SickKids VS Breathlessness

Hannah Bank: Around half of kids wheeze at least once by the time they're six-years-old. You probably recognize the sound of a wheeze--that high-pitched, whistling noise while you breathe. It happens when airways are inflamed and swollen. And if they only have one wheezing episode in their life, don't worry about it. But about 20 per cent of kids have recurrent wheezing — this means they have trouble breathing more than twice a year. It means missing soccer, and dance lessons. They miss school because they can't stop coughing. They end up in emergency rooms because they can't breathe.

As a baby, Hannah was one of these kids. Here's Melanie, her mom, sharing their experience.

Melanie: So it all started when Hannah, I would say, was under one-years-old. She was getting sick very often. And every time we entered the hospital, they would tell us that, "Oh, it's pneumonia. Here's some antibiotics. Go home." To be honest with you, it was very scary. So Hannah's dad he was kind of like "Mel, I don't think this is a virus. I don't think this is pneumonia. Like, this is something else." And essentially, it started with a cold. The runny nose and the cough. But then with Hannah, it progressed where she had labored breathing. But like if you look at your child's neck, you could see it going in deep. That's what Hannah was experiencing. As well as when she was breathing, her tummy would kind of dig in deep where her ribs were sticking out. So, it was a lot of that and that was happening very quickly. And as a parent, when you're seeing your child having these issues, you're like freaking out, right? Very stressful. I lost a lot of days of work because Hannah used to be sick a lot. Like that, in itself, was scary.

We've been to the ER so many times and they're constantly would give her the puffers. And a certain point in time you're like, this is not working. And mother's intuition, right, or like a parent's intuition, you know, something's wrong. You know what, I'm challenging this. So, I think after a certain amount of visits, you kind of figure out, like, this is something more.

Hannah B: Leaving the hospital, often with puffers and antibiotics but no concrete answers, is a common experience. But, for Hannah and other kids like her, antibiotics don't solve the problem long term. Because Hannah wasn't sick with pneumonia. Or bronchiolitis. Or a respiratory virus. What she needed was the right diagnosis — and the right treatment. And without it, they kept ending up back where they started.

Melanie: There was this lovely doctor I'll never forget. She was like this: "You're back again?" And she was like, "this isn't pneumonia." Let me refer you to our SickKids clinic.

Hannah B: You're listening to SickKids VS, where we take you to the frontlines in the fight for child health. I'm Hannah Bank, and this is SickKids VS Breathlessness.

Hannah B: In children under five, wheezing is common. It impacts so many infants and preschoolers, but is rarely linked to a chronic, diagnosed condition. One reason for this is that most kids only wheeze once— and its usually related to a bad viral infection. So it makes sense to hold off on more invasive testing.

Lung tests, like pulmonary function tests, are widely available to older kids, but only available at specialized clinics for babies and toddlers. An added layer of complexity for preschoolers is that most medications for wheezing, like inhaled steroids, aren't always safe or effective, so doctors kind of hit a

wall where there are no more medications that can be given, and it's not until a child turns six that they can start exploring alternatives.

So what do we do for kids like Hannah? Because having a toddler with persistent wheezing is incredibly stressful for parents and disruptive to family life, too. It can be upsetting for parents to see their child struggle to catch their breath and, in spite of repeat visits to health care providers and the ER, fail to get concrete answers. Here's Melanie again, talking about the burden of illness on parents.

Melanie: The amount of time I missed from work. And I had amazing bosses who realized, like, "We get it. Take care of your family." Because the amount of in and out, out of ERs and, you know, like, just going to the hospital is draining in itself. The amount of walk-in clinics we've gone to. It was just it was stressful.

Hannah B: Reducing the stress and burden of breathing disorders on parents and children is important to Dr. PJ Subbarao. She is a clinician-scientist in paediatric respiratory medicine at SickKids. And she's been studying breathing disorders for nearly 20 years. She's interested in improving the diagnosis and treatment of pre-school children with persistent wheezing.

Dr. Padmaja Subbarao (PJ): The biggest issue that I face as a paediatrician in paediatric hospitals is the fact that we have kids clogging up our emergency room due to recurrent wheezing exacerbations. And we keep going: "It's viral bronchiolitis. It's this, it's that." But we don't want to label them. I think regardless of whether we label it or not, it means that we should start thinking about how to treat it, because then we can reduce the risk of kids coming to emergency rooms because of wheezing.

Hannah B: I asked PJ what she meant by improving the diagnosis and treatment of wheezing.

PJ: So that means simpler tools that will empower patients to know when to seek medical care and seek advice, providing tools, simple tools and algorithms to family practitioners and paediatricians, and simple practice guidelines to improve their comfort and improve outcomes. And identifying the small proportion of children who don't respond to available treatments, and earlier identifying them for specialist referral for medications and personalized treatments that are going to be effective.

Hannah B: PJ was the first doctor who saw Hannah at SickKids. I asked her about what she remembered from that visit.

