**Fighting Blindness Canada Podcast**   
**Season 1, Episode 3: Focus on Advocacy**

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**Morgan:** Welcome to the Fighting Blindness Canada podcast. I’m your host, Morgan Ineson, manager of education at Fighting Blindness Canada.

In this series we will be interviewing people who focus on the treatment and prevention of eye diseases. We’ll go behind the scenes to learn not just about research, but also why these individuals are passionate about what they do.

In every episode we will also pose a question to the vision loss community to learn first-hand about how living with vision loss affects them.

On this episode we are focused on the role of advocacy in amplifying the voices of people who are living with vision loss. As individuals we have all experienced frustration when we feel like no one is listening to us. Unfortunately, living with vision loss, or a disability, can mean that it's even harder to be heard on important issues of equity.

Today’s guests are all using their voice to advocate for a better world for people who experience blindness or low vision. Their reasons for advocating are diverse – more funding for research and resources, access to treatment, accessibility, acceptance, and awareness – but their passion for these issues is palpable.

Our first guest is the Honorable Judy Sgro, MP for Humber River-Black Creek in Toronto, who will tell me about her journey to elevate Bill C-284 to create a National Eye Care strategy. Then I will talk with three advocates about how they got started in advocacy, why is it important to them and what drives their passion to inform and connect with others.

Any information provided in this episode is not a substitute for medical advice. If you have questions about your eye health, please speak with your doctor.

This is the Fighting Blindness Canada Podcast.

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**Morgan:** Judy, thank you so much for joining me today on the Fighting Blindness Canada podcast. It's an absolute pleasure to have you join us.

**Judy:** Thank you so much for the opportunity.

**Morgan:** I hope we could start out today talking a little bit about Bill C-284. So what prompted you to propose and introduce this act, to establish a national strategy on eye care.

**Judy:** I have an aunt who has macular degeneration and has completely lost her vision. I had a grandmother who also was blind from the age of 50 on, and my mentor also had macular degeneration and, and lost his sight as a result. So, when I had the opportunity to present a private member's bill, I wanted to make sure I did it on something that mattered to me a lot. And that I thought really was in the best interest of Canadians and our country, given the fact that we've never had a national eye strategy. And so I was thrilled to have the opportunity and, and will rejoice along with the community when we get this through the house, hopefully later this fall .

**Morgan:** So a very personal cause to you for sure. Can you walk us through some of the main priorities of the bill? What is the bill actually asking for?

**Judy:** It’s about developing a strategy at a national level, bring the partners across the country together, focus on where we are, when it comes to vision health, vision care in Canada. And what do we need to do to open those doors so that people are looking to prevent blindness, prevent vision problems. One in five Canadians have a vision problem or eye disease. And many of them are even unaware of it until it reaches a point where it starts to really impair their ability to function that they reach out. I heard a story of a 10-year-old indigenous Boy, that that was blind but didn't know he was blind, his family didn’t know he was blind either. Until he actually had an eye test. And they said, well, this boy, there's nothing wrong with his intelligence level. He has a vision impairment, he can’t see. And again, that would how many times does that go on because they don't have access. So one of the things that bill's going to do is bring people together that champion vision care that are knowledgeable about it. The best way to solve a problem is bring the partners to the table. And I'm a big advocate of putting the partners at the table and saying this is the issue. How do we how do we improve vision health in Canada, for all Canadians from from birth to death?

**Morgan:** As you mentioned, we don't really have this unifying strategy in Canada. So I think it would be a really wonderful thing for our community, to bring more attention to the needs of people who are living with vision loss, and for people who may have conditions that will lead to preventable vision loss as well. So what is the current status of the bill? And sort of what are the next steps?

**Judy:** Well, I have to confess they're driving this bill very hard. My, my fellow colleagues and all parties, when they see me, that's what they think about is Judy’s is coming after me to do something. On September the 27th, which is a Wednesday afternoon at 5:30, I will have the third hour of debate on this bill in the House of Commons. And that allows a certain amount of time for me to speak. And then for representatives from the other parties to speak for that hour. At the end of the hour, if no one else asked to speak to the bill, the bill then would go to per vote the following Wednesday. And then it's referred to the Senate. And the Senate is aware of the bill is supportive of it. So I'm hoping to have it law by the end of end of the year.

**Morgan:** Well, that sounds very promising. We'll be watching and waiting to hear hopefully a positive result very soon.

