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Winter 2016

We are excited to share another issue of our newsletter with you. As you can see, we have lots of news to share. I must begin by thanking Aimee Costello for all of her years of dedication to survivors and families. Aimee and I started the Survivorship program together in 2008, and I will always be thankful for her creative thinking, and all of the talents she has shared along the way. We are truly excited that she will remain involved with the survivorship team and know that she will do great things in the time that she is not spending with us. I am super excited to welcome Amanda. She will be a wonderful addition to our team, and has already started to “settle in”. She will continue Aimee’s tradition of providing the education and resources you need for your lifetime. We continue to build upon our research activities and we are thankful to Bethany for leading us in this venture. And, I don’t know what we would do without Noelle – who created this newsletter, in addition to contributing in so many other ways. Finally, a note of thanks to our guest authors and their “survivor stories.” This program is about survivors, and for survivors, and we are so very fortunate to share in your journey.



Goodbye Aimee!



Dear Survivors and Families,

It is with mixed emotion that I have to tell all of you that I am leaving CHP. Many of you I have only known a short time and I am working hard to make sure you experience a smooth transition. I know you will be in good hands with the rest of the Survivorship Team. Many others of you I have known for so many years and I know that any transition will be difficult, regardless of the superb care you are left in, and I am sorry for that. Regardless of the length of time we have worked together, I will miss each one of you. I love my job and it is the only one I have ever had! After 15 years though, I recognize that the time has come for a change.

I am really excited about my next chapter in life, starting my own business, [Grace 2B Free](#). I am doing professional organizing and wellness coaching (shocking change I know!) and I find that I am able to function nearly just as much as a nurse in that as I have at the hospital! I am grateful for the privilege you have all bestowed upon me, to have allowed me to walk beside you in your cancer journey. We have shared laughs and tears and hardships and celebrations together and you will always be a part of who I am.

I will be working through March at least, and hope to maintain an “as needed” role in Survivorship as we continue to plan different events and explore new projects. I'm sure our paths will continue to cross! Thank you all for being such an amazing group to care for!

Love, Aimee

Welcome Amanda!

I am very excited to be joining the Survivorship team and look forward to meeting and caring for our extraordinary survivors and hearing their stories. Professionally, I've been a Physician Assistant at Children's since 2012 in the Outpatient Hematology/Oncology clinic, caring primarily for patients who are receiving chemotherapy. I worked in a small family practice office in Connellsville before coming to CHP. As far as schooling, I earned my undergraduate degree from Grove City College in 2008 and my Master's of Physician Assistant Studies from Chatham University in 2011. Personally, I'm a Western Pennsylvania native and graduated from Greater Latrobe School District. I have a wonderful husband and two energetic little boys, Joshua (age 4) and Theo (age 1). On the rare occasion that I have a free Saturday, I can be found running, hiking or biking.



A Survivor Story - Ashley Taylor

As a childhood cancer survivor, it gradually becomes clear to you as time passes that the "normal" you wished for so desperately during treatment is an elusive state of being henceforth. Your hair grows back, and your blood cells start behaving, but you are not the same anymore. Survivorship is a beautiful gift in so many ways, and the biggest way may also be the toughest: you are different from the young people around you. It sounds cliché, but there truly are things that you just appreciate more than your peers do: being permitted to attend school in a classroom, being able to curl your hair, being allowed to hold a stuffed animal, and so much more. Of course you occasionally slip into typical adolescent moments of taking your parents for granted, but there are many other moments where you feel older, wiser, and just plain different than other people your age.



Being diagnosed at the start of the millennium when Facebook, Instagram, Twitter, and Tumblr did not exist, the previous Children's hospital was much less of a child-friendly building than it is today, and Child Life options were much more limited than the various options and events that are now held regularly, I often felt lost. At the age of eleven, I was neither a teenager nor a child. Post-treatment, I never found anyone who was diagnosed at a young age and had to grow up with a different knowledge of the world around them the way I had. All the survivors I met were older, had lived their lives without cancer experiences for so long before entering the journey. I longed for just one person my age who would get what it was like to wonder if your body would let you be a mother someday, to

worry if cancer would come to get you again, to even just laugh at the simple things like chemo vomit stories or cafeteria food least-favorites.

Thanks to Noelle, Amy, and Dr. Tersak's survivorship program, I found exactly who I was looking for. When Becca wrote her own survivorship story in the e-newsletter last winter, something in her story just made me certain she would understand my own. This feeling caused me to look her up through Gmail, and a few months later, we exchanged phone numbers and began a friendship unlike any other I have. We decided to meet in person for a summer weekend in Erie, her hometown. In the fall, she visited me at my home in Pittsburgh and enjoyed some of my favorite downtown activities. We have dreams of attending CancerCon together someday, and we share fears, hopes, and stories almost daily - cancer related or not.

A friendship like the one I have with Becca was something I waited 13 years to find. I am so thankful for CHP's dedication to constantly improving their community and support for survivors. Without them, I might still be floating along without a true companion in this survivorship journey. I am excited to see where CHP's survivorship program can take other patients in the years to come. Connections are waiting more than ever before.

