

TEEN TALK

Years in Review

Winter 2008

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Four Years in Review

Over the last four years of our high school career, my brother and I have learned a lot about the bleeding disorder community through Teen Talk. Sadly, we have had to make a decision to make this our last issue. We are both going to different colleges and could not figure out the logistics, which would make the creation of Teen Talk feasible. As this is our last issue of Teen Talk, we decided to highlight the journey we took as well as trying to entice your to pull up those old editions when you start missing us!

In our first issue, we covered: Bleeding Disorders 101 so that we could all start with a common base.

Our second issue, covered the History of Bleeding Disorders. The close connection between hemophilia and the royal families (the romantic side) as well as gaining perspective on how far we have come as a community (the practical side) is essential before we can move forward

The next issue about Famous People with Bleeding Disorders was an attempt to add to our historical perspective. Knowing that there are famous people with chronic conditions can empower us and provide the incentive to pursue and do almost anything we want.

The next topics such as Blood 101 as well as Gene Therapy are essential to understanding and then discussing your situation with your treatment staff. This helps in the transition we, as teenagers need to make as we take responsibility for our health.

These topics inspired my brother and I to look at prevention as seen in the next issue. Until better treatment or gene therapy is an option, we need to do everything they can to prevent worsening of the disease. Sometimes, it is hard to think we aren't invincible and that we have no time to exercise, but hopefully prevention means more now.

Not wanting us to be a compliant generation, the idea of prevention leads

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to advocacy. It is important to be an advocate for yourself, but also to achieve bigger change through advocacy.

As we both approached the college scene, we realized that the next step in putting this all together is to continue the whole transition outside of high school. It is very important to find the right school, especially for students with a bleeding disorder. We wish all our readers “Good Luck”!

We would be happy to talk to anyone who may be interested in taking Teen Talk over. Please feel free to contact either of us at pjstacen@wisc.edu with a subject heading Teen Talk. We see these publications a smorgasbord that each teenager may relate to.

Thanks for this opportunity to share. It was incredible!

GLHF could not be a better organization to work with. We especially appreciate the efforts of Tammy Molter and Mary Anne Schall. Thanks again! Alison and Derick

Transition to College

Just as we are transitioning from high school, so will all of the other teens. This is addressed to. While not everyone goes to college, the principle here would apply if you are getting a job or going on for any type of schooling. Beginning college directly after high school is a big transition for many students. However, students with bleeding disorders have a far larger transition to make than those without one. However, having a bleeding disorder is not a barrier to higher education. What is different for those of us with any chronic condition is the need

to be proactive and plan for this transition.

Besides dealing with the college classes, and daily responsibilities like roommates and laundry, we will have to be able to manage our chronic condition on our own. We need to know where the nearest treatment center is, what we can and can't do, and how to tell other college friends of our condition. One way to make this transition much easier, is to take responsibility of your healthcare while still in high school. While in high school, you should:

- Learn how to refill your medications,
- Talk to doctors about your condition in emergency and non-emergency situations
- Participate in getting the accommodations that you need

Getting ready to leave for college is not a process that begins the week before you leave. The high school years are the time to take small steps towards independence when you still have your parents for backup. Lisa Maiale-Howell, a social worker at the Hemophilia Program at the Children's Hospital in Philadelphia, says, “When you go to college, schedules get turned on end, and the structure you had at home isn't there”. That's why starting early is so important.

Choosing the right school is also very important. Factors that could contribute to a successful college transition include location, size, public versus private, and access to care. Regardless of the setting, you need to feel safe being far away. If you choose a college that is large or is in a big city, you need to consider different things than if you go to a small or rural school. Regardless of the setting, public schools tend to be larger and require more walking and may be spread out. Since

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many people with chronic condition have knee and ankle problems, it is important to look at the layout of the campus. Public school will usually have a formal policy regarding disability accommodations, but you may end up dealing with a larger bureaucracy. Private schools are more expensive, but, generally, have the ability to give you more accommodations and one-on-one attention. In any setting, you must look at the student health centers on campus and make sure that you have access to well-qualified staff that will work with you. Also, get a feel for how accessible the campus is. How long will it take you to get to your medications and where will they be sent? Sometimes colleges have older, less accessible buildings that don't have elevators or the ability to accommodate wheelchairs.