**Judy:** Well, thank you for all of the support that I have received from Fighting Blindness and all of the vision care organizations throughout Canada. This is a win for me, but it's a bigger win for them. Because all of them, all of the multitude of organizations that care about vision care and vision health have been aggressively lobbying Members of Parliament, ensuring that they're aware of the bill, the importance of the bill. And so it has been a lot of people working on this behind the scenes that I very much appreciate. So it will be a major win for all of us.

**Morgan:** Absolutely. So that's a great lead into my next question. So how can our fellow Canadians advocate for this national eyecare strategy and help it become a reality?

**Judy:** Reach out to any of the members of parliament in your area or another areas, phone them, text them, email them, ask them to support C 284 on vision health. I was quite shocked to learn how many people have had some association with issues of vision health for themselves or their family or even a constituent. So when people are calling saying please help push this bill along because we need it. They're very receptive to it. So people should not feel intimidated. The MPs whoever you write to, or communicate with will very much appreciate the the intervention and the encouragement because when it came for the initial vote, out of the house, there were 324, yeses, and no nos. So they all understand the importance of the issue. We just have to get the job done.

**Morgan:** And so this episode of our podcast is all about advocacy. So just to close off today, I wondered if you could talk a little bit about what advocacy means to you, and why it's so important for us to champion causes that are near and dear to our hearts.

**Judy:** When people take the time to advocate on behalf of their particular cause, that they feel action is needed. That's when action does happen. You don't have to think that there has to be professional lobbyists, and know someone. I was once told that a letter from a constituent one letter is equivalent to 100 because 100 people might have wanted to write a letter or a text or an email, but only one did it. So that's always an indicator to me when I get some communication that there's a lot more people out there that care about issues. So I just want to encourage any of your listeners to not be intimidated by the process. Reach out to your MP leave messages and, and communicate. We very much do appreciate hearing from constituents across the country.

**Morgan:** So well thank you so much for joining us again today. We're wishing you all the best of luck in the fall, and I look forward to celebrating together very soon.

**Judy:** Thank you very much, Morgan.

**Morgan:** We'll be back after this short break to hear more about advocacy within the vision loss community.

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**Jackie:** Fighting Blindness Canada is the largest charitable funder of vision research in Canada. To date, we have contributed over $40 million in funding for the development of sight-saving treatments for blinding eye diseases. With your support, we are advancing research to understand why vision loss occurs and how it can be slowed or restored. To learn more, visit us at: fightingblindness.ca.

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**Morgan:** For the second half of today’s episode, I spoke with three individuals who are involved in advocacy in the vision loss community. As you will hear they are all focused on different facets - research, access to care, accessibility – but all have in common a desire for greater awareness and acceptance for people affected by vision loss.

Let’s meet our guests:

**Ben:** My name is Ben Akuoko. I'm an individual who lives with low vision to be specific retinitis pigmentosa, I was diagnosed the eye condition at two years old. And as I got older, it started degenerating. I am also in the field of social work. I just recently graduated from my Master's of Social Work from the University of Waterloo. And then on top of that, I'm working at the CNIB. Currently, so I am the advocacy and accessibility community engagement program lead.

**Adam:** Hi there. My name is Adam Brown and I live with retinitis pigmentosa. I am a content creator as well as an aspiring voice actor and music producer.

**Carol:** Hi, my name is Carol Lithwick and I have a son with retinitis pigmentosa. And I am an activist.

**Morgan:** Thank you all for joining us on the Fighting Blindness Canada Podcast. I’d like to start by talking about how you each got involved in advocacy. Ben, what are some of your earliest memories of advocacy?

**Ben:** I find that becoming an advocate it, it was ingrained in me early in my life, especially coming from a West African household. Because in the 90s, when I was growing up, it wasn't too much talk about disability. And it wasn't much talk about intersecting identities as well as disabilities. So it was so many assumptions made when I was growing up, whether it was in the school system, or even just interacting with friends and family. So I always remember having to have that advocacy muscle of telling people, okay, I do have sight loss, or I can't do certain things. And when it came to my safety as well. So slowly, it developed right now I feel like I'm at like my highest peak of advocacy. Since it's my workplace, and I work with so many people with blindness or low vision.

**Morgan:** What inspired you to pursue advocacy professionally?

**Ben:** over the years, what I have seen is these policies and regulations that only work for a certain demographic of people. And I find that certain people fall through the cracks. And to be honest, we're not even aware that that's the case. And for the longest time, growing up as a person with a disability, and more specifically a person who lives with low vision, it was so many times where I fell through the cracks. And I felt dismissed. So not only because of my disability, but me being a first generation, Canadian with Ghanian parents, and with not having awareness of the different services out there for people who have low vision of blindness. So I been highly motivated. And I started Social Service working when I was only 18 years old. And I always been highly motivated to to address people who fall through the cracks and give the opportunity for people to have voices, who historically have always been individuals who didn't have voices, so I want to amplify it. And just going into this job, it's the best of both worlds its something I'm very, very passionate about when it does come to getting voices aplified, fair treatment, equity, equality, and then at the same time, my community of persons with low vision and blindness.