PJ: She is just such a sweetheart. And so, the way I met Hannah actually was really interesting because she presented to the emergency room, and she was diagnosed with pneumonia. And I remember seeing her with the fellow saying something, you know, let's look at this x-ray. Have her come back to my clinic because we need to make sure, one, it fully resolves. And two, we didn't understand why they keep telling her she has pneumonia. There's something funny going on here. And the mom had been going to different family care providers, different walk-in clinics, different paediatricians and different health care providers trying to get an answer as to why her child kept getting sick so frequently. When we went through some of the questions and we really started to delve into her history, the first thing that came up is that she had quite a bit of mucus production. We needed to figure out what kind of inflammation did she have that was causing all this mucus buildup, and that was causing her to have plugs in her lung that looked like pneumonia, but was actually just mucus plugs and inflammation.

Hannah B: PJ started treating Hannah to make it easier for her to breathe. But she also wanted to understand the type of her inflammation. She carried out further testing to look at some of the cells in her lungs and discovered that Hannah was having recurrent infections caused by changes in her airway microbiome. The microbiome refers to the bacteria that naturally lives in our guts and on our bodies. And so she treated that as well. Here's Melanie explaining Hannah's additional treatments.

Melanie: She had a bronchoscopy. Hopefully I'm pronouncing that right, which essentially, like, cleans out her airways. And then we actually had surgery because Hannah also had a sleep apnea too. For anyone doesn't know what sleep apnea is, it's pretty much when the child goes to bed and all they do is snore. They sound like a 50-year-old person snoring all day. And Hannah was not getting sleep properly, again always sick. So she had to, like, remove her tonsils and adenoids. And Hannah was two-years-old when she had the surgery. So a little bit nerve wrecking, obviously, like having your child do surgery.

Hannah B: Kids with large tonsils and adenoids often have disruptive snoring as well as a lot of inflammation in their upper airway, and this can make it hard to swallow. And when you have difficulty swallowing, there's a theory that bacteria is introduced into the lower airways and lungs. Using antibiotics reduces some of the inflammation in the nose and lungs. Removing the tonsils and adenoids can decrease breathing and coughing symptoms.

Melanie: The funny part is, once your surgery's done, you know, after staying in the hospital, they come home after a couple days. The first night they slept in their crib, I was awake, because I'm like, they're not snoring. Are they breathing? Like, is this okay? And I remember telling Dr. PJ, like, I remember the first night, they came home to sleep, I was like, up all night because I was just checking. Are they breathing? Like, I can hear her, but the snoring, like it was totally, it was different, right?

But the outcome of it was just amazing. Like I said, like, her asthma has improved drastically. Like we're not in the ER anymore. Like, it's just a good news story, I can say from two years old and Hannah's nine now, we haven't been in the ER for asthma problems at all, which is amazing.

Hannah B: PJ diagnosed Hannah with severe asthma. Wheezing is the cardinal symptom of asthma. Asthma is one of the most common and chronic conditions in children. It causes airways to narrow, making it very hard to breathe. But with a diagnosis and the right treatments, asthma can be controlled.

Melanie: I think the silver lining was that diagnosis that Hannah got. Because I think that put me at ease. There was less stress because we knew that there was something wrong with her, but we didn't medically know as parents. So once you know that your doctor's like, this is asthma. I was like, "Thank God, we found what the problem was." Once we got referred to the SickKids clinic and we saw Dr. PJ, it has been a blessing from there.

Hannah B: As Hannah's grown older, her type of lung inflammation has changed — which means her asthma has changed, too. But her control of it has remained constant because PJ continually reassesses her to make sure she's getting the right treatment.

Melanie: We do go to the clinics a lot, like every three months. But again, it is amazing because they go through like this check and balance that Dr. PJ has, which is like, how is she doing? When does she cough? Like, it's all these series of questions that kind of understand where her asthma is.

Hannah B: Those questions that Melanie's talking about? She's talking about CHART — short for CHILDhood Asthma Risk Tool. CHART is a symptom-based screening tool, designed by PJ and a team of researchers at SickKids, that detects asthma risk in young children. With CHART, PJ's team identified 90 per cent of 3-year-old kids who would go on to have persistent wheezing by age 5. That was significantly better than prior tests which only identified kids with allergic asthma — and just 30 to 40 per cent of kids with persistent wheezing in the same age range. I wanted to know why a predictive tool like CHART is so important to PJ.

PJ: The one message I would like people to leave with is asthma runs the spectrum from very mild in the community to very severe. But in any scenario children die from asthma.

Hannah B: Earlier detection and diagnosis of asthma allows doctors to treat kids sooner, so they suffer less, and avoid going to the hospital — which, in turn, lowers costs to the health care system. For PJ, waiting for a child to turn six to be diagnosed with asthma is too late. And that's why she wanted to develop a screening tool like CHART — to try and predict which kids would go on to have breathing disorders like asthma. Beyond identifying children at risk for developing asthma, PJ wants an overhaul of how preschool asthma in the community is managed. She thinks that paediatricians and family doctors need to be better supported. And that parents — and patients — need more information, too.

