

# Targeting the Toughest Diseases

## Episode 5 – Targeting Pain

*Quána Madison: I wake up in pretty intense pain in my joints and my hands. Sometimes I wake up in tears and cry and give myself space just to feel what I'm feeling, and then slowly begin to figure out what's the safest way for me to sit up without crying the entire experience through.*

**That is how Quána Madison starts every day.**

*Quána Madison: It's all the time, it makes me tired, and for things like taking a shower, for instance, the temperature change causes pain on my skin. Putting on clothing is actually a painful experience. It hurts.*

**What she's living with is pain: A simple concept, but a complicated medical problem.**

*Quána Madison: I've gone so long now that I don't even remember what it feels like to not be in constant pain.*

**Hi. I'm Jordan Gass-Pooré, a member of the University of Southern California's Center for Health Journalism.**

**This is *Targeting the Toughest Diseases*, a podcast produced by Bloomberg Media Studios and Vertex Pharmaceuticals. In this series, we look at some of humanity's most challenging diseases, and how Vertex – a Boston-based biotech company – is using innovative tools, methods, and a unique philosophy to search for treatments and cures.**

**Today, we're looking at pain.**

**You might think “pain” is just a sign that something else is wrong in your body, but Vertex is looking at pain as its own unique condition. They're treating it as a disease – something that might need its own specific treatment.**

**For people like Quána Madison the label doesn't matter. For her, pain is a daily reality.**

**But you wouldn't know it from looking at her.**

*Quána Madison: Well, I have a Afro Mohawk and I'm a short African American woman. And I would say I have a bold or funky style, enjoy fashion and expressing myself as a artist. Very Bohemian chic.*

**Artistic and creative expression has helped Quána over the years cope with the compounding impact of her chronic pain.**

*Quána Madison: I'm very active in the arts community, and I also do a lot of advocacy work with different organizations that support people with disabilities, the LGBTQ community, Habitat for Humanity, and Catholic charities.*

**Most of her volunteer work is focused on helping other people – which is amazing because she's never really gotten the help she needs to deal with her own condition.**

*Quána Madison: When I was in childhood, I was not talked to at all about dealing with the pain beyond being told to just deal with it. I would say I was undertreated, and my pain was often dismissed or downplayed.*

**When someone says they have cancer, or some other specific disease, we all have an idea about what that means. But when someone says they're "in pain." That's harder to wrap your head around.**

*Quána Madison: I could try to describe what I was going through with my pain, but they didn't understand it because they couldn't see it.*

*Quána Madison: It's really depressing and overwhelming. It makes me feel much more isolated and it's incredibly, painful emotionally, just to know that I'm not taken seriously with that, that I'm undertreated, and it causes a lot of depression and despair.*

**Quána's pain started when she was a child. She had a bacterial infection in her left ankle. That infection led to sepsis. That's when the body has an extreme response to an infection. The doctors told her parents she had a thirty-percent chance of surviving.**

**She beat those odds. Doctors were able to treat the infection, but her body was never the same.**

*Quána Madison: Over the years, when I was a teenager, my pain got worse and became chronic.*

**The pain just kept getting worse. And doctors didn't exactly know why.**

**Pain is classified in one of two ways: *acute* – meaning it can happen suddenly and may not last more than a few weeks. Or *chronic* – meaning it can last several months or longer. And of course, it can range from mild to severe.**

**Pain isn't a bad thing – it's actually an important warning system – it's our body's way of telling us something is wrong. But when it continues, it becomes a problem.**

*Dr. Norman Buckley: Typically, you expect a broken limb to hurt a lot when you injure it, gradually get better, it'll be achy for a few weeks, but as it heals, you, after three months, you would not expect someone to still have pain from that broken limb.*

**Dr. Norman Buckley is the Director of the Michael G. DeGroot National Pain Center in Hamilton, Canada.**

*Dr. Norman Buckley: There certainly are settings where people continue to report pain and then you have to consider, you know, what is, what's the reason for that?*

**He says doctors have used medicine to manage pain for centuries.**

- **Opium in the 1600s**
- **Ether and chloroform in the 1800s**
- **Then morphine and even heroin in the 1900s**

**Today, opioids are the go-to treatment for people with severe pain. And while this powerful class of drugs definitely helps people cope in the short term, there are risks associated with long-term use. Innovation in pain management has been slow.**

**Pain is both common and complex. It affects people differently. Those differences might be influenced by gender, genetics and age.**

