

AYA NEWSLETTER

ADOLESCENT & YOUNG ADULT (AYA) PROGRAM • JULY 2020



ALYSSA'S STORY

My Life - Living with Multiple Myeloma

I have been living with multiple myeloma for 10 years now, but what makes my story unique is I am only 42 years old. It is possible to live a full life, even when you are diagnosed with an incurable cancer at 32.

My diagnosis was delayed, partially due to barriers often faced by young adults, but also by the stereotype that multiple myeloma does not occur in young people.

Fainting and a heart arrhythmia eventually led me to ER. My doctor never actually said cancer but he told me there was something really wrong with my blood work. My protein was

very high and I was anemic. 20 vials of blood and a chest x-ray later I went to an urgent follow up with internal medicine.

There I was told I probably had multiple myeloma. I had never heard of multiple myeloma! The doctor drew a picture to show the layers of blood cells with emphasis on the plasma cells (mine were about 90 percent). I was told myeloma was very rare for 30-year-olds, so it was not something doctors were looking for.

I was referred to Princess Margaret Hospital for my first stem cell transplant. I knew it was the place I needed to stay to access cutting edge treatments. Luckily, the Myeloma team agreed with me.

The hardest part of multiple myeloma is hearing there is no cure. At first, I did not think I would make it to 40 but then I was determined not to miss out on life. Since my diagnosis I got married, bought a house, drove across Canada, and went to Europe, Mexico and Ireland! I do my best to keep up with my peers but my body does need more time to recover.

The event which shaped my life the most after being diagnosed with Multiple Myeloma was becoming a mom. Growing up I always wanted kids. But the high dose chemotherapy used for stem cell transplant is toxic to fertility so I was referred to a reproductive endocrinologist to talk about my options.

My doctor recommended IVF to freeze embryos for when I was healthy enough to have a baby. I had a one month window after my induction chemo before I started my stem cell transplant procedures to try one cycle. After a difficult egg stimulation and retrieval procedure we had 9 embryos.

A few years post transplant we met with specialists at the Hospital for Sick Children to discuss pregnancy and multiple myeloma since it is so rare. We were told to wait a few years but to go for it if I was healthy. In 2013, we went for it! I had maintained a complete response and was feeling healthy.

Getting pregnant was not easy but miraculously, our last try worked. My baby was born in 2015. Unfortunately a trace protein appeared in my bloodwork in 2015. Every 2 months I checked in with my

Myeloma team while we watched and waited. I made it through all the sleepless nights and early days as a parent but by 2017 my myeloma was in full relapse and I needed to restart treatment.

I am realistic about the future since my cancer will relapse again. I have hope, but know I must also live presently by making memories and enjoying the small moments. I want my child to remember me. I think they will because I have clear memories at 5. Not typical worries for most parents of 5 year olds, I know, but reality when you are living with cancer. Though I experienced delays getting diagnosed with cancer, after I was diagnosed my medical care is excellent. At this point in my journey I have had countless rounds of chemotherapy, two stem cell transplants, and ongoing treatment. The Myeloma team at PMH have done their best to access the newest and best treatments for me. I hope sharing my story gives others hope that you can live a good life, even if you are diagnosed with cancer as a young adult.

AYA PROGRAM UPDATES



JULY 23: VIRTUAL AYA MEET-UP

Our Virtual AYA Meet-up will be scheduled on July 23rd from 6:00 p.m - 7:30 p.m. The meet-up will be hosted on the Ontario Telehealth Network (OTN) so all personal health information is safe and protected. We will have a limit of 15 participants so if you are interested, please let us know ASAP by emailing us at aya@uhn.ca and we will send you the invite link.

COMMUNITY EVENTS & UPDATES

MINDFULNESS IN NATURE RETREAT

A weekend in nature for ages 18-32, with nourishing food, community, and practices to ground you in Mindfulness and Compassion during these change-making times.

Reserve today!:

<https://form.jotform.com/201685535898>

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