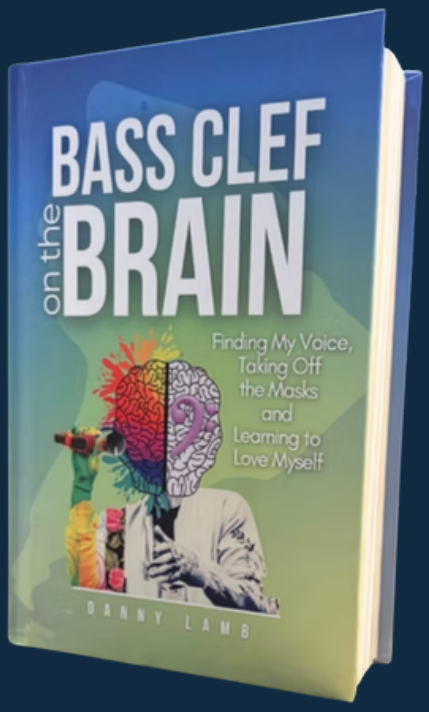
COMMUNITY VOICES

Danny Lamb





Finding his voice

A conversation about music, lived experience and the power of connection

IFSBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Canadian musician, songwriter and advocate Danny Lamb joined the 31st International Conference on Spina Bifida and Hydrocephalus in Montréal in October 2026 as a special guest, sharing his perspective on hydrocephalus and co-facilitating the Youth Forum alongside Ina Åkerberg. Danny has built a journey around music, advocacy and connecting with others.

In this interview with the International Federation for Spina Bifida and Hydrocephalus (IFSBH), he reflects on finding his voice, the importance of community and why making space for every voice to be heard matters.

When Danny Lamb talks about finding his voice, he is speaking about much more than music. It is about identity, belonging, purpose and learning how to use his experiences to connect with others. It is also about recognising when to step forward and when to make space for someone else's voice to be heard.



Born with spina bifida occulta and diagnosed with hydrocephalus at the age of three, Danny grew up with an approach that encouraged him to explore life and pursue his interests without allowing his disability to define what was possible. As he recalls, his doctor had some simple advice for his parents:

"You can't wrap him in cotton wool or put him in a bubble"

It was a message that stayed with him.

An active child who loved football and other sports, Danny was encouraged to take part, follow his interests and believe in his possibilities. That sense of possibility would be challenged during his teenage years.

When life takes a different direction

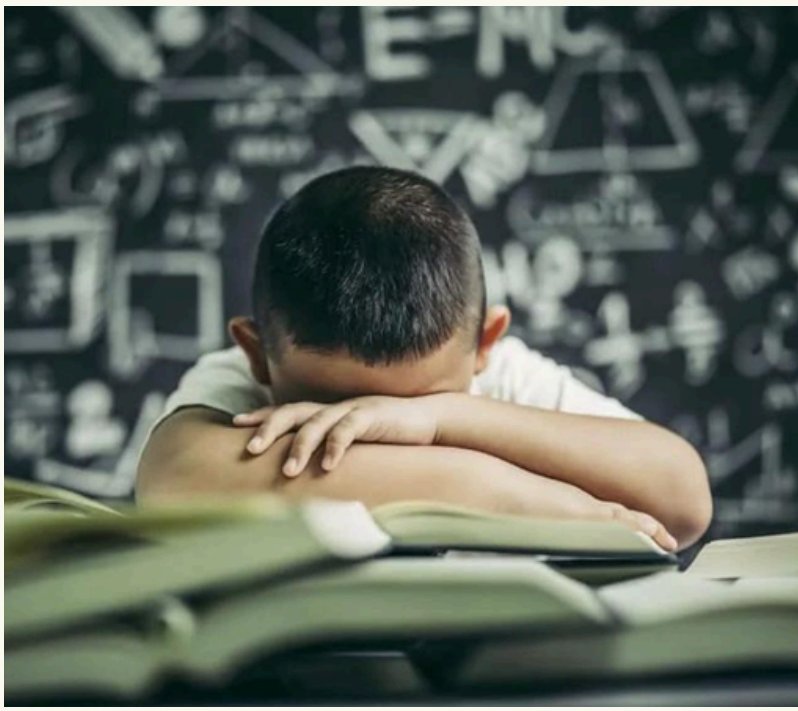
Danny's ambition was to become a professional football player, following in the footsteps of his father, who had played semi-professionally in Canada. Football gave him more than a sporting goal. It offered a sense of belonging, community and identity, as well as an escape from a classroom where he often felt unsuccessful or misunderstood.

At 14, his shunt broke twice within two weeks, leading to emergency brain surgery. Afterwards, he was advised not to continue playing football. The loss of a dream he had worked so hard towards left him feeling lost, confused and angry.

"I was faced with the reality that maybe I couldn't be anything that I set my sights on, and that was incredibly hard."

A difficult period followed. But, after around a year and a half, Danny describes reaching a point when he made a conscious decision to change his attitude and how he approached life. He also met two people at school who would become an important source of support. It was a turning point, although he did not yet know where the next chapter would lead.





