

**of Hasbro  
Children's  
Hospital**

# The Adolescent Leadership Council

**Issue 3, Spring  
2008**

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## From the Editors

The Adolescent Leadership Council of Hasbro Children's Hospital (TALC) was founded in September 2005 by Dr. Gary Maslow. Brown student mentors and adolescents, all with chronic illness, meet monthly to discuss the issues surrounding chronic illness and plan ways to take leadership in their unique community. In our third year, we have spend a lot more time on the leadership projects you will see described in this newsletter: TALC Jr., our pre-teen program; art projects; a documentary; and TALC camp. You will be invited into our experiences with articles detailing each part of our curriculum for the year; doctors and hospitals, transitions, family, and friends. If you are interested in joining TALC, please see the back cover for contact information.

## TALC Loves Turkeys

### Parent Council

The Parent Council is an environment where parents of TALC participants can talk freely about the ways chronic illness impacts families. The Parent Council meets at the same times as the monthly TALC teen/mentor meetings. If you are a parent of a teen with a chronic illness who qualifies for TALC and would like to participate in the TALC parent council, please contact Jen Shucard (see pg. 4 for TALC qualifying and contact information.)



Members of TALC gathered at Brown University in November to celebrate our turkey friends at a Turkey Party. Here, TALC teens and mentors imagine what it's like to be a turkey.

## The Cool Kids' Camp by Joelle '08

Most people think that sickness is the exact opposite of fun. I beg to differ. Two years ago, I found that being diagnosed with a chronic illness gave me a chance at fun that others didn't have. I got to go to camp – but not just any camp. At my camp, I was surrounded by campers like me – campers with diagnoses ranging everywhere from cancer, sickle cell, and neurological disorders. Campers who understood what it was like to be sick, to feel different, and to feel limited.

One of the “best” parts of camp is that I wasn't limited. Many camps for children with chronic illness are challenge-by-choice, and totally accessible and prepared for a range of medical needs and disabilities. Climbing to the top of a tower without limited mobility is a normal occurrence. Campers with seizures can swim and boat. Wheelchairs have access

to every building on site. Factor infusions are done daily, and a full medical staff of physicians and nurses make sure that every medical need it met with skillful hands.

Another “best” part is fun. It's around every corner, in every activity, and even manages to pop up while waiting for dinner to start. It is part of that wonderful feeling termed “camp magic,” and it's the central mantra. These camps make chronic illness and fun a wonderful partnership. Through their combination of shared experiences, challenge-by-choice attitudes, and amazing people, it's truly a silver lining that comes with being chronically ill.

The truly, number one, most important “best” part is the people. The campers are special, the counselors are special, and the weekly volunteers are special. People at camp are comforting, considerate, and

supporting. Bonding occurs within cabins, within units, and within the whole camp. Friends I made at camp will be there for the rest of my life.

While I've made it sound like I was a camper, that's only partly true. To be completely honest, I've been a counselor at summer camp and weekend programs for the past two years. However, having a chronic illness has made me a simultaneous counselor and camper. I see the experiences from both sides, and I'm truly lucky because of that.

Here's a list of local camps:

Hole in the Wall Gang  
Camp

\*(I don't know anymore but I'm sure Gary does)\*

### Top Ten Things NOT to Say to Someone with a Chronic Illness

1. Oh my gosh, can I catch it?!
2. “The Look”
3. Let it go.
4. Do you need a cup of water?
5. Oh, I've heard of that...My mom's sister's cousin's friend has it— she's fine.
6. I know EXACTLY what you're going through.
7. Is that all?
8. But you don't LOOK like you're sick.
9. Stop it!
10. I would have never guessed that!

“Oh, NO! I'm SO sorry! That must be so hard!”

