



Impact Report

2021-2022



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A Message from The Founder

Denise Bebenek

The theme for this year's HUG was "Hope Changes Everything". Hope, at the heart of this organization, is consistent with the vision I had more than 20 years ago of a HUG that welcomes all. The hand we extend is one of support, inclusion, compassion and community.

We believe that we can make things better, that the future can be influenced by the actions we take today. We hope.

The isolation brought by the pandemic strains all. Never has hope been more important. And despite these challenges, this community remains resolute. The focus remains on finding answers about brain tumours and how they can be treated effectively while giving young patients a better quality of life, a more promising future.

We continue supporting each other, staying connected, and walking side by side.

In May 2022, after two years of virtual events and activities in our own neighbourhoods, raising funds for research, the Meagan's HUG community gathered together for our signature HUG. An emotional day- seeing familiar faces, greeting new friends, and, sadly, missing some of our Heroes. We always remember, honour and are inspired by them.

It was stirring to hear our young Heroes, Jess and Chris, speak during the Closing Ceremony. Dr. Rutka, Director of the Brain Tumour Research Centre, spoke about the beginning of clinical trials for treating youngsters with Diffuse Intrinsic Pontine Glioma.

Now there is a hope on the horizon with these new trials. Our actions make this difference. Together we believed that something more could be done, and our actions have now given rise to optimism.

Hope is resilient and sometimes needs "grit". It also takes time. I continue to be inspired every day by this community that makes change possible. Yes, hope changes everything.

Denise Bebenek
Founder & President – Meagan Bebenek Foundation

A Message from The Chair

James Wilson

Two years ago this organization took its first steps as a registered charity, Meagan Bebenek Foundation (MBF). Change brings challenge. We adapted, we stayed resilient, we grew. Our mission remains strong and focused.

Brain tumours are complex. there are over 120 types of brain tumours- and for more than 20 years this community has dedicated its effort to helping researchers unravel the mysteries about how brain tumours work, what can be done to stop their growth, and the often devastating effects they have on our children and youth.

While research is painstaking and its progress at times difficult to measure, there are some remarkable developments that are due to your support. MBF fosters a culture of discovery and care that is changing lives. Findings at the laboratory bench are translated into more precise diagnoses, leading to refinements in treatment, and healthier lives for young patients.

Over the years MBF has allocated funds to numerous seed grants, projects that allow researchers to explore new ideas, build evidence that these will work, and help develop new approaches. An outstanding example is the seed grant MBF funded approximately five years ago allowing pre-clinical research using guided ultrasound to target Diffuse Intrinsic Pontine Gliomas (DIPG), aggressive tumours that are notoriously difficult to treat. With your support, this work quickly led to the development of clinical trials that hold great promise.

Our support is truly global in its effect: research is collaborative and knowledge is shared. In May it was a privilege to hear Dr. Michal Zapotocky, the second Meagan's HUG Neuro-oncology Fellow (2014-15) speak about his work in the Czech Republic. Dr. Zapotocky continues his work in his home country, producing benefits for all, transforming the world of brain tumour patients, as well as the work of researchers and clinicians.

As a community, we are known by our determination to support each other, walking this path together, and extending our hands to each other in our "circle of hope". After the constraints of the pandemic, it was inspiring and uplifting to be able to gather again as a community, both at our drive in Honks for Hope event in September 2021, as well as at the HUG in May.

The HUG is for everyone. At the heart of our work together are the families affected by a brain tumour diagnosis. Their voices are compelling and keep us mindful of our commitment to being a community of hope. We are stronger together.

James Wilson
Chair – Meagan Bebenek Foundation



Hope for Ukraine

An International Collaboration

February 24, 2022 marked the day that Russian military invaded Ukraine and the world took notice. News sources were streaming coverage 24/7. We witnessed attack after attack, damaging critical infrastructure that would interrupt daily life for millions, including those receiving cancer treatment.



Within days, the Supporting Action for Emergency Response (SAFER) Ukraine program was activated. A global collaboration led by St. Jude Children's Research Hospital, called upon strong relationships with many international organizations, including the International Society for Paediatric Oncology (SIOP).

