

Stepping into the Spotlight



Danny Lamb & Em Jordan are breaking barriers & living each day to the fullest – on stage and off

Danny Lamb is 31 years old with an infectious laugh. He loves being alive and isn't shy to let you know.

Em Jordan is less than half Danny's age. She is quiet and reserved but has a voice and a message that can't be ignored.

Although these two people are very different, they do have a few things in common: they are both talented singer-songwriters; both feel most comfortable on stage; and, both live with spina bifida and/or hydrocephalus.

Diagnosed with hydrocephalus and spina bifida occulta, Danny had his first shunt surgery when he was 3 years old. At 14, he experienced massive, persistent headaches, vomiting, and felt his energy dropping dramatically. He says he knew the shunt was failing but was worried about what that would actually mean and what the repercussions would be."

What it meant was having another brain surgery to replace the shunt, accepting that he would have to give up his dream of one day becoming a professional soccer player, and finding a new outlet for his energy.

At his Mom's insistence, Danny reluctantly started to explore music. Getting over his bias that "dudes don't sing", music is now the primary focus of his life and it is a life that he shares openly on the world stage.

Today, Danny asserts that he is privileged not to have to worry about his shunt and accepts that it keeps him alive. He says, "It's the reason I am here and thriving. My challenges are less about the shunt and more about cognitive function and understanding, but I have learned how to work through those."

What would you say to a younger you?

When asked what advice he'd share with his younger self, Danny doesn't hesitate to answer. "Things are not always going to go as planned. Sometimes things hurt really bad and they just suck. How you choose to use your circumstances to be a better version of yourself is what matters. Be open to new experiences -- to being shocked and awed by the unknown. Your perseverance makes you stronger, amplifies your ability to tell your story, and results in a rippling effect that makes you -- and those around you -- better."

Danny's rippling effect has reached many people, including Em Jordan, a 13-year-old performer who is also breaking through the many barriers imposed on her by spina bifida. Danny has been a fan of and mentor to Em and is more than happy to step out of the spot light so Em can shine.

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And shine she does! Em released her first original song, House of Cards, in 2018 and has three more songs to be released. She says that she is always nervous before each performance but that once he starts singing, everything feels natural and doesn't want to get off the stage.

Em lives with many ongoing challenges as a result of lipomyelomeningocele. Her mom, Charlene, says she had no idea what spina bifida was before giving birth to her daughter and that the diagnosis was shocking. "I wondered what her life was going to be like. I was afraid to touch her and I was so discouraged to be told about all that my girl would not be able to do. But now, I look at Emily and just think, WOW! I see this beautiful, humble, talented kid. She is amazing."

Determined to empower her daughter to live beyond the diagnosis, Charlene and Em work together everyday to find solutions. Charlene notes that Em was in AFOs when she was young and didn't like to walk long distances. She adds that Em has trouble sitting for

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long periods of time but believes this has made her legs stronger and gives Em the strength she needs to stand on stage to perform.

Charlene also notes that Em has learned to do everything related to living with spina bifida herself. And, although there are always challenges to deal with, Em finds that a strict routine and anticipating challenges before they happen helps.

"Emily is an honest, humble person who is nice to everyone," says Charlene. This made some of the bullying Em endured at school difficult to bare. Em says she writes about her own experiences to inspire and help others. "I don't care about people's opinions as much any more. I have learned to overcome my anxieties. I now know that I want to build a music career and one day run my music school so I can help and empower other kids."

Charlene will echo Em's comments saying that music has brought out her daughter's confidence and made her feel good about herself. Charlene encourages all parents to look

beyond the limitations imposed by the condition and to ask children with spina bifida to start considering what they are good at and then pursue those interests and talents.

Danny, Em and Charlene have a respect and affection for Hydrocephalus Canada noting that the support and sense of community the organization has provided is incredible.

Danny says he is thankful that Hydrocephalus Canada (HC) embraced his passion and abilities. He remembers receiving a scholarship from HC and being inspired at a conference by one of the speakers to write a song. He says, "I am grateful for the opportunity to use music to unite the hydrocephalus and spina bifida communities. HC created the space for me and others living with the conditions to be heard and to show our strengths."

Charlene adds, "Hydrocephalus Canada was – and continues to be -- very supportive. They are who I turn to. I remember seeing Shauna (who has been with HC for over 20 years and lives with spina bifida herself) at Emily's clinic appointments and speaking with her. She listened to me, was supportive and provided information. Shauna helped me understand that even though we are going through things and struggling, it doesn't define you – or your child.

"Everyone has problems but our children have full lives to live. Don't let a diagnosis stop you because our kids can lead beautiful lives."

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