Once you choose your school, it is important to contact the Office of Disabilities. An excellent contact point before and certainly after acceptance, this office will help you with any multitude of accommodations that might be needed including, but not limited to as a dorm assignment closer to classrooms, the possibility of a single room, and voice recognition on your computer for less hand strain or a first floor dorm just to name a few.

No matter what school you choose, there are a few precautions that every student with a chronic condition must take. First, you should wear your medical alert tag everywhere. It may cause people to ask questions, but it could also save your life. For your own safety, it is important to inform the campus health clinic, dorm reps, and lab instructors of your condition. In fact, you should create an emergency treatment plan, in case anything should happen.

Included in your emergency plan, should be some information regarding the nearest federally funded treatment center. As a college student, you should know where the nearest center is and how you would get there if you didn't have a car.

A sample plan may include:

Pre-College Years

1. Make your doctor appointments
2. Develop your own rapport with your treatment staff
3. Take responsibility for ordering your medication
4. If you infuse, learn how to do this yourself
5. Find a way to comfortably handle your condition in public and how to deal with the "need to know" with high school staff and your friends.

Investigating College

1. consider the location as far as accessibility to routine health care as well as emergency care
2. Can you maneuver comfortably within the campus?
3. Do dorms or other campus building provide access?
4. What on-campus resources are available (this means campus health facilities) as well as disability services?
5. Do you feel comfortable with a large system or a smaller administration structure?
6. Is a treatment center available in the area?
7. Does this college require health insurance? (Some college require and charge you for, health care coverage if you do not have any or yours doesn't meet certain criteria)

Once you have made your choice:

1. Contact the local treatment center
2. Contact the on campus health care center

3. Make contact with the local hospital emergency and hematologist, if applicable
4. Work with the disability coordinator, this means as soon as you make your decision (this may mean doing a lot of front end education before any of the following)
5. Are there funds for this you need for accommodations?
6. Do they have software programs such as voice recognition?
7. Are there accessible dorms?
8. Does the college have money to help with the purchase of a light laptop or a computer itself?
9. Figuring out any transportation issues especially if you are moving out of the state.

Legislative Self-Advocacy

As we reviewed the issues of the last four years, that ability to advocate stuck out as one of the most important aspects of taking care of yourself as well as building for the future. Over the past few decades, awareness of bleeding disorders has grown tremendously, and with it a strong support network offering a variety of services to those afflicted by bleeding disorders. Specifically, national organizations like the National Hemophilia Foundation (NHF) as well as regional organizations such as the Great Lakes Hemophilia Foundation (GLHF) offer a centralized source for information and act on behalf of the bleeding community as advocates. However, as helpful as these organizations are, we cannot sit back and depend on them to be the exclusive sources of advocacy for those of us in the bleeding disorder community. For this reason, I attended the Wisconsin

Statewide Advocacy Training provided by GLHF. Over two days of varied presentations by experienced leaders within the bleeding disorder community, I learned a great deal about the processes we can use to create positive, lasting change for those with bleeding disorders, and in particular legislative advocacy.

