



As part of the Genetic Support Network of Victoria's Lived Experience Interview Podcast Series, patient, mentor, counsellor and advocate George Helon of Toowoomba (QLD) talks with our Project Facilitator Kari Klein about Pallister-Hall Syndrome (PHS) and Gelastic Seizures (URL: <https://www.youtube.com/watch?v=AZGwNBguEI0&t=2948s>).

The purpose of the series is to explore the impact of genetic conditions across a range of life stages – from the patient's perspective – so that people might better understand the concerns, and appreciate the realities of a patient's development and experiences as they get older.

George Helon is the founder and administrator of both the Facebook:

Pallister-Hall Syndrome (PHS) Support Hub
<https://www.facebook.com/Pallister.Hall.Syndrome/>

Gelastic Seizure Support Hub
<https://www.facebook.com/Gelastic.Seizures/>

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Interview with George Helon

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GSNV Facilitator Kari Klein, Project Assistant

Podcast transcript (edited)

Time stamp	Speaker	
00:00	GSNV	It's good to see you, we haven't seen you in about a year. A year since the last time you were here, yeah?
00:07	George	Yes.
00:08	GSNV	So, we are going to be conducting the second part of our Lived Experience series with you and we're seeking to understand the life experience of a person living with a genetic condition. This series of questions is designed to explore the impact of the condition across a range of life stages and in different aspects. We want to understand from your perspective the reality and way a person views their life and we would like to capture this information with our new podcast.
00:43	George	Okay.
00:43	GSNV	So, George, if you don't mind telling us about you and your condition.
00:49	George	Well, first of all, I'm from Toowoomba in Queensland. My overall, primary condition is Pallister-Hall Syndrome. It's what they class as a multiple anomaly genetic disorder. Part of one of the main features of that is what is called a hypothalamic hamartoma or a benign brain tumour, whether they're one millimetre or whether they're 45 mm like mine, it doesn't make any difference. They can cause you a hell of a lot of trouble.
1:20		And as a consequence from the hypothalamic hamartoma you get what is called gelastic, or laughing seizures, which people mistake for laughing. You can also get what's called dacrysic seizures, which is crying for no reason at all.
1:35		Pallister-Hall also has a number of secondary features like syndactyly, polydactyly. You have a bifid epiglottis which is central to the diagnosis. The epiglottis has a cleft in it which can cause breathing and swallowing difficulties. It just has a whole array of, well, there's a spectrum of things, and you can get extreme, you can get moderate, you can get mild. No one's the same. In my case it was classed as sporadic which means I didn't inherit it from anybody, supposedly, but still with genetics we're not that advanced to know whether that actually is the case. That's what I have in a nutshell.
2:29	GSNV	Yeah, great. And how has your condition impacted you as a child?
2:35	George	Well, well, well, where shall we start? Well, first of all, when you have physical anomalies like hand issues, where your hand is not exactly, let's say "normal", you have a tendency to be bullied. You become, let's say "Outcast", "Picked on", you

- name it. Left out of groups, you become isolated. That doesn't help too when you have issues with a hypothalamic hamartoma that puts you in different emotive states. So you can be hyper-aggressive or hypo-emotional. So you go from one to the other. People take that as you being weird. You know, "he's a strange person". When nobody actually stops to have a look at the reasons why.
- 3:30 Well, it also causes problems later on in life because as a bullied person, ostracized person, you don't have that ability to make relationships, retain relationships. You become distrustful of people. And that thing, unfortunately, carries through all your life. And causes more trouble as you get older.
- 3:56 GSNV And going on that transition into getting older, how has that affected you as an adult?
- 4:04 George Well, it's the same thing. If you don't have relationship building blocks early on in your life, you thrust out into adulthood where you're supposed to be developing more permanent relationships with partners or whatever, doesn't exactly work out that way. Because again, people have a tendency, you become self-conscious about the way you look and someone looks at you and you think, "Oh, what the hell are you looking at?" or something like that and you become aggressive. And that's off-putting for people. You know, you get eyes rolled at you.
- 4:43 And like in my case at the moment, the hypothalamic hamartoma is causing me neurosensory hearing loss. I'm now almost profoundly deaf. I find it very hard to speak to people, even if I was to take these [hearing aids] out now, you're two feet away from me, I would not understand what you're saying to me unless I'm trying to lip read. And therein lies another problem. So amongst everything you have, you are then dealing with people as you are a deaf person. So you then have something else wrong with you.
- 5:20 And you have demeaning attitudes from people. You have people ignorant of hidden disabilities. Like if I say to you, "Could you speak up, please? I've got hearing aids", you start talking down into your shirt, looking away from me, you're not listening to me, you're not appreciating my situation. So therefore again, I get reactive. And this is through no fault of my own. It's a person who is in frustration. Genetic disorders cause all that array of other things wrong with you, that you get that frustrated that it's like, I'm not doing anything wrong. It's people that are not looking at me in the way I'm expressing myself or trying to understand why I am expressing myself a certain way.
- 6:16 GSNV Yeah, that's good. And it's true that there is this misconception of people's behaviours or attitudes and "Oh, why is this person acting this way?" And you just don't know, they don't understand.
- 6:28 George Well, I had a typical example the other day checking into the hotel. The girl was basically to me mumbling into her shirt, alright? And I said, "Excuse me, I'm almost profoundly deaf, I cannot hear you. Can you please speak to me?" She went, "Tsk", and rolled her eyes around.
- How rude is that? I'm causing her a problem? Hello, how about turning around and saying "Look, I'm sorry. How can I help you much better?" You know, instead of

