

Noncompliant Podcast, transcript

[“The most effective way to stop it is public pressure”](#): Talking about Spectrum10K with Irish autistic activist Ryan Hendry

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Transcribed by Julie Ann Lee

Anne: Welcome to the Noncompliant podcast. I'm your host, Anne Borden King. The podcast has come out of hiatus, briefly, for this episode about an issue that's impacting our community now: the Spectrum 10K Project that's being pitched in the UK. Also, please note everyone: I'm recovering from a reaction to one of my cancer drugs and I'm a little wiped out. So, if I miss a few beats that's why.

Today, my guest is Ryan Hendry. Ryan is a 27-year-old autistic and ADHD advocate from Carrickfergus, Northern Ireland. Whilst Ryan's advocacy covers a wide range of topics related to autism and ADHD, he is particularly focused upon the issues that autistic people face when finding employment, as well as issues that particularly affect young people between the ages of 16 and 21.

Ryan, welcome to the show!

Ryan: Thanks for having me on!

Anne: So, let's start out for listeners that are new to this: Ryan, what is Spectrum 10K?

Ryan: Spectrum 10K is a genetic study that was announced in August of 2021, however, it has been in the works for some time before that. The idea is to collect DNA samples from 10,000 autistic people across the UK and to use it. Now, what they are going to use it for, they will not tell people, they're just very vague; they basically said it's 'to help'. When people ask for details as to how it's going to help, they the organizers got very evasive – evasive and defensive. When a few people started to look into it more, we didn't exactly like what we found. There's one of the ambassadors for Spectrum 10K, they tweeted at me after this, basically went on a prolonged flaming attack. Basically, any autistic advocate who asked any questions about this was told 'shut up, sit down, know your place' effectively.

Then people started looking into the individuals running the campaign. One of them is a guy from California who founded a group called *Cure Autism Now*. So, I think it's pretty clear what his aim's going to be out of this, despite their assurances, and I use that term very lightly, that it 'will not be used to try and find a cure for autism'. However, having it led by a person whose

sole career aim being trying to find this cure does sort of seem that it's a bit of hypocrisy, to say the least.

The study has now been paused and now the questions are being asked. There are some recent articles about the ethics around it and there's a big question as to whether this should have been approved in the first place. So, at the minute the pause button's effectively been hit.

They have already gathered samples. According to Spectrum 10K they have gathered over a thousand. We don't know what happens now: there's a possibility the study could be scrapped; there's a possibility it could continue; there's a possibility it could change. At the minute, it's all up in the air, but it's a case of now everybody's trying to work out what happened, and what happens now.

Anne: The players involved in it, for example Wellcome... do you know much about Wellcome, the company that gave £3,000,000, I think, towards the development of it? Would this be maybe that some companies are interested in developing and then bringing to market [genetic] tests for autism and then profiting from them?

Ryan: I think that's certainly a really big possibility from it. When I tried to research the funding, like you said, [with] Wellcome, I found that they gave £3,000,000 but what I also noticed is when you try to dig into the details of the companies, it would start linking you to different ones and you'd be getting sent down a million rabbit holes. Any material I could find saying what they do was all 'we provide health care solutions' and it was all very, very vague, you know, and so it sort of set off alarm bells that when people go to those lengths to basically hide what they want to do, it just seems inherently suspicious.

You know, the autistic community... maybe we sometimes can be hypervigilant with these sort of things because we've had our fingers burnt so many times before, but it's a case of it's more, you think if these things genuinely were good they would not be trying to hide what it is they're doing. My worry is they're going to create a genetic databank which can be sold to the highest bidder, because from what I can work out, the people backing this do have a commercial interest.

These companies are in it to make money, you know, they're not in it for charitable purposes. Look, I have no problem with companies operating at a profit – that's what a company does; I do have an issue though when the company is very opaque about it.

