

# Event Impact



The "Celebrate Live Dream Walk" organized by Hydrocephalus Canada is our inaugural 2km/5km walk, wheel or run being held on June 2nd in Downsview park, Toronto. This day celebrates 5 decades of creating a community of support and resources for the hydrocephalus and spina bifida communities across Canada.

This event serves as a platform to raise awareness, provide support, and foster a sense of community among individuals and families impacted by these conditions. The overarching goal is to celebrate life, inspire dreams, and promote a positive and inclusive environment for those impacted by hydrocephalus and spina bifida.

One of the key initiatives highlighted during the event is the "Reaching Families, Changing Lives" program. This program plays a crucial role in offering personalized support and resources to individuals and families navigating the challenges associated with hydrocephalus and spina bifida. The impact of this program can be outlined in various aspects:

## One-on-One Support:

The provision of individualized support ensures that families and individuals receive tailored assistance based on their unique needs and circumstances. Trained and empathetic professionals or volunteers may offer guidance, share personal experiences, and provide practical information to help families cope with the complexities of these conditions.



"This is our daughter Otylia, she is 3.5 years old. Otylia was born with Spina Bifida and Hydrocephalus. She had an EVT put in when she was 6 months old, shortly after it failed and she had a VP shunt placed in. May, 2022 she had a shunt revision. Otylia is a wheelchair user. She is currently working on crawling and using a walker. We love being part of the SB & Hydrocephalus family and are grateful for the support you show our family. We really enjoy and appreciate all the seminars we are able to attend and learn from through Hydrocephalus Canada."

Dominka Kurpiel

## Important Webinars:

The program includes a series of webinars that cover crucial topics related to hydrocephalus and spina bifida. These webinars serve as educational tools, offering valuable insights into medical advancements, coping strategies, and other relevant information that can positively impact the lives of individuals affected by these conditions.



"My brother, Ajoniloju turned 28 years old on April 7 and he was born with congenital hydrocephalus and had 4 surgeries before he was two to correct the surgeries and now due to shunt issues he has violent epileptic seizures, brain damage, cognitive impairment and loss of motor function in certain areas. I grew up as his primary care giver with essential emergency training as my father is a professor in epidemiology and a medical doctor. He has not had a surgery in years. Below is a picture of both of us back home in Nigeria. I'm his younger brother."

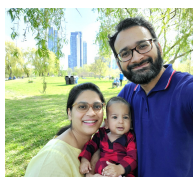
Inioluwa Osagbemi

## Vital Support Groups:

The establishment of support groups is instrumental in creating a sense of community and shared understanding among caregivers, new parents, youth, and individuals impacted by spina bifida and hydrocephalus. These support groups provide a safe space for individuals to share their experiences, ask questions, and find emotional support from others who can relate to their journey.

## Impact on Caregivers:

Caregivers play a pivotal role in the lives of individuals with hydrocephalus and spina bifida. The program acknowledges the challenges faced by caregivers and offers resources to help them navigate their caregiving responsibilities. Through support groups and tailored resources, caregivers can find solace, information, and a network of like-minded individuals who understand their unique journey.



"Husian, 6 months old was diagnosed with Hydrocephalus due to congenital Aqueduct Stenosis. He is shunted at 1 week old and thriving since then. Proud parents, Zainub and Ammar"

Zainub Gilani

## Empowering New Parents and Youth:

The program focuses on empowering new parents by providing them with essential information, resources, and a supportive community to navigate the uncertainties that come with a diagnosis of hydrocephalus or spina bifida. Youth impacted by these conditions are also supported through specialized programs that address their unique needs, fostering a sense of independence and self-confidence.



"Sharing this picture of Nora and I, two 18-year-olds living with hydrocephalus. In 2018, we both experienced our first shunt malfunction, and although we've had different experiences relating to hydrocephalus since, it has brought us closer than ever.

None of this would have been possible without the incredible support of Hydrocephalus Canada. We are truly grateful for connecting us and fostering our bond.

I am forever thankful for the connection I have with Nora. Our friendship is something truly special and unique. From our first FaceTime call, we have continued to connect weekly for the past 2.5 years! It's comforting to have someone who understands and shares similar experiences. Nora has always been there, supporting me through all the ups and downs. Together, we navigate life's challenges with resilience, laughter, and unwavering support. Thank you, Nora, and thank you, Hydrocephalus Canada, for bringing us together and reminding us of the power of connection."

Emma St.Aubin

In summary, the "Celebrate Live Dream Walk" with its emphasis on the "Reaching Families, Changing Lives" program creates a positive and empowering impact on the hydrocephalus and spina bifida communities in Canada.