

FROM OUR NEW DIRECTOR

Hello, readers. First off, I would like to thank you personally for your lasting commitment to SickKids. You are creating a legacy of healthier kids.

As the newest member of the Gift & Estate Planning team, I am excited to play a part in unleashing the full potential of SickKids. Like most Canadians, SickKids has always been part of my life. Although I was fortunate to grow up without having to visit the hospital, I remember watching SickKids telethons and wishing I could do more to help. It feels serendipitous indeed that we're featuring the story of Meagan's Walk in this edition – it's one that stuck with me from watching those telethons.

This edition of SickKids Legacies highlights many inspiring stories, from innovation in research to families touched by the care they've received. No matter what our personal connection to SickKids, all of us are fighting the same battle: to make every kid a healthy kid. Thank you again for being a part of a winning fight.

Should you have any questions about your estate plans, please know that we are always here to answer them.

Sincerely,

Kelly Trickett
Director, Gift & Estate Planning



The SickKids GEP team. Seated: Kelly Trickett, Angus Gordon, Sydney Clark Christine Kang. Back row: Eva Avramis, Jessica John



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BEQUEST INFORMATION

If you plan to make a bequest, the name you should include in your will is: 'The Hospital for Sick Children Foundation'. SickKids Foundation is the hospital's parallel charity, raising money, performing estate administration, and managing endowments on behalf of The Hospital for Sick Children (SickKids).

If your estate plans include SickKids Foundation, we want to know, so we can thank you. Donors who wish to be included in our J.P. Bickell Society are invited to the annual luncheon, and celebrated, with their names placed on our Donor Wall of Honour.

PRIVACY

SickKids Foundation respects the privacy of its donors. Our full privacy policy is at www.sickkidsfoundation.com.

ABOUT SICKKIDS LEGACIES

SickKids Legacies is a charitable gift planning newsletter. The information provided is not intended to be a substitute for professional legal and financial planning advice. We encourage donors who are planning a donation through their estate plans to seek such advice.

SHARE WITH US

If you have an idea for a story, or would like to make a suggestion about the contents of the newsletter, please call 416-813-8271 or email gift.planning@sickkidsfoundation.com.

ABOUT THE COVER PHOTO

This is cystic fibrosis patient Ava. Her bowel ruptured in utero (common with CF patients). She spent 230 days at SickKids after birth. Today, Ava is doing well.

SICKKIDS LEGACIES



SICKKIDS GIFT PLANNING NEWSLETTER
SPRING/SUMMER 2018 ISSUE 38

HEAD AND HEART

For people with depression, cardiovascular disease is the leading cause of death. Why is this relevant at SickKids? We know that if you develop depression in your youth, you are at increased risk of dying from cardiovascular disease up to 10 years earlier than your non-depressed peers. So early intervention is the key.

The SickKids Children's Integrated Mood and Body Program (CLIMB) is all about early intervention. It's a highly innovative model that integrates clinical care with cutting-edge research. We know depression and cardiovascular disease are linked. The thrust of CLIMB's research is understanding how, so we can prevent heart disease early.

Since the program launched in June 2016, 92 patients between the ages of 7 and 18 have been assessed. Dr. Daphne Korczak, the SickKids psychiatrist leading the program, aims to enrol a total of 150 patients during the three-year project.

From a clinical perspective, the integrated, single access point for mental and physical care has been well received by patients and families. The average satisfaction score for the program has been 6.3 out of 7.

On the research front, it's still too early for a formal analysis of the data collected so far. But anecdotally the team has noticed a few patterns: one is the severity of the patients' depression when they present to the program. The mean depression severity score for the kids in the program is 53 (research suggests that

a score greater than 15 may be clinically significant). The team has also noticed that many patients – in particular, female patients – exhibit mood-related binge eating behaviours. This, coupled with cravings for more carbohydrates – and for more processed foods – could put them at greater risk for cardiovascular disease.

Dr. Korczak is hopeful that the team's research will help their clinicians determine where to focus their treatment efforts. "Depression and cardiovascular disease are two major contributors to the global burden of disease," she says. "So if we can make any improvement to that risk, that impact is potentially massive."

One of the key sources of support for SickKids research is legacy giving. Dr. Korczak's research is just one example of the incredible impact you can be a part of – through a gift in your will.



Dr. Daphne Korczak (fifth from right) and members of the Children's Integrated Mood and Body (CLIMB) team at SickKids.

A MOM'S HUG

A movement started by a mom – that's Meagan's Walk. Now in its 17th year, Meagan's Walk culminates in a human hug that surrounds SickKids with love and hope. Denise Bebenek is the mom behind it. Meagan is her daughter, treated at SickKids for an inoperable brain tumour. When she passed away, Meagan was 5.

Her journey as a SickKids mom galvanized Denise. During Meagan's illness, she'd felt surrounded by a circle of care. But, as those who've been touched by Denise's energy can tell you, she's not someone who thinks of herself first. She thought of all the other mothers: "The journey that a mom goes through with a sick child – not just kids with brain tumours – it's so huge that you feel alone."

Before Meagan's diagnosis, Denise had no idea that brain tumours are the leading cancer-related cause of death in children. She turned to her daughter's doctors, asking what could be done. And then, literally, she had a dream. Which kept repeating. The dream was a human hug.

