

# Teddy News

Your Donor Impact Report

{ Spring 2023 Vol. 18

## Brie and Aria's Story

My name is Shaleena Hall. My husband and I live in Brandon with our three wonderful children — Brie, Aria, and Cole. I'm telling my story because I want people to understand the level of complex care that our amazing Children's Hospital in Manitoba provides.

Our girls were growing up as smart, happy and healthy children. We never suspected a thing was wrong.

At 18 months old, Aria began to lose every milestone she had. She couldn't sit up, talk, or walk. None of our local doctors could figure out why.

We took Aria to a doctor in Winnipeg, and were referred to the only hospital that could give us the answers we needed: HSC Children's Hospital.

Within a week, Aria was admitted, and had nearly every test under the sun. Bloodwork, urine tests, ultrasounds, a spinal tap, echocardiogram, and eye exams.

Everything kept coming back normal!

But an MRI showed changes in her brain which suggested a condition called leukodystrophy — a rare genetic disorder that affects the brain and spinal cord.

We had genetic testing done and discovered that my husband and I are carriers of a genetic mutation



Aria and Brie with their mother, Shaleena

called ARSA, and Aria had inherited this rare and fatal disease.

As the year went on, Aria needed a wheelchair, neck brace, wrist braces, leg braces, hand splints, a chest therapy machine.

Finally, palliative care came to see us to make an end-of-life plan. I'm sure you can imagine how devastated we were.

I'm writing this story to say this: although our lives have been more difficult than most — our daughter was cared for so incredibly well by all of the amazing people at Children's Hospital. They truly went above and beyond to make sure that Aria had the best possible care — and to take care of us, too.

You see, at the very same time that Aria was initially taken into hospital, my daughter Brie became ill too. One day we noticed a huge lump on her cheek and a swelling on her jaw in front of her ear.



Aria in hospital

*Continued on next page...*

# Will you Help us Keep our Promise to Children with Cancer?

Childhood cancer is life-altering. Every one of us — whether we are parents or not — can imagine how mothers and fathers feel when they are told that the child they love has cancer.

Although survival rates continue to improve and new treatments are emerging all the time, the treatments themselves can be stressful and exhausting — and often have long-term effects.

With your support, Children's Hospital Foundation of Manitoba and our Children's Hospital Research Institute of Manitoba have made a PROMISE to children with cancer and their families.

Through the PROMISE research theme (**P**ediatric **R**esearch in **O**ncology in **M**anitoba: **I**nnovation, **S**cience and **E**xcellence) we are strengthening the connections between cancer researchers and clinicians, and increasing collaboration between pediatric research programs. This is improving the prognosis, treatment outcomes, and quality of life for children with cancer.

Together, we are transforming research into real-world care. We're keeping children here at home in Manitoba — and now have international leaders

in childhood cancer treatment working with us.

You can help kids with cancer and other sick children by supporting our Better Futures campaign. This history-making campaign will transform child health, by funding the most innovative research projects.

One of the most important pieces of research is in leukemia, the most common cancer in children. This research, headed by Dr. Cedric Tremblay, aims to understand why leukemia returns in some children and how leukemia cells can “hide” from the immune system.

Another piece of vital research is led by Dr. Cielle Stapleton. It focuses on learning more about the genetics of cancer, to allow for targeted therapies. Dr. Stapleton says:

*“I love establishing relationships with children and their families. Striving to improve outcomes and decrease toxicities is what drives my passion.”*

Thankfully, today, eight children out of ten who receive a cancer diagnosis will survive.

Our dedicated teams won't rest until that's every child.

## Brie and Aria's Story Continued...



Brie in hospital

After an ultrasound, CT scan, and biopsy, we learned the news: Brie had a rare form of bone cancer.

You can imagine how the days and months blurred into each other. And we had a new baby as well.

My brave girl underwent chemotherapy and an extensive reconstructive surgery.

But I'm so happy to tell you — on September 13<sup>th</sup> of last year, Brie had her last cycle of chemotherapy. She got to ring the bell and we had an awesome “no more chemo” party!

Both my girls are home now. Brie is in remission and is active at school and in gymnastics. She'll be cared for as an outpatient at Children's Hospital for a long time.