PJ: We need to be reaching out to paediatricians, primary health care practitioners, the front lines of who are really struggling with identifying these kids. And more importantly, we need to simplify this so that parents who actually are the ones really suffering and watching these kids can answer it really quickly. For me, the aha moment was who's the audience here? It's not, it's not doctors, and it's not specialists. It's parents.

Hannah B: CHART can be used by parents, and by family doctors and nurses. It non-invasive and can be done on the spot. And it's free. PJ and her team have shown CHART's benefits and they're working towards validating its use in clinical practice.

Out of all the research, what did you sort of filter down to the five most important questions that one needs to answer?

PJ: So one is how many times has your child wheezed in the last year. We asked them, have they been to the emergency room or to have they been hospitalized for wheezing? And then we asked them if they've had medications for wheezing. Do they wheeze with exercise or activity, and do they wheeze in between colds? And then the last question we ask is how troublesome is that wheezing? Does it wake them from sleep? And those are kind of the questions that we ask. And you know, the number of wheeze episodes is probably the most predictive. And then the fact that you have a wheezing attack that causes an emergency room visit or hospitalization, that is the second most predictive question.

Hannah B: And then does that help categorize patients into high risk and low risk? What is sort of the next —

PJ: Yes. After you answer those questions, it really helps us understand whether you're high risk, which is you've had wheezing with it, you've had more than two episodes within the last year and you went to the hospital or you were given a medication. And if you're high risk, you need to have a conversation with your family doc or pediatrician to really understand is this asthma?

In the past, most of our algorithms to diagnose asthma in preschool have really focused on only identifying those children who have allergic asthma, because that meant at the time of screening, you could automatically give them a medication that would work against the form of asthma that they had. And all the other kids who had a different form of asthma were notal identified. And what we also learned is that those other forms of asthma lead to changes in your lung function and they affect the growth of your lungs. So we have to treat it. We have to figure out better ways of treating it. And we have newer treatments that are effective for that form of asthma.

Hannah B: I asked PJ how the journey would have been different if their doctors had access to CHART when kids like Hannah started showing symptoms. She'll answer that question, right after this brief break.

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Hannah B: Since Hannah was diagnosed with asthma before PJ started using CHART, I wanted to know how her health trajectory might have been different if it was in use when she first presented to PJ in the emergency room.

PJ: CHART would have would have identified her a year or two earlier in her disease course. I think that would have helped identify for her paediatrician or family doctor to sort of say, okay, this is somebody who's at high risk.

Hannah B: I asked PJ what her hopes were for the future, especially as it relates to preschool asthma treatments and research.

PJ: What we really strive for each one of our patients and, and Hannah's a really great example is with the use of personalized therapy and with really delivering the proper types of treatments earlier on, you reduce the number of asthma attacks and burden of asthma on each child. So they are taking part in dance lessons earlier. They're missing less school. They're not going to emergency room. It's treating the breathing disorder, so it doesn't limit their life.

The only way these kind of really novel discoveries are possible are through these discovery platforms. Because when you start something like a cohort study, it's not just to answer one question, it's to answer millions of questions that we haven't even planned yet. And that's where philanthropy — it really changes the paradigm. It gives you that flexibility to let your imagination lead where the data is taking you.

Hannah B: Melanie and I spoke about the importance of a collaborative approach to health care — one that empowers parents and paves the way for a new generation that is actively engaged in their well-being. Like Hannah’s. Here she is — showing me how she uses her puffer.

Hannah: So first I'm just going to put in my mouth and then I just say, “blow it.” I count to ten breathing slowly.

Hannah B: And do you feel better right away when you take it or do you notice a difference?

Hannah: I feel better when I take it. So like, let's say I don't take it, I feel like, I'm like out of breath, but when I take it, I'm not out of breath and I feel way better so I can do more.

Hannah B: And you just take one puff, or do you take two puffs?

Hannah: One puff in morning and night.

Hannah B: One puff in morning and night. Thanks for showing me that.

Hannah: You’re welcome

Hannah B: Is there any sort of advice or words of wisdom that you received from PJ that stick with you?

Melanie: She actually told me to keep her active. Keep her active. Put her in swimming. That was the first thing is put her in swimming and don't limit her. She's a kid. Let a kid be a kid. Right? And I think that's what we've done with her since she was small. Hannah has been very active. We always have her enrolled in sports. If it's not sports, it's dance.

Hannah B: Or swimming.

Melanie: Or swimming.

Things will get better. Things will get better. Like it's going to get better. And that's what I've taken from the team.

Hannah B: From SickKids Foundation, I'm Hannah Bank. Thanks for listening.

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