Reaching Beyond Disability

By Caitlin

Recently, the CYWH peer leaders were privileged to meet Alexis Goolkasian. Alexis is an absolutely amazing ice-skater. She trains hard after school five days a week and competes in regional figure skating competitions. What makes her story so compelling is that she has had vision problems since she was 12 years old and is now legally blind. Her vision impairment is caused by Stargardt’s Disease, a form of macular dystrophy that occurs early in life which effects her central vision. She is able to see peripherally. She told us that the disease has made it difficult for her to read and see things far away but it has not stopped her from pursuing her dream to be an Olympic skater.

Alexis started skating at the age of four because a lot of her friends took skating lessons. As she grew older she began to really enjoy it and started competing at 9 and most recently placed 6th in the 1st round of a regional competition. She told us how her vision problem was difficult to manage at first, but since ice-skating requires mostly peripheral vision she was able to keep skating. Her schedule is very intense and it can be hard for her to manage her homework after skating all day, but she pulls through.

In regards to Alexis’ future, nothing is stopping her. “I want to go to nationals for skating and maybe the Olympics one day! I hope to become a skating coach and attend the University of Delaware after I graduate.” She also has a message for other teens like herself facing a disability: “You should work on your disability and not let it stop you from doing what you love.” ❤️
On December 16th, the 2005 graduates of the Peer Mentoring Program and the CYWH staff came together to celebrate the holidays. The party also gave the mentors and mentees a chance to reunite and stay in touch. The room was filled with an array of holiday decorations, which included a talking Christmas tree. As the girls entered, they were given a warm welcome by the staff of the CYWH and encouraged to participate in the craft and karaoke activities. At the craft station, the girls made homemade snow globes and decorated an ornament with their name. Then there was the karaoke machine, which gave the party a special spark as everyone took their turn at the microphone. Aside from the pizza dinner, the girls also enjoyed decorating a gingerbread house and sugar cookies at the sweet station. Before leaving the festivities, each of the girls received a small surprise gift from the CYWH staff, and they got to take home their snow globes, ornaments and cookies they had made. Calling the reunion a blast would be an understatement. The holiday Peer Mentoring Program reunion was a huge success but most importantly, the goal to reunite the participants, staff, and friends of the PMP was fulfilled!

www.youngwomenhealth.org

Resources for Teens with Disabilities

Below are some of our favorite resources for teens living with disabilities or chronic illness. Stop by the Young Women’s Resource Center to pick up a free copy of our complete Resource Guide.

INTERNET SOURCES:
4GirlsHealth: Illness and Disability, from the US Department of Health and Human Services Office on Women’s Health http://www.4girls.gov/disability/index.htm

Disability Central: @ctlvTeen
A fun interactive web site for teens with disabilities, including chat rooms, message boards, and informational links. http://www.disabilitycentral.com/activteen/

The National Information Center for Children and Youth with Disabilities
The central source of information on youth with disabilities, resources available to these youth, and special education laws. http://www.nichcy.org

BOOK SOURCES:
Easy for You to Say: Q & A’s for Teens Living with Chronic Illness or Disability, by Miriam Kaufman (2005)
Answers to those “tough-to-ask” questions for teens with disabilities.

Teens with disabilities share life experiences, challenges, and successes.

FOR PARENTS:
The Resilient Family: Living with your Child’s Chronic Illness or Disability, by Paul Power (2003)
A sensitive and spiritual information guide to help families cope with and overcome the difficulties of raising a child with special needs.

10 Tips to Empower Yourself

By Brienne, Visiting Nursing Student

1. Get to know and love yourself! Realize that you are a unique and special person with your very own strengths and valuable qualities!
2. Keep a positive outlook - it’s contagious!
3. Learn from every experience.
4. Surround yourself with true friends.
5. Keep your situation in perspective and be thankful for what you have.
6. Be proud of the skills you excel at, and embrace them - there are many!
7. Accept help when you need it.
8. Create a list of goals and keep your eye on them.
9. Be assertive in what you need and want. You are your best advocate!
10. Have fun - it keeps you alive!