



Survivor Connection

An electronic newsletter from SurvivorConnect
A project of the Survivorship Clinic
Division of Pediatric Hematology/Oncology

Children's Hospital of Pittsburgh | of UPMC

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Meet Bethany Thelen...



Hello my name is **Bethany**. I graduated with my Bachelor's degree in Nursing in 2010 from the University of Michigan and took a position as a staff nurse on an inpatient oncology unit. I moved to Pittsburgh in 2011 to attend

National Cancer Survivors Day is on June 2!



National Cancer Survivors Day is a **CELEBRATION** for those who have survived, an **INSPIRATION**

for those recently diagnosed, a gathering of **SUPPORT** for families, and an **OUTREACH** to the community. We are pleased to celebrate this day along with communities across the United States. For more information about this day, visit the website at <http://www.ncsd.org/>

SurvivorConnect celebrates NCS D with a Celebration at Kennywood Park

Invitations have been mailed, the website updated with details, and plans have been made for a big celebration for all of you at Kennywood park on Sunday, June 2, 2013. Please join us for a complimentary lunch in the Main Pavillion, followed by a group photo.



Greetings from your Survivorship Team!



We hope you are having a wonderful Spring. In this issue you will find information about an exciting upcoming event as we invite you to join with us to celebrate **National Cancer Survivors Day**.

Although the event will be a great celebration, it also serves another purpose. It is our hope to remain connected with you and to continue to be a part of your life and your health care team as you begin to work more closely with your primary care provider to meet all of your health care needs.

It is great news that you do not need lifetime follow up with an oncologist.

graduate school at the University of Pittsburgh where I am pursuing my PhD in Nursing. My research interest involves examination of effects from cancer and cancer therapy in survivors of childhood cancer, with a particular interest in survivors of adolescent cancer. I have grown to love the city of Pittsburgh and the friendly nature that seems to accompany it.

I plan to write a short section in each newsletter regarding recent research on survivors of childhood cancer taken from the nationally conducted study [Childhood Cancer Survivor Study \(CCSS\)](#). Begun in 1994, the CCSS is a multi-institutional effort to examine the survivorship of over 35,000 childhood cancer survivors who are **5 or more years past diagnosis for cancer**, leukemia, tumor, or similar illness diagnosed during childhood or adolescence. I sincerely look forward to learning with all of you and sharing the exciting work that has arisen out of this important study!

Survivors of Children Cancer at Risk for Hospitalization

A study published in 2012 examined more than 10,000 survivors of childhood cancer and reported number and reasons for hospitalizations throughout their lives. Survivors of childhood cancer are more likely to be hospitalized than the general U.S population.

Kennywood has reduced the price of admission for our group to \$22.50 per ticket. You can purchase an unlimited amount of these discounted tickets by going to <http://www.kennywood.com> and entering the **PROMO CODE: CHILDREN602** in the box at the top of the screen and click GO.

To RSVP for the lunch, please call SurvivorConnect coordinator, Noelle at **412-692-6658. We need to hear from you before MAY 24!**

Invite your friends and family and join us! We hope to see you all there!

Useful Information from Nurse Aimee



Hi Survivors! Spring has finally sprung! Hopefully that means we'll be seeing some more sun. That means I have some friendly, seasonal reminders:

- you need to protect yourself from the sun
- you need to get some sun in order to absorb vitamin D.

You may ask what you are supposed to do with this conflicting information. I will try to explain that here so you can have a safe, healthy summer.

Doctors at St. Jude Children's Research Hospital looked at the survivors enrolled in the Childhood Cancer Survivor Study. They found that **survivors of a childhood cancer are 2.5 times more likely to develop melanoma**. Melanoma is the most serious type of skin cancer. It begins in skin cells called melanocytes. Melanocytes are the cells that make

However, in order for your primary care provider to provide the best care for you, he/she needs to be well versed as to your prior therapies and special health care screening needs. That's where the continuation of our partnership comes in! We want to help you to continue to live the healthiest fullest life possible as a childhood cancer survivor.

So, come out and celebrate with us. Continue to build relationships among friends, family, other survivors and your survivorship team.

We hope to see you there!

Grapes for Gilda's Event for Survivors



Survivors over the age of 21...you are invited to celebrate **National Cancer Survivors Day (NCSD)** with us on **June 1, 2013 at 6:30 - 9:30 PM.** **Great Grapes for Gildas** will be held at Gilda's Club of Western PA located at 2816 Smallman Street in the Strip District of Pittsburgh.

Great Grapes is an annual event spearheaded by childhood cancer survivor, Marty Randal. Diagnosed with Hodgkin's Lymphoma at the age of

Female gender, a second cancer, radiation treatment, and chronic health conditions (such as high blood pressure) were some of the reasons survivors were hospitalized more. The most common reason for hospitalization was cancer- or tumor-related.

