

## SickKids VS The Odds

When you first meet Dr. Ronald Cohn, it's easy to feel intimidated by the sheer volume (and weight) of his titles: paediatrician, geneticist, scientist, President and CEO of SickKids. Honestly, though, he just prefers Ronni.

Ronni is leading SickKids through a new era of care called Precision Child Health. Or, as he likes to call it: PCH. PCH is a transformative leap in children's healthcare, tailored precisely to each patient. And to kick off this new season of SickKids VS, Ronni is here to preview some major PCH breakthroughs and discoveries. He'll also be explaining what Precision Child Health is all about and how this movement will heal the future.

You're listening to SickKids VS, where we take you to the frontlines of child health. I'm Hannah Bank and this is SickKids VS The Odds.

**Hannah Bank:** Ronni, thank you so much for being with us today. This is such a pleasure. I know you are incredibly busy, so we really appreciate you taking the time.

**Dr. Ronni Cohn:** It's really my pleasure to be here. Thank you for having me.

**Hannah:** So alongside all your responsibilities as CEO, you've also been spearheading this Precision Child Health movement. Can you tell us what PCH is all about?

**Ronni:** So I'm glad you called it a movement, because this is really what Precision Child Health is all about. It is about a movement to transform how we provide clinical care for the children we take care of here. And we actually hope that that's going to be a blueprint for how we take care of children even outside of the walls of SickKids. And in a nutshell, really, what Precision Child Health means is that we are moving away from a one size fits all approach to a truly individualized approach of the child. Taking really into account that each child has their unique circumstances. And we are going to use technology and things like artificial intelligence and machine learning to really capture the entire spectrum of the child, all the way from the genetic code with the data you are born with, across the whole spectrum until the postal code. Recognizing here that the social determinants of health — like where a child grows up, what the environment of the child is in the family and where they live — are as important as all of the biological data along the spectrum that we collect. And by really integrating all of this eventually into our decision making for children, that's how we're going to transform the way we take care of children.

**Hannah:** You know, this season, we're really excited about one of our families: a daughter went undiagnosed with persistent wheezing and breathlessness for a really long time until they came to SickKids. Just hoping you could shed some light on how PCH might help families like theirs get a faster diagnosis.

**Ronni:** It's actually one of many perfect examples of how we are utilizing the knowledge of the breadth of the data around the spectrum of a child's life to understand that there are certain signals, almost, that tell us whether a child is at higher risk or at lower risk for either developing asthma altogether. Or, if we know that the child is developing asthma, we know whether this is a child who is at high risk for more severe asthma — that often goes along with lots of emergency room visits, that goes along with sometimes hospital admissions. And knowing this very early in the trajectory of the child, rather than finding it out over a period of often years, is going to change the way how we not only make that

diagnosis faster. But how we're also going to treat much smarter. Because each of these children, depending on whether they have mild forms of asthma or more severe forms of asthma, will require a slightly different approach to therapy. And you do that then from the get go. So what's the right thing for this child at this point in time?

**Hannah:** Thank you for sharing that, Ronni. Another episode in this season explores getting to the roots of unexplained seizures. And so the approaches involve studying genes, which is a topic you discussed last time you were on our podcast, and how genetic advancements are driving new discoveries. Can you speak a little bit about that from your unique perspective as a CEO, but also as a geneticist?

**Ronni:** At any given time here, if you walk through our hospital, it's about 70 percent of children who have an underlying genetic disorder, sometimes characterized and sometimes not characterized yet. You know, when I started in genetics, our diagnostic rate was probably around 20, 22 percent of children we saw. And now we are up to 50, 55 percent. And this just only going to increase. And making a diagnosis, sometimes has very clear implications on the treatment of a patient. But sometimes we tend to underestimate the value and the power of knowing what is causing the problem of your child. Even if you don't necessarily have a solution. So taking this all together, it has already transformed a lot of what we do in paediatrics, and it's just going to continue to do that as we will probably eventually approach being able to make a genetic diagnosis in the child that has a genetic disease, hopefully close to 90, 100 per cent.

**Hannah:** I love this concept of knowing and providing agency to families, and patients that way. You know, we spoke to Dr. Devin Singh and he spoke a little bit about, you know, knowing that things are happening behind the scenes in the emergency department, while you're sitting there, provide so much comfort.

**Ronni:** And I think it's particularly important in times like this where knowledge seems to be sitting at your fingertips, right? If there's something you don't know, what do you do? You go to your computer. And then having a child. And not knowing, and often many families have been on the diagnostic journey for years and years and years. It really has been one of my most humbling experiences in my professional career to see how much pressure you take off from families to at least have an answer.