A Survivor's Story - Marissa Gingras



On January 7, I walked through the doors of the Hem-Onc clinic for the last time. It was quite a surreal feeling, as I had been an oncology patient since 1993! Before they set me free, the survivorship clinic staff asked me if I would briefly tell my story.

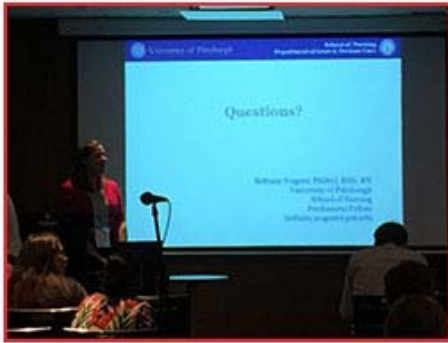
I was four years old when Acute Lymphoblastic Leukemia (ALL) invaded my little world. I stayed in the hospital over my birthday that fell just a few days later, which is a big deal when you're turning five! But my mom and dad said I was sick and I had to do this to get better.

My parents would often say that phrase to me over the coming years. From my dad carrying me into the ED in the middle of the night to my mom holding my hand through procedures, I remember my parents coaxing me through everything. I made it through any physical and emotional pain thrown my way thanks to my parents. They were, and still are, my heroes.

It was actually my dad who, a decade later, would suggest to me that I should become a nurse. I'm so glad he did; in college, I quickly fell in love with pediatrics and never looked back. I knew what it was like to be a sick kid and I wanted to help other kids since I was blessed enough to make it through illness myself. My dream came true in 2011, when I was hired as a nurse at...guess where...**Children's Hospital of Pittsburgh!**

In working at CHP, I am constantly amazed by the spirit of my kiddos. My heart feels for you, and I hope I always remember what it is like to be on the other side of the nurse-patient relationship so that I may provide you with the best care I can muster. May you, too, survive and flourish; the world so needs your light.

Survivor Connect Research Update



Members of the Survivorship Team and I recently presented some of our work at the International Congress of Adolescent and Young Adult Oncology in Sydney, Australia. The conference was a wonderful opportunity to meet other care providers and researchers interested in the health and wellbeing of cancer survivors. Since many of you have participated in research that we conduct, so we wanted to take a moment to share with you some of our results.

I presented a review of research about how cancer survivors' cognitive function is affected after cancer diagnosis and treatment. I was specifically interested in patients diagnosed during adolescence and young adulthood (AYA). We found that few studies have looked at patients diagnosed during the AYA time period. However, the limited work that has been done suggests that cancer survivors report higher levels of memory problems, fatigue, and difficulty with task completion.

Interestingly, AYA Hodgkin's Lymphoma survivors who have heart or lung problems scored lower on cognitive testing. Still, more research is needed. My dissertation research is looking at how cancer during AYA affects cognitive function as well as how cancer and treatment might affect a survivor's ability to obtain work and carry out work-related responsibilities.

Aimee presented some of her work looking at whether there or not there is a link between Metabolic Syndrome and low blood levels of Vitamin D. Metabolic Syndrome is a group of risk factors that make heart disease, diabetes and stroke more likely to occur. These include high fasting blood sugar level, low HDL (good) cholesterol level, high blood pressure, increased waist circumference and high body mass index. Other studies have proven that cancer survivors are at higher risk of developing Metabolic Syndrome.

Aimee's study questioned whether or not the patients diagnosed with Metabolic Syndrome also had low levels of Vitamin D. Other studies have suggested that Vitamin D is important for heart health and immune system function, not just bone health. The results of Aimee's studied showed that there might be a significant link between Metabolic Syndrome and low Vitamin D levels in male cancer survivors. The number of patients studied was very small and more work needs to be done in the future.

We look forward to keeping you up-to date on the research projects we are involved with!

Bethany Nugent, PhD(c), BSN, RN
Graduate Student Researcher



Survivorship Team
(minus Dr. Tersak) in Sydney
Harbor.



In Manly Bay.



Sydney Opera House.

Save the Date - Our fourth annual Survivorship Picnic!



Kennywood Park - Sunday, June 5, 2016

The Kennywood Park Charitable Trust has awarded our program 250 tickets again this year for our Survivors! SurvivorConnect will be sponsoring a lunch again this year in the Main Pavillion and feature entertainment such as balloon animals, face painting and music! Mark your calendars now and look for an invitation in the mail as well as online in May! First come, first served...so be sure to respond as soon as you get the invitation! We can't wait to see you!



Do you want to share your story?



Each of you has a very unique and inspiring story to tell. While the details of each story are different, you all share the experience of having survive pediatric cancer! And that is no small feat! Your stories reflect courage, strength and wisdom beyond your years. And as we read in Ashley's story this month, sharing your story may just be the inspiration that another survivor needs to hear.

Please consider sharing your story. Contact Noelle at survivorconnect@gmail.com. We hope to hear from you!

Join our closed and private Survivorconnect Facebook Group! Send an email to survivorconnect@gmail.com and we will send you an invitation to join!



SurvivorConnect

www.chp.edu/survivorship

Survivorship Clinic of the Division of
Hematology/Oncology at
Children's Hospital of
Pittsburgh of UPMC

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