2019 IMPACT REPORT

MEAGANJ

Raising funds, hope and awareness for paediatric brain tumour research



WELCOME TO MEAGAN'S WALK meaganswalk.com

Deloitte.

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FROM THE FOUNDER Denise Bebenek

Your generous spirit helps Meagan's Walk make a difference in the lives of children with brain tumours, and their families. You will see in the pages of this 2019 Impact Report, that our donors help us in many ways: our support of leading-edge research into paediatric brain tumours; our developing network of global experts through our fellowship program; global advocacy and awareness-raising; providing hope to children and those who love them.

OUR MESSAGE IS SIMPLE: YOU ARE NOT ALONE.

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Through your support, we've been bringing that message to life since 2001. Over the past 18 years, Meagan's Walk has directed more than \$5.7 million to research. Now in our 19th year, Meagan's Walk attracts global interest and acclaim for its impact on the advancement of paediatric brain tumour research.

New discoveries about paediatric brain tumours bring new challenges. While scientists are moving towards faster diagnoses, personalized treatments and improved outcomes, at the same time more and more subtypes of tumours are being discovered, complicating the treatment process. Thank you for your support of Meagan's Walk. In 2020, we ask again for your help raising funds, awareness and hope. We must stand together.

Denie Bebenek



WELLUME IUMEAG meaganswalk.com

TD Securities Underwriting Hope

Harnessing the power of community, to raise awareness and funds for paediatric brain tumour research, so that we can improve outcomes for affected children and their families.

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SPENDIDG

BRAIN TUMOUR FACTS

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- BRAIN TUMOURS ARE THE LEADING CAUSE OF CANCER RELATED DEATHS IN CHILDREN
 - BRAIN TUMOURS IN CHILDREN ARE DIFFERENT FROM THOSE IN ADULTS AND ARE OFTEN TREATED DIFFERENTLY
- ALTHOUGH AS MANY AS 60% OF CHILDREN WITH A BRAIN TUMOUR WILL SURVIVE, THEY ARE OFTEN LEFT WITH LONG TERM SIDE EFFECTS
- **O4** CHILDHOOD CANCER IS CONSISTENTLY UNDERFUNDED ACCOUNTING FOR ONLY FIVE PERCENT OF ALL CANCER FUNDING RESEARCH IN CANADA TODAY

OUR IMPACT











OUR RESEARCH PRACTICE IS BENCH TO BEDSIDE

Meagan's Walk makes an indelible mark on paediatric health care, improving outcomes, quality of life, and survival rates for children and young people with brain tumours. With a "bench to bedside" philosophy, the goal is to translate research observations into tangible benefits for our children who are affected by brain tumours.



DISCOVERY

Donations support seed research projects, some resulting in seminal discoveries, such as in medulloblastoma genetics, or the establishment of clinical trials.



EQUIPMENT

The purchase of cutting edge equipment and the ongoing funding of the Toronto Brain Tumour Network tissue bank.



FELLOWSHIP

The Meagan's Walk Neuro-oncology Fellowship supports clinical researchers as they train in one of the world's largest paediatric brain tumour programs; they are also affiliated with the BTRC and its global reputation of excellence.

FUNDED PROJECT HIGHLIGHTS



DIFFUSE INTRINSIC PONTINE GLIOMA (DIPG) RESEARCH

Dr Cynthia Hawkins' laboratory was awarded funding to determine if they could target DIPG by starving the tumour of a necessary amino acid called methionine. When they analyzed the genome of several tumour samples from DIPG patients, they found several elevated enzymes that all belonged to a pathway dedicated to conserving methionine, and they questioned if DIPG tumours had a dependency on methionine. The experiments they proposed would determine the effects of methionine deprivation on DIPG cells. If this approach inhibited the ability of the cancer cell to grow, it would suggest that targeting this pathway may be a new way to treat DIPG.



EPENDYMOMA RESEARCH

Dr Vijay Ramaswamy's funded proposal investigates how ependymoma evades radiation treatment. Ependymoma is the third most common brain tumour of childhood and can arise anywhere in either the brain or spinal cord. In children, current therapies for ependymoma consist of surgery and radiation, which only cures half of all patients, and leaves survivors with the side effects of radiation therapy. Radiotherapy works by damaging DNA, and the resistance to treatment likely involves the ability of ependymoma cells to repair this damage. Dr Ramaswamy will investigate the DNA repair pathway by systematically deleting all repair enzymes using CRISPR gene knockout technology. This work is anticipated to determine if targeting one or more DNA repair enzymes makes radiation and chemotherapy work more effectively in ependymoma patients.