- 7:07 giving someone a tsk and an eye roll. That is the worst thing you can do to a person who is struggling with hearing.
I was hearing fairly well up until may be 10 years ago. And I'm losing that. That's a big loss amongst everything else and someone's treating you like that? It's not an easy thing to swallow. People have got to realise the hidden disorders. Ok, hands and whatever might be visible, but it's what being caused... You know, a genetic disorder. You get into your adulthood age, people don't know because we've only in the last 20-30 years started to bunch these type of things collectively and give them names. We don't know where those people are going to go. Like, if I've got the condition, I'm one of the oldest alive with my condition. They tell me I should have been dead by the time I was in my 20s.
- 7:55 Hello?! You should be following that person. "Hell, we better watch and see what happens to him", because I kid you not, I've spoken to people 10-15 years my junior, they ask me what happened to me when I was their age. Six months later they ring me up and say, "You wouldn't believe what happened?" It seems to be a progressive deterioration in health, but it's common amongst people with the disorder. But not until people start to put all of this together like before, the hypothalamic hamartoma didn't grow, now they say generally don't grow. Hearing loss wasn't associated with Pallister-Hall Syndrome, but hello, today hearing loss is one of the secondary symptoms of Pallister-Hall Syndrome. Because the more people they look at, the more feedback they get from people, that's why I am here today. I want people to know these things are called Pallister-Hall Syndrome, gelastic seizures, hypothalamic hamartoma. You are not alone, there are other people out there with it. Seek them out.
- 9:02 Because you need to know instead of sitting there... I've always been the type of person, I'm not going to sit there crying and carrying on "I'm going to die". No, I've got years left in me as far as I'm concerned. I put it down, I write it down, I put it on the internet. I want other people to know about it. Because that way, if you become self-aware of your condition, you become more informed. And then you irritate the crap out of doctors and specialists, because they've got no idea what *you're* talking about.
- 9:34 GSNV Yeah, and we'll get to more of that later, I have some questions on that. Back to the relationships. How has it affected other relationships? Maybe friendships or family relationships?
- 9:47 George: Well. Let's just the say the majority of people, they see you walking, they don't believe anything is wrong with you. Right? If you decide that 9:30 you get out of bed every morning, you're lazy, right? "What the hell are you doing up at 3 o'clock in the morning?" Because, the hypothalamus is the auto-response for everything: sleep, urination, eating, weight gain, loss, it's on autopilot. If your autopilot says you're not tired at 3 O'clock in the morning, guess what? You're not going to go to sleep. And all the tablets in the world are not going to help you except dope you out.
- 10:27 So, it becomes a case of relationships, the biggest sticking point is a lack of understanding of people, like if someone doesn't know I have, to even when I talk to people I haven't seen in a while, I have to explain to them about them about my hearing loss. Because otherwise, they think I'm being obnoxious, rude and ignorant because I'm not responding or I'm not talking or I'm not engaging or I am repeating

