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Merel during treatment

From Our Director



Get ready to celebrate! Happy Spring from your Survivorship Team. We are very excited about upcoming events and would like to share additional

information.

Please join us on **June 1, 2014** for the **Survivorship Program 2nd Annual National Cancer Survivors Day Celebration** at Kennywood Park.

Reunite with old friends and make some new ones. You will see familiar faces from your doctors, nurses and other staff persons as we gather on this important day.

Thanks to a generous donation from the

Spring 2014

National Cancer Survivors Day - 2014 Mark Your Calendars!



It is that time again! The second annual Kennywood Picnic to celebrate National Cancer Survivors Day will be held on **Sunday, June 1, 2014** from noon - close of park.

This year, we are the recipients of 250 free tickets for survivors and



Receiving Chemo



Merel at Relay



Kennywood Charitable Trust, we are able to offer each survivor a **free** ticket as well as the ability to bring three additional guests at no charge. (Advance registration is required while supplies last). Additional tickets will be available for purchase at a reduced rate. We will have live music, face painting, and a picnic lunch together at what we fondly call "Celebration Pavilion".

Later in the Summer on **Saturday August 16th** we are planning our *1st Annual Survivorship Symposium* to be held at Gilda's Club in the Strip District. This event will be open to health care providers, patients and families – all survivors and their guests attend at no charge. The day begins with a light breakfast followed by a few speakers that will provide important information for all in attendance. We will then have a Survivors Panel with question and answer time over lunch. In the afternoon we will break into small groups discussing a number of topics with separate groups for Medical providers and for patients/families.

Finally, a thank you to our first survivor guest columnist! We hope the article in this edition will be the first of many guest articles written by our talented, inspiring Survivorship patients. After all, this Program is for you, and about you. If you have a story you would like to share, please contact us by emailing

up to two guests.

Details will be mailed in an invitation soon! Watch your mail! We cannot wait to celebrate this day with you at our favorite amusement park.

Heart Problems in Survivors of Childhood Cancer by Bethany Thelen, Research Nurse



While most survivors of childhood cancer will not develop heart problems, certain types of chemotherapy and radiation might make some people more vulnerable to developing heart problems.

Possible problems include (CureSearch, 2014):

- Coronary artery disease: Blood vessels in the heart can be damaged not allowing oxygen-carrying blood and nutrients to freely flow to other areas of the heart or tissues in the body



We love to hear from you!
If you would like to tell
your story in an upcoming
issue of Survivor
Connection, call us at
412-692-6658 or email
noelle.conover@chp.edu.



survivorconnect@chp.edu or calling
412-692-6652.

A Survivor's Story- Meet Merel

My name is Merel, and I've been an Oncology patient at Children's Hospital for 15 years.



My Children's experience began when I was diagnosed with an optic chiasm glioma (brain tumor of the visual pathways) in the first grade after failing a vision screening test at school. I began the long journey of treatment at Children's with chemotherapy, which once completed, stabilized me for 2 years. After that, a routine MRI showed a recurrent growth in my tumor. I returned to Children's for a 6-week radiation therapy regimen, and I'm happy to report that I've remained cancer-free for 12 years now.

As a survivor, I firmly believe that I have a responsibility to advocate and support issues surrounding oncology and survivorship. Even as some details surrounding my battle with cancer grow foggy and others slip away altogether, I continue to learn more about what it

- Heart failure: The muscle cells of the heart can be damaged badly enough that it prevents the heart from pumping properly
- Valvular disease: Heart valves can be damaged leading to stiffness or leaking of valves, the "gates" which control the flow of blood as it flows through the heart
- Arrhythmia: The complex electrical pathways in the heart responsible for making the heart beat normally can be damaged leading to an abnormally slow, fast, or irregular heartbeat

A recent study from the Childhood Cancer Survivor Study examined heart problems in adult survivors of childhood cancer. The study also looked at factors that increase a person's risk for developing heart problems. High blood pressure was the biggest risk factor that predicted who developed coronary artery disease, heart failure, valvular disease, and arrhythmias. High blood pressure is referred to as a "modifiable risk factor" because it is a problem that can be controlled with a healthy body weight, regular exercise, and in some cases, medication. Controlling blood pressure is important for everyone, but it is especially important for survivor

means to be a survivor. I'm about to graduate nursing school, and I'd like to think that the past 4 years have enlightened me of the emotional toll that cancer survivorship has taken on my life and the consequent lessons that that impact has taught me.

One of the ways I have found I can cope is through action. I have developed cherished friendships with fellow Children's patients and survivors through the Adolescent and Young Adult Oncology (AYA) group, have attended events through SurvivorConnect, and I'm even running my 5th Pittsburgh Half Marathon on the Run for Children's team!

Outside of Children's, and the reason I am writing this, I am involved with the American Cancer Society's Relay for Life. Relay for Life is a nationwide movement that raises much-needed funds for cancer awareness, research, and services. Teams come together to remember, celebrate, and fight back. I am inviting you to come celebrate with us. Relay for Life kicks off with a Survivor Ceremony, where cancer survivors are honored and take part in a special "Survivor's Lap." Survivors receive a free t-shirt and complementary dinner. I have been privileged to work with the group organizing the University of Pittsburgh's event, and would be so honored if you would join us this year! Let's put faces and stories to cancer

of cancer who had treatments (e.g. chemotherapy; radiation) that may have damaged the heart.

Healthcare providers at the Survivorship Clinic often refer patients to have testing of the heart to check for problems. The information from these tests provide information that can help prevent problems from getting worse. The two most common tests to check for heart problems include an electrocardiogram (EKG) and an echocardiogram (AKA "echo"). The EKG looks at the electrical impulses of the heart and how it is beating. Echocardiograms are ultrasound images of the heart which give your healthcare provider a real-time picture of the heart as it is beating. An "echo" helps to make sure the muscles and valves of your heart are working adequately and that blood is moving well through the heart.

If you have any questions or concerns about your heart and how your disease and/or treatment may have impacted how well your heart works, please talk to your healthcare provider. If you are interested in reading more about heart problems that may occur as a result of cancer and cancer treatment, or reading the study which looked at risk factors for heart problems, please see the citations below.

survival together!

To register for Relay for Life at the University of Pittsburgh, on April 5th, 2014, go to:

<http://www.relayforlife.org>. Search for Pittsburgh in the “Sign up for an Event” search bar, and select the event for the University of Pittsburgh. Select “Sign Up” and then “Walk the Survivor Lap,” and fill out your information. On behalf of the entire Pitt community and myself, we can’t wait to see you at the University of Pittsburgh’s Relay for Life on April 5th, 2014!

Citations:

Armstrong, G., & Oeffinger, K. (2013). Modifiable risk factors and major cardiac events among adult survivors of childhood cancer. *Journal of Clinical Oncology*, 31(29), 3673–3680.
Cure Search for Children’s Cancer. (2014). Heart Problems. Retrieved from <http://www.curesearch.org/Heart-Problems/>

Merel

SurvivorConnect - upcoming events

We have been busy planning some great events for this year. We hope to see you! Mark your calendars for the upcoming events from SurvivorConnect:

- **Sunday, June 1** - National Cancer Survivors Day Celebration - Kennywood Park
noon until the park closes
- **Saturday, August 16** - Moving Forward: A Symposium on Child & Adolescent Cancer Survivorship
Gilda's Club Western Pa
8:00 - 3:00 pm.
- **November 6** - Survivorship Fundraiser Dinner

Casbah Restaurant - 7 PM

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