MEDULLOBLASTOMA RESEARCH

The proposal from **Dr. Peter Dirks** lab examines a rare population of tumour cells in medulloblastoma that have stem cell properties, which are capable of generating entire tumours. They are also resistant to standard therapy and promote relapse of the tumour post-treatment. The cancer stem cells can be either in a dormant or activated state, and the factors that control this switch are largely unknown. The Dirks lab proposed experiments to look at one factor, Olig2, that plays a role in this switch during normal development and is highly abundant in other types of brain cancers. They will test if Olig2 persists in medulloblastoma stem cells to promote abnormal proliferation, which will help to understand how to target these cells better.

OUR 18TH ANNUAL HUG



MAY 12, 2019 - PROCLAMATION



STARTING LINE CEREMONY



ALONG THE ROUTE



CHEERING ON THE WALKERS



SUPPORTING OUR DOCTORS



HUGGING THE HOSPITAL

OUR GLOBAL IMPACT

The Meagan's Walk Neuro-Oncology Fellowship Program

brings doctors from around the world to Toronto to work alongside some of the very best in the world. This collaboration fosters better outcomes for children across the globe. Every doctor who has come through the program has witnessed the power of our message and our Hug is waiting for us to bring Meagan's Hug to their home countries.





Dr. Alvaro Lassaletta Spain - 2014/15



Dr. Michal Zapotocky Czech Republic - 2015/16



Dr. Christine Dahl Denmark - 2016/17



Dr. Lorena Baroni Argentina - 2018/19



Dr. Liana Nobre Brazil - 2017/18



Dr. Anirban Das India - 2019/20

OUR PROGRAM IN ACTION AROUND THE WORLD



Dr. Alvaro Lassaletta is taking what he learned as a Meagan's Walk Neuro-oncology Fellow at SickKids to bring health and hope to children in Madrid, Spain.

There, Dr. Lassaletta has drawn upon the experience he gained to introduce improvements to the existing program. His goal is to strengthen the multidisciplinary team that provides care for sick children building a super paediatric brain tumour program providing the care and research that the patients deserve. He continues his research into brain tumours, working tirelessly to gain a deeper understanding to bring the world closer to a cure.

"None of this would have been possible without my Meagan's Walk Fellowship"



With support from Meagan's Walk, **Dr. Michal Zapotocky** is improving the way his team approaches clinical practice as a paediatric neuro-oncologist in Prague, Czech Republic.

"During the Meagan's Walk fellowship I learned about the management of various types of paediatric brain tumours and how to implement the newest molecular biological findings into clinical practice." Along with starting multidisciplinary neuro-oncology rounds, these new practices are improving the effectiveness of surgery, diagnostics and prognoses.

Dr. Zapotocky also established the Prague Brain Tumour Research Group, where innovation and dedication come together in an effort to deliver the best possible outcomes for kids.

WELCOME TO TORONTO



DR. ANIRBAN DAS

We welcomed our sixth Meagan's Walk Neuro-oncology Fellow to Toronto in July 2019. Dr. Das is a faculty member of the Department of Paediatric Haematology/Oncology at Tata Medical Centre (TMC) in Kolkata, India.

"I am grateful to Meagan's Walk for supporting me in taking these initiatives forward."

MY STORY

I am working as the Chief Fellow, Neuro-oncology, SickKids. This involves managing patients in clinic and emergency, consulting on neuro-oncology patients in allied departments, coordinating their care in ward and clinic, and organizing and coordinating the weekly academic, interdisciplinary and multidisciplinary tumour board meetings.

This clinical experience will enable me to better lead the paediatric neuro-oncology program that I have begun at home in India, collaborate and participate in current international clinical protocols for the more challenging tumours, and, in time, lead the paediatric neuro-oncology program in India under the aegis of the Indian Pediatric Oncology Group, where I have been fortunate to lead the brain tumour subcommittee in the past.

My current research focuses on an increasingly recognised cancer predisposition syndrome for children with brain tumours, known as the Constitutional Mismatch Repair Deficiency Syndrome (CMMRD), where tumours do not get cured by traditional chemo and radiotherapy approaches. I plan to continue to work on developing a blood test to diagnose tumours in these children and track high grade tumour development and their response to a new kind of therapy (immunotherapy) by using molecular signatures in the blood. This work is being done in collaboration with an international consortium centered in SickKids.

Anirban Das



MEET JASPER

Meet Jasper! A vibrant and fun loving boy whose smile lights up the room.

Within a few days of his birth, doctors suspected that something was wrong. An ultrasound revealed a large bleed in his brain. Jasper was rushed to the hospital for an emergency craniotomy when he was only 4 days old. At 8 months it was discovered that a brain tumour was hidden by this bleed. His treatment plan included 4 types of chemotherapy including a clinical trial. Now, at the age of four Jasper is a sociable and fun little boy starting kindergarten like many other little kids his age. One of the differences is that Jasper must have regular MRIs to closely monitor his condition.