- 11:11 myself for someone to repeat what they've just said. Because the simple thing is, those little things, if you're in a crowded room with, honest to god, hearing aids do not restore hearing. They just make it better.
But you go into a shopping centre, where you've got plates, you've got kids, you've got trolleys, you've got everything. Guess what? You can't hear the person in front of you, but you can hear all that. And then someone's forever repeating themselves and saying "What? What? Why can't you hear me?" Hello - you know? You might have hearing aids but that doesn't mean anything. And then frustration, yes, you do lose a lot of friends, honestly. Even acquaintances. They're like "ugh, can't carry on a conversation with him."
- 11:46 But you know, they ignore people that have, let's say "hearing issues", you can get quite a good conversation out of someone if you want to sit and listen. If you speak up a bit the person can engage properly. But if you don't have any understanding, you know, people with hypothalamic hamartomas, like "Oh, that's not a brain tumour. You'd be dead if that was a brain tumour." Because people automatically assume brain tumour, malignancy, cancer. A benign growth can do just as much, if not more, damage than cancer because a cancer is in one place unless it metastasised and goes somewhere else it's fine. But if you have a benign brain tumour, in the middle of your autopilot, that decides to set your weight off, you've got absolutely no control. You could do every diet in the world, it's not going to do anything.
- 12:41 Because your body is just going to do what it wants to do. And therefore, it's not only you're your immediate health. It affects those around you. It might affect a partner who says, "What the hell's wrong with you? You're getting fat." Right? You're getting these types of reactions from people. It's very hurtful, very spiteful, instead of understanding someone. You know? "Where's this going, "how can we help" or "is there anything I can do?" It's like a "I don't really want to know." I'd rather not, thank you very much.
- 13:16 GSNV So, you find that more often than not?
- 13:19 George Oh, God yeah. People don't want to sit and listen. Everybody's an expert. If I tell you, "I've got a hypothalamic hamartoma, it's part of Pallister-Hall." "Oh, I know a lot of people with brain tumours."
"Who? Name them." Name the person who is supposed to have Pallister-Hall, I bet you couldn't. The Federal Government still tells me there is an expert in Australia on Pallister-Hall Syndrome. Then can they please explain why the so-called specialists ring me? Hello? There is no one in this country.
- 13:56 A lot of the problem with these medicos is they love to write papers; they love to have their names in lights. They've discovered this person with Pallister-Hall has an array of this, and we found ten other people. They make such a big deal out of it. But they don't actually help the person that's got the thing. You know, it's a case of we want something on the board, but after we finish getting what we want...
- 14:24 GSNV I guess that goes back to telling us about your condition. So it's really rare, not a lot of people have Pallister-Hall. Or has there been a rise in diagnosis?

- 14:35 George George: The last figures Pallister-Hall, I would say now from the people I get contacting me via Facebook, there is probably only about 400 known.
- 14:45 GSNV Ok, just in the whole world?
- 14:48 George In the whole world. And the specialist is Doctor Biesecker. See, another problem of the Pallister-Hall is it can mutate into acromegalia and when that happens, you've got a small person who's all of a sudden going to end up seven-foot-tall and three foot wide. And that can kick in at adulthood, it can kick in at any time. And you're sitting there waiting and thinking: "is that going to happen to me? My God, I hope not".
- 15:20 GSNV: We might just pause for the recording and just say that Monica Ferrie, the CEO of the Genetic Support Network of Victoria has just stepped in the room. (The interview commenced again at 16: 09 on the recording)
- 16:13 GSNV Has there been a financial impact because of your condition?
- 16:16 George Oh yes, definitely. Well, financial, let's talk about the biggest one. When I first got diagnosed with Pallister-Hall Syndrome I ended up in hospital for eleven or ten days, or whatever it was and going from top to bottom. "Oh, Mr Helon, I'm very sorry but you've got a genetic disorder so if you ever have children, you know you could pass it on. You also have a benign brain tumour; that could cause you issues. Oh, uh... you also have this thing called gelastic seizures, you know it can be rather embarrassing and cause this and this. Um, um, you also have bifid epiglottis, you may have trouble eating, you know, and swallowing, losing your breath, catching your breath etc." And, it's like, "hello? Have you got any good news?"
- 17:00 So, you go from a person who is basically fit and able until this thing actually started to get, let's say, aggressive, the things that were happening. I was on a very, very good salary, working a very, very good job. All of that went out the window to a pension. Now you're talking an 80% drop in finances. From "whoa" to "low".
- 17:30 You know, that is a hell of an adjustment to make. 'Cause then you start finding you lose the house, you lose the car, you've lost the job, you lose the relationships. You end up with almost nothing. You've got all this thrown on you, got nothing left physically. Two options: sit there and waddle and go "aw, I'm a poor man" or dust yourself off and get up and keep trying. One or the other?
- I'm the latter.
- 18:11 GSNV Just because I want to keep these questions together, have you had any experience around life insurance?
- 18:20 George Experience with?
- 18:23 GSNV Life Insurance?
- 18:26 George Oh, life insurance, oh yes. Specifically, let's try travel insurance, for one. As soon as they get aware you have anything wrong with you, right, you've got give them doctor's reports. You've got to have a certification fit to fly. Why are you carrying medication? What have you got it for? As soon as you start that it's 50%, 100%, you