Anne: Right, right...and the kind of tests that they would be offering... I mean, it's very alarming. We've certainly seen it with other conditions. It's prenatal testing. When someone's having a baby they get prenatal tests to see if possibly there might be conditions. And I think what they want to do--and I've very dubious about whether this would ever be successful--but I think what they want to do is they want to identify the, whatever, 300 genes that they think they can identify related to autism, and then package that into prenatal tests. In which case, people

would be getting these prenatal tests and they would be having selective abortions of healthy, intended pregnancies if they get the news, you know, that there's an 'autism gene' in their baby. So, I think when we talk about it in terms of eugenics, everyone needs to understand that's what we're talking about. They want to create and commercialize – whether they can is another story – but what they want to do is create and commercialize a genetic test for autism prenatally. And then it's very simple, you know...we all can figure out what would happen if that were to come to fruition, right?

Ryan: I've known that that's the aim if you look at it over the years, how much money, how much time, and how much resources have been devoted to finding the 'autism gene'. You know, there... it's a case of 'our interest is purely scientific', and you're going 'yeah but you're going after this in such a way that suggests that that this could be potentially a very lucrative source of income'. And..., I don't buy from this how people could identify it, *identify* certainly... but to what end?

Anne: The website itself actually says, you know 'we're not doing eugenics', and you have to say like, if they have to come out that much and say 'we're not doing it', it's because it's very obvious that everyone is inferring that that is indeed the way things are going to go.

I think that it is a hedge on their part to say that they're not doing eugenics. What they're providing is a DNA database that they've already made clear they're going to make available to hundreds of researchers with various projects and goals and including, obviously, the prenatal test. So, it's very two-faced of them to say that [it's not eugenics], I think.

So, let's talk a little a bit about the double rhetoric happening in the campaign: to activists who are upset by Spectrum 10K they say one thing, but then to their broader audience and funders they're saying something quite different. Is that right?

Ryan: That's pretty much it. What they don't seem to realize is that a lot of autistic advocates talk to each other. We mostly all know each other in some respects because we work together. So when this was first announce--and this did come out of the blue--we started to find out that around January or February of 2021, they were contacting certain people in the community, approaching them and asking them if they wanted to be 'ambassadors'. Now, a lot of people said "No" straight off the bat. I wasn't one of the ones approached...I don't know if I should be insulted or complimented by that. But it was one of those things then when we started asking the question, we started realizing they had approached quite a lot of people and the vast majority turned them down or started asking questions, at which point Spectrum 10K backed out of it.

But as you said, the double-speak they're employing is very disingenuous. For example, they say 'we'll not do the genetic tests'. That's good, but do you promise you'll not provide the DNA to anyone who's seeking the data? 'We can't promise that.' My response to that was, okay, so you'll not do it, but you'll sell it to someone who'll do it. You know, it's things like that. It's a bit

of a shell game there. You know, they're busy saying that 'it's not us that's going to do it', but someone else *is*.

Like I said, the whole thing is that... in the UK we have the National Health Service. To think that you could have stuff being sold for profit, that is supposed to be essentially a health care issue and it does tend to really get people's backs up, especially as someone's pointed out, that people are being paid or being compensated for providing their DNA. And I was open at the start... when I first heard about it, I was impressed really and I thought this sounds interesting... but it was very, very brief. And my opinion was I'll have a look at this, and if it's something I genuinely think is beneficial, I'll probably participate. But then I started to dig into it and I was 'okay, this is a bit worrying'. And like you said, they then went silent. Basically anybody who asked them anything on Twitter got basically a copy-paste reply, you know they said 'check our frequently asked questions' thing, which again did nothing to answer the questions being asked... Okay, maybe it was just someone employed to run their social media and was told 'you can only reply this way'.

But we know for a fact they were aware of the problems this would cause. Because when they started approaching advocates back in January, they were told of what the problems would be, that this would kick off a firestorm, you know that [they needed] to have answers to these very specific questions and comprehensive ones, because no one is going to just be, 'oh, don't worry about it'. That's not going to work.

I think the whole way Spectrum 10K went about it, was their initial opinion they just thought 'oh, we can just push past this and everyone will forget about it in a week'. I think that was their plan, in all honesty. And when it started getting media coverage, I think that's when Spectrum 10K started to panic because as someone pointed out--and I don't know if there's any truth but--[allegedly] some of the financial backers started to query why this is being received so negatively (and I'm assuming these are the American backers who don't understand the culture of the UK). But from what I can understand once they started raising concerns that's when Spectrum 10K hit the pause button – when the money was under threat. Not because of any genuine concerns about how autistic people would react to this, but because they were worried about losing financial backing.