For most of us, advocacy cannot be a full time job. We have demanding lives outside of the bleeding disorder community. Still, as I learned during the Wisconsin Statewide Advocacy Training seminar, we all have the ability to take responsibility for a certain amount of individual advocacy. In particular, individuals have the power to help in grassroots advocacy campaigns to advance legislative goals. A quick guideline to becoming involved in legislative advocacy consists of the following steps:

- 1) Contact your local chapter or the GLHF regarding national, regional, or state-wide legislative efforts that they are currently working on or bring ideas or issues to their attention that you would like advocacy efforts to occur in.
- 2) Learn about the advocacy priorities to which you can best contribute if an effort is underway OR help develop the approach.
- 3) Work strategically WITH the organization to collectively and collaboratively enhance legislative efforts. This might mean taking the initiative to contact your local public officials (state senators, congress, etc.) in regards to a legislative issue concerning the bleeding disorder community,

participating in Wisconsin Legislative Days/Washington Days (which involves talking with legislators) or simply making phone calls or stuffing envelopes. Remember, the best “gift” you can give is your time, contributing your time is a BIG help.

The advantage of working with GLHF or NHF on advocacy initiatives is that you are not only working with an established organization, but individuals efforts can be combined and can potentially have more impact. Since advocacy’s goal is to get something change or simply addressed, it is important to develop a clear message in each communication, making sure that your points are clear and concise using the support already in place with our established bleeding disorder organizations.

As a personal side note, I would like to really encourage anyone reading this to consider participating in some form of advocacy. Although I was one of the youngest people at the Wisconsin Statewide Advocacy Training, everyone treated me with respect and really listened to me. I was surprised how fast the time went and how interesting it was to hear the difference perspectives and stories from others. That’s saying a lot since the training was on a Friday night and all day Saturday, popular personal times in a teenager’s life. It really isn’t hard to participate, in fact, participation opportunities are just seven days digits away by contacting GLHF at 257-0200 (Area Code 414).

Sports Skinny

Of all the issues addressed in past Sports Skinny columns, they all had an underlying theme. Regardless of what type of sports or exercise discussed, the main goal was prevention. While this theme is applicable to everyone, it is especially important when you are faced with a chronic condition. Staying as healthy as you can will ALWAYS be a benefit. It takes some time, planning and sometimes a lot of effort. But, be honest, you know you feel better if you pick the right sport or exercise you will have fun. So, our final message regarding exercise is get out there, find you sport, and practice with a good technique, which may require that you get training first. Enjoy yourself. Maybe we will meet in the gym!

Links

As we finish our run of Teen Talk, we wanted to share one last college link. The transition from high school to adulthood is the biggest change we see in our lives as teens. So, in this issue of Teen Talk, we reviewed College Confidential, a leading website that helps to demystify many aspects of the college admissions process. It helps students make decisions such as choosing a college, paying for college, and finding jobs and internships. You can find College Confidential at www.collegeconfidential.com.

College Confidential has assembled an editorial team to help students get the best and unique college admissions content. Some popular topics on the website include college admissions, college forums, Harvard, other Ivy League

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Schools, and Online Colleges. In addition, there is no need to register for these services. College Confidential is free! When choosing a college, this site can provide information through the postings by talking about what other students had to say about their experiences. Reading blogs posted by other college students and admissions representatives really helps in identifying what is really going on.

In addition to helping you find a college, you are able to post questions about certain schools and a response is provided. There are questions ranging from: "What's the acceptance rate?" to "What is their football team like?"

Many people use this college site to learn about the different schools that they are interested in. It can provide an inside view about what the students thought, how the professors were viewed and a general sense of the culture that the particular school had. For example, some schools have a more structured atmosphere involving events that are more formal while others may attract those interested in hiking and other outdoor activities. Sometimes, the site of the college also affects the atmosphere including metropolitan versus rural settings.

Not only can you get your questions answered, but you can see how other college students who used College Confidential are doing on exams and overall grades. In fact, there is a page that gives you College Counselor contact information. You "meet" with a college counselor and get help writing essays and filling out applications. This page is helpful if you are unsure of where to begin and need to be inspired by others who started in the same spot as you.

Overall, College Confidential is a valuable resource. It has lots of information about college, and fabulous search engines. It has a good reputation and is updated frequently. So, visit this site and plan your college future!

	Excellent	Very Good	Good	Poor
Amount of Info	*			
Info for Teens	*			
Easy to Use	*			
Searchable	*			

Overall Rating: Excellent