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Survivor CONNECTION

*An electronic newsletter from SurvivorConnect
Division of Pediatric Hematology/Oncology*



Fall 2016 - Transitions

"It is hard to believe it is already September! It seems not long ago we were at Kennywood Park celebrating National Cancer Survivors Day. We are so happy that many of you were able to attend. Please read ahead to hear about awareness and fundraising events such as the "CureSearch walk" on September 24 and "Wear a Hat for Cancer" on October 7th. We are also extremely excited to tell you about a Symposium being presented by SurvivorConnect and Lending Hearts on **October 1, 2016**. This symposium will focus on the concept of transitions including working with our team and your primary care provider to live the healthiest and fullest life possible as a survivor of cancer in childhood or adolescence. Finally, we are so excited to introduce to you the newest member of our team – Dr. Teal Fitzpatrick. Have a wonderful September!"



--Dr. Jean M. Tersak, Medical Director, SurvivorConenct

Building Bridges: Pathways to Transition



BUILDING BRIDGES:

Pathways to Transition
A Seminar for Those Living After a Cancer Diagnosis
Presented by SurvivorConnect & Lending Hearts

SATURDAY, OCTOBER 1, 2016

A Seminar for Those Living After a Cancer Diagnosis

Participating Organizations:

SurvivorConnect
Lending Hearts
Our Clubhouse

Saturday, October 1, 2016
9 AM - 1 PM

Continental Breakfast and Registration begin
at 8:30 AM

Free Admission (RSVP to
survivorconnect@gmail.com)

Welcome and Introduction
Tranistions with Keynote Speaker, Dr.

9 AM - 1 PM

Continental breakfast & registration at 8:30 AM

Our Clubhouse 
 2816 Smallman Street • In The Strip • Pittsburgh, PA 15222

Beverly Barkon
 Importance of Primary Care in Cancer
 Survivors with PCP's
 Lunch Panel Discussion with Survivors
 CHANGE - Children's Hospital Advisory
 Network for Guidance and Empowerment

Please join us! Meet other survivors and their families.

This is the first in a series of three on transition and survivorship.

Welcome Teal!

We would like to introduce the newest member of our team, Dr. Teal Fitzpatrick. She comes to our Survivorship program out of private practice. We are thrilled to have her as part of our team where she is available to consult with survivors and their families as part of your annual visit or on an as needed basis. Teal is a part of the Behavioral Medicine program at Children's. Her email address is teal.fitzpatrick3@chp.edu. Teal will be writing a regular column in our upcoming issues of Survivor Connection. Look for her at your next visit with us.



Lending Hearts

By Vasso Paliouras. Founder and Executive Director

Lending Hearts provides emotional and social support to children and young adults with cancer and their families through unique activities and community outreach. The youth of Lending Hearts are either in treatment for cancer or in remission and currently range in age from 3-26 years of age.



Activities include large group outings for the entire family and free of charge. They focus on health & wellness, arts & culture and are educational and recreational in nature. Additional monthly activities also include Lending Hearts Art Expression (also outside of the hospital setting) and Lending Hearts Yoga (inpatient oncology unit). Together with Children's Hospital of Pittsburgh of UPMC, Lending Hearts offers educational symposiums to families, school nurse, educators and university student health centers. Lending Hearts also presents other forms of public outreach and childhood cancer awareness events each year.

CHANGE - Children's Hospital Advisory Network for Guidance and Empowerment

Children's Hospital's Advisory Network for Guidance and Empowerment (**CHANGE**) is a youth-led and youth-driven initiative that advises youth, families, and professionals about the transition process.



CHANGE works to support interdependence and success for individuals who have faced, currently face, or will face transitional barriers in health care.



CHANGE supports youth (up to age 26) as they:

- Claim their voice to grow as advocates
- Find support as they transition from adolescent healthcare to adult medicine
- Host educational events for other young people and their support systems
- Encourage medical providers to embrace and incorporate youth development, advocacy, and empowerment in their practices
- Positively affect the policies, procedures, and processes at Children's Hospital to better serve the needs of adolescents and young adults
- Be empowered to make important and educated decisions in healthcare and other aspects of life

Can youth make a difference?

Absolutely! It is important that young adults get involved with issues in our society because change takes time, energy, and commitment. CHANGE needs the perspectives, experiences, and voices of all types of youth so we can help our diverse community grow. Experiences only get better when we take educated action and serve as leaders. CHANGE is all about leadership, education, action, and progress.

How to get involved:

- Attend a youth event to learn about self-advocacy, healthcare, and transition
- Become an adult ally
- Join the advisory network and start sharing your story

To learn more, send an email to change@chp.edu.

Learn more on their [website](#).

Representatives from CHANGE will be presenting at the upcoming BRIDGES seminar!

SurvivorConnect Research

By Bethany Nugent, PhD (c)

We recently completed a research project, the Pitt Innovation Challenge (PINCH) to help improve the experience of cancer survivors who transition their cancer follow-up care from oncology to primary care.

The goal of the project was to improve communication between cancer survivors, oncologists and primary care providers through the use of telemedicine. Telemedicine is the use of video and voice to communicate with patients and healthcare providers who are in different locations communicate in real-time using a secure internet connection. You can think of it kind of like Skype or Face Time where the patient, oncologist and primary care doctor can see and hear each other although in different locations.