		<p>name it. But as for life insurance I don't think I've even attempted life insurance, I don't think I'd bother. Because I tell you what, there would have to be a registrar somewhere with my name on it. For sure.</p>
19:07		<p>I'm not a social media ghost, I'm actually plastered everywhere so plug my name in and you'd quickly find that I've got something wrong with me. Everybody uses social media, go for a job interview, the first thing they do is look on social media. They're going to find out. They use it to their advantage, and they should not be, if a person has disclosed what is wrong with them, "hey, I've let you know." So, if something is, as they say, directly resulting from, fine. But you might go skiing, you might be covered for skiing, but then they'll turn around and say "No, you had a seizure before you had the fall." So you'll end up fighting them. So technically, be bold. Don't tell them anything. Take a punt. And if they find out, they find out.</p>
20:00		<p>But better to be covered for something, than for nothing. That's the way I look at it. They've got enough money. A person that has a genetic disorder, it doesn't matter what disorder it is, crook arms or features or anything like that, they have that used against them. Hello? The person making that insurance decision, I hope to hell one day has a child with exactly the same condition. Then they'll learn all about it. Because it's not until you're wearing those shoes, don't go telling someone else or making a prediction on their life 'cause you might not have it yourself.</p>
20:43	G S N V	<p>So just moving onto the next part, we're going to be asking some questions around your experience with the health system and we are asking these questions to develop an understanding of how well the health system is serving you.</p>
21:00	George	<p>Don't even go there. All right. I'll tell you for starters...</p>
21:04	G S N V	<p>Well let's just start with how would you rate your experience with the health system in regard to getting information on your conditions?</p>
21:12	George	<p>Zero. Zero. There is nowhere I could ring up or go, or specialists I can see that can tell me anything about Pallister-Hall syndrome. It's impossible. Especially in Australia. In the states you would fare better. That's what I said earlier, I actually have people contact me. I actually have medico, medical secretaries will ring me from Sydney and say, "I'm looking for Dr. George Helon." And my mum will go, "He's not a doctor, he's actually a patient." "Well, I need to speak to him."</p>
21:44		<p>I'm speaking to these people, and as I said before, the Federal Government has to yet to produce this so called expert in Australia on Pallister-Hall Syndrome, which there ain't. But if I have something that is supplementary to Pallister-Hall like for instance kidney issues or spine issues, like I was a few years ago diagnosed with tumours on my spine. I can get a specialist for that. They are very good. I have a coordinating specialist, that's what you need to do, you need to have a good GP that can find you a coordinating specialist in a hospital so that if something is wrong with you, a report can be sent directly to that person who can say, "this person needs to see so-and-so." And it happens.</p>
22:37	G S N V	<p>Can you just explain a bit more about what a coordinating specialist is?</p>

22:42	George	Well, like when I was in the hospital I saw an Endocrinologist who became the contact person for me. I don't know if it's standard for them to do it or what but she turned around and said, "Right. I'm going to be you coordinating facilitator here. If you or your GP need anything, let me know." Because they have everything to do with my conditions, they have my medical records. They know all of that. So if I need something I get it; I get it fairly quickly. And I pat them on the back for that.
23:20	George	In regard to actually finding out information about my condition, per se, nothing. There's nothing.
23:32	GSNV	The next question I have is about transitions. Was there any services or facilitation between paediatric care into adulthood?
23:43	George	Well, I really wouldn't know about that because I came into the system as an adult but I do know in the States, once you can get a diagnosis of something, yes, you will move along through the system from paediatrics to adolescence to adulthood. But their health system is worse than ours because once you become an adult you're thrown out on the scrapheap because you've made no contributions to social security system, so you can forget it.
24:10		You know, people over there can't even get medication. We're very fortunate here. As I said, I came into it in adulthood. I give advice to parents when they are particularly concerned about things like gelastic seizures or "Is it abnormal that my child is feeling like this today?" And what I do is let them talk with each other. For instance, someone says "I'm from Houston in Texas." So you'll put something, "Parent in Houston, Texas with 5 year old who has this, this and this. Would like to make contact with..." and it's actually someone down the road, who they didn't even know about.
24:54		People, I think, are doing a better job for themselves in regards to finding care because when you talk about gelastic seizures... Gelastic seizures, as I said before, when children have a gelastic seizure when they're very young people assume it's ADD or ADHD. Now I have a big, huge article on gelastic seizures online. It talks from start to finish what the symptoms are etc. I've had to stop myself basically in the middle of a seizure to write down what's happening. [Laughter] And I'm trying to remember, but anyhow.
25:30		People read this and they think, "hang on a minute. That's exactly as my son or daughter has described this." So, the GP says to them, "Oh he's got ADHD" or whatever. This guy says this, I tend to lean with this. So, they take that to their specialist but 9 times out of 10 they tell me they've got to force them to read it, because as far as their concerned, "No! That person has got that!" They don't want to know, they're very narrow minded. They don't want to look outside of that blooming cylinder, that there's a world out there.
26:05		They just think "no, no, no. That's this." But then, some of them will read it and think, "Oh right, ok, this is new." I've had a woman who had an 18-year-old daughter in Melbourne, whose life went to absolute poop because she was having seizures and all sorts of things. She had