Around Denise's dining room table, Meagan's Walk was born. Each year, the fundraising walk and hug take place around Mother's Day – something that was meant to be. Denise had taken her idea to the mayor, the Chief of Police, and city officials. No one had tried something like this before: administrators thought it was too huge a feat, especially for a mom who had just lost a child. But Denise's passion obviously resonated.

The next day, representatives from the city and the police were at her door, tears streaming down their faces. They put a permit in her hand, with these words: "This is serendipity. The only day we can close the streets is Mother's Day."

The emotional impact of Meagan's Walk has been incalculable; the financial contribution to brain tumour research – \$5 million to date – has put SickKids on the cutting edge. Today, Meagan's legacy is the circle of hope Denise envisioned around SickKids. It's perpetuated by an endowment – the *Meagan Bebenek: Creating a Circle of Hope Fund* – dedicated to finding a cure for all the other Meagans.



Denise and her daughter Meagan, the namesake of Meagan's Walk. The love between a mother and child is the original circle of hope.



A SickKids mom on the receiving end of the hug says it best: "When we saw all the smiling faces and waving hands – I felt overwhelmingly that I wasn't alone."

“IT'S A VERY SIMPLE MESSAGE: THE HUG REPRESENTS LOVE AND HOPE – THE BEST MEDICINE FOR A CHILD.”

TREATING EPILEPSY THROUGH DIET

Ball hockey, basketball, video games, swimming: these are the things Jack loves to do. He's a happy, loving, typical nine year old boy. He was a typical baby, too, with two doting older sisters. At two years, two months, Jack had his first major seizure. This was when the journey of Jack and his family (mom Tara, dad Jamie, and sisters Grace and Julia) with MAE (myoclonic astatic epilepsy) began.

Jack suffered different kinds of seizures – from grand mal-type seizures where he lost consciousness, to 'drop seizures' – where his entire body would drop like a marionette with cut strings. Different medications were tried, and Jack had an MRI, to determine if his seizures were localized in the brain – if they were, surgery might be an option. It was not.

For his family, seeing what was happening to Jack was devastating. "He began to regress cognitively, his speech declined, he couldn't concentrate. Jack's sisters suffered a lot because they had to watch it," says Jamie. Medications meant Jack "wasn't himself". His family felt they were losing him. So they started researching possible treatments – which led Jack's parents to discover a program at SickKids that treats epileptic children with the ketogenic diet.

For the 20-30% of kids who develop drug resistant epilepsy, ketogenic diet therapy is a low-carb, adequate protein, and high-fat diet. Instead of using carbohydrates for energy, the liver converts stored fat into what are called ketone bodies, which the body uses for energy. This can help control seizures.

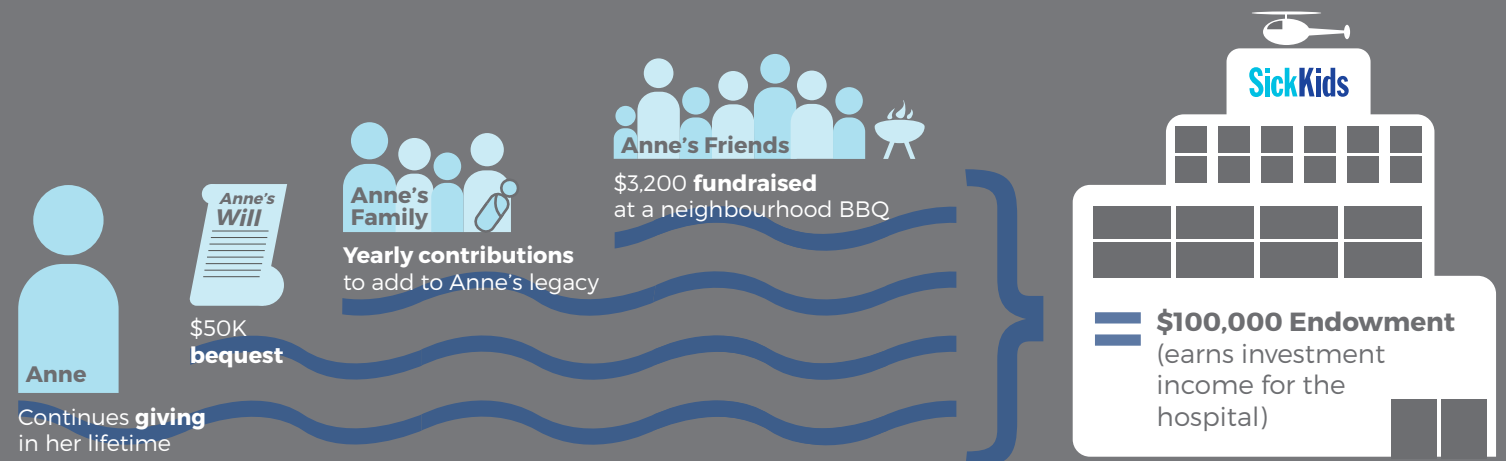
Results took a while. But today, Jack is five years seizure-free, and no longer on medication. Even better, closely supervised, he's being gradually weaned off his diet. It's research into treatments like this, made possible through gifts in your will, that give us the opportunity to tell stories like Jack's.



SickKids patient Jack, 5 years seizure-free

CREATING A LASTING LEGACY: AN ENDOWMENT

Anne – the grateful grandmother of a SickKids kidney transplant patient – decides to create a \$100K endowment. Friends and family also contribute in her honour to fulfil the endowment.



*This illustration should not be construed as legal advice. Please consult your financial and legal advisors to discuss tax-effective ways to make a charity part of your estate plan.