*Dr. Norman Buckley: Those things vary from person to person, those are the kind of things that are I think leading us towards better pain treatments.*

**Pain represents exactly the kind of medical problem Vertex is targeting:**

- **There is a long history of research to build on**
- **There is new technology available, or Vertex thinks they can develop it**
- **There is a large unmet need**
- **And Vertex thinks it may be possible to eliminate the symptoms or tackle the underlying disease**

*Dr. David Altshuler: We've picked a set of diseases: cystic fibrosis, type 1 diabetes, sickle cell disease. Also, pain.*

**That's Dr. David Altshuler. He's the Chief Scientific Officer at Vertex Pharmaceuticals.**

**What he's really on is a quest for something innovative. He's in search of new ways to solve old problems.**

*Dr. David Altshuler: The real question in our mind is can we succeed? Can we make a difference?*

*Dr. Paul Negulescu: Pain itself can be a disease.*

**That's Dr. Paul Negulescu. He's leading Vertex's research in this area.**

*Dr. Paul Negulescu: So, while pain is a symptom of diseases, many diseases: diabetes, cancer, arthritis. It can also be a disease in and of itself.*

**Dr. Negulescu's journey to researching pain is an interesting one. He spent many years studying cystic fibrosis at Vertex.**

**Now, he's using that understanding and applying it to pain, since both conditions involve sodium ion channels.**

*Dr. Paul Negulescu: There are tens of millions of people in the U.S. that get severe pain experiences every year, either acute or chronic pain.*

*Jordan Gass Pooré: One thing that really interested me is why does it seem like some people are more sensitive to pain than others?*

*Dr. Paul Negulescu: It's a very subjective thing, pain, and we don't understand what makes different people sensitive or not to pain. I would say though, there are outliers. I mean, there are definitely some people that are way off the charts in terms of their ability to detect pain or not.*

*Jordan Gass Pooré: Would you be able to break down for me a little bit further into what exactly is pain?*

*Dr. Paul Negulescu: That's a really good question. So, pain is an unpleasant sensation. It's something that you experience and so, therefore, it is something that has been processed by your brain and depending on your state of mind, literally, that affects your ability to sense pain. So, it's a complicated process by which we perceive pain.*

*Now, the way that we're trying to approach it, which is to kind of take it out of the brain part. In most cases, it's due to an injury or a surgery or damage to a nerve that's outside the brain. So that part of the body is sending signals to the brain. "It hurts! It hurts!" And then you're processing those signals and depending on whether you're awake, asleep, distracted, you feel different levels of pain.*

*Our goal is to try to cut it off at its source, where it starts. And so it never really gets to the brain. And therefore, you don't feel it.*

*Opioids work at the level of the central nervous system, they actually suppress the inputs that are coming into the brain. And so, we're trying to work from the outside of the brain to reduce the pain signals into it.*

**That's the unique aspect of Vertex's approach – to target pain at the source.**

*Dr. Paul Negulescu: The way we're approaching both acute and chronic forms of pain is by targeting these proteins that have been identified through human genetics as playing a key role in the transmission of pain signals in pain-sensing neurons.*

*If you think about the pain-sensing neuron as a wire, it's transmitting a signal that says, "I've got pain in one part of my body" to the other part of your body. And for that signal to get transmitted, it has to be conducted along that wire and the sodium channels serve that function – to conduct that electrical signal through that sensory nerve.*

*It's kind of like a bucket brigade. One sodium channel opens at one end and it passes the electrical signal to the next. And that gets passed to the next one and so on. And that's how the signal gets propagated.*

*And so, we're trying to interrupt that transmission. We're trying to interrupt that passing of the bucket and we believe, we hope, that by inhibiting those channels, we will be able to block pain signals.*

**The work is focused on the mechanism of signal transfer at a molecular level, with the hope that this would make a big difference for patients on a larger scale.**

**For Quána Madison, until an additional effective treatment is available for her pain, she'll continue to rely on the tools she has at her disposal to manage the condition: meditation, self-care and self-compassion.**

*Quána Madison: I have also have learned to use painting and writing as a way to help me cope with my pain as well and to help me support the mental health aspects of just being honest about how I'm feeling, and being able to use the arts as a way to help me express those feelings.*

**And art has also helped Quána make visible what's been invisible most of her life.**

*Quána Madison: Sometimes I use my paintings to help other people understand, like, what my pain feels like to me, or how it's impacting me, and to use it as a launch point to be able to start discussions about invisible disabilities such as pain.*

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**I'm Jordan Gass-Pooré, thanks for listening.**