Paediatric oncologist Dr. Eric Bouffet, the former president of SIOP, knowing well and first-hand the mission of Meagan Bebenek Foundation (MBF), requested that MBF be asked to join the SAFER Ukraine project providing practical support to families arriving in Toronto for cancer treatment at SickKids.

Providing hope and support to families affected by paediatric brain tumours is what we have done for 20+ years, so helping during this humanitarian crisis was a fitting match for this organization. Our team sprang into action, working closely with numerous corporate partners to prepare for the arrival of new guests.

The corporate response demonstrated the strength and compassion of Toronto as, one by one, partners stepped forward to contribute and make a difference.

- ▶ Canadian Apartment Properties Real Estate Investment Trust (CAPREIT) arranged housing close to the hospital to ensure patients had quick access to their medical teams.
- ▶ Sleep Country Canada provided beds for all the Ukrainian guests.
- ▶ IKEA provided bedding, dishes and kitchenware.
- ▶ Peg Perego supplied the families with young children with highchairs and car seats.
- ▶ Members of the Marriot Hotel Group furnished the housing units with the missing components that made these units feel like a new home.
- ▶ FreshCo stores began to collect donations that would be presented to the families in the form of gift cards.

"The number of international partners that came together very quickly, all with this singular mission, in order to step in and help address this emergency has been really amazing. SAFER Ukraine includes hundreds of individuals and dozens of organizations, all working under the same umbrella to get these kids not only to physical safety, but really to the best available medical care in the world."

Dr. Asya Agulnik, MD, MPH Director, Global Critical Care Program St. Jude Children's Research Hospital – Memphis, Tennessee



Beginning in March we welcomed 7 families, ranging in size from 2 to 5 members. All have been equipped with a fully furnished apartment within the GTA, making access to hospital appointments less burdensome. The families receive a monthly allowance for groceries and incidentals, along with cell phone service allowing them to stay connected with each other.



!! CAPREIT was honoured when Meagan Bebenek Foundation (MBF) asked us to participate to assist families fleeing Ukraine for urgent medical care for their children. CAPREIT immediately rallied our partners and our Operations team to offer free fully furnished and fully equipped homes in our communities to these families who needed housing desperately, while they focused on their children. As a provider of homes for families across the country, we know the importance of having a safe and secure home to raise children, celebrate milestones, and enjoy peace of mind. We enjoyed working with the team at MBF and we are proud of the work this partnership accomplished together. !!

Mark Kenny

President & CEO

Canadian Apartment Properties REIT

As the war drags on, so too do the needs of these families. Since it remains unsafe for them to return to their lives in Ukraine, we have shifted to providing longer term support. To find out how you can help, please visit our website – meaganshug.com

Thank You Community Partners:



Together Again

Honks For Hope

After an almost 18-month hiatus, in September 2021 Honks for Hope marked our return to in-person events. The HUG community gathered at Downsview Park for a drive-in concert with Canadian comedians Patrick McKenna and Debra McGrath serving as the masters of ceremony.

Renowned children's entertainer, Sharon Hampson, of Sharon, Lois & Bram fame performed with her daughter, Randi, keeping the young toes tapping. They were followed by award-winning Canadian singer-songwriters Jim Cuddy, Devin Cuddy and Sam Polley.



The stars of the show were our Meagan's HUG Heroes and doctors who, by sharing their challenges, their hopes, their dreams, reminded us all of why we come together.



Julian spoke on behalf of all our Heroes, sharing his story and encouraging words for the many families in attendance. Dr. James Rutka, neuro-surgeon and Director of the Brain Tumour Research Centre (BTRC), and Dr. Bouffet shared uplifting stories of diagnostic and treatment advancements, attributed to funding provided by Meagan Bebenek Foundation.

The stage presentation closed with MBF Founder and President, Denise Bebenek, speaking of the challenges the pandemic posed for members of our community, as well as for our fundraising efforts. Denise reminded us too that no matter what challenges we face, **Hope Changes Everything!**



Thank You Honks For Hope Sponsors:



Together Again

Meagan's HUG 2022



Since its inception, the HUG has been about creating a circle of hope around those in need of support: a community sharing a message of hope and demonstrating that we are stronger together. This year we did just that, in the first in-person HUG since May 2019.