**Special Report:****Foreign Correspondent Chelsea '08 provides tips for travelling when you have a chronic illness**

When traveling anywhere with a chronic illness it is always essential to be prepared. The question is: how can I be prepared? Traveling is stressful enough, especially when going to a foreign country where many things may be lost in translation. I am currently spending three months in Salvador, Bahia, Brazil and the following is a list of essential things one should do before getting on the plane and a few after you arrive at your destination:

1) Fill prescriptions, making sure you have extras to bring with you.

This is very important because you cannot always get your medications in country. Make sure you bring extras. Also, carry them on the plane in your carry-on.

2) Talk with your Doctor.

Tell them where you are going, how long you will be away, and ask for suggestions. They can be a great resource for information about what to expect and what to avoid while traveling.

3) Make a plan for emergencies.

Create a list of what to do in case of an emergency, including medicines, emergency contacts, doctors names, numbers, and emails

4) Get a travel letter from your doctor.

This is very important to travel with medications in case you are questioned at the airport. You need to have proof from your doctor (especially with needles and liquid medications!)

5) Get vaccinated and fill out your WHO card.

Depending on where you are traveling you will need to receive vaccinations against certain diseases. Make sure you know your area, what you will be at risk for, and also bring documentation of your vaccinations and your medical history. This is very important information to have handy in case of an emergency.

6) Wear a Medical Alert Braclet and always have some form of identification when touring

around in a foreign country.

7) When you arrive, find the nearest hospital and the emergency medical service and police numbers.

This is important because in case there is an emergency you want to know where you can go and where you will be taken.

8) Know your food and your water!

Be careful of the food you will encounter. Make sure you are always asking what is in it. Also, if you are in a country that has a problem with water treatment, make sure you are aware of it. It can be very dangerous to get an illness related to poor sanitation on top of dealing with a chronic illness.

and 9) Have fun, take lots of pictures, and enjoy every moment! Traveling is exciting, just take some time to plan ahead and no matter where you are going you will have an unforgettable experience.

Tchau do Brasil,  
Chelsea

**Talc Jr. by Eliza '09**

This year at TALC, teens, mentors, and advisors have teamed up to plan a new event with an important goal: sharing everything that's great about TALC with the next generation of leaders. TALCjr., a one-day retreat for pre-teens, is currently recruiting 10-12 year-olds with chronic illnesses to participate. The event, which will last about six hours, will be a sort

of "TALC sampler," giving pre-teens the opportunity to meet peers who also have chronic illnesses while playing games, tie-dyeing t-shirts...maybe even drawing their illnesses! Just like TALC, TALCjr. will even have a one-hour parent group that meets separately during the afternoon. TALC teens and mentors are all encouraged to lend a hand and share their experience (and drawing skills!).

# Poetry Corner

## A Special Friend

by Taylor, 13

I have a special friend  
With me at the hospital  
He stands tall and proud  
We have an on and off relationship  
When he speaks out to me he can be pretty loud  
But he is always giving me what I need  
Please allow me to introduce you to my friend

Steve the IV Pole

## Transitions, by Deron, 19

Dr. Chawla's office  
I am here by myself, cool  
No more mother here.

## Mystery meat, by Will and Kristen

What are you sandwich?  
Pink good wrapped in a wheat bun.  
Yikes! Mystery meat.

## Spring, by Chio '10

Springtime is now here  
Pollen, ragweed, tree, grass, mold  
Allergens galore!

## Transitioning, by Julie '13

## “BAM”: Thoughts for the Newly Diagnosed, by Kate '08

BAM.

Being diagnosed with a new chronic illness is like any momentous event in which your life completely changes in a day. Think the bombing of Pearl Harbor. Your first child's birth. The signing of the Treaty of Versailles. The day you got into college.

Any of these events will change you completely. Yet, it's impossible to fully grasp the meaning of the doctor's words in that one moment: You have ----. It is chronic. Here is what we're going to do.

Chronic means forever. This illness has entered your life and is here to stay. At first, you probably think, okay. What's been happening to me has a name. Great.

Alternatively, some people go through the stages of grief, beginning with the ever-famed Denial. Their first thought is, “Nope. Sorry. You must be

wrong.”