Despite an increased risk for hospitalization, you can do something about this! Regular visits with a Primary Care Physician are important to prevent and monitor health conditions, decreasing your risk for hospitalization.

In addition, [Children's Hospital of Pittsburgh of UPMC](#) has established a **Late Effects Clinic** for survivors that are 5 or more years past cancer therapy completion. The Late Effects [team](#) can provide you with your treatment summary and help you to establish a follow-up plan to maintain and improve health. If you were treated at Children's Hospital and are more than two years out of cancer therapy and have not yet made an appointment with the clinic, feel free to call 412-692-6506 or email survivorconnect@chp.edu to ask a question or make an appointment.

Citation:

Kurt, B., Nolan, V., & Ness, K. (2012). Hospitalization rates among survivors of childhood cancer in the childhood cancer survivor study cohort. *Pediatric blood & cancer*, 59(1), 126–132.

melanin, which gives skin its color. Melanin also protects the deeper layers of the skin from the sun's harmful ultraviolet (UV) rays. When people spend time in the sunlight, the melanocytes make more melanin and cause the skin to tan. This also happens when skin is exposed to other forms of ultraviolet light (such as in a tanning booth). If the skin receives too much ultraviolet light, the melanocytes may begin to grow abnormally and become cancerous. ***If you have received radiation therapy you may have higher risk of developing a skin cancer in that spot.***

Advice for everyone:

- **Cover up.** Wear tightly-woven clothing that blocks out light. Try this test: Place your hand between a single layer of the clothing and a light source. If you can see your hand through the fabric, the garment offers little protection.
- **Use sunscreen.** A sun protection factor (SPF) of at least 15 blocks 93 percent of UV rays. You want to block both UVA and UVB rays to guard against skin cancer. Be sure to follow application directions on the bottle. Initial use should be 20-30minutes before sun exposure and you must reapply every 2 hours (even waterproof sunscreen).
- **Protect your lips with a lip balm** that has an SPF of 15 or higher
- **Wear a hat.** A wide brim hat (not a baseball cap) is ideal because it protects the neck, ears, eyes, forehead, nose, and scalp.
- **Wear UV-absorbent shades.** Sunglasses don't have to be expensive, but they should block 99 to 100 percent of UVA and UVB radiation.
- **Limit exposure.** UV rays are most intense between 10 a.m. and 4 p.m. If you're unsure about the sun's intensity, take the shadow test: If your

17 Marty is now a 28+ years cancer survivor and thankful for every day. Marty works closely with the SurvivorConnect team on our events.

Tickets can be purchased at the door OR [on-line](#). Gilda's Club provides free emotional and social support to anyone impacted by any cancer. Everyone who has attended this event has remarked about the openness and warmth of Gilda's facility and our event allows you to see the facility which we support. All proceeds stay here in western PA.

Survivor! Perseverance! Survive! Those are the key words for this year's event! Marty writes a blog about Survivorship. Visit his [blog](#).

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Raising Awareness for Childhood Cancer.

Share Your Survivor Story



The Survivorship Clinic team is always interested in hearing your story! If you want to share it with us for an upcoming newsletter, the website or on social media, please contact **Noelle Conover**, Project Coordinator of **SurvivorConnect** at 412-692-6658 or email her at noelle.conover@chp.edu. We hope to hear from you!

shadow is shorter than you, the sun's rays are the day's strongest.

BUT, if we use sunblock all the time we prevent our bodies from absorbing the Vitamin D that we need. We know Vitamin D is important for bone health. It may also be important for preventing heart disease, cancer, diabetes, depression and autoimmune diseases.

Sensible sun exposure can provide enough Vitamin D3 to be stored in our body fat. It is then released during the winter when Vitamin D3 cannot be produced by our bodies. Exposing your arms and legs to the sun for 15-30 minutes twice a week is often enough. This should be done without sunblock between the hours of 10AM and 3PM. Your vitamin D absorption will depend on the time of day, season, latitude you live in, and your skin pigmentation.

Bottom line...everything in moderation! Allow yourself some safe, unprotected sun time, take precautions for prolonged periods in the sun, and stay away from the tanning beds. I hope this helps!

Do you have insurance? Learn more from our social worker, Jess

Survivors, did you know that if you are over the age of 18 and under 26, you can stay on your parent's insurance? Under the Affordable Care Act, any young adult under the age of 26 can continue to receive coverage on their parent's insurance policy.



You can join or remain on your parent's policy even if you are married, not

residing with your parents, attending school, not financially dependent on them, and/or even if you are eligible on your own employer's plan.

There are also insurance options through your County Assistance office, there are many different ways to receive Medical Assistance based on income and/or disability.

To get more information and criteria on Medical Assistance, please contact your local county assistance office or I can be reached at 412-692-5339. ***Don't go without coverage, you might be eligible through the programs above!***

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