		Pallister-Hall, she was having a hard time coping. Because, you know, for a male, look, you take a punch on the head, you get up.
26:35		But for a woman, someone says something about her looks or something like that, it becomes very emotional, emotive etc. And it's the end of the world for them Anyhow, the lady talks to me and says she's been through this medication and this medication and I said, "Well, get your specialist to try <i>this</i> medication. Six months later, "I don't know how to thank you, my daughter got her life back." Now, I tell ya, that's good to hear that. Because from someone whose life was going down the pooper and to the tip, you know, they've just totally changed themselves.
27:10		But getting through to these GP's and specialists to think outside the square, it's very hard to do. I've met a neurosurgeon who didn't know the difference between the hamartomas. He goes, "There's no difference." I said, "Yes, there is. There is one <i>in</i> the hypothalamus and one <i>of</i> the hypothalamus." "Who told you that?!" So, I've got to give the name of the other person who did that. But I don't know whether it's their training or whether it's their egos. I'll put my life more on egos, probably. But they don't really want to know anything that they don't know [laughter].
27:52	GSNV	I feel like that answers a few of the questions about your experience with the health system and how that's been. So, we might just move on to the next part. But before that I wanted to ask, are there things that you wish were different?
28:10	George	Yes. We've got Medicare system but I do believe, that the system, the actual electronic system, is not set up correctly. When you get admitted to hospital you get a diagnosis or cause of admission, right? If a cause of admission is "syncope episode caused by hypothalamic hamartoma relative to Pallister-Hall syndrome". Those key words should be there. So, if I'm a GP I should be able to type in "Pallister-Hall Syndrome", "syncope", or whatever, and bingo! There have been 20 admissions in Sydney, let's have a look!
28:55		That way, people can find information. All they do basically these days is they go straight to their database and look for research articles. Now, how many people are going to research Pallister-Hall Syndrome or gelastic seizures? Because there is only three or four hundred cases worldwide. Until you start actually promoting something and getting it out there like we here are trying to do today, you might find out the condition is quite prolific.
29:26		When people's ears prick up and think, "hang on a minute, laughing seizure? I've heard that before. Where?" People have a tendency to remember things and then all of a sudden, three or four hundred? You've got three or four thousand! You know? And that's where the system is under-utilised. The actual electronics gizmos, it could be put to more productive use.
29:55	GSNV	Just for people listening to this podcast, what would be some of those key words that would be useful?

30:00	George	Well, for a start, if you've got headaches, laughing for unexplained reasons, emotional {inaudible}. It might not be depression. People throw you straight into the depression basket, throw you some Epilim, go home, right? You can look up bifid epiglottis, you have breathing issues, all sorts of things like that. You can put those key words for conditions, for someone like me has the condition, get what I have, type all that in. So the key words are there, and people can latch on.
30:34		If you look up gelastic seizures Australia, 9 times out of 10 you're going to end up back at me. People read that article, but the article is also developed from what other people are giving feedback.
30:46		I've got the two groups, the Gelastic Seizure Support Hub and the Pallister-Hall Syndrome Support Hub. The good thing about that is, and the good thing about social media, is that people will rather give their details on social media than give it to a GP or a specialist. Which is the interesting thing. So, people will turn around and say "well, my son has got this, this and this" and then another one, "my daughter's got this, this and this" or "I've got this, this and this."
31:18		And you can look and all of a sudden see there is a pattern there. And from the pattern you can develop a symptoms chart and start including these other things. So, from four or five main things like, they say the primary diagnosis with Pallister-Hall is you've got a mutation on your gene, right? Secondly, the feature is you have to have a hypothalamic hamartoma. Then you've got to have a bifid epiglottis, right?
31:49		Those are the central feature they expect to see. BUT, the symptoms of those things can be such a long array of things that all come from those three or four things. If people don't know what's underneath, they're never going to get to what's at top. If you come across as very emotive, or if you become...like I had no idea until I started looking more at hypothalamic hamartomas, there's things called "hyper-aggression", where it just gets out of someone's control, switches flipped and that's it. Well, you can't do anything.
32:35		There's the increase in nocturnal morbidity, at night, with people with the hypothalamic hamartoma. These are things I'm just becoming more aware of. But when you become aware of these things, you sit there and you think "Hell, that explains a lot of things. I've got all of that stuff." There's people who have been saying "Oh, you've got depression. You need to do something about your anger. You need to do something about your attitude."
33:02		If I don't like what you're saying, I'm not going to hold back and be nice and say, "oh gee, you're very nice". I'm going to turn around and say, "what a crock of crap". Because it's not confrontational, that's just the way it's going to make you react. You're not being confrontational, you're not being aggressive, you're just like "I'm not holding this in, boom, I'm going to hit you with it."
33:33	GSNV	So, George, the next set of questions we have are on the effectiveness and relevance of support networks. So, as we know, you provide most of the support ["that's exactly right"] worldwide on Pallister-Hall Syndrome and Gelastic Seizures. I'll still ask, how do you rate your experience with support groups? Is there any support besides what you provide?