Brie today



# In Honour of Kellan

Kaylene Pryor and her family have chosen a beautiful way to remember their son, Kellan, who passed away from a blood disorder when he was just four years old.

At an event they held in Crystal City, which featured the superhero theme that their son loved, Kellan's family raised an amazing \$20,000 to donate to HSC Children's Hospital.

There was a silent auction, a 50/50 draw, and three volunteers even cut off all their hair to support the cause!

"We spent so much time at Children's Hospital, so it's nice to give back," explained Kellan's dad Justin.

Kaylene paid tribute to hospital staff: "The doctors and nurses took very good care of him. He loved them all and so did we. We'd like to see that care continue to happen for other families."

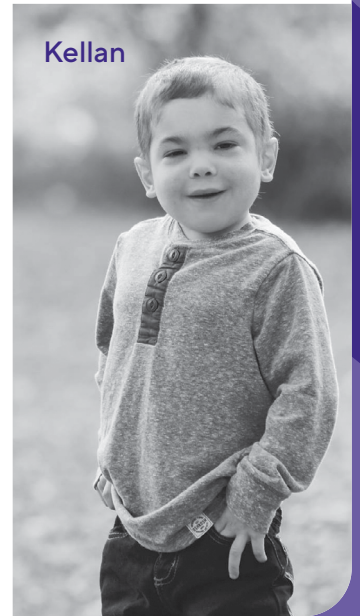
"We want to keep Kellan's memory alive."

We are so grateful to the Pryor family for choosing to honour their son, Kellan, by sharing their love and compassion in this generous way.

If you would like to host your own fundraiser to raise money to support Children's Hospital or make an in memory donation, please email us at [info@goodbear.ca](mailto:info@goodbear.ca).



Pryor family



Kellan



Aria resting at home

Aria is at home too and we are continuing her complex care here. She is four years old, and the sweetest little girl.

We are making the most of every day we have with Aria. And we cannot find the words to say thank you for the staff in every department who care for her, and Brie, and our whole family, so lovingly.

That gratitude extends to each and every supporter of Children's Hospital who has ever made a donation to fund life-saving equipment and the patient support programs that families like us rely on.

Please know that in the good times and the hard times, your love and care is felt throughout every hallway and room of this hospital. By every child and family who spends time there.

Thank you.

*Shakeena Hall*

# You Help Patients Play

Alongside groundbreaking research and world-class care, our supporters help fund important programs to bring smiles and relief to our young patients and their families.

We want children to get the chance to still be kids. We also know that there are deep emotional, mental, and health benefits to play. And so our Child Life Specialists find opportunities for kids to play at every chance they have.

Child Life Specialists and puppet Lizzie work with children daily at HSC Children's Hospital.



They engage kids in “medical play” — acting out scenes where Lizzie needs special tests or medical treatment. This helps children become comfortable with their own journey of illness and recovery.

You see, puppet Lizzie has cancer herself. So watching her go through a cancer journey has really helped patients like Aiden, who was diagnosed with leukemia, years ago.

Aiden thinks the puppets are a great idea and tells us, *“They’re a fun thing to work with if you’re learning something new. Like what happens when you have cancer.”*

The puppets help minimize the scary and painful part of being in hospital.

They’re less threatening for children. There’s a lot of playfulness and practice and rehearsal. Children start to acquire a sense of mastery — and a deeper understanding of what is really going on with them.

Made and designed here in Winnipeg, all the puppets with varying conditions, some including amputations, teach children to understand and accept differences amongst themselves.

We will always be grateful to Ruth Kettner, director of the Child Life Department from 1971 to 1987, who helped pioneer puppet play in our Child Life program — and whose memory continues to help the children she cared for through an endowment fund her family has created in her name.



## Did you know?

- While cancer is relatively rare among children aged 0-14, **more than 100 children** die from cancer every year in Canada.
- **Leukemia** is the most commonly occurring type of cancer (33%), followed by brain & nervous system cancers (20%), and lymphomas (11%).
- Over the last 30 years, **childhood cancer survival rates** have improved from 71% in the 1980s to **82%** in the 2000s.

*(Statistics from the Government of Canada)*



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