We continue to fund ground breaking research to help improve the outcomes for Jasper and all of our Meagan's Walk Heroes. "I was in the hospital for my first Meagan's Walk. I looked down through the window and when I saw people hugging the hospital, it sent a message – they're here to see me. They care about me and I'm not alone."

JULIAN'S STORY

For eight-year-old Julian, watching his first Meagan's Walk & Hug from the windows of SickKids was healing and hopeful. Just one year earlier, Julian had undergone emergency surgery to remove a brain tumour that had caused him powerful headaches and persistent vomiting. Thirty days of radiation were needed to remove the rest of the tumour.

"Looking back, SickKids was nothing but awesome—the doctors, the staff, everyone." Julian is passionate about the work of Meagan's Walk that advances the kind of compassionate care that helped him become the healthy young man he is today.

Now 24 years old, Julian is a graduate of George Brown College and works as an architectural technologist. He continues to attend Meagan's Walk & Hug and shares messages of hope as a patient advocate and ambassador.



CIERRA

At just 17 months of age, Cierra lay on an operating table. Ten hours of surgery would follow in an effort to remove a dangerous and aggressive brain tumour.

Since receiving the MRI results confirming the tumour, Cierra's mom Natosha was living a nightmare. "There are no words to describe the feeling that came over me," she shares.

Following the complex surgery to remove the tumour, Cierra had difficulty walking and was reliant on a feeding tube. Unfortunately, a small part of the tumour remained, and further surgery to extract the entire tumour proved too risky.

Natosha never expected that Cierra's next MRI results would release her from her turmoil. The doctors hadn't been able to remove it, but no trace of the tumour remained. Cierra was healed, and Natosha felt whole again.

"We're so grateful for the thousands who come together at events like Meagan's Walk to raise money for brain tumour research, finding better treatments and cures for children."



"Kohen is our inspiration and he gives us strength to keep going"

Five years ago, Jessie Paschek was told she would have to start preparing for her two-year-old son Kohen's funeral. Today, spirited and outgoing Kohen, big brother to Everly and Audrey, is playing, learning and growing alongside his classmates in Grade Two.

"Waking to our beautiful son, looking and behaving as normally as any other little boy, is just amazing," smiles Jessie.

Jessie will never forget the day she learned that Kohen's frequent bouts of sickness, seizures and difficulty walking were caused by a very large brain tumour—one unlike any other seen by neurosurgeons and specialists. Hours after the diagnosis, Kohen was airlifted to SickKids, where he underwent surgery to remove the tumour, and later, intensive chemotherapy with a stem cell transplant.

Kohen's surgery and treatment were successful, leaving no evidence of a tumour and lifting Jessie from a place of unimaginable grief. Kohen still requires regular MRI scans, but Jessie is embracing hope with every step of the journey—and that's what support from Meagan's Walk can do.

"Without the research that has been done in the stem cell field, we probably wouldn't have our son here with us today," shares Jessie.

"Meagan's Walk helps give me a sense of purpose to help save our children through fundraising and supporting research to help end our sadness."



IMPACT OF OUR SCHOOL PROGRAM

Our vibrant school program has been embraced by many school communities throughout the GTA and across the province. With the theme of "kids helping kids" our program aims to empower young people to make a difference and foster compassion within their school communities. By providing unique leadership opportunities, the program encourages students to share their gifts and talents as well as come together to support those in need.

"My experience with Meagan's Walk and Hug has been nothing short of life-changing. I have developed into a more compassionate and aware individual through my interactions with so many children. Through events like our school hugs, crane ceremony and signature walk, I have witnessed the power and impact of people united in hope and love ."

Emma D. Former Student Ambassador and current volunteer



"Without the united and dedicated team of volunteers at Meagan's Walk we would not be recognized as a leader in paediatric brain tumour research – providing hope to children and their families across the globe"

Denise Bebenek



WE COULD NOT DO IT WITHOUT YOU

Meagan's Walk is a volunteer driven organization that functions year-round with the generous support of our 60+ volunteers. It is because of their support that we are able to run an Arts Team, Communications Team, Events Team, Family Connect Team and a School Team. Thank you all for your dedication and support!



HOW CAN YOU HELP US ?



Visit our website to see how you can make a difference: meaganswalk.com

Donate and help us fund cutting edge research that is saving lives.

Come walk with us! Register as an individual or with a team and come experience the power of our Hug.

Volunteer and join an enthusiastic team dedicated to making a meaningful difference in the lives of children and their families