	George	Look, there are support groups, but, the support groups that exist... again, mainly in the States. And you asked the question before about how has it financially effected and impacted you? This is the biggest thing; all of these support groups want money. They all want money. And they badger you for money. And they remind you, you should give money. But what services do they actually provide to the person who needs it? Ah, I'd say nearly nil.
34:30	G S N V	So, no outcomes?
	George	Well there is no outcomes for the person. You can throw a brochure at someone and say, "Here. This is about your condition." But what, and how, am I supposed to deal with it? On the bottom you say, "Write to us." Hello? For what? You're not going to tell me how, you're just going to send me another leaflet that says, "If you've got this, go and see this person." But there's some basic techniques.
35:03		We talk about Gelastic seizures, right? For instance, I told you about the incident with police. You might be arrested, and you start getting a Gelastic Seizure. Obviously, the policeman is going to say, "Well, you're being obnoxious. You're being rude. What's so funny?" So, I recommend to people that you carry a medical card with you that actually says "Gelastic Laughing Seizures".
35:30		So, if you do get pulled up and they do try anything heavy handed with you, well your only comeback is to say, "Hello, I've informed you. I'm not being a smartass, I'm not being obnoxious, I'm not being rude, I'm not acting against the law. I'm just acting beyond my control because it's not within my control." If, for instance, a person gets into a hyper-aggressive state with a hypothalamic hamartoma, their rage is just off the scale.
36:05		If they react in a situation, like one day you might actually find someone that is arrested for such a thing and then when you hear the word "hypothalamic hamartoma" or "hypothalamic rage", you'll know exactly what I'm talking about because these things people don't know about until something happens. That's where it is with that.
36:25	G S N V	What do you feel constitutes a good support group?
36:33	George	Well, a good support group is people sharing and helping each other, rather than someone trying to make advantage out of it. Parents contacting parents, you know, they've got similar ages of children, similar sexes etc, they share common knowledge; they help each other because they can feed off each other's knowledge. What one has had today may be what one has tomorrow. As I've said, my age outs me further out there but I've had people before me that might be 10, 15 years and they contact me and said, "Look, I'm having this happen to me. What am I likely to expect?"
37:19		So, if I talk about things, and as I've said, they ring me up six months later and guess what? It happened, or it's happening. It seems to be that the further we get with genetic disorders, the more we understand because back then we never had a name for a certain group of symptoms or whatever the case is. But now, when you've got this name for things and you've got people with it, you can actually see genetic disorders are not the beginning and end of everything, they are progressive things. What they start today is a chain of events that effects your life ongoing.
37:58		Like I said, the episode I had two weeks ago, that neuro-cardiogenic arrest thing I had. That's something I never had before. Maybe, at my age group, that's something that happens. People coming behind me might read about that and think, "Oh God,

38:27		<p>that happened to me last week, so I've got nothing to worry about." Because they can see me 10 years ahead of them, that I'm still alive.</p> <p>Now, as I said, they told me I should've been dead by the time I was in my early 20s because the Pallister-Hall was considered an early lethality disorder or at worse by the size of my hypothalamic hamartoma I should be a dodo bird. Well guess what? I'm neither. Either that or I'm reincarnated.</p>
38:45	GSNV	<p>Do you feel since there has been an increase in genetic diagnosis that there's more attention on early intervention or paediatric care and not the whole life experience?</p>
38:55	George	<p>Look, if you're going to ask for, or anybody is going to ask for support for a genetic disorder has to realise genetics is not the beginning and end with children. I'll give you a typical example, if you choose to edit it out, that's fine. When I was first diagnosed, I approached people like Jeans for Genes Day. Jeans for Genes Day absolutely refused to help me, "You're an adult."</p> <p>And I'm like, "Excuse me, I'm an adult with a genetic disorder, a child is going to be following in my footsteps. Wouldn't it be nice to know how that genetic disorder is progressing?"</p>
39:30		<p>So, I ring Cancer Council. "I'm sorry, you've got the wrong type of brain tumour." Hello?! You're taking money from people, for cancer research, for genetic research, but not giving it to those that need it. I desperately need it.</p> <p>You were talking about support groups. When I was first diagnosed, I sat in hospital being told all of those things were wrong with me, you would not believe, what the hell am I going to do?</p>
39:58		<p>I had an endocrinologist come in, he said, "Listen, the only thing I can do is to put you in touch with the specialist in America. Problem is getting you there. I will do a referral letter the best I can."</p> <p>Referral letter was done; the Australian government refused to help me. The only people in the world that know about it are in The States. Because I'm not going for treatment. How do I know what treatment I need if I can't even get diagnosis confirmed properly, that everything I have is actually that disorder?</p>
40:30		<p>So, they throw this at you. They put up this barrier. Then when you get there, they will not believe what they did six months later. They had the cheek to write to America to ask for my medical records.</p> <p>Where do they get off on that? Because they want to put it in their little database and learn.</p> <p>Well, how about you help the person in the first place? And that's with any of these people collecting for money. If you're going to collect, you give it, because a genetic disorder does not begin and end with a child.</p>
41:02		<p>Imagine the parent has got an infant with Pallister-Hall Syndrome, Gelastic Seizures, hypothalamic hamartoma. They're going to be at wits end when the child starts having seizures. They're going to be at wits end when the child comes home bullied. They're going to be at wits end with all sorts of things that happen, and they're going to want to know from someone who's been there and done that. Hello, is this normal? What can I expect? What can I do?</p> <p>They need to follow it as it goes to adulthood.</p>
41:30		<p>It's very important.</p> <p>I've never had the luxury of being a parent, but god help any parent that actually has a child with a genetic disorder, because I tell you what, it is very, very hard.</p>