Eventually, we all get it. It's real. So what happens now?

The first day is easy to get through. You're allowed to be upset. You're allowed to think about it and tell your close friends and family. Your mind is full of what adjustments you're going to have to make.

Then comes week two, month two, year two. It's different for everyone, but there will come a time when you start to realize that this isn't going away. Actually, the truth is, you'll probably have to realize this multiple times over the next few years as you face new challenges. Don't worry, that's normal.

Which brings us to the next challenge: making the illness “Normal.” It takes awhile to integrate it into your life, to reach that Acceptance stage and be termed “adjusted.” Remember—it will happen. Eventually

you won't think twice about popping pills in the morning, reading labels for carb counts, or dropping by your doctor's office for a quick blood test. Hopefully you'll even begin to feel empowered about your illness—maybe go to a camp or two (see page 2), do a fundraising walk, or write a cookbook for those similarly afflicted.

But that first day, man.

BAM.

Just have faith that you will figure it out. Know that it's normal for it to take time, it's okay for it to be hard, and it WILL get easier. Take the time, but be proactive. Learn what you can. Reach out to the resources you have. Engage in some self-reflection. And oh yeah--join TALC along the way.

Kate '08 was diagnosed with Celiac Disease three months ago and Ulcerative Colitis 12 years ago.

## Transitioning to College by Zach '10

Transitioning from high school to college, even without a chronic illness is a challenging process emotionally, physically, and intellectually. Having a chronic illness can make this already-difficult transition seem more daunting.

Reflecting on my first semester of college is something I do often. Rarely is it a pleasant experience. In my first semester of college I: had my first flare-up of Crohn's disease in 7 years; was on 60 mg of prednisone; endured living with a beer-guzzling, girl-attracting, rarely studious but generally jovial football-playing roommate; considered transferring; struggled with depression; re-thought many of basic assumptions about how to approach school; learned a lot about how to manage my illness at college.

Since my first semester, college has been a much more positive experience for me. Having experienced the ups and downs of having a chronic illness at college, I would like to offer some practical and philosophical advice as well as some words of encouragement about how to have a smoother transition to college and how to manage your illness in a college setting. In retrospect, being sick with Crohn's disease and going on a medication with many miserable side-effects was a major reason for my frustrating first-semester experience, but it was compounded by mishandling of other factors over which I had more control.

If I could offer one piece of advice to incoming freshman it would be to be flexible, try new things, be true to who you are, and seek out help if you need it. This sounds cliché but if I had followed this advice a little more I think I would have had a more positive transition to college.

The first thing to note

about college is that it is better than high school, especially because it is not high school. In college people are generally much more open-minded and accepting. There is tremendous opportunity to (re)define yourself and explore new activities and classes. You might be worried about making friends but every other freshman is in the same boat. People are generally excited and eager to meet new people and make new friends. Compared to high school, you are awash in freedom. With this freedom comes increased responsibility – the onus will be on you to get up for class, manage your time and decide what does and doesn't work for you.

That being said, you're not on your own. Your parents didn't suddenly abandon you because you went to college and try as you might, it's not a great idea to neglect your parents now that you are separated by distance. Institutional support networks are there for you too, but rarely will you seek them out. Deans, peer counselors, professors – they are there to help and guide you, but you will need to seek them out. If your school has a disability support services, or related department, it is a good idea to sit down with them to discuss any accommodations you need.

In terms of managing your chronic illness specifically here are a few tips that have helped me.

**Create a special medical folder** to keep your medical records, prescriptions, insurance information and any other information you might need for medical purposes. Also set up a notebook to record symptoms, and take notes with during doctor's visits. Especially if you have been in remission for a while, it is a good idea to do this so that you will not be caught off-guard if you get sick.

**The importance of sleep cannot be overstated.** In the shuffle of academics, friends, and activities sleep is often lost-out in college. Don't let your classmates serve as an example. Sleep is vitally important and should be treated as a sacred time not to be infringed upon.