**Morgan:** I love that, I’m so glad to hear that you are in a place where you can both pursue your passions and make a difference within the community. What is something you’ve learned about advocacy, through working with other people who have vision loss?

**Ben:** One thing I love about this role is the fact that I get to educate people on advocacy, and especially people who are blind or low vision. And the one thing I find just so magical is I'm starting to learn that advocacy is an art form. A lot of people assume that advocacy is something we're oh something happens, or you try and convince people to change their ways, or are you bringing it up or sometimes even using the word of complaining, right, like complaining is advocacy, but it's such art form, where if you do want to make a change, you do have to have research behind it. Also, you do have to have a certain temperament as well. To be assertive and not passive or passive aggressive or aggressive. And to just know what rights you have when it comes to legal rights and when it comes to legislation.

**Morgan:** something you and I have talked a lot about over the years is the idea of intersectionality, and how the different facets of our identities affect how we are treated but also how we need to show up as advocates. How do you try to incorporate these ideas into your advocacy work?

**Ben:** Really, really great question. And I really love this question. Because, like I've made mentioned by just for years, you couldn't speak about your identities intersecting. So it was once upon a time where, when we looked at disability, it was only disability, that was the main factor. When we looked at issues of being a black racialized male, that was only one factor. But as an individual, we’re so complex, we're so complex, and we've so much dimension to us.

So the podcast I have is the *Lens Living Diverse* with the CNIB. And it looks at like different intersecting identities. And every time I host an episode, or every time I even have a conversation with people with diverse identities with sight loss, I always learn something new myself. And I find as a person in advocacy, or working professional or someone in the helping field, the more stories I hear, the more I'm equipped with helping other people and not letting people just stay by the wayside for sure. So I find it's so important to definitely talk about these intersecting identities because myself as a black man with a disability, my experiences are going to be different.

**Morgan:** Thanks Ben, I really appreciate you sharing with us. I’ll come back to you in a little bit.

Adam, I’m so glad you are here wth us today as well. To start, let’s go back to the beginning, when were you diagnosed with RP and what has that experience been like for you and your family?

**Adam:** Well, I was diagnosed with retinitis pigmentosa, pretty much at birth. So it wasn't as much of a journey for me as it was for my parents. My mom and dad would would tell me that when I would look at when I would look at my mom, I wouldn't be looking at her, I would be looking kind of through her. And the same thing goes for my sister, because my oldest sister Jenna has the same condition. So when I was born, and I would try to look at mom, she would immediately she could immediately tell that something was off, and that I was visually impaired as well.

**Morgan:** So you were diagnosed very young, and now you’ve grown up. You’re just 20 years old now. You had a social media presence, and as you mentioned at the start you love making music and are an aspiring voice actor, so you were making these funny videos on TikTok. And then one day, back in 2021, you posted a video talking about your sight loss and the gene therapy Luxturna. Let’s listen to that video.

**Adam:** You want to know something amazing? Well, I'll tell you, but since more than three people follow me now I feel like I should make this more well known. I'm visually impaired! Wooo! For real, I was born with a disability called retinitis pigmentosa. It's a genetic disorder that makes it hard to see things in the dark, see things on the side, read smaller print. It's basically just Walmart brand vision.

What's scary about it, though, is that it progressively gets worse as you age until eventually you start seeing... that. But wait, here's the amazing part. A special gene therapy has been approved in Canada that can stop the progression of RP. Awesome, right? Well, if you ask the Ontario government, that's not the case. Surgery hasn't been made fully available yet, because the Ontario government thinks it's so expensive. Now I hate the idea of begging for views but could you please share this video because this surgery is well worth it. And I'm definitely not the only one who needs it.

**Morgan:** That was the audio from Adam’s now viral video from TikTok where he is known by the username adam.tfm – Adam can you tell us a bit about what inspired you to post that video?

**Adam:** at the time when I was doing TikTok making videos for the first time, I didn't have that many followers, so I didn't think it would be that big of a deal. I think I only have like four. But, you know, as my, followers grew, I figured, okay, people are going to ask questions, they're going to ask why, why are your eyes twitching, why is your right eye going off to the side. So I knew I eventually have to address that. And around that time, that's when the gene therapy Luxturna was approved for use in Canada.