42:00		<p>I feel great empathy and great admiration of any parent that struggles. I've heard it many times, mothers will do anything for their children. And that's true, and so will anybody who has got it.</p> <p>If I can help someone and say, "Look, I've been there and done that." That's why we did that article last year and you asked me what happened when I was a child. And I've got no qualms, I'm not embarrassed to say at all; I was bullied, I was shamed, I was ostracized. Because that's the fact of a genetic disorder. You look different – by crikey! People treat you like a blooming leper.</p>
42:24	GSNV	<p>And, I mean, this is just off of our questions but, you know, was there any support in school? Did teachers understand or-</p>
42:34	George	<p>[Bursts out laughing]</p> <p>Are you kidding? No way in hell. It was a case of "This is the way it is, it's normal. You've just got to fit in somewhere."</p> <p>The only best thing that ever happened, the best thing I ever did was, one day, and I didn't realise it 'til the last 10-15 years, but my hypothalamic hamartoma kicked in. Because you know what? I was bullied that much that I was sitting there in the front of the classroom and all of sudden I get this antagonism from behind me. These taunts. I lost it.</p>
43:13		<p>I was only four foot two, and this is my third year in high school. Besides the other time I did something but anyhow.</p> <p>I get into the back of the classroom, I pulled this fella out of his desk, and he was five foot something. I actually lifted him up against the back wall and I smacked him right in the mouth. Right? And it wasn't until I went to this school, something like ten years ago, that I actually met the form master who was there at the time. And he said to me, "You know what, George? That was the best thing you ever did. He said, "Did you get bullied after that?"</p> <p>I said, "Nah!" And I said, "Why didn't you tell me that?"</p> <p>He said, "I couldn't tell you that back then."</p>
44:00		<p>This is a reaction you get from being pushed, pushed and pushed. This might seem like going off the subject for a minute, but when they have these shootings in America all the time, no one ever stops to ask "Why?"</p> <p>Maybe, just maybe, that person has just had enough of being bullied. They could have something physically wrong with them. No one knows. You get teased for all sorts of things.</p> <p>But that's only the second time. The first time I threw a boy through a plate glass window at another school. [Laughter]. It's surprising what you can lift when you're very aggressive, by the pants, the scruff and vroom through the window.</p>
44:45		<p>But school support, no. And I bet you it still doesn't exist today. All they do is they'll send the child to remedial English or something like that to keep them away from mainstream. What they should do is get recordings like this, of people like me, to come in these schools and go, "Hellllloooo, I'm here!</p> <p>Don't look at me, and don't put that person down, because guess what? You might look like the big school captain now and everybody grovels at your feet, but you might be the father of a child with a genetic disorder one day."</p>
45:18		<p>Then watch it come home to roost. Because the worst thing for someone to realise that could be them, or someone in their family. Genetics is indiscriminate, it doesn't</p>

