And he um he just started bawling. I mean I’ve never seen it. He’s never real emotional at all. I’ve never seen him cry and all of a sudden he’s crying. And all of us just break down. I’m not much of a crier so I got teary eyed. But you know I think I’m pretty strong. I think everybody cries in their own time. I think I’m more that part. Seeing him that day I knew how impactful this disease was.

Guy?- I may have it. You know, and I haven’t been tested yet. I would like to get tested here in the near future. I am waiting for my wife and my parents to be alright with it so they can you know handle the news good or bad. You know, you go through it that one time and it’s kind of a crushing blow. You know can they handle it if it’s unfortunate. I am ready to be tested. I would like to.

Guy?- I’m the type that It eats at me more when I have to think about it on a daily basis. Do I have this, do I have this?

Guy?- I think it’s comforting to have that feeling that if I get tested positive then there’s gonna be a cure. Down the road so I may not hit the bad part of it.

MVI 3049

NULL

MVI 3050

Guy?- It scares me.

Guy?- It gets worse as it goes down the line. If that’s the case and the repeat goes up for each individual. They could be worse off and it could start earlier. And just to know that could happen you know with your kids. It’s a- it’s a helpless feeling. If came to that. You don’t want anything to happen to your kids. It’s a scary thought.

MVI 3051

NULL

MVI 3052

Guy?- I think it’s the worse disease out there.

MVI 3053

(Good info but not good quotes)

MVI 3956

Jennifer: My husband is 44 years old and has huntingtons disease and now resides in a nursing facility. I also had a 12 year old daughter who passed away this past January who had juvenile huntingtons disease.

Jennifer: My definition of huntington's disease is um to put MS, ALS, parkinsons, Alzheimer's, muscular dystrophy, um as well as numerous neurological disorders into a big bowl and mix it all up. The only difference is that Huntington's disease is strictly genetic. And that I found out the hard way.

Jennifer: when the discussion of children came up and Huntington's and had done as much research that I could at the time. And I saw that the only way to prevent passing the disease was through in vitro. At the time. That was back in 1995-96 when they were really starting to get more involved with in vitro. But I also knew that it was a very expensive process. Something that we definitely could not afford. And I also knew that if we were to do in vitro it would also tell us whether or not he was positive which was an absolute taboo subject for his family. Absolute taboo. You couldn't say HD, just the initials, without somebody in the family getting very upset and walking away from you and just shutting the entire conversation down. It was very very difficult.

MVI 3959

(Good info but not good quotes)

MVI 3960

Jennifer (husband is Ronnie, daughter was Olivia, older daughter is Reinia:

Jennifer: in January of 2012, I made a decision to sign a DNR, it was my decision. With the help of pediatrician, they helped me. They helped me through that. In the event something happens, you can rip that card up at any time. She had an infection every four to six weeks, she got through all of them, then final in January, I had made plans to go away for the weekend. I went to Rehoboth to spend a night at my brothers. An hour after leaving, she was having seizures—

MVI 3961

Jennifer: Later that night, back and forth with the hospice nurse. At one point, and then finally on Sunday morning, the hospice nurse. We want to try to give her a release. Get home. I had put the call out to my sisters and my cousins. So they were here with the nurse and the hospice nurse. It's a 2 hour ride from Rehoboth. The phone just would not stop ringing. I drove back from Rehoboth. We were half way home. I knew. I pulled up to the house and my sister was outside. She didn't even say a word and I knew she was gone. I know that she is in a better place but I know that she didn't want me here either. She couldn't do what she did with me in the house. (Audio only, no video for this part: she had a rough time without seizures. There was a small gap with no nurses. She- she stopped

breathing. I said, you can't do this to me when I am by myself and she started breathing again. I believe she couldn't let go with me near here. So she let go with me away. It's been a rough year. Because of how bad Huntington's is, you start to lose compassion and you can't concentrate on one.)

MVI 3962

NULL

MVI 3963

NULL

MVI 7207

NULL

MVI 7208

NULL

MVI 7210

NULL

MVI 7211

(CAPTURED MOVEMENTS ASSOCIATED WITH HD)

MVI 7212

NULL

MVI 7213

NULL

MVI 7214

NULL

MVI 7215

NULL

MVI 7216

NULL

MVI 7217

CHRISTINE: My name's Christine Ryan and I'm here to speak for the other Ryan's that suffer from Huntington's like I do.

CHRISTINE: I'd rather know than no know if I had it and then go from there.

CHRISTINE: I say that it's a neurological degenerative disorder that's in the Huntington's gene. And what's it like. It's kinda like having several diseases rolled into one.

MVI 7218

NULL

MVI 7219

CHRISTINE: A lot. He couldn't deal with the Huntington's part of the um – it's put a lot of strain on our relationship. And we're even divorcing now because of it. We are divorcing because of it.

CHRISTINE: It's because of the Huntington's. No other reason.

MVI 7220

NULL

MVI 7221

NULL

MVI 7222

MOM: When we first found out she had Huntington's and uh she came out of the office and she just looked at me and said "I have it." And there was a lot of embracing, a few tears, but then you'd think okay, I gotta be strong, we'll get through this. The thing being a mother is, as your child is growing up you always kiss their boo-boos and make it go away. And this was one that I knew I couldn't.

MOM: We joke about it all the time, shell slap you and say, "oh I'm sorry that was Huntington's"

MOM: I don't want this to be part of my future either. I don't want to have to watch her suffer it and get worse. And you know, because I've already seen what it does.

MOM: Something that makes it so somebody can live a life. (Pause) that one day their not laying in a bed, not being able to hold still. Or not being able to get up or do anything for themselves. We want them to have a life…

MOM: not to give up, not to give into it. Cause it's already – its already taken away her marriage. It's taken away full time living with her daughter. It's not because she's unfit. It's because of this disease.

MVI 7223

NULL

MVI 7224

CHRISTINE: I'd say never give up, no matter what live throws at you.