**Hannah:** I wanted to talk a little bit about one of the topics that we talk about a lot in Precision Child Health now, which is treating smarter. Can you elaborate a little bit on this idea for our listeners?

**Ronni:** There are a few things that are happening right now around treating smarter that is supported through the Precision Child Health Initiative. And one of the examples for that would be pharmacogenetics.

So pharmacogenetics refers to the field of medicine where we know that certain genetic sequences can predict how you react to a certain drug in terms of: is the drug going to work and all with you? And if the drug is going to work, do you need maybe a little bit less of this drug, a little bit more of this drug? Previously, without pharmacogenetics testing, what we have done is we tried a drug that we knew would work in 80, 90 percent of patients, and if it didn't work, then we were surprised if it was a side effect or it didn't work at all, then we tried something different. With pharmacogenetic testing, you know, ahead of time. And that is just the beginning of what we do right now and will become more and

more apparent as we make more diagnoses, understand how we treat children and how we get a better understanding of what specific drug is going to work for which child.

**Hannah:** I think it's incredible to hear about all these different ways in which Precision Child Health is happening at the hospital. Just want to tell you a little bit more about one of the episodes that we're doing this season. One of your colleagues — Dr. Paul Nathan — we're talking to him about childhood cancer survivors and really trying to help more survivors manage and minimize a lot of the long-term side effects that they have received from the cancer treatment that's used to save them. And just was interested in your thoughts about these kind of approaches helping to advance PCH.

**Ronni:** Yeah, so I think a lot of the work that Dr. Nathan is doing — it's really not just looking at the physical toll cancer takes on children, but also the emotional and psychological toll. And these are always really very individualized. They are different for every single patient. There is no blueprint that you can use for every child. It is the awareness that you need that each child may face some mental health challenges around emotional and psychological well-being. And as soon as you're aware of this, you can start designing support systems for these children, as they're not just going through therapy, but as they get out of therapy. And dealing with a trauma that's often, often very complex for them and sometimes for the family, too. He is really designing an individual path for children for long after the treatment of the acute cancer is done.

**Hannah:** So I want to share some other questions that we're asking in the podcast. In one episode in particular: *what if there was a way to know if you were the kind of patient that would probably never have a brush with sudden cardiac death, or the kind that might? And if you knew these odds, what if you could be ready and even prevent it from happening?* Which in many ways, Ronni sounds very sort of sci-fi and just intangible. But you know what's happening at SickKids. We might be able to answer these questions. I'm hoping you could speak a little bit about the importance of prediction.

**Ronni:** This is really our third pillar of Precision Child Health. So we talked about diagnosing faster and treating smarter. The power of prediction is really almost two-fold. You know ahead of time what kind of risk your patient is facing. That can be as simple as a risk of whether somebody has a high risk to go to the emergency room with asthma, as we discussed earlier. And what is it you can do about it?

But taking it even one step further: eventually prediction would lead to prevention. And that's not true for everything. But I mean if I allow myself to dream about 10 years from now, I would love for us to predict a certain problem and do something ahead of time to prevent it altogether. Not just to be ready for a problem, but to prevent it altogether. And I think that's where the power of prediction is going to lie.

**Hannah:** So it sounds like knowing what's coming can help SickKids better predict what's around the corner. Where else do you think precision child health may help with predictions?

**Ronni:** I would hope Precision Child Health is going to help with prediction in every aspect of child health care, even the well-being of children. So often, like most children are well, sometimes they become ill. And some of us have become ill with something more severe that really is requiring intense medical care. We'll get to this point eventually that we can predict that a certain child eventually will run or be at high risk of a medical problem that we could prevent altogether from happening. I mean we do some of this already: we do genome testing. And while we are looking for a primary diagnosis of the underlying

disease, there are about now almost 60 genetic disorders that if you knew ahead of time that you have that mutation is going to allow you to do something about it to prevent it from happening, or at least mitigate it. So I think the entire spectrum of children's health care will hugely benefit from the predictions.

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**Hannah:** I want to turn to the state of the emergency department and how Precision Child Health may improve wait times. It's a topic we've explored with Dr. Devin Singh and his team. But from your perspective, [I'm] just interested in and how you see technology — specifically AI and machine learning — helping families and patients in the emergency department.