45:46		care if you're male, female, rich or poor. If it decides it wants to take someone, "boom". Tough titties, as they say. You've got it, and you've got to live with it. Things like what's happening to me, no one knows what's happening past latter age groups. Where's it going to go?
46:10		Now, genetic disorders are like a turning wheel, a cog. Waiting for the next cog to engage. What's going to happen next? We don't know.
46:25	G S N V	I could outlive you all. Right? I could die at a hundred. Do you put that down to the hamartoma, the second brain? What do you do? It might be a source of a long life [laughter].
46:36	G e o r g e	No one is immune to it and actually, from what you're saying, that's kind of something we're doing now. Do you believe that genomics should be in schools? That we should be learning about genomics in schools?
47:29		Yes. I think that, you know, you've just used the word "genomics". Plain English, please. Let's talk about effects of DNA. Don't give it fancy words. Fancy words is what loses people. If you put something in the simplest of language, right; if I'm going to write an article about Gelastic Seizures, sure enough I will start by saying 'gelastic' or 'laughing seizures'. But when I continue paragraph two, three, four, etc. I will say, "if you have a tendency to laugh." Take out the big word. OK, you could leave it there for its reference, fine. But talk general to people. Don't come in there, like I could say "hypothalamic hamartoma" but people don't understand that so I say "benign brain tumour", they can cope with that.
47:59		If I say to you "neurocardiogenic" you can be like, "ah, what the hell?" And you say, "Well, brain was affecting my heart which caused this to happen." Simple. If you want to teach kids, keep it as simple as you can. And I think too, they could go a long way, you know it doesn't have to be wait until biology classes of year nine or ten or whatever it is. Get it in early.
48:30		If you can read books about being different and accepted sexually, and all these different things, why not about being different physically? Actually physically different? Why does that woman there have two small arms, you know? Why has that woman got a clumbed foot or walking funny, right? It's not funny. That's what you've got to tell people. It's not funny to laugh at someone. You know, you laugh at a dwarf.
48:58		And say, "geez, he's funny." Well you know what? The small people like that are actually the most potent. You look at the one on the Game of Thrones. That guy's a multi-millionaire, for god's sake. You know? He's probably got fifty women hanging off him {Laughter}. People make a judgement and think you're lesser of a person. I was asked... Like I was born with twelve fingers. I had to have three removed because they were totally useless. I had a neighbour ask me, "What's it like to have nine fingers?" And growing up I said, "How the hell would I know? I don't know any different." Two weeks later, he lost half a finger in an accident, so I said, "What's it feel like?" See? I'm not any different to you. Believe it or not, you can find positive things out of genetic disorders. For instance, your height. Small people can get to places where taller people can't, right? For instance, with a smaller hand, if I want to reach into a car and get something down in the engine, I can put my hand where a normal person can't. Because, that's just the way it is. But people should learn to utilise people with let's say a "difference". They can fit in all sorts of places.

50:00		The person that's deaf, might be deaf but might be a fantastic writer. Don't write people off, because they're physically different.
50:15	G S N V	That's a good message. The last set of questions we have for you, George, is have you participated in Clinical Trials or research?
50:22	George	I have been in, as I said, I've been to the NIH in American, National Institutes of Health. I was part of their study into Pallister-Hall patients. I went over there, and I spent, I think it was twelve days at the NIH and I think there was about six of them were as an inpatient in the hospital where they had me hooked up to everything you can think of. Went from top to bottom and it's quite fascinating that when you have things anatomically different to other people, you learn about those things that you can tell someone.
51:09		Like, for instance, I had to have carpal tunnel surgery. And I've said to the hand specialist, "Look. I had this study done. My anatomy is not the way it should be normally, let's say." "Well, look, everybody's the same blah, blah, blah." So, anyhow, they decided they're going to do my hands under local anaesthetic, didn't they? So lo and behold, he makes the first incision and all I hear is it's not where it should be.
51:40		Now, I had warned him. The first thing I did was go to raise my hand I swore the nice little f-word at him and they knocked me out. When I had the second hand done a few months later, "We're not going to take any chance this time, we're going to knock you out." Because they had to do that to learn, but they weren't listening.
51:59		Which goes back again to what you were asking me at the very first instance about medicals. They don't listen to you. If I am telling you I've been there, part of this clinical trial, they've told me this, listen to what I'm saying. Now the good thing about the clinical trial, it puts you in with other people. The clinical trial in things like genetic disorders are no cures. Right? There is no cure for a genetic disorder, all you can do is deal with the things that result from the genetic disorder.
52:29		They can tell you who you need to see, what you need to look out for, what they've experienced. And you provide them feedback. Like, as I've said, hearing was never part of it until when I started having hearing loss, by that time it's a few years later, it's then been reported by other people. So now hearing loss becomes part of it because of the hypothalamic hamartoma. It's a shame we don't have anything like that in Australia.
53:01		But I've seen many times on television that people want to get to the States for this, that and the other thing. But the government will not help because it's not a cure. There is no cure, get that through your thick head, government. But it's a chance to learn. If you can go over there and support that person, that person comes back to this country and hello, the next person won't have to go. Because you already know about it. So that's why clinical trials I recommend if anybody can get the option given to them, go. No matter what genetic disorder, if it's a case of you learning and if you don't mind.
53:40		Like I say to anybody, if you don't understand something, ask for it to be explained. Ask for someone to draw a picture. Talk to someone else. "Can you put me in touch with someone else who can explain this to me?"

With your specialists, and things like that, you know. A lot of people don't like ... information is power. And if come across as knowing about your condition, to a specialist, they get actually the back up. And that looks like it.

54:15 GSNV [Monica] That's the Public Announcement to say, "George, stop talking!"

[Kari] George, that was great.

- ENDS -