



- Survivorship Clinic Celebrates National Cancer Survivorship Day!
- June 2, 2013 - Kennywood Park
- Academic Accommodations for Cognitive Late Effects
- Dr. Meghan Eberle

### FALL SURVIVORSHIP CELEBRATION

We are in the planning stages for hosting a **Fall Survivorship Dinner** at a very nice Pittsburgh Restaurant. We are hoping it will be in mid November. If you are interested in helping us plan this evening to benefit The Survivorship Clinic, please contact Noelle at [noelle.conover@chp.edu](mailto:noelle.conover@chp.edu). We would love to have your input.

**A film is coming to Pittsburgh and they are looking for SURVIVORS!**

## Survivorship Clinic Celebrates National Cancer Survivorship Day!



### June 2, 2013 - Kennywood Park



## Academic Accommodations for Cognitive Late Effects

## Summer 2013

From our Medical Director



It is not too early to save the date! Sunday June 1st, 2014 will be the second annual Survivorship Clinic celebration of **National Cancer Survivors Day** at Kennywood Park. We are so excited that so many survivors, friends and families joined us for the celebration this year. National Cancer Survivors Day, held the first Sunday in June, is a day to celebrate and share with all those whose lives have been touched by cancer. This day is a **CELEBRATION** for those who have survived, an **INSPIRATION** for those recently diagnosed, a gathering of **SUPPORT**



The feature film, *The Fault in Our Stars*, shooting in Pittsburgh this fall, is looking for **teens and young adults 13-23 years old**, who have been affected by cancer, to appear as extras in the film.

The film is based on The New York Times Bestseller of the same name written by John Green. *The Fault in Our Stars* is the story of teenagers who meet at a Cancer Kid Support Group.

The production would like to give teens and young adults, who have been or are currently cancer patients, the opportunity to appear in the movie.

The roles are non-speaking and there is no experience necessary. Those cast for these roles will be needed for approximately two to five days of filming this September. All roles are paid positions.

If you are interested and **are between the ages listed above**, please email Nancy Mosser Casting at: [tfiosextras@gmail.com](mailto:tfiosextras@gmail.com). Include a recent snapshot of yourself and a brief description of your experience with cancer. Please include your age, your parent's name (for those under 18 yrs.) and phone number.

Hello Everyone!  
As "**Back to School Season**"



approaches, I thought it might be helpful to provide some information about academic accommodations for cognitive late effects from treatment. Included are a few tips about how to navigate the educational system for yourself or your loved one.

**Step One:** Be educated yourself about possible neurocognitive late effects. Some of these late effects may include organizational struggles, short term memory deficits, attention/focus problems, and reading and math comprehension. These late effects may continue to develop even after treatment ends and can affect academic skills for an entire educational career. Knowing this can help you to be an excellent advocate for accommodations as many educational programs are not aware of what late effects are and assume that once treatment is complete, the need for academic modification ends.

**Step Two:** Begin a conversation with the school. An excellent place to start would be with the school guidance counselor or school psychologist. If there are not current educational needs, this conversation alerts the staff to the possibility of future needs. If there are current concerns, this discussion opens the door for a conversation about possible academic modifications.

**Step Three:** Learn about your state and federal laws regarding the rights of students with medical and educational needs. The guidance counselor at your or your loved one's school should be able to provide you with this information.

**Step Four:** Formally request that neuropsychological testing be

for families, and an **OUTREACH** to the community. Read more about this event in the current issue and we hope to see you next year!

-Jean

### From our Research Nursing Student



Hello again! As I mentioned in the last newsletter, I will update you on some of the recent publications from the **Childhood Cancer Survivorship Study**. Knowing the current research regarding you or your loved one is important because so much is being discovered—it is incredible the amount of new information that emerges every month!

The article that I am going to focus on for this newsletter is related to sleep, fatigue, and cognitive impairment (including difficulty with things such as memory, efficiency, attention, and the ability to organize) in cancer survivors compared to their siblings without history of cancer diagnosis.

Cancer survivors experienced higher rates

Good luck!



completed. This requires that you make a verbal request to the school guidance counselor, followed by a signed request. Once this has been completed, the school will likely complete the testing themselves. This testing will include an IQ test, achievement testing, behavioral rating scales, classroom observations, and a clinical interview. Upon the completion of testing, the school will compile a report summarizing the results and will meet with you to plan the next step. It is possible that this next step may be in the form of an Individualized Education Plan (IEP). This plan helps to organize the academic modifications and to ensure that the school follows the plan exactly as it is written.

**Step Five:** Be an advocate! You know yourself or your child better than anyone. Use this knowledge to make suggestions to the school about the types of accommodations that may be helpful.

Some examples of accommodations are:

- Two sets of books, one for home and one for school
- Reward charts for staying on task
- The addition of an academic aide in the classroom
- Extra time for tests
- Decreased amount of work
- One-on-one instruction
- Teacher assignment

**Step Six:** Know when to ask for guidance. If the school is not providing you with the help you need, please feel free to contact me and I can act as an additional advocate for you or your loved one.

- Dr. Meghan Eberle

## Dr. Meghan Eberle

Dr. Eberle is a Psychologist who works with the Survivorship Team. She is

of cognitive impairment. The researchers found that poor sleep and higher fatigue were both associated with experiencing cognitive impairment. These findings are important because they suggest that improving sleep and minimizing fatigue in survivors of childhood cancer may be important to improve cognitive abilities and functioning.

So, what can you do to improve your health and cognitive function? It is well-known that participating in some form of physical activity each day typically helps to decrease one's level of fatigue. In addition, 7-9 hours of sleep are recommended each night to allow the body and mind adequate time to rest. Consistency in the amount and time of sleep are important in preventing daytime sleepiness. If you are having difficulty with sleep, fatigue, and/or cognitive abilities please talk to your healthcare provider about your concerns. If you are interested in reading the complete study report, please see the citation below.

- Bethany

### Citation:

Clanton, N. R., Klosky, J. L., Li, C., Jain, N., Srivastava, D. K., Mulrooney, D., Zeltzer, L., et al. (2011). Fatigue, vitality, sleep, and neurocognitive functioning in adult survivors of childhood Cancer: A



available to discuss educational, emotional, survival or psychological issues. Her number here at Children's Hospital of Pittsburgh is 412-692-7593 or email her at [meghan.eberle@chp.edu](mailto:meghan.eberle@chp.edu).



report from the childhood cancer survivor study. Cancer, 2559-2568. doi:10.1002/cncr.25797

***Remember that every person deserves an excellent education tailored to his/her unique needs!***

**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!

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