Two of our Heroes, Jess and Chris, shared their powerful stories of their own experience with a brain tumour, and recounted the impact that Meagan Bebenek Foundation, more specifically the HUG, has had on their cancer journeys. They reflected on the unwavering support they received from this community; that has uplifted them and their families during trying times; a community that has celebrated their success stories as if they were their own.

For some, the HUG is about coming together to remember a loved one. There is strength in our circle of hope. Strength in knowing that others have walked your path. Strength in knowing that you are not alone.



This is the case for parents, Cindi and Jay. For over 20 years, they have been part of the HUG, surrounded by friends and family who all come together to remember their son, Cosimo.

Cosimo was diagnosed at the age of 9 with medulloblastoma. He loved life and fought hard against the 5 tumours found in his brain and his spine. His initial prognosis of life expectancy of 3 months turned into 18 months.

A parent should never have to bury their child. Cindi says "It never heals in your heart. Being part of Meagan's HUG is medicine for all of us." Knowing that if Cosimo were diagnosed today, the outcome could be quite different, Cindi continues, "I feel thankful. The funds we have raised for research mean we have come so far. The kids now have a better chance."



Changing the World of Brain Tumour Patients



Researchers and clinicians focus their efforts on understanding how brain tumours work and finding the most effective and least toxic therapies for young patients. The ultimate goal is to ensure that no one suffers with a brain tumour.

For over 20 years, Meagan Bebenek Foundation (MBF) has worked tirelessly to raise funds for research, including for numerous seed grants, allowing research into novel ideas that can lead to major research initiatives.

Collaboration and sharing of resources and knowledge are key to advancements in brain tumour research. Discoveries in one area of brain tumour research benefit all.

Diffuse Intrinsic Pontine Glioma, more usually found in children, is difficult to treat. It tends to spread to other parts of the brain, affecting nearby tissue, and is located in the pons of the brain stem, an area that controls essential body functions.

Dr. Cynthia Hawkins

Dr. Cynthia Hawkins is one of the Senior Scientists and Principal Investigators at the Brain Tumour Research Centre (BTRC). Her laboratory studies paediatric glioma, the most common type of childhood brain tumour, with DIPG as a major focus of their work. With a recent grant, the Hawkins laboratory will investigate how a specific drug functions and takes effect on DIPG.

Currently, the standard of care for DIPG is radiation for symptom control. No chemotherapy thus far has been found to extend survival of patients.

By investigating drugs specific to the biology of DIPG, Dr. Hawkins and her colleagues aim to identify novel therapeutic strategies for this devastating disease.

Their approach of testing drugs already in the clinic for adult cancers will facilitate rapid translation of these combinations into clinical trials for DIPG patients.

In recent work, Dr. Hawkins' laboratory group and others have discovered that mutations in a DNA packaging protein called a Histone is the earliest and thus thought to be the activating event that leads to malignant changes in the brain cells of DIPG patients. However, targeting this mutation directly has proven difficult.

Dr. Hawkins and her colleagues undertook a screening study to identify drugs that can kill DIPG cells harbouring this specific histone mutation but not normal cells. They analyzed more than 2500 drugs chosen because they had been previously used to target cancer and so could be rapidly moved forward into clinical trials. They then identified 36 drugs that showed promising effects on cells with the specific histone mutation.

One of these drugs, PU-H71, targets a stress response protein in cells, kills 80% of DIPG cells and shows low toxicity for normal cells. In this proposal, they will investigate the mechanism underlying the effect of PU-H71 on DIPG.

Then they will look for ways to extend PU-H71's ability by combining it with other promising drugs to achieve 100% lethality of tumour cells without harming normal cells. The most promising of these combinations will be taken forward into animal studies to provide preclinical data for clinical trial design.





Dr. Xi Huang

Dr. Xi Huang, also a Principal Investigator at the BTRC, led his team of researchers as they uncovered the mechanics of the blood-tumour barrier. This barrier shields the brain, controlling to what extent molecules in the blood stream can enter into the brain tissue. However, while helping to prevent harmful substances from reaching the brain, and allowing some substances, such as water and oxygen to pass into the brain, this barrier also prevents many small molecule drugs from entering the brain, meaning that brain tumours can be difficult to reach.

