

[“They prey on unsuspecting parents who think they’re helping their child”](#):  
**Interview with Amanda Seigler about bogus autism research at universities,  
Part 2**

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Transcribed by Julie Ann Lee

(Theme song - soft piano music)

**Anne:** Hi and welcome to the *Noncompliant* podcast. I’m your host **Anne Borden King**. This is part 2 of an interview with children’s rights advocate and autistic activist **Amanda Seigler**, talking about when university research exploits and harms children. We spoke in the last episode about the recent Yale Study where researchers frightened children as part of an experiment that proved...that didn’t prove anything and we also talked about a nicotine patch study which has evidence of risk but no evidence of benefit. We’re now going to discuss the **Duke stem cell autism trials**.

Welcome to the show, Amanda!

**Amanda:** Thank you for having me.

**Anne:** I’m going to summarize the Duke study as quickly as I can. Basically, Duke University is falsely supposing that stem cells are a plausible autism treatment that should be studied. This is not true. There’s no reason to be studying stem cells. There’s no plausible mechanism to believe that stem cells would have any impact on autism and in fact in Duke’s own early research as well as other research confirms that there’s no evidence of benefit to injecting children with stem cells. (Big surprise.) And that there’s clear evidence of harm in Duke’s current endeavor. ...And then in a separate revenue stream Duke is now charging families \$12,000 each, encouraging them to fly across the country during our pandemic to have the Duke team inject these children with stem cells to see... I don’t know what they’re trying to see...and there’s clear harm which we’re going to be discussing.

The important issue here gets back to what we talked about in the last episode about universities and **research funding**. The money here is important. The Duke study is solely funded by Home Depot co-founder Bernie Marcus’ foundation which is the Marcus Foundation. Marcus has a bit of a personal interest in stem cells, believing their potential for a lot of conditions. He’s associated with a for-profit, off-shore, stem cell clinic that’s not FDA regulated, called the Stem Cell Institute of Panama.

The director of the Stem Cell Institute of Panama, Neil Riordan, has photos of himself with Bernie Marcus as well as with the Duke Study lead, Dr. Joanne Kurtzberg on his website and he claims that he reviewed Duke’s application of funding to the Marcus Foundation, whether or not he’s as close as he is to them, he does leverage that hype around Duke’s stem cell autism program--and as Amanda and I, and **Melissa Eaton** and others have learned from studying social media groups as well as **Leigh Turner**, the bioethicist who’s been studying GoFundMe campaigns, there are a lot of parents who are doing GoFundMe campaigns to try to travel to Panama after they’ve been to Duke.

So they go to Duke, they get the stem cells put into their kids, and then they want more stem cells and

they go to this off-shore clinic. This is really risky in and of itself to have multiple donors involved in stem cells at all.

There's another financial connection that I'll just quickly mention that I think is important and that is the company Cryo-Cell. Cryo-Cell is a stem cell company that has a patent agreement with Duke. And Dr. Kurtzberg, who's Duke's project lead, is on the medical board of Cryo-Cell. There are many people in autism research who are trying to find that kind of silver-bullet autism cure that they can patent and sell and that may be some of what is going on here with the Duke study.

I'd like to talk first about the *harm* these studies cause and the risks and then we can talk about the validity (which obviously there isn't) and finally get back to the money again that flow here between the for-profit centers, the funders, and the university studies.

Amanda, what are the FDA's warnings about the risks of stem cell therapy, especially for children?

**Amanda:** There could be administration site reactions, they can lose the ability of cells to move from placement site and can change into inappropriate cell types or multiply because stem cells are cells that haven't decided what they want to be yet.

**Anne:** Hmm.

**Amanda:** There could be a failure of cells to work as expected and they could even cause the growth of tumors. It could be a very scary process. Kids are either sedated or they are restrained while these stem cells are usually infused slowly. Because if they get infused too fast the cells will break down.

[5:07]

**Anne:** Mm-hmm.

**Amanda:** And having to be there for several hours just for this infusion can really cause some **psychological damage**. 'What's wrong with me?' 'Why am I not good enough?' and things like that.