**Diet.** Eating a healthy, balanced diet, making time to eat is also critical but often overlooked.

**Exercise:** get a healthy level of exercise. Yoga is a personal favorite of mine. In my experience it can be very therapeutic for people with chronic illness.

**Do one thing each day that is guaranteed to make you happy** or put you in good spirits. For me any combination of Curb Your Enthusiasm, Ultimate Frisbee, baseball is guaranteed to do the trick.

**Don't sign up for too many extracurricular activities.** In your first semester, academics are the main priority. Also, make sure to join extracurricular activities because you really want to do them, not because you think you have to. I joined too many activities my freshman year and spent too much time on activities that I wasn't that passionate about.

**Decide how you will approach alcohol and other substances and discuss this decision with your parents and with your doctor.** Many people with chronic illness cannot drink alcohol because of the medication they are taking. Although some people drink in excess in college, not everyone drinks and many who do so moderately. If you're not drinking there is no reason you can't go out with your friends and have a great time. You should expect to receive a few questions about why you don't drink but for the most part people are very respectful of other's decisions. Plan out some answers or excuses to these questions if you want to avoid a discussion about why you aren't drinking.

**"Outing yourself."** For me de-



**Organization**

Primary Business Address  
 Your Address Line 2  
 Your Address Line 3  
 Your Address Line 4

Phone: 555-555-5555  
 Fax: 555-555-5555  
 E-mail: someone@example.com

**OF HASBRO  
 CHILDREN'S HOSPITAL**

*Your business tag line here.*

**We're on the Web!**  
 example.com



*This would be a good place to insert a short paragraph about your organization. It might include the purpose of the organization, its mission, founding date, and a brief history. You could also include a brief list of the types of products, services, or programs your organization offers, the geographic area covered (for example, western U.S. or European markets), and a profile of the types of customers or members served.*

*It would also be useful to include a contact name for readers who want more information about the organization.*

## Back Page Story Headline

This story can fit 175-225 words.

If your newsletter is folded and mailed, this story will appear on the back. So, it's a good idea to make it easy to read at a glance.

A question and answer session is a good way to quickly capture the attention of readers. You can either compile questions that you've received since the last edition or you can summarize some generic questions that are frequently asked about your organization.

A listing of names and titles of managers in your organization is a good way to give your newsletter a personal touch. If your organization is small, you may want to list the names of all employees.

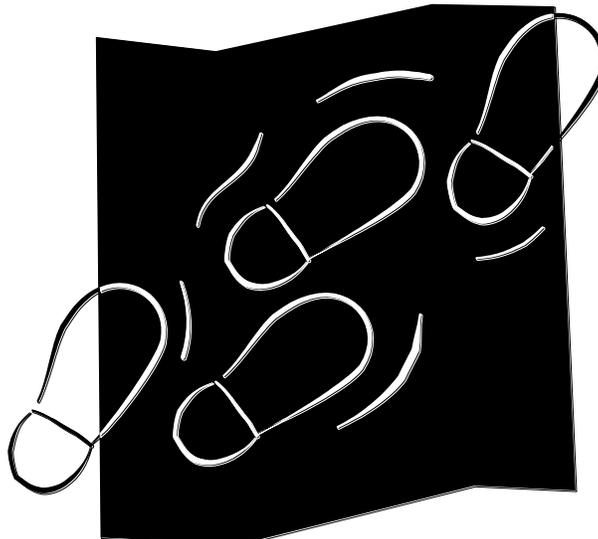
If you have any prices of standard products or services, you can include a listing of those here. You may want to refer your readers to any other forms of communication that you've created for your organization.

You can also use this space to remind readers to mark their calendars for a

regular event, such as a breakfast meeting for vendors every third Tuesday of the month, or a biannual charity auction.

If space is available, this is a good place to

insert a clip art image or some other graphic.



***Caption describing picture or graphic.***