Anne: It's a P.R. move, right? And I think also the other thing that happens with the pause is that they hope that if they pause long enough that people will move on to the next shiny object and forget about Spectrum 10K, then they can quietly start up again. And, you know, that kind of shows in their rhetoric. They say one thing to the community, and they say one thing in public, but when they're talking to investors they talk about other things.

They make a lot of claims to investors about the "costs" of autism. They're attempting to put a dollar figure on how much autistic children "cost" society, and that's of course reminiscent of *every eugenics effort*--from those in the US, to those in Nazi Germany which would portray

disabled people as a drain on society or as a burden and put a dollar figure on how much we could reduce that burden if those disabled people were removed from society.

I guess my big question for you is when we hear and when we see Spectrum 10K talking about the “costs” of autism, what’s the impact of that to have to hear that as an autistic person in the UK or Northern Ireland?

Ryan: Well, it’s not an enjoyable statistic to read. The thing is that the statistic actually became quite a handy way of being able to almost at a glance tell – if someone includes it, it’s like, ‘okay we know where *they’re* going’. Because it’s a paragraph that’s literally the same among ABA organizations [who say] autism costs the UK more than cancer, heart disease, ...combined. This figure has been proven to be flat out false countless times. I think to the point that people are just sick of explaining why it’s wrong: “This is wrong, please refer to the numerous other times it’s been explained.” But basically, from the second I’ve seen that paragraph I just went, oh, I know where this is going. That was a lot of people’s reactions too.

It’s still not enjoyable to see because they’re clearly approaching this from the lens of ‘[autistic people] are a burden on society, how do we lessen this burden?’ You know, the inevitable answer to that is *have less of us*. You know, that’s the blunt way of putting it. I don’t think anyone is going to turn up to our house with a shotgun, but you know, it’s [also not] ‘let’s find more efficient ways of helping people, or let’s see if we can invest that money better in different services that would help’. It’s a case of “how do we reduce that figure? We reduce that figure by having less of ‘them’ to spend money on.”

And, you know, they’ll not come out and say it directly, but it’s a bit like a connect-the-dots, you know. The dots are *very easily connected* and the thing is obviously, you can’t say that quiet bit out loud, but everyone knows that’s the aim. If you look at the thing in common that all the organizations that use that stat have, the same thing they have is that they want autistic people to be *less autistic or not autistic*. It’s a common thread that runs through all these organizations from the likes of Spectrum 10K, where the scientific head of it runs an organization called *Cure Autism Now*. That’s as explicit as it gets!

Obviously then there’s the ABA organizations and their ultimate aim is to make us, you know, less autistic...indistinguishable robots. The common thread’s there. You know, it’s things like that, and that’s where it comes in with the pitch to the commercial backers: ‘look at the money we can save, therefore look at this money we can put into our own pocket.’

Anne: Right, and that could also be pitched to policymakers later on when trying to publicly fund a test, for example. So, we’ve already connected the dots. They’re very, very easy to connect and I find it quite offensive when anyone representing Spectrum 10K tries to say this isn’t what’s happening. They’re working...they’re collecting genetic data which will be sold-- if it would work – would be sold to people who would do genetic testing, the genetic testing would

be marketed out, and it would be commercialized. Private equity is involved, and the pitch to the investors talks about how, you know, the costs [of autism] would be reduced, et cetera, et cetera. It's very, very simple to understand this as a project that could lead to eugenics.

The other issue that I don't think we've seen enough about is the consent factor. Now they know that autistic people aren't exactly *lining up around the block* to give their DNA to this project because it's self-destructive, right? So they have to find other ways to try to collect this data. They're not going to get it from consenting adults, you know. So, they're going to be trying to get it from kids, and this is where Liam O'Dell comes in.