With this improved understanding of how the blood-brain barrier works, the hope is to improve the efficacy of treatments that are affected by the blood-brain barrier, but also preventing the return of cancerous cells.

Dr. Huang and his colleagues have helped lay a foundation that will lead to more effectively treating medulloblastoma, the most common paediatric brain tumour. This discovery illuminates the way for overcoming obstacles in treating other types of brain tumours, including DIPG. This work by Dr. Huang's laboratory was funded in part by MBF.





Dr. James Rutka

Approximately five years ago, MBF also provided a seed grant to support pre-clinical research about focused ultrasound and how it could help target DIPG during treatments. Dr. James Rutka, Director of the BTRC says, "The data from this research formed the foundation of our clinical trial proposal to Health Canada. Without the support of Meagan Bebenek Foundation for this research, we would never have been able to progress rapidly to the development of the clinical trial".

This clinical trial for treating young patients diagnosed with Diffuse Intrinsic Pontine Glioma (DIPG) is the first of its kind in the world. MRI-guided focused ultra-sound will help open the blood-brain barrier, to ensure the effective delivery of chemotherapy to fight the tumour. This focused ultrasound technology can be used to temporarily open the blood-brain barrier, using the power of soundwaves, allowing the drug treatment to cross the barrier and treat the brain tumour.

Hundreds of clinical trials have been attempted over the years to treat DIPG patients, and, unfortunately, none have been successful, due to the limited understanding of how this brain tumour operates.

Clinical trials are always measured in regards to safety for the young patients and the avoidance of any adverse consequences. And, of course, the benefit of the treatment must be determined.

Neuro-oncology Fellowship Updates

In the summer of 2014, the first Meagan's HUG Neuro-oncology Fellow arrived in Toronto to begin working with and learn from the neuro-oncology specialists at SickKids. The Fellowship offers the Fellow opportunities to pursue work in the academic clinical area, and also to do research. Toronto is home to one of the largest and world-renowned brain tumour programs and paediatric brain tumour research centres. Both the clinical and research programs have reputations for state-of-the-art multi-disciplinary care for young patients, and excellence in clinical and research training. Fellows are mentored so they can further develop strong clinical academic skills with involvement in clinical trials, and focused clinical projects.



Dr. Inci Yaman

In July 2021, Dr. Inci Yaman started her work as the 8th Meagan's HUG Neuro-oncology Fellow. Before coming to Canada, Dr. Yaman worked as a staff paediatric oncologist at Hacettepe University in Ankara, Turkey.

As the Meagan's HUG Fellow Dr. Yaman was involved in the diagnosis and treatment of all the patients with a diagnosis of paediatric brain tumours and helped them to get through this hardest time of their lives. Her goal was to learn the most updated research practices about the diagnostic tools and treatment strategies available in the world, and to be able to present the best treatment options to her patients.

It was a pleasure to welcome Dr. Yaman and some of her family to Meagan's HUG in May 2022. During the opening ceremony, she delivered a special greeting from the International Brain Tumour Alliance (IBTA), wishing Meagan's HUG participants well. This year our Meagan's HUG kilometres walked are symbolically "donated" to the IBTA's 16th annual, global awareness campaign, Walk Around the World for Brain Tumours, and its target to circle the Earth at its equator, a distance of approximately 40,000 kilometres.

With her Meagan's HUG Fellowship year now complete, Dr. Yaman works as a Garron Family Cancer Centre Research Fellow at SickKids, with the aim to continue research to find more effective treatment strategies, and also to find new ways to help increase the quality of life of the survivors.



In the last couple of years, the new molecular era changed the way we diagnose and treat patients with paediatric brain tumours. I decided to expand my knowledge in neuro-oncology. The Neuro-oncology program at the Hospital for Sick Children is one of the best programs in the world. The Meagan's Hug Fellowship provides a wonderful opportunity to work with the leading experts in the field and learn from their expertise.

Dr. Inci Yaman - Meagan's HUG Neuro-oncology Fellow



Dr. Mari Wilhelmsson

In July 2022, Dr. Mari Wilhelmsson began her tenure as the 9th Meagan's HUG Neuro-oncology Fellow, training and working collaboratively at the world-renowned paediatric brain tumour program at SickKids.