**Anne:** Right and I think even in Duke's own reports, they talked about children that 'agitation' was one of the main side effects that kids had in the study. So, they were agitated at having to be in the lab and that's why they ended up chemically restraining them with various sedatives and things like that to get them to get through the procedure. Now this would be one thing I think if they were getting, I don't know, *chemotherapy* or something that was literally saving their life, but *this is literally for nothing*. *There is literally no benefit whatsoever to the child ...no health benefit to anyone in doing any of this.*

**Amanda:** No.

**Anne:** Why would parents think that something like this would work?

**Amanda:** They want a miracle cure. They were exposed to autism with what I call the tragedy narrative, that they should be grieving their child after a diagnosis or do everything they can to make them have "normal life as possible." When they're exposed to that type of thinking they want to be able to "fix" their child and when someone says 'this treatment may help fix your child', they don't even ask questions and they just go. This is the same mentality that people have when they try bleach on their children to try to cure them.

**Anne:** Hmm. Right. You've been inside the social media groups. There was an NBC story about you and Melissa Eaton going into the social media groups of these parents that were using bleach, that were using MMS and some of these other phony cures for autism. And you've been in contact with parents who were in the Duke program and maybe moving on to the program in Panama.

I'm wondering, it seems to me that often the parents that are doing the stem cells have tried other things as well. I'm wondering what other autism treatments they're using on their kids.

**Amanda:** Oh, they've tried the bleach as we talked about before, they have chelation which is either IV, orally where they have a spray. The spray is more readily available. Then you have pumping them full of supplements without bloodwork to see if the child is deficient. Then...there's so many.

**Anne:** Yeah, you and Melissa shared a lot of screenshots with me from these groups where it was a group, a stem cell-based group but the parents were talking about how they weren't just using stem cells. They were using this, they were using that. It almost seemed like there was a *type* of parent that ends up joining trials like the Duke trial. And it's a parent like you said taking this 'throw everything at the autism' type approach. So there may be multiple areas of trauma that are affecting the child because they're undergoing multiple treatments. And like you said, they're getting this message over and over again.

**Amanda:** Yes. Definitely. It's almost the same mentality if you're putting an [LGBTI+] person through conversion therapy. Conversion therapy is illegal in several states now.

**Anne:** Mm-hmm.

**Amanda:** It would be a very similar psychological side effect from all of this. 'You're not okay. The way you are is not how you should be. Don't worry, I'm going to fix you.'

**Anne:** Mm-hmm.. When you think about what was done to [LGBTI+] people in the olden days (and in some places still being done but that is often being regulated out), things like conversion therapy or castration therapy or various things being done to the bodies of gay people to try to make them not gay, it was seen as an act of *kindness* to do this the person. I see this kind of the same way, that the parents – many of them-- think that they're doing something to help their child and they also have great hope and they really believe, even though it's an experimental treatment, that it's going to work.

And I think one of the reasons for that is because of the hype that we see in the media and it's a big frustration. I was [talking with Eric Garcia](#) a couple episodes ago – he's a journalist – about why it is that some journalists will defer to the "experts" even when the experts are really, you know, you could say scammers hiding behind their PhDs, right?

[10:11]

**Anne:** You can do some things that are pretty shady and call yourself an expert, not even people with PhDs, sometimes it's just someone selling some vitamin supplements and they end up on major network shows as an 'expert.' So I guess I'm wondering: I know the media outlets are in a hurry, but it seems like we need to combat that somehow. We need to get media outlets to understand that when they create

hype around something like the Duke experiments they're inadvertently actually driving people into a lot of pseudoscience, including the off-shore, unregulated clinics.

I don't know what to say more about it except that it's very easy for people to exploit the media to sell their products and...

**Amanda:** Mm-hmm.

**Anne:** ...as activists it's very frustrating to see.

**Amanda:** One thing I did see that was interesting about this. There was, I don't know if you remember Dr. Klop out of Canada...