Liam O'Dell is an amazing activist who filed freedom of information requests and found some really interesting things about the project. One of them was a memo from within Spectrum 10K where they talk about what are they going to do, now that there's pushback and they don't have community buy-in. Well, what they're going to do, in their words, is "target autism assessment centres through a dedicated P.R. campaign." So, basically, when your child is diagnosed, the recruited--or possibly incentivized-- Developmental Pediatricians will promote the program.

And I have to say this has happened before. This is how they did it in Canada. When my son was diagnosed, it was the Developmental Pediatrician. [My son] was being diagnosed at this appointment...[the DP] gave us brochures about Speech Language Pathology, and Occupational Therapy and here comes a third pamphlet from her about the DNA project that was happening here at SickKids Hospital. And she told us that we should do it, that it would be beneficial because it was 'free genetic tests for other conditions', and you know 'don't you want to know – don't you want to know what conditions your child might have? This is a great free way for you to find out what conditions your child has.'

Basically, she was suggesting that we'd be irresponsible parents not to share his personal health information through this DNA database and it would benefit our family if we gave his DNA to this database, and it absolutely *filled me with fury* that they did it that way. That is incredibly dishonest and that's the playbook, and I believe that with Spectrum 10K, they will do the same thing. They will target Developmental Pediatricians; they will tell them to give this spin to the parents; the parents will proxy consent to give their child's personal health information – their DNA--to a database where they can never get it back. I'm just feeling like in terms of a rights perspective as well, the rights of these kids are really being trampled on with such a project.

Ryan: Yep. Absolutely. That was my main concern when I found out that they contacted health departments. I thought...that memo, funnily enough when I read it, I actually laughed because I just went NOPE, it literally put into writing what exactly I thought they would do [and then when autistic people] kicked up a fuss their answer was 'let's just try and ignore them', because step one in the playbook is 'ignore them and hope they go away'.

But the thing like you said is, when it's coming from doctors, 100 per cent you don't have to participate but the thing is you inherently trust what a medical professional will say to you. You already trust what they're telling you is generally in your best interest. So if your child's just been diagnosed, and you're told 'by the way here's this thing, it's not going to cost you- it's free. It's relatively painless and will help your child,' especially if your child's just been diagnosed and you're very new to this and everything your doctor said has helped, you're going to go, 'okay'. You know you're not going to look into it particularly. And especially if your doctor is laying it on thick and saying 'yes this is really good,' you know.

My personal opinion is that maybe doctors should look into it more. However, I could maybe understand if they don't because certainly in Northern Ireland our doctors are under immense pressure right now. From what I can gather, no GPs are actually telling any parents this, I don't think it has gotten that far. There was a question asked down in the Assembly, which is our legislature, basically asked to the Minister of Health what role has Spectrum 10K had in the Department of Health. Basically, it was a request to start handling their data in diagnostic situations, so something similar to what you described in Canada. I don't believe it has happened--at the time with the study being paused, it's unlikely to happen--but they will try again, in my opinion.

Like you said, the amount of [autistic] adults who would sign up for this would be very low. I would say, easily the vast majority of the people whose DNA they will have harvested by now are kids. And, again they've already got this, I don't know whether if the study's cancelled they get to keep this; I don't know whether they have to destroy [the data]. Once the genie's out of the bottle, so to speak, it's a case that there doesn't seem to be a lot of constraint as to what they can do with this DNA in terms they can sell to pretty much whoever they want. There doesn't seem to be any restrictions on that- like, Spectrum 10K can say 'there's a lot of restrictions on what we can do,' but they can just as easily sell to anybody. And they say: 'We won't sell, we pinky-promise we won't sell it to anyone bad.' I'm thinking, no, I don't trust that- I don't trust that for one minute.

Anne: I mean that's the *whole purpose of the project*. I think that to even entertain the argument that this is being done for some altruistic reason is completely foolish. It's all about making money, and even if they don't find the magic genes and things like that that they're looking for, there's going to be a lot of knock-offs who will [leverage] the hype...They're building hype around this idea of genetic testing for autism. All that hype is going to translate into a lot of scammers creating products to try to detect autism prenatally. So, they've... in a way the genie is already out of the bottle.

I guess the question is now, what should the Spectrum 10K project do instead, to make up for the damage that they've already caused?