Finding connection through music

Music had already been part of Danny's life from an early age. He began singing at 12, after a retired singer from The Phantom of the Opera recognised his voice. Yet, as a child, singing was not something he necessarily identified with. A few years later, a **Rotary Youth Exchange** programme took him to Brazil. It was there, at the age of 16, that he began to understand the power of music to bring people together, even when they did not speak the same language.

"I loved that music had the ability to build a bridge between strangers who didn't know each other. It was magical."

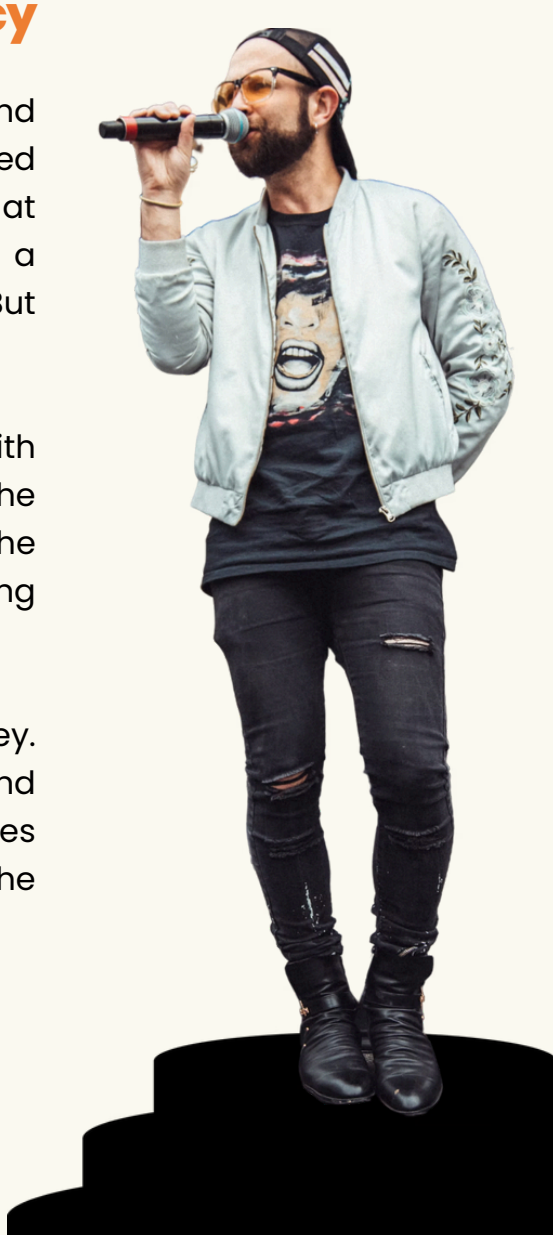
That experience helped shape the role music would play in his life. What began as a personal passion gradually became a way to connect with others and contribute to the wider spina bifida and hydrocephalus community.

From personal experience to advocacy

Danny's connection with the spina bifida and hydrocephalus community deepened when he attended an annual meeting of **Hydrocephalus Canada** at around 18 years old. He was there to receive a scholarship, which would help with university costs. But the experience gave him something more.

For the first time, he was sharing time and space with other people from the wider SBH community. The experience moved him, and it inspired a song, The Simple Things, as well as a new role as Young Ambassador for Hydrocephalus Canada.

It also marked the beginning of a learning journey. Danny realised that being part of the community and contributing to change meant understanding the issues and challenges people face, and recognising how he could best use his own position and abilities.



"I've always wanted to be useful. Provide value, and use my abilities to drive positive, more equitable change."

In 2013, he took this commitment further by creating **A Song, A City**, a music initiative that brought awareness of spina bifida and hydrocephalus to cities across the UK and Europe.

During the tour, Danny wrote a song inspired by each city he visited, using music as a way to start conversations and bring people together. The initiative also included a collaborative music workshop in İzmir, Türkiye, where Danny worked with young people with spina bifida and hydrocephalus to co-write a song called P.U.S.H. (People United for Spina Bifida and Hydrocephalus). His connection with IFSBH was already part of this journey; during the 2013 tour, Danny visited the Federation's office in Brussels, where an episode of A Song, A City was recorded.

Watch the 2013 Brussels episode A Song, A City, recorded at the IFSBH office.

The initiative continued to evolve beyond the original tour, developing into the PUSH Project Podcast, livestreams and community conversations. After a period of slower production, Danny and the project are now looking towards a new chapter, returning to the power of music and collaboration. In 2027, A Song, A City is set to bring together performers, voices and instrumentalists from across the Spina Bifida, Hydrocephalus and wider disability community, creating new music and new opportunities for connection.

Getting back to the basics of why we exist

For Danny, this next chapter is also about revisiting the purpose behind the initiative: finding sustainable ways to work with and support people and organisations across the SBH community. His continued involvement with IFSBH, including his participation in international conferences and workshops over the years, reflects this longstanding commitment to connection, visibility and shared advocacy.



A memoir about identity and self-acceptance

Danny's reflections on identity and finding his voice also feature in his memoir, ***Bass Clef on the Brain: Finding My Voice, Taking Off the Masks, and Learning to Love Myself***.

