



# Teen Talk

youngwomenshealth.org

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The Center for  
Young Women's Health  
Children's Hospital Boston



Children's Hospital Boston

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## 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." ♡

# Memorable Holiday with the Girls of the PMP

By Pauline



**PMP girls & peer leaders decorating holiday cookies**

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.youngwomenshealth.org](http://www.youngwomenshealth.org)

# Winter in the Tropics

By Asharee



Pauline and Asharee making bracelets

Can you imagine yourself on the beach, your hair flowing in the tropical breeze only to discover that in reality you are in the middle of winter? It may seem like a fantasy, but believe it or not on December 13th, the creative minds of the Teen Advisory Committee (TAC)\* at Children's Hospital Boston hosted a winter celebration party with the theme "Winter in the Tropics," exclusively for teen patients.

As the patients arrived, the members of the TAC dressed in grass skirts, and tropical shirts greeted, and handed each patient a lei to wear around their neck. Everyone had a great time... whether it was shaking their maracas like the islanders, listening to music, dancing the night away, making personalized bracelets or mastering the art of the turn tables. Although the party had to come to an end, the TAC made sure that the patients did not leave empty handed. Each patient chose pajama bottoms, a sweater, gloves, a blanket or a hat to keep them warm. After weeks of planning, the party was truly a success!

*\*The Teen Advisory Committee consists of 10 teen girls (all three CYWH peer educators are members) from the greater Boston area that volunteer their time to organize fun and meaningful activities for adolescent patients at Children's Hospital Boston. If you are between 13-18 years of age and want to make a difference in someone's life, you may want to consider becoming part of the \*TAC. For more information, please contact: Christine Rich at 617-635-4991 or Miranda*

## Resources for Teens with Disabilities

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.

Taking Charge: teenagers talk about life and physical disabilities, edited by Kay H. Kriegsman, Elinor Zaslow, & Jennifer D'zmura-Rechsteiner (1992)  
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.

"You must do the thing you think you cannot do."  
- Eleanor Roosevelt



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: @ctivTeen  
A fun interactive web site for teens with disabilities, including chat rooms, message boards, and

## 10 Tips to Empower Yourself

By Brienne, Visting 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! ♥



Rebecca, Dez, Asharee, Rebecca's mom, Pauline, Phaedra, Caitlin and Freedom of the Center for Young Women's Health were honored & thrilled to be invited to the Junior League of Boston's Annual Ice Ball. Rebecca, a former CYWH Peer Leader, gave a moving speech about how positively the CYWH has affected her life and the lives of many teen girls. Our deepest thanks to the Junior League for their support over the years! ♥