Ryan: Well, in my opinion they should just disband, say we're sorry, this is a bad thing to do and just cancel it, but unfortunately I know that's not going to happen. But it's a good question, obviously I don't know. I don't think they will do anything to apologize. Certainly, the people who run it...for example, Simon Baron Cohen is involved in it and he has a notorious reputation for *not apologizing* for any of the stuff he's done that went wrong over the years. So, expecting him to apologize is a bit like expecting me to suddenly sprout a pair of wings and fly. It's just not going to happen.

They're not thinking about 'what did we do wrong?' They're probably thinking 'how do we get around the current roadblock?' Now, I'm under no illusions that the current statement isn't all a P.R. exercise. I would say as well, like you said yourself, I think they're waiting for everything to quiet down, try again and see if it slips through unnoticed.

Anne: Are there regulators that could take action and shut it down? I mean, I know there were people reviewing it and again Liam O'Dell's documents from the Freedom Of Information request had a comment from a reviewer, an ethics reviewer of the Spectrum 10K [application], who said "they're creating a registry, a DNA bank of a vulnerable group. Not sure it should have gone through as basic science."

Ryan: Yeah.

Anne: So it might be possible to appeal to the reviewers or to health regulators to try to show the ethical implications of this project, from the eugenics perspective and also from the consent [for giving] private health information perspective as well.

Ryan: I think there is a mechanism for particularly unethical studies to be stopped. I think, though, a lot of it within academic circles tends to be self-regulating, the idea is that everyone acts above board and fair play. However, in some cases, I think Spectrum 10K is kind of showing they're not willing to play on a level playing field. My opinion is from day one they've been evasive. They've been deceptive. They tried to hide things. My opinion is that they're not going to suddenly come out clean *now*. They're just going to try to find other ways to game the system.

I think there are ways to stop them. Certainly, I do think the most effective way is public pressure, basically. One thing I've found is trying to explain to the general public why [stopping Spectrum 10K] is a good thing is quite difficult, because it requires going into detail, and that is always difficult to hold on to people. You know, when you need to go into detail about things, that's when you start to lose people. ...I would say the biggest challenge for autistic advocates has been trying to explain to people quite quickly and easily why this is bad. And the best I have basically said is what they're basically creating is *a DNA databank that they want to sell to the highest bidder to basically find a way to do a prenatal test*. I find that tends to get people's attention because it's sort of a good, sharp summary of what they really want this to do.

My other worry as well is that I understand that in America (and I think in Canada to some extent) financial muscle tends to be quite a lot more persuasive in terms of financial players, they are much bigger players, whereas in the UK a lot of universities tend to rely on funding from the government for a lot of things. So then there is regulatory framework that does come into play. In the UK we don't have this spectre of *Autism Speaks* hanging in the background. I think that is maybe, potentially about to change.

Anne: Yeah, I would think so, because one of the people (as you mention) who is involved with this is from *Cure Autism Now*, which was the first group that broke off from *Autism Speaks* and he's from California. And the MSSNG project in the US... *Autism Speaks* is very heavily involved in collecting tens of thousands of DNA profiles on autistic kids in Canada and the US, so, it would be surprising if they didn't really start to have, or fully have their hand in this project and in this kind of venture that's happening there.

Ryan: It wouldn't surprise me. They've made numerous attempts to move into the UK in the past, most of the times they've been repelled mainly because, I will say this, that the National Autistic Society I will say they do some things horribly, but I've always said that in terms of actually having autistic people involved, they're light years ahead of the likes of *Autism Speaks*. I wouldn't say the NAS are brilliant about it, but I think with the NAS a lot of it depends on the local level. NAS of Northern Ireland I would work closely with, and I found them to be fantastic for most things. I find at the national level, sometimes it's a bit more iffy, let's say. But they're infinitely better than *Autism Speaks*.

My main argument is that, obviously, in the past few years, *Autism Speaks* is basically engaged in a P.R. re-write of their entire thing. Obviously they've made the big thing about 'we're no longer looking for a cure, we're now looking for a solution' – which is like, *isn't that the same thing?* But they made a concerted effort to try and clean up their act, but in my opinion once you start digging it's still the same organization; still the same people running it; still the same projects they're running; still the same funding split--they're still funding the same projects.