**Ronni:** So I don't want to take too much away from Dr. Singh's outstanding innovation and creative thinking around developing an algorithm that, yes, on one hand, it provides parents with the information of, "So where am I in the queue and what can I expect?" But it really takes it much further.

So here we are using an algorithm that helps us to identify whether a certain test that a child needs to do while the child is waiting. Are there certain risks that we need to be aware of — that we may need to see a child sooner rather than later that otherwise to our regular triage process would have a risk to be missed. Happens very rarely, but here and there it does. So it's kind of a clinical decision support tool.

So I think it's just one of these perfect examples of how you have a true impact on the outcome of the patient, on the patient experience, and also on the health care system, because obviously you're improving the flow through your emergency room, particularly during busy times. So it's like a triple threat solution for our emergency room. And I would anticipate that we will have a lot, a lot of algorithms over the year that will help us with multiple aspects of a patient's journey, whether it's the experience, the outcome, and/or the flow of care.

**Hannah:** You know, in one of our previous episodes we spoke a lot about hope. Nobody can take hope away from you. Which I think about a lot.

**Ronni:** And you know what? No matter how grim sometimes situations appear, you don't want to create some unrealistic hope. But there's always hope for something. There's always hope for something.

**Hannah:** Absolutely.

**Ronni:** And I think that is something for us as health care providers to make sure that we play a role in trying to provide hope for our patients, no matter how significant the medical complexities or issues are.

**Hannah:** Yeah, I absolutely agree. I am, you know, interested in what gives you hope, both personally and professionally.

**Ronni:** I would say the first big reason why this is giving me hope is we have an institutional approach to this vision into this movement. This is not something that a few groups in silos can accomplish. This is an institutional approach where everybody has to and will play a role. And, you know, when we talk about healing the future, we thought a lot in long about what that means. And what I love about this term is there's a little bit of healing there for everyone. Even for the children who have very complex medical conditions. I often tell people I don't like to talk about "cure" because there are many, many diseases that we may never be able to cure and that we may only be able to make better. But making things better, even if it's just a little bit, is part of healing. At least the way I see it.

**Hannah:** Can you talk a little bit — just having you here and being able to pick your brain a little bit — about prioritizing different issues that come up in your role as CEO: trying to build this movement, working in the lab, working with patients. How do you how do you prioritize all of that?

**Ronni:** That's a tough question. I'm probably pretty good at multitasking. And what I try to make sure is as much as you multitask, if you're dealing with a certain problem, a certain issue that you're spending time on one thing, even if it's just for half an hour or an hour. Make sure that you dedicate your mind to this before your mind has to deal with something else. But sometimes when you have to deal with a big problem, you also need to make sure that you still devote your time maybe to a smaller problem that requires your attention during the next half an hour. And that's a skill set that I think over time you learn. My daughters call me Mr. Compartmentalization. And I think that's part of the skill that one needs, that sometimes you need to park something that may even occupy a lot of your time thinking about it for a little bit.

**Hannah:** We talked a little bit about the power of prediction earlier. We wanted to speak about the power of philanthropy as well when it comes to Precision Child Health and, and how important it is even small amounts.

**Ronni:** We cannot achieve our goals without philanthropy. If you really want to be bold and change the system and change the way you take care of paediatric patients inside and outside of the hospital, you need to really innovate and be creative and do things differently. And sometimes, to be honest, most of the time, this is going to require us to first try a few things. Maybe adjust them a little bit and then finally move them into the clinic. And all of this work that often is in the research institute or between the research institute and the hospital can only be supported by philanthropy. And I hope that if you listen to us and if you listen to me and you get excited about this too, and that you would feel that supporting us will make you part of this journey and will make you part of the success of transforming the care for our children.

**Hannah:** You have really inspired me today, and I want to make sure that you have a chance to speak about anything that we didn't touch on today.

**Ronni:** What I would say to close out is I learned about the concept of individualized medicine as a resident at Johns Hopkins in Baltimore, and one of my very, very senior physicians taught me about this. I met him usually once a week for an hour, and he would tell me about all sorts of complicated things, but always around the concept of individuality. And I've dreamt and thought about this for my entire career. And the fact that we are now on this journey, and can really make a big difference, is probably one of the most exciting professional experiences I ever had.

**Hannah:** From SickKids Foundation, I'm Hannah Bank. Thanks for listening. To support breakthrough research and care at SickKids, please visit [SickKidsFoundation.com/podcast](https://www.sickkids.com/podcast). And if you liked this episode, subscribe and rate us wherever you listen to podcasts.

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