At this "virtual" visit, we talked with the cancer survivor and primary care doctor about the survivor's cancer

SurvivorConnect
Caring for Cancer Survivors at the Virtual Bedside

Just M. Terek, MD, Anne Coates, DNP, CRNP, FPCNP-BC, Heidi Conner, MD, Bethany Nugent, PhD, RN, Kathleen Thompson

Cancer Survivorship is on the rise!

Percent of Patients Cured

Year	1980	1985	2000
Survival Rate	40%	50%	80%

The Problem

- 2/3 survivors experience at least one life care event
- 1/3 of survivors experience a severe or life-threatening condition
- Every System is Impacted

The Plan

Closing the Gap

- Survivor
- PCP
- Survivorship Team
- Video

Survivorship:

- Highly mobile young adult population
- Need strong, interdisciplinary care gaps
- Need to transition from curative to PCP

PCP:

- Lack of current, national transition model
- Need national leadership of survivorship, prevention, and follow-up care
- National survey supports PCP interest in caring for survivors with guidance from Survivorship Team

Survivorship Team:

- Interest in building PCP Partnerships
- Proposed to use video/telemedicine technology to create "virtual" meeting space - connecting survivor, PCP and specialist in real-time
- Opportunity to create national standard
- Sustainability through CME, interdiscipline resources, and planned future services

SURVIVOR **UNIVERSITY**

history and the suggested follow-up and allowed for questions and discussion by the group. All together we completed 19 visits.



About 88% of survivors who participated in the study were either satisfied or very satisfied with their visit. And, 94% of cancer survivors who participated felt that the visit helped them to feel more confident that their primary care doctor knew their needs as a cancer survivor.

We are excited to use what we have learned in this project to help future cancer survivors transition to primary care be as positive and smooth of an experience as possible.

SurvivorConnect Transition



Amanda Moore, PAC, answers some basic questions about transitioning for our survivors.

Q. How and when do we transition care from Survivorship Clinic to a patient's primary care doctor?

A. We start to think about transitioning care when a survivor is older than 18 and has a good relationship with a family practice or internal medicine doctor who would be able and willing to take over his or her care.

Q. How will my primary care doctor know how to care for me as a cancer survivor?

A. We will send a packet of information to your doctor, including a letter explaining your history and the recommendations for your continued care, your treatment summary, and any recent testing you have completed. We will also work to make sure that you have access to your treatment summary and recommendations (which will be automatically updated when the guidelines change) through Passport for Care®, an interactive internet resource for cancer survivors developed by faculty members at Baylor College of Medicine and Texas Children's Cancer Center.

Q. Is there an age when I have to transition care to a primary care provider?

A. No, we are currently able to see survivors of any age in our clinic.

Q. What if I have questions or my doctor has questions after I have transferred care?

A. We're always here for you! When we transition your care, we give you all of our contact information and also pass that along to your doctor. You (and your doctor) are always welcome to call, email, or schedule an appointment.

CureSearch Walk 2016

Join Us! Pittsburgh CureSearch Walk

Welcome to the 2016 Pittsburgh CureSearch Walk

September 24, 2016 - Pittsburgh, PA

Schenley Park
Pittsburgh, PA 15213
Walk Distance: 1-2 Miles



Registration / Check-in: 9:00am

Opening Ceremony and Walk: 10:00am

Join us as we celebrate and honor children from the Pittsburgh area who have been affected by children's cancer. This special day will include prizes, music, food, and fun activities for the entire family!

To learn more about the Walk, click [here](#).

New this year, your Team's fundraising level will be highlighted on your Team sign at the CureSearch Walk! For every \$1,000 your Team raises, your Team sign will feature a Gold Ribbon decal. From one decal to 50 decals...show your Team's success in a new way on Walk day.

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!

National Cancer Survivor Day a success again!

In spite of the rainy wather, we hosted 410 people at the Large Pavillion at Kennywood to celebrate National Cancer Survivor Day with us on Sunday, June 5! The weather held long enough to get in a few rides and some great fun with balloons, games, music and great food! The Nacho Bar was a great hit! We love seeing many of the same faces year after year but we also saw many new ones this year! We are grateful to the Kennywood Charitable Trust for their donation of 250 free tickets for survivors and a guest. And this year, because it stormed at the end of the day, many of those who were still in the park received a raincheck voucher to come back! You can't beat that.

Mark your calendars for next year! We will be celebrating on **Sunday, June 4, 2017**. See you there!



Dr. Tersak and some of our survivors at Kennywood.



Bethany Nugent, our Research Nurse and Amanda Moore, our PA enjoying nachos.



One of our many survivors who enjoyed National Cancer Survivor Day on June 5, 2016.

Children's Hospital of Pittsburgh FOUNDATION
Cancer and Blood Disorders Auxiliary

WEAR A HAT FOR CANCER

Join us on Friday, Oct. 7* and wear a hat to school or work in support of children being treated for cancer at Children's Hospital of Pittsburgh of UPMC. **or date of your choice*

SIGN UP NOW

CJ, leukemia patient, (second from left) with Wear a Hat participants

Children's Hospital of Pittsburgh Foundation
One Children's Hospital Drive • Central Plant, Floor 3 • 4401 Penn Avenue • Pittsburgh, PA 15224-1342

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Enter your description

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



THE MARIO LEMIEUX Foundation

SurvivorConnect is supported by a generous grant from the Mario Lemieux Foundation



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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