What I have noticed is the trend, especially for these organizations that sort of basically put up a nice P.R. front, is they tend to pick out [autistic] people who are relatively new to [autistic self-advocacy], you know, so maybe aren't fully clued into to what *Autism Speaks* really is. So, you know, you see them using all the right language, using all the right terms. They seem to be supporting this person, you know.

Something similar to me happened to me when I first moved into advocacy, I started working with a charity that on the face of it said the right things and then helped me arrange like speaking opportunities and that. So I thought, this is great! But, then, I sort of started to hear whispers that it wasn't as good as what I thought it was. When I asked them about it, naturally they said, 'no, no, no, we're brilliant'. You know, as they would have done. But, then a lot of

people started saying the same thing and hang on, a lot of people here are saying the same thing, and they don't even know each other. So I started doing my own digging, and that's sort of how I ended up quitting the organization, which they did not take too well. But, it's a case of basically keeping on doing what we're doing, and trying not to fix it too much from what they're doing unless they *directly impede the work that myself and other advocates are doing*.

I tend to stay clear of *Autism Speaks*, unless it's a pertinent issue I feel the need to address. ...

Anne: We just have a minute left – what would your advice be for autistic advocates who see this kind of thing coming to their local hospital in terms of how they can act?

Ryan: I would say that if it's being brought up with the hospital, find out where it's coming from and ask questions about it. Don't be afraid to talk about it. Also, don't be afraid to go to other advocates and ask for a bit of help with it, because I understand, especially if you're relatively new to it, it can feel daunting to take on administrations. You know, it's not easy singlehandedly, but you'll find you have a lot of people support it. I find especially when I went to people- I've been doing this about 8 years now, but I would still go to other people for advice and support and ask 'what's the best way to approach this?' Cause there'll be other people with more expertise in it.

I would in particular reach out to people who are quite *new* to advocacy just to try and help them because it can be quite daunting. I think sometimes some autistic advocates can sometimes apply a bit of a purity test, and can sometimes get a little irate at people for using the wrong type of language and all, but... put it this way, there's a picture of me when I was 19, standing outside Belfast City Hall supporting the Light It Up Blue campaign. Now, you know, if I'd done that now...but I was only in advocacy 3 months at this point. I had no idea what it meant. You know, in my opinion it was a good thing ...so I use that picture [of me] almost like this – people don't know unless people make mistakes, don't hold it against them.

If I had gotten a backlash of people that *went at* me for that, I would've probably deleted my Twitter account and 'I'm not touching this'. But what I did have, I had several very polite, very educational messages sent to me through Twitter and Facebook from other advocates who explained to me and said, 'it's great you want to advocate but here's this thing about this campaign you might want to know this'. You know the approach- they tried to educate me, they didn't shout at me.

I think that's the thing--always remember sometimes people acting with the best interests in mind, sometimes not the best actions. But, you know, it's not always malicious, sometimes it is just mistakes. And, I know not everyone maybe sometimes has the patience or, you know, the sort of attitude that they're basically dealing with and I know it can be tough, especially that

campaign. Like I look back at that picture sometimes and I just think ‘what was I doing?’ But, equally I always use it as an example that *people make mistakes*, you know. I have no problem with it, I shouldn’t have done it, but equally, I didn’t know any better. With younger advocates that are the same age as I was then, I would send them the picture, say ‘look, I know what it’s like to sometimes make a mistake,’ and I’ll step in and tell some of my colleagues... ‘you know, they’re still a kid. Give them a chance’.

Anne: That’s great advice. I love that advice and I think everyone should take that to heart. This is a pivotal time in our community.

Thank you very much for being on our show, Ryan. It’s great to speak with you!

Ryan: Thank you very much for inviting me!

Anne: I was just speaking with autistic advocate, Ryan Hendry. He spoke to us from Northern Ireland.

You’ve been listening to the Noncompliant Podcast. I’m your host Anne Borden King. Noncompliant is recorded at MCS Studios. This episode was engineered by Francois Heroux. The podcast is transcribed by Julie-Ann Lee. Thanks to everyone on the team, and thanks for listening.