# MEAGANSHUG NEWSLETTER



### **MISSION**

Harnessing the power of community to raise awareness and funds for paediatric brain tumour research to foster hope and improve outcomes for affected children and their families.

### **VISION**

A world where no children and their families suffer from brain tumours.

### A Message from our Founder

Dear Friends,

I could not have anticipated in March 2020 that this year would be a year like no other! Life does take unexpected turns, one of which gave rise to a vision of a "circle of hope", Meagan's HUG. At the approach of 2021, our 20<sup>th</sup> anniversary beckons to our community joined by hope.

No doubt, these are trying times. As I did 20 years ago, I reach out to my family, friends, community, so we can support and encourage each other, and, as we have done so well in the past, face challenges together.

I am told often that Meagan's Hug's contribution to changing the course of care, and outcomes for children affected by brain tumour diagnoses, is significant, life-altering. All these achievements and advances in research and improved care, we have accomplished together.

Despite the change in all our circumstances, Meagan's HUG remains committed to its mission, and to harnessing our power as a community. We will move forward with our eyes firmly set on our goals, and continue to dream of a world where no child, no family will suffer with a brain tumour.

Be well!

Denise Bebenek, Founder- Meagan's HUG

Alemin Behenek

### **Year End Giving Gifts of Hope**

This year is particularly trying for all of us, as we cope with the strain of the pandemic including the pressures it places on the day to day happenings in our lives. Seeing loved ones, families, friends, day to day routines- all is different. We miss the simple pleasures!

One thing that has remained unchanged is your generosity in supporting Meagan's HUG and the ground-breaking research into paediatric brain tumours. With the holidays approaching, now is the time to plan your year-end giving, a way to get into the seasonal spirit is to plan.

Hope matters! Hope changes everything! And your commitment to changing the lives of children who have been affected by a brain tumour diagnosis has given hope to countless families.

#### **CLICK TO DONATE**



### **Meet Nooah**



In April 2018, nine-year-old Nooha and her mother Samima received the news that changed their lives forever—a 4.5 centimetre medulloblastoma had manifested itself in Nooha's brain.

Nooha had been experiencing headaches and trouble with balance and movement, but to Samima, a brain tumour was a completely unthinkable diagnosis. Those words cast a shadow of grief and terror.

After Nooha's operation to remove the tumour, the little girl began weekly chemo sessions. Devastated, Samima watched as her daughter lost her sight, speech and ability to walk. The strong drugs robbed Nooha of her beautiful dark hair.

Big-hearted Nooha had lost so much, but she continued to give. While grappling with the aggressive treatment, she insisted on donating the hair she'd lost to other SickKids patients.

The new year brought new hope for Nooha and her mother. At the beginning of 2020, Nooha's voice came back, and with the help of her glasses, her vision improved. The sweet and resilient eleven-year-old can move and walk on her own and will start Grade 7 in September.

"She's my miracle," says Samima.

The journey to recovery has at times felt isolating for mother and daughter. But in the open arms of the Meagan's HUG family, they've found a sense of community and know they are never truly alone.

Submitted by Anna Muir

# **Research Story**



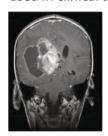
Dr. Annie Huang ( $5^{th}$  from right) with her team at the Huang Lab in 2019

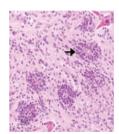
Brain tumours cause the greatest number of cancer deaths and disability in children and young people. And this includes infant brain tumours as well.

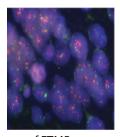
Meagan's HUG recently provided funding for a research project into a rare tumour of the central nervous system. Dr. Annie Huang, clinician scientist, and her colleagues at the Brain Tumour Research Centre are researching how to develop new biology based treatments for a highly fatal infant brain tumour called embryonal tumours with multi-layered rosettes (ETMRs).

A molecular marker for ETMRs was first discovered by the Huang lab in 2009, which has made it easier to recognize this rapidly growing and aggressive brain tumour. ETMR is now thought to make up one of the largest categories of malignant brain tumour in infants and younger children under 4 years old.

As little is known about what drugs work in this disease and how best to treat children with ETMR, the Huang lab proposes to use advanced genetic technology to examine the effect of different drug classes on ETMRs. They will test a large library of 1400 drugs alone and in combination with the hope of identifying drugs and drug combinations that can be used in clinical trials.







MRI, Histology and molecular features of ETMR



# **Community Partners**



Don't miss your chance to purchase some new Meagan's HUG branded gear. You can order caps, t-shirts, bags, sweatshirts, all featuring the new look and logo for Meagan's HUG!

Proceeds from the sale of gear will support the Meagan Bebenek Foundation, operating as Meagan's HUG.

Orders can be placed until November 22. Delivery to your address will take place by mid December.

### **Thank You Pizzaville**

#### SHARE A MEAL & A HUG WITH OUR PIZZA & POPPERSPECIAL

In celebration of our first steps as an independent charity, Pizzaville launched a special campaign to raise awareness and funds for Meagan's HUG. In September, every Pizzaville location donated \$1 from the sale of every Pizza and Popper Special to Meagan's HUG. The campaign ran from September 8<sup>th</sup> - 30<sup>th</sup>.

With your support, Pizzaville generously donated a total of \$7600 to Meagan's HUG.

Thank you to our friends at Pizzaville. Meagan's HUG looks forward to collaborating with you again in the near future.

## Swaddles + Hugs + Hope



#### **CLICK TO SHOP NOW**

A project based group, Xylem & Loom has joined forces with Meagan's HUG and has an exclusive offer that promises hope for all!

Swaddles are now available for purchase – 100% organic cotton and bamboo, silky and soft, all natural and breathable swaddling blankets, safe for any sweet baby's skin.

Proceeds from the sale of each swaddle are directed to Meagan's HUG and its efforts in support of paediatric brain tumour research; and sharing a message of hope for all, including children and their families affected by a brain tumour diagnosis.

Order a swaddle online at xylemloom.com

Purchase a swaddle for someone you love. Or choose to donate a designated swaddle design to send to Mamas for Mamas, an inclusive community for mamas and caregivers, where no mama or child is left behind.

### **CONTACT US**

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Thank you to Meagan's HUG newsletter volunteers, Debbie Tong, Anna Muir, Blair Day

