

## Jordan Beat the Odds

The fear and grief that Paula Sarraf and her husband Isam describe are common for parents awaiting the birth of a child with hydrocephalus and/or spina bifida. Their son, Jordan, born with congenital hydrocephalus, suffered seizures as a newborn and will have to be monitored by medical professionals throughout his life. Paula applauds Hydrocephalus Canada (HC) for supporting the family and helping Jordan become the happy, active 16-year-old he is today.

“In the early days after Jordan was born, I don’t know how I got out of bed some days, not knowing what the future held and I’m sure many other parents can relate to this,” says Paula. “When I contacted HC, they were a wonderful source of understanding, kindness, support and education that benefited our family greatly. We received vital information about hydrocephalus in the form of reading materials, journals and testimonials. The more we learned as a family, that we could utilize in our home environment, the greater the opportunities would be for Jordan to become a successful member of society.”

Jordan also suffers from two other neurological conditions, an agenesis of the corpus callosum (an underdevelopment of the membrane connecting the two hemispheres of the brain) and mild cerebral palsy. These conditions make him more repetitive, literal and hampered his early language development. But these challenges did not deter Paula and Isam, from hoping for a bright future for Jordan.

“My husband is my pillar,” says Paula. Both have worked hard to guarantee the best possible life for Jordan. Their daughter, Sarina was four-years-old when Jordan was born and loved being a big sister from the start. “Sarina is a fabulous role model and is very loving and compassionate,” says Paula. “When you have a sibling who has a disability it does teach you an element of compassion and inclusiveness.”



*Photo caption: Jordan has grown up to become a remarkable young man with Hydrocephalus Canada at his side supporting him and his family.*

Paula says that educating herself about Jordan’s conditions and treatments has been key. Hydrocephalus Canada and its resource centre have been valuable sources of information: “That was very important for me because in educating myself, it really took away the fear and it allowed Jordan to have a better quality of life as a result.”

Jordan has grown into a charming teenager who loves his Nintendo DS, eats like a champ, enjoys competitive 10-pin bowling and swims weekly.

Attending a life skills program, he is also a visual artist and his work is featured (right) in the 2015 and 2016 TGIF Lottery Calendars.

“He’s truly an inspiration for our whole family,” says Paula. “Both Jordan and Sarina bring us tremendous joy. Jordan is such a comedian and Sarina is an amazing person, especially in the way she supports and advocates for her brother! When you have a child or sibling who has challenges, it certainly tends to ground you. Even the simple things like learning to tie shoes are cause for celebration.”

Paula offers this encouragement for other parents: “Be proud of their milestones, each and every day. Live in the moment and try not to look too far ahead and be fearful. I wouldn’t be the person I am today without Jordan. For any family, you have to hang together and never give up because anything is possible.”

## Hydrocephalus Canada

We are the voice of  
Canadians living with hydrocephalus.

Every day we strive to empower those impacted by the condition to experience the best life possible.

We do this by establishing environments that protect, support and enhance the lives of those living with, or at risk of developing, hydrocephalus.



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