**Anne:** Mm-hmm.

**Amanda:** ...that was sanctioned by the College of Homeopathy? Is that-

**Anne:** The College of Naturopathy in British Columbia.

**Amanda:** Thank you! I'm not from Canada, I was trying to remember. So two of the people who were involved with the fecal transplants were also trying to recruit people in certain groups to the Duke study.

**Anne:** Hmm. Wow. Is that through the social media groups that you've been seeing?

**Amanda:** Yes.

**Anne:** What's the environment like in the social media groups? How many people do you think are even in these social media groups where the parents get together and kind of bond around these phony cures?

**Amanda:** So, there's some [groups] with thousands of people in there. I think there's one that I'm in that has about 12,000 people. I mean it's really, really scary how many people come into these groups to exchange ideas on what to do to their child next. It's very scary! And you know about these people who were doing the fecal transplant before where they actually had to go into Mexico to have it done because in Canada and in the US it just would not be legal. It just would not be sanctioned.

**Anne:** Mm-hmm.. Right. But they find each other *and* they can network for their own companies. I see in the stem cell groups that I was monitoring on Facebook, the sort of private parent support groups that I went into to see what was going on. What I saw in those groups was actual *sellers* going in. These are sellers in the US who are marketing stem cells out of their clinic which is illegal. It's illegal. Now what Duke is doing has FDA approval. So I'm not talking about what Duke is doing, but there are clinics in the US like Naturopathy clinics, even MDs who are marketing stem cells as an autism treatment.

What they do since it's not allowed is they don't necessarily advertise it on their website...although sometimes they do and the FDA issues them warning letters. But more often than not what they're doing is going into the social media groups and marketing their services *right in the group*, directly to the parents and that's how the parents find out. It's almost like an underground network of non-approved treatments. And now, they *say* it's stem cells. I don't even know what they're injecting the kids with at some of these clinics.

**Amanda:** And we don't know if they're testing it for safety - if the donor of these stem cells had any type of disease or history of certain cancers in the family.

**Anne:** Mm-hmm.

**Amanda:** It's very, very risky.

**Anne:** It is very risky. And then the risk is for nothing! Which is- it just adds the insult to the injury.

**Amanda:** Mm-hmm.

**Anne:** And it's a scam. I think the hype around what's happening at Duke, with their repeating and repeating these unproven (exasperated sigh) this unproven treatment is inadvertently perhaps helping a lot of these even shadier outlets that are doing it.

I was wondering since you've spent a lot of time in these groups on social media and you've studied this, your website, the **Fierce Autie** website, debunks a lot of phony autism cures. I was wondering what kind of change-- in your [opinion]-- needs to happen with social media to help educate these parents?

[14:47]

**Amanda:** What I see a lot is some of these treatment are even run by Facebook ads --and as much as we report it, they don't do anything. They will keep them up and they **prey on unsuspecting parents** who will think they're helping their child but instead they're harming them.

And the algorithm goes against people trying to do the right thing, trying to help parents to have their child lead a happy life when the parents really don't know better when they first start out. Because when you get a diagnosis you are handed a package from Autism Speaks and 'have a nice day'!

**Anne:** Mm-hmm.

**Amanda:** Social media does need to do its part in controlling content that these people are putting out. I mean even with the anti-vaxxers they weren't until recently taking down anti-vaxxer content.

**Anne:** Mm-hmm.

**Amanda:** And just recently a prominent anti-vaxxer activist was taken off of Facebook. Thank goodness. I'm sure everybody knows who Larry Cook is.

**Anne:** Larry Cook, right. Yeah. But one of the problems is they can reinvent their websites or reinvent themselves quickly as well.

**Amanda:** It just never ends. Well, we did get lucky at one time. We were able to report somebody in Spain who had the most unique name where he was the only one in the world with that particular name and we were able to get him reported.

**Anne:** Mm-hmm.

**Amanda:** But Telegram is also anonymous. It's also hard to pick out who they are so we can report them. So most people go unreported because we have a hard time identifying them.