But the Ontario government and pharmaceutical companies that were providing it, were still negotiating on a price. And it took over two years for them to actually make it available in Canada. So it was like a big waiting game of just getting my voice heard and letting people know that this is an important surgery that can save tons of people's vision.

**Morgan:** Did you set out to become an advocate? Or was that sort of an accidental thing that happened just through sharing your story? And was there any moment that you thought, oh, wow, this is actually really starting to make a difference for people?

**Adam:** Yeah, it was kind of an accidental thing. Because, you know, when I hopped on Tik Tok for the first time, I didn't really do it with the expectation that I’d become a big influencer, or a big advocate for the visually impaired community. I just kind of wanted to, you know, hop on, you know, make silly videos. And, you know, see to see if that goes anywhere.

Pretty soon after, that is when I first revealed my visual impairment, Luxturna, and that video absolutely blew up. It has over a million views right now. But, you know, just a few days after I uploaded it, and went from like, 100 views, to like 10,000 views to 100,000 to 600,000. And seeing all the responses to it was like super heartwarming. People who didn't know about, about the surgery, who didn't know about the visual impairment. There’s people who had family members that did have retinitis pigmentosa. So, like, seeing all the responses to that video was fantastic. I had no idea that that I could have that much reach with that one video that I literally recorded lying on my bed. Becoming an advocate just kind of that just kind of like, came out of that. I didn't expect that at all. But you know, I'm super glad that that I'm able to.

**Morgan:** And we are so glad at Fighting Blindness Canada that we were able to help you in a small way in amplifying your story – our audience may have heard Adam on the news as we were working together to advocate for the approval of Luxturna, which of course it ultimately was, and we are thankful that Adam was the first person to get the publicly funded Luxturna surgery in Ontario. I’ll be back in a bit, but let’s hear from Carol now.

Carol, thanks for joining us. To start off can you tell us about the defining moment that started you on your journey to become an advocate and activist?

**Carol:** For 30 years, I was the chief psychologist at the local school board here in Ottawa, and I had many different responsibilities but one was, of course to do assessments on children who were experiencing challenges. Perhaps they were on the autism spectrum, they had learning disabilities, or perhaps they had a hearing impairment or we're visually impaired. And and part of my job in that role was to also help parents accept their children as being differently abled, and giving them strategies on how to develop resilience and how to accept the child as a whole child, who is very capable, just will traverse their lives in a different manner. So that was 30 years of my life. Then on the defining moment was Monday, November the 10th, 2003 at 2:30 in the afternoon. Now that may sound overly specific, but this is what happened. Our older son was doing graduate work at the University of Toronto, in medical and molecular genetics, highly successful. He was looking at continuing graduate work and had always been interested in the eyes and was hopeful to be an optometrist. So on that very day, November the 10th, 2003, he went to see an optometrist to find out about the profession. And to make a very long, complicated story shorter, he asked to have his eyes reassessed. He had always seen a pediatric ophthalmologist, but he needed new glasses. So this optometrist in Toronto took one look at his eyes and said, You will never be an optometrist. I need to take your license away because you have retinitis pigmentosa. We were supposed to talk at 2:30 in the afternoon, for me to understand the outcome of his meeting with this optometrist. He did call me as Stuart would sharp 2:30 And he said this will never been my career. I have retinitis pigmentosa and I'm going blind. So, for a person who has spent her whole career trying to help parents deal with children with challenges, now it's in my own backyard. So then the rest is history. It's actually it'll be 20 years this November the 10th. And so that was the defining moment because my life changed significantly, and advocacy became part of my heart and my soul.

**Morgan:** I imagine as a a parent, learning about your son’s diagnosis had to have been quite a shock to the system – how did you react?

**Carol:** Well, the first action I took, which was not exactly efficient, as a mother, I cried, I cried because I perceived that diagnosis as a tremendous loss. My son who I thought I knew, completely, medically, intellectually, emotionally, is now a different person. So that I think that's a typical maternal or parental response when something very different happens to your child that's totally unexpected. So, I spent a great deal, well, it was actually two full days, I just couldn't get my head around the diagnosis. Then I decided that that was useless behavior, crying and wallowing in my own sorrow. I started to do what I thought I needed to do was to raise my awareness or raise my raise my knowledge base and understanding. But the defining action for me was calling Fighting Blindness Canada, because I called them and somebody could feel the trauma, the stress in my voice, and they put me on to somebody, honestly, I don't remember who it was. And they spent three hours with me. Sorry, it's just so raw still. Anyway, they were so so good. They explained the disorder, even though I knew somewhat about R P, they clearly explained the disorder, and what the future was going to look like. And I said, Okay, that's it. No more tears, I'm moving on, I'm going to spend the rest of my living years trying to advocate and originally it became, I was advocating for my son. But as I moved through this process, I realized that it's not a singular activity. This is now for every Canadian, anybody in this world who is dealing with a visual impairment. So yes, I still want to help my son. I still do research as often as I can, but I, I am not an expert in that type of research. So it became that's, that's now my life is is advocacy, which then transitions into becoming an activist.