Through personal experiences and honest reflections, the book explores identity, relationships, personal growth and self-acceptance. It invites readers to look beyond a diagnosis and consider the many experiences, ambitions and possibilities that shape a person.

Danny believes that everyone should have the opportunity to express who they are and pursue their aspirations.

"I genuinely hope that people can connect to the Memoir in one way or another. I hope readers can feel something inside of the pages that reminds them that they are enough. Their voice matters. Their dreams matter, and the world needs those dreams to create a greater, more equitable place for all."

The memoir is also a reminder that finding one's voice is not a single moment, but an ongoing process of understanding oneself and deciding how to move forward.





Making space for young voices in Montréal

The importance of listening to young people was also reflected in the Youth Forum at the 31st International Conference on Spina Bifida and Hydrocephalus in Montréal. Danny co-facilitated the session alongside Ina Åkerberg, bringing together young participants around the theme of Self Leadership.

The 90-minute workshop offered a space to get to know one another, share experiences and reflect on how spina bifida and hydrocephalus can shape the relationship people have with themselves and the world around them. Through paired conversations and a body-focused reflection activity, participants explored their own strengths and challenges, how they see themselves and how they navigate different situations. Although the young people were strangers at the beginning, the session helped them build connections that continued beyond the workshop.

For Danny, youth participation is not simply about preparing the next generation to take part in future discussions. Young people already have knowledge, perspectives and experiences that matter today.

"Young people are here. Right now. Not just in the future."

Creating spaces where young people can meet, exchange ideas and contribute to conversations is an important part of recognising this. The Youth Forum offered one example of what can happen when young people are given the opportunity to connect and learn from one another.



His message to young people who may be struggling with confidence, identity or uncertainty about their future is honest. There will be difficult moments, and sometimes getting back up will not feel easy. He does not offer a simple promise that everything will work out. Instead, he encourages people to allow themselves to feel what they are experiencing, take time to heal and reflect on why they want to keep moving forward.

"You're the one that gets to decide how you heal through it. You're the one that gets to decide what happens next."









INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Looking ahead: every voice matters

Danny's story brings together music, lived experience and advocacy, but it is also a story about connection. From discovering music's ability to build bridges in Brazil to creating A Song, A City, and continuing his involvement with IFSBH, he has found different ways to bring people together and make space for others.

His reflections underline the importance of shared experiences, mutual understanding and listening to voices across generations. A stronger spina bifida and hydrocephalus community grows when everyone has the opportunity to contribute, connect and be heard.

"We all, regardless of age, have something to teach, and we all have something to learn. We need to be listening. We need to be solution focussed. We need to build bridges and find ways to work together across provinces, borders, and oceans."

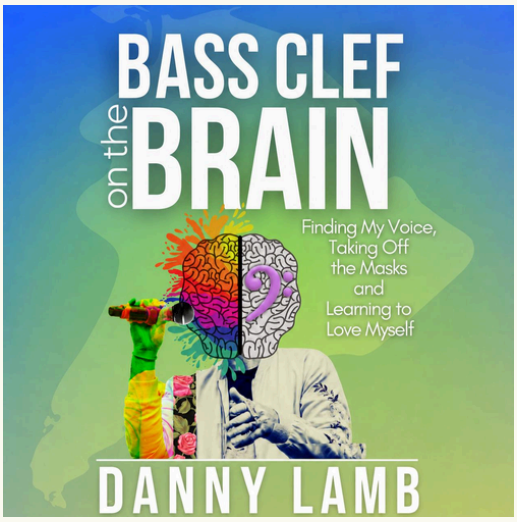
Danny's story is not simply about finding his own voice. It is also about how he chooses to use it: to connect people, support others and help create a community where more voices can be heard.

Find out more about Danny and his work: **www.dannylamb.com**



Bass Clef on the Brain

Finding My Voice, Taking Off the Masks, and Learning to Love Myself



A story about finding your voice and learning to embrace it

Danny Lamb's memoir is a personal reflection on living with hydrocephalus and spina bifida occulta, navigating identity, overcoming challenges and discovering the importance of self-acceptance.

Through honest reflections and personal experiences, Danny invites readers to look beyond a diagnosis and explore what it means to find their own voice, understand themselves and embrace who they are.

Featuring a foreword by Dr Sylvia Roozen, IFSBH Secretary General.

Discover Danny's book

Find out more and order your copy.

About IFSBH

The International Federation for Spina Bifida and Hydrocephalus (IFSBH) is the global organisation working to advance the rights, inclusion and quality of life of people with spina bifida and hydrocephalus.

Through a global network of member organisations and partners, IFSBH brings together people with spina bifida and hydrocephalus, their families, and a wide range of expertise and perspectives to share knowledge, shape policies and promote equal opportunities throughout life.

We work to advance the rights of people with spina bifida and hydrocephalus, addressing barriers and promoting equitable access to healthcare, support, education and opportunities, so that everyone can participate fully in society and make independent decisions about life

Every voice matters. Every experience counts. Together, we can build a more inclusive world.

Discover more about our work
www.ifglobal.org



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