**Anne:** Right. Right. I mean another way to get rid of the problem...the second part of it besides regulation and enforcement in social media is to *just get rid of the market itself* by educating parents not to pursue these things. How is that starting to roll along? How is the neurodiversity movement involved with taking that industry down through education?

**Amanda:** It's getting better. There are more and more autistic led groups, including mine and **Emma Dalmayne's** that are pushing education and what these different substances do to children, and [letting people know] your child isn't broken, they're just different. If you're not sure how to react or how to remedy a situation, there are groups like **Autism Inclusivity** which is run by autistic people for neurotypical parents of autistic children. [Parents] can come in and ask any question and they can be educated on what to do so they don't make the same mistake that we went through.

**Anne:** Right. There's even websites and platforms like the **Foundations for Divergent Minds** that educate parents on how to, like we were talking about in the last episode, **change the environment** instead of change the child. So just making very simple changes to the environment – accommodations like you would do with any other disability to make it so that if the child isn't as frustrated and things aren't as difficult, that's part of the problem. The other part of the problem is **acceptance**. And of course the message from Autism Speaks is not 'accept your child,' it's 'grieve the child you lost and purge the autism from the child,' it seems, in some of their messaging.

So then, if that's the first message that parents are getting when their child is diagnosed, then we also need to reach out to physicians and developmental pediatricians so that they can get the right information into the parents' hands right at the time of diagnosis, eh?

**Amanda:** I completely agree. One comparison I always draw for people - this might seem a little out there, but I'm a Veterinary Technologist, I really can't help it – is look at what Jackson Galaxy does with cat owners. 'My cat is doing this' – change the environment – magic! The cat's not lashing out and using the same principle, change the environment and the autistic child will be acting different because **behavior is communication**.

**Anne:** Right.

Right. That's a lot of what your organization is doing through **Autistic Inclusive Meets** US Chapter which you're involved with and then also the group that you've been involved with for a long time called **Fierce Autie** where you're trying to bring a dialogue between non-autistic parents and autistic adults to try to educate the parents through basically grassroots dialogues on social media, is that right?

[20:02]

**Amanda:** That's correct. The organization is called **Fierce Autistics and Allies**. The theme is based off of my internet persona – I guess that's what you would call it. I want to bring autistics and non-autistics together because there is this big rift between both groups, and it really shouldn't be. We should all be working together.

**Anne:** Right.

**Amanda:** If you do this through education...we were able to reach out and there was a little girl who was being sent to her Mom and her stepfather, but the stepfather was abusing her and we were able to

reach out to the courts and to media and the judge did not force them to send the child back to the mother's, which was amazing.

**Anne:** Mm-hmm.

**Amanda:** Because they were just not listening to her, just on the sole fact that she's autistic. That was the only reason they were giving.

**Anne:** Right.

**Amanda:** We got justice for this child which was amazing.

**Anne:** That is amazing. I'm lucky enough to know you well and hear stories from you like this, a lot about you and other individual advocates intervening and getting children put into safer situations. And every time that that happens, it's just incredible and all of the work that you and other autistic self-advocates are doing on this issue is all being done *for free*. It's just being done out of love and caring, for trying to make things better and safer for kids.

It's really the diametrical opposite of what we see with the big funders and the big programs where some of what's being done to "help" autistic kids is really clouded by money and financial issues, financial interests, fiduciary relationships and even politics sometimes in a way that's really divorced from what really needs to happen, which is really just about human rights and protecting people's safety. I'm so thankful for everything. You are constantly an inspiration to me in the type of work that you're doing with Emma Dalmayne and Melissa Eaton and the others that are working on the ground on this. Thank you so much for everything that you do.

**Amanda:** It's been absolutely amazing working with you, too. You do more than I think you give yourself credit for.

**Anne:** And thanks again for coming on the show, Amanda Seigler from Fierce Autie and Autistic Inclusive Meets US.

Thanks Amanda!

**Amanda:** Thank you!

(Theme song - soft piano music)

**Anne:** You've been listening to Noncompliant: The podcast. I'm your host Anne Borden King. Noncompliant is recorded at MCS Recording Studios. Engineered by TJ Liebgott and Nathan Greavette