**Morgan:** Let’s talk about your advocacy work – you've dedicated so much time and passion towards raising funds for vision research and awareness, especially through Cycle for Sight. You were recognized in 2022 by the Canadian Association of Optometrists with the Vision Champion award, which was so fantastic. Through all this work how did you move from being an advocate to an activist?

**Carol:** I think that's a brilliant question. So my opinion is that when it's singular, when Stuart first was diagnosed, I only wanted to be his advocate. I wanted to solve his, what I saw was his individual unique problem. I wanted to make life easier. But as we know, it's a much broader based issue. And I think you transition from being a strong advocate to being an activist, when you take the cause from not individualism, but to the broad public. And I saw that as my purpose quite early on in the process that yes, maybe I can help my son, but now it's a bigger issue. So I am now an activist, and nobody's going to keep me quiet.

**Morgan:** I love that spirit. Thank you all for sharing your stories with us. As we wrap up today, I would love to find out what advice you would have for other aspiring advocates who are listening.

Ben as we've been talking today, we've mentioned several aspects of being a successful advocate, including having the right information and attitude. Over time, facing obstacle after obstacle can get quite frustrating, to feel like you’ve not been heard or respected. How do you counsel people to deal with these strong emotions?

**Ben:** Advocacy is draining for sure, advocacy is draining, and it's so hard to take the emotion out. Because when you're in something that you live, and something that you've seen over the years, and the unfair treatment you've seen over the years, it's so draining for someone not to get your side of your perspective. So perfect example is just like talking over the phone with a cell phone company, and letting them know that something's not accessible. And I'm telling me back, oh, no, we have individuals who, who are the tech team, and then asking them like, Well, does the tech team know anything about adaptive technology or low vision and then coming back and be like, Well, no. And just constantly hearing that and constantly hearing other people make decisions for the community? It can be very frustrating. Like, we're human beings. And this is our life. Sometimes it feels like you're getting the short end of the stick, when you're just kind of living your life, right? And you're trying to work as hard. And it's okay to be frustrated. It is okay to be frustrated, it's okay to be angry, it's okay to be annoyed. But to know to put that in a different outlet. And then you go for the advocacy issue. Because if it's pure emotion, people are not gonna listen, it's going to be very difficult for people to listen.

**Morgan:** Adam, do you have any advice for other advocates who are trying to get their message out?

**Adam:** I'd say be louder. Because the visually impaired community is super quiet. And I feel like the only way that, that we can raise awareness for the blind or visually impaired is just to be louder and have more people representing, representing us accurately and authentically. So that more and more people can understand what it's like to, to live the way that we do, because people outside of the blind, visually impaired community that they just don't know, they don't know what it's like to to live like me. That's why I think it's very important for for me to be authentic. In my videos, even if I'm being silly. I want that to be, I still want to show that, that this is entirely me.

**Morgan:** Carol, what advice would you give other parents whose child has been diagnosed with an eye diseases and they are are just finding their way on their own advocacy journey?

**Carol:** The first instinct as a parent is to protect your child. And if your child is differently abled, they're still a whole person. A parent needs to take a strong responsibility to build resiliency in their child, to have the child accept that what they're going to accomplish in the world, the outcome may be the same, but their path may have to be different. Parents need to build confidence in their children, to accept comments from society in the community. What I have found over the years, if I tell somebody that I have a son, who's legally blind, severely visually disabled, there's usually pathos there's usually sympathy for me, there's Oh, I'm so sorry. But over the years, I've learned that that sympathy as much as I appreciate it is not helpful. Children need to learn to cope with what the community is going to tell them and to have a strong response that they're able capable, and they will accomplish things, but they just need a different path.

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**Morgan:** Thank you for joining us for this episode of the Fighting Blindness Canada Podcast. I want to thank the Honorable Judy Sgro, Ben Akuoko, Adam Brown and Carol Lithwick for joining me and sharing their perspectives and stories and a special thank you to my colleague Jackie Rosen who helped produce this episode. Stay tuned for our next episode coming soon. I’m Morgan Ineson. Thank you for listening.

This podcast is brought to you by Fighting Blindness Canada.

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