

# Survivor Connection



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

- Survivorship Clinic Hosts First Fundraiser at CASBAH!
- A Survivor's Story - My Cancer Story
- After Cancer

## Survivorship Clinic Hosts First Fundraiser at CASBAH!

## Fall/Winter 2014

### From our Medical Director



### We NEED your help!

The Survivorship Team would like to plan a **Golf Outing** as a fundraiser to benefit the Survivorship program. If you are interested in serving on the planning committee for this event OR if you have any connections to a Golf Club where we could host the event, please contact Noelle at [Noelle.conover@chp.edu](mailto:Noelle.conover@chp.edu) as soon as possible! Thanks!



It has been a busy Fall season for the Survivorship program. We hope you enjoy this issue that will highlight new information that will be of interest to you as well as new and exciting activities within our program.

We are thankful for the accomplishments of the past year, and look forward with hope and excitement towards continuing to expand the program in 2015. We could not do it without you!

Thank you for your interest, your support, and helping us to work together to advance awareness of childhood cancer survivors and to work with you to live the healthiest fullest life

### SAVE THE DATE

**National Cancer Survivor Day** is Sunday, June 7. Mark your calendars for our Kennywood Celebration! Details in the SPRING issue of Survivor Connection.

### Photos from the CASBAH dinner

On Thursday, November 13, 50 friends and supporters of the Survivorship Program paid \$125 each to enjoy an amazing five course dinner prepared by the chef of CASBAH and paired with wines. This amazing evening focused on our program and our survivors, who will benefit from the proceeds raised.

At the beginning of the evening, Dr. Tersak welcomed everyone and took a few minutes to highlight the program and some of the trials faced by survivors



Our guest for the evening, Dr. Wollman, spoke about the changes in survivorship over his career, highlighting the survival rate of over 80% in some cancers. He was joined by Mrs. Wollman and some of his former patients, now members of this program and survivors of cancer.



Members of the Survivorship Team, including Bethany Nugent, Kate Dempsey and Noelle Conover, spoke about their work with Survivorship.



Our favorite entertainer, Mark helped make for an enjoyable evening. Three auction items, an IPAD, concert tickets for Dave Matthews Band and a portrait session with locally known photographer Annie O'Neill provided additional funds for the program.



We are extremely grateful to all of the supporters for an amazing evening and their generous support! We hope to do this again soon!

## A Survivor's Story - My Cancer Story

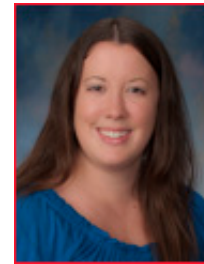
by *Becca Meyer*



What is cancer? It is not just a zodiac symbol and it is not just a word. Cancer is an evil word that should be a swear word. Cancer can destroy what you love and leave mean scars behind. Cancer is an awful disease to see someone go through. Cancer is the devil of fighting for your life. Cancer is something I fought. Cancer is something my mother lost her battle to. And yet, cancer is forever going to the reason why I have hope.

Cancer changes your life and the lives of those around you forever. At the age of five I was getting poked and losing my hair because of my diagnosis of leukemia. Most five year old girls are

## Version 4 of the Survivorship Guidelines are here!



by *Aimee Costello, RN, DNP*

The **Children's Oncology Group (COG) Long-Term Follow-Up (LTFU) Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers** were developed as a joint effort of the Nursing Discipline and the Late Effects Committee within the COG. The purpose of these guidelines is to:

- Provide recommendations for screening and management of late effects that may potentially arise as a result of the treatment for childhood cancer
- Increase awareness of potential late effects
- Standardize and enhance follow-up care provided to survivors

These guidelines were developed as a resource for clinicians who provide ongoing healthcare to survivors of pediatric cancers. They are appropriate for asymptomatic survivors of childhood, adolescent or young adult cancers presenting for routine medical follow-up. More extensive evaluations are

**Do you have a survivor story to share?**



Contact Noelle at [noelle.conover@chp.edu](mailto:noelle.conover@chp.edu) if you would like to share your story!

princesses and their friends. Those days were robbed from me and replaced with trips to Pittsburgh for chemotherapy. At the age of five, I knew the meaning of blood counts, spinal taps and hair loss, when all I wanted was to be cancer-free.

When I went back to school it was difficult to tell people that I had cancer and had beaten it. I remember one parent who literally removed her child from the house because she didn't want her child to get cancer. I remember her words to this day. Little did she know that cancer isn't something you can catch like the common cold.

I participated in the Relay for Life because I know that by raising funds and walking for the American Cancer Society, I can help save lives. I want to make noise and help finish the fight! It's overwhelming to think that millions of people will be diagnosed with cancer this year. It might someone close to us—or might even be you or me—but I am making it my mission to make sure that other children don't have to suffer through seemingly endless chemotherapy.

## After Cancer

survivors presenting with signs and symptoms suggesting illness or organ dysfunction.

The guidelines task force has undertaken the responsibility to update these guidelines every five years as more and more information is learned about survivors. Version 4 of the guidelines was just recently released and is being used in the Survivorship Clinic at CHP. Some of these updates may result in slight changes to your individualized treatment summary.

As a companion to the Long Term Follow-up Guidelines a series of Health Links have been developed to provide more in-depth information about some of the more common late effects.

[Click here to download the HEALTH LINKS.](#)

## Survivorship Team wins PINCH award



Your Survivorship Team competed in a competition called the Pitt Innovation Challenge (PInCh), sponsored by the University of Pittsburgh. PInCh is a competition designed to find solutions to challenging health problems in a fresh, exciting way. Each year,



Teams first had to submit a brief video proposal to be selected to move forward in the competition. ([Watch our video here](#)).

We know our survivors need life-long follow-up due to the potential late effects of treatment. However, patients do not need to continue to be followed by an oncologist. Eventually, each survivor will transition away from oncology follow-up and into primary care. Currently, there is not a standard model to accomplish this. For the PInCh challenge we proposed the use of a telemedicine visit that will “virtually” connect the survivor, their own PCP, and the Survivorship Team — Jean M. Tersak, MD; Aimee Costello, DNP; Noelle Conover, MS; Bethany Nugent, RN; and Kate Dempsey, telemedicine coordinator.

There were 60 applicants for this competition. There were 7 awards total with 4 teams winning at the \$25,000 level. The Survivorship Team is delighted to have been chosen for this prestigious award. We know that it will enhance the process of transition for our survivors and believe it can become a national model for other survivorship programs to use.

For more information about the Survivorship Team, go to [www.chp.edu/survivorship](http://www.chp.edu/survivorship).

