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Compass guides families of young neurosurgical patients

Book the brainchild of three moms who saw need for 'family-friendly road map'

EDMONTON – Parents of pediatric neurosurgical patients at Stollery Children's Hospital now have a new book to help guide them through their children's medical journey.

The Compass includes real-life stories of coping from patient families, provides medical and technical information about brain and spinal cord injuries, and explains everything from diagnosis and medical terminology, to how to navigate the hospital, to where to find specialized clothing and shoes. The book also includes a workbook with space for parents to take notes and keep information organized.

The Compass was written by Dr. Vivek Mehta, Divisional Director of Pediatric Neurosurgery at the hospital, along with Wendy Beaudoin, Melissa Da Silva, and Melody Willier, all of whom are mothers of pediatric neurosurgical patients.

"This book is the brainchild of mothers who had the insight to know that a family-friendly road map would serve the needs of our neurosurgical community," says Dr. Mehta.

"Families may have questions or concerns once they leave an appointment and can get frustrated wading through information they find on the Internet. This manual is designed to address everything from understanding the medical jargon they'll hear to dealing with the psychosocial aspect of a child's illness."

Every year, about 1,500 children are treated at the Stollery's pediatric neurology program for injuries and/or illnesses affecting the brain or spinal cord. About 275 pediatric neurosurgeries were performed at the hospital last year.

Dr. Mehta and the three moms spent more than two years developing content for the book, which was reviewed by staff, physicians and patient families.

"Learning your child has been diagnosed with a brain or spinal cord disorder can be overwhelming and scary for patients, parents and family members," says Beaudoin, whose daughter, Olivia, is patient in the program.

"As a mother, I have gone through the same things that Melissa, Melody and other parents are going through. We thought there was an opportunity for those coming through the program after us to learn from our experiences. We wanted to develop a streamlined one-stop resource for parents and caregivers that would make their path feel less confusing and more supported."

The Compass is a project of the Neurosurgery Kids Fund (NKF), which is supported by the Stollery Children's Hospital Foundation. The NKF's mandate is to improve the journey for the families of children diagnosed with a brain or spinal cord disorder treated at the Stollery.

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“Family-centred care is one of the areas of the hospital we support,” says Mike House, Stollery Children’s Hospital Foundation President and CEO. “When you’re dealing with serious illness, education is power and the personal accounts in this informative resource will provide families with knowledge, strength and hope to help them cope with what’s ahead.”

All funds raised by the NKF go directly to programs and initiatives that improve the quality of life of those affected by pediatric neurosurgery.

Production of the book was made possible by a \$100,000 donation from the Building Trades of Alberta Charitable Foundation. About 300 copies of *The Compass* will be printed for existing and new patients over the next three years. The donation also supports the development of an interactive app version.

“*The Compass* guidebook for families and patients is about helping people; that is a philosophy that aligns perfectly with the Building Trades of Alberta,” says Warren Fraleigh, President of the Building Trades of Alberta Charitable Foundation.

“The 75,000 unionized skilled trades people who are members of 16 trade unions across Alberta have identified investing in our community as a priority. We look forward to continuing our partnership with the Stollery Children’s Hospital Foundation and NKF and the development of future resources that will give hope, guidance and direction to families in our community along their neurosurgical journey.”

The Stollery Children’s Hospital Foundation is committed to funding excellence at the Stollery Children’s Hospital: state-of-the-art equipment; sub-specialty education to train the brightest medical minds; research to pave the way to the discovery of new treatments and cures; and specialized programs that enhance family-centred care, and patient and family outcomes.

Alberta Health Services is the provincial health authority responsible for planning and delivering health supports and services for more than four million adults and children living in Alberta. Its mission is to provide a patient-focused, quality health system that is accessible and sustainable for all Albertans.

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