Originally from Sweden, Dr. Wilhelmsson is a graduate of medical school at the University of Turku, Finland. During medical school, she also completed several clinical courses at Karolinska Institutet in Stockholm. Her PhD studies at Karolinska Institutet focused on the late effects after allogeneic stem cell transplantation in childhood and adolescence. Dr. Wilhelmsson defended her thesis in May 2018.

After graduating from medical school, she worked mainly in Stockholm, Sweden, including her internship at St. Görans Hospital, and completed her paediatric residency at Astrid Lindgren Children's Hospital, Karolinska University Hospital. Dr. Wilhelmsson has worked in the oncology unit there since January 2019.

Dr. Wilhelmsson's work has included the care of paediatric patients with a variety of cancers and she has been part of the long-term follow-up team after completion of therapy. As well, she has prepared the patients when transitioning to adult care and/or for long-term follow-up.

During this year as the Meagan's HUG Fellow, she will pursue the more specialized focus on the care of children with brain tumours, while planning for their long-term care and follow-up.

When Dr. Wilhelmsson returns to Sweden, she will draw on her experiences as a Fellow, and so help improve the care and long-term outcomes for children diagnosed with brain tumours. She is passionate about bettering the quality of life for these children, and is excited about learning new emerging therapies and diagnostics that improve survival and decrease the need for treatments known to be associated with serious long-term side effects.

The Fellowship has now included candidates from countries around the world, including **Spain, Czech Republic, Denmark, India, Brazil, Argentina**, as well as **Turkey** and **Sweden**.

This diversity helps illustrate the significant role that collaborative work plays in advancing the care of young brain tumour patients. Research has no boundaries, as knowledge is shared and benefits all around the globe.





A Message from the Treasurer

Huw Thomas

Fiscal 2021/2022 was the second year of operation of our organization as an independent charity and I am pleased to share the financial results for the Meagan Bebenek Foundation.

Our second year saw the fundraising landscape as we knew it pre-pandemic begin to return as people began to feel comfortable in public spaces once again. While participation numbers have not fully recovered, we were able to raise \$450,000 of revenue through our various events and the generous support of our sponsors.

In addition we were pleased to support a very special initiative providing assistance to Ukrainian families whose children were receiving cancer treatment at SickKids. Through various efforts we were able to raise \$92,000 of support as well as providing many in-kind benefits to these needy families due to the generosity of various local businesses and individuals.

Once again this year, resources and infrastructure as well as event expenses were the key areas of spending as we continue to build the capabilities of our operations for the longer term. Ultimately despite the challenges for all charities we were able to create a modest surplus of approximately \$17,000 as well as having nearly \$64,000 available at the end of the year to continue to support Ukrainian families.

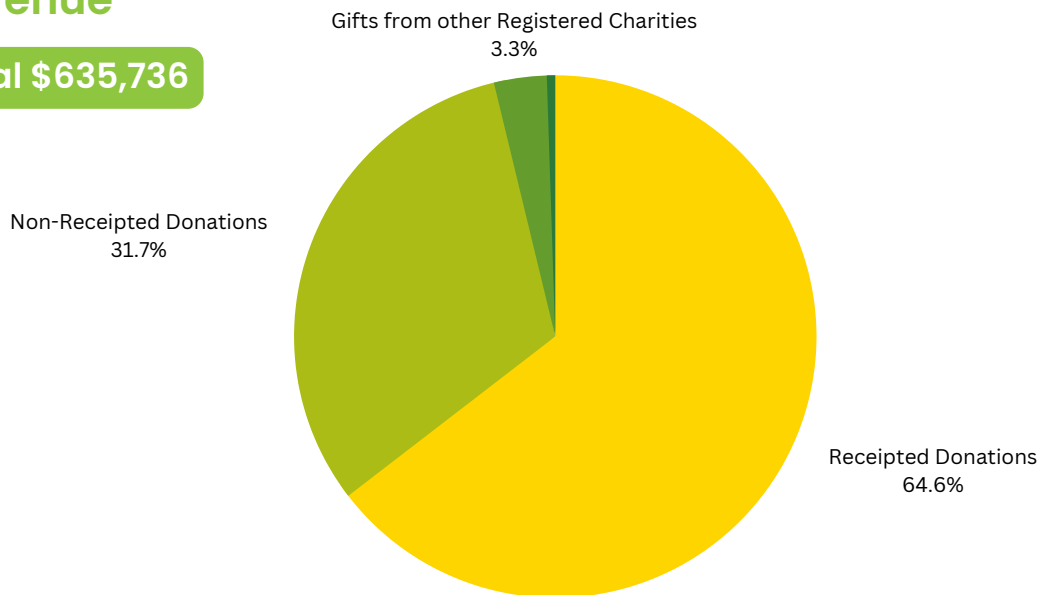
Looking forward, we are optimistic that we will be able to hold the HUG this year in May. This, as well as a number of other events, will keep us in a solid financial position and enable us to continue to fund critical brain tumour research at the Arthur and Sonia Labatt Brain Tumour Research Centre.

Huw Thomas
Treasurer, Meagan Bebenek Foundation

By the Numbers

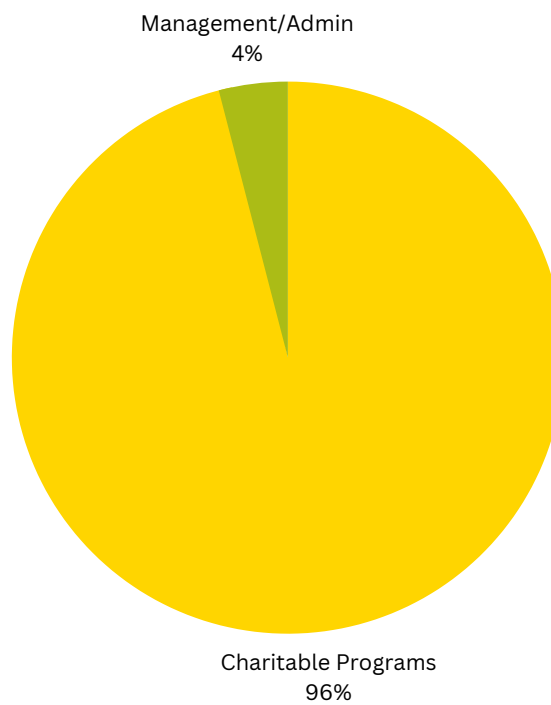
Revenue

Total \$635,736



Expenses

Total \$554,917



Additional details of the T3010 Registered Charity Information Return can be found on the CRA website. Fully audited financial reports are available upon request.

Here We Grow

Together, over the past 21 years, we have demonstrated the impact of our collective efforts in Toronto. Its time to expand our programming across the country and around the world.

1

HUG Expansion

The Meagan's HUG signature event, a 5 km walk to raise awareness about paediatric brain tumours and funds for research, culminates with a giant human HUG, a circle of hope, around the hospital. The HUG has been described by many patients and families as healing, empowering and a reminder that they are not alone.

Soon other Canadian cities and families outside of Toronto will feel the power of the HUG. The time has come!

2

Family Support

A child's illness affects the whole family. A parent's focus is on caring for your child. Other responsibilities often fall to the wayside.

Meagan Bebenek Foundation can provide more direct support to families affected by paediatric brain tumours.

Our programming, focused on daily chores, will focus on easing the burden on parents by offering meal services, housekeeping and yard work.

3

School Program

Through our "Kids Helping Kids" school program, Science, Technology, Engineering and Mathematics (STEM) learning opportunities are used to promote the development of compassion and empathy. Teacher-led programming aligned to provincial curricula, will include support resources, including age-appropriate learning goals, activity sheets and Lego STEM kits.

4

National Research Program

Meagan Bebenek Foundation has built our proven research funding model in partnership with the Brain Tumour Research Centre and SickKids in Toronto. Regional programs across the country will create additional funding opportunities for larger collaborative projects.

Acknowledgments

Without the dedicated support of countless individuals, the achievements outlined in this report would not be possible.

Meagan Bebenek Foundation wishes to recognize the efforts and support of the following groups and individuals:

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MICHAEL SMITH
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THREE ANGELS
TOM KNOWLTON

A very special thank you to the amazing group of volunteers who work throughout the year to further the mission of Meagan Bebenek Foundation.

It is because of your tireless efforts that we proudly enter our 23rd year!

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Our Angels



Hunter
2012 - 2022



Jake
2015 - 2022