

# TEEN TALK

## Advocacy

Summer 2006: Volume 1, Issue 8

Editors: Ali and Derick Stace-Naughton

### What is Advocacy?

If you are familiar with the National Hemophilia Foundation, you'll know that one of its main purposes is to act as an advocate for the bleeding disorder community. In fact, there are hundreds of organizations that exist as advocates for various groups of people or causes. Different types of professions, causes such as health issues, and even species of endangered animals all have advocacy groups. With so many advocacy groups in existence, it is likely that you're familiar with at least a few of these organizations. It is less likely that you're familiar with the exact goals of these organizations; what they do to "advocate" for their beneficiaries, how they go about achieving these ends, and why the support of such an organization is so important. In other words, "What is advocacy, and why is it important to you?"

Despite the vast number and types of advocacy organizations, they all have a few underlying principles in common. Essentially, advocacy means to support or defend a group of people, or a cause. Whether it's The National Association for the Advancement of Colored People (NAACP), Greenpeace, or the National

Hemophilia Foundation (NHF), they all seek to actively support a specific cause. For the NAACP and NHF, along with many other organizations, this means improving the lifestyles of a minority of citizens that are at a disadvantage to the majority. For groups like Greenpeace, advocacy aims to change social norms that are thought to be destructive to society in general. (In Greenpeace's case, this means changing attitudes and actions towards the environment.)

So why is advocacy important? Instead of working with advocacy groups, why not simply leave the individual to defend its own best interests? There are a few good reasons. Some groups simply aren't able to defend their own best interests without help. This is why advocacy groups exist. Plants and animals need advocates too. Plants and animals can't go out and tell people not to litter, so organizations like Greenpeace exist to stop destructive behavior that affects our environment. Advocacy groups also exist to unify, and thereby strengthen, the efforts of individuals. It's hard enough for a minority to create change, but even harder for individuals to advocate on

**In This Issue:** [What is Advocacy?](#)  
[Social Graces](#)  
[Sports Skinny: Disabled Actor](#)

[Legislative Column](#)  
[Links](#)  
[Quickie Quizlet](#)

# TEEN TALK

their own. Unifying people with similar needs makes the individual's efforts more successful, and makes the individuals more likely to reach their goals. The National Hemophilia Foundation is more effective than individual people with bleeding disorders trying to find quality care and relevant information about their disorder. This is true of any of the hundreds of groups that rely on organized advocacy efforts by a formal organization or group.

Advocacy groups can use a variety of effective methods to meet their goals. Advocacy efforts can be aimed at individuals who have power to make changes, like a governor or mayor. Advocacy can relate to the development of public policy and legislation that helps a group of people. Also, advocacy groups may work towards voter education and social awareness, including peer education. Some groups may work to protect individual rights as well as the group as a whole. Advocacy, Inc., for example, is a nonprofit corporation funded by the United States Congress to protect the legal rights of people with disabilities in Texas. This includes protecting the rights of people with disabilities, as described by the Americans with Disabilities Act. Another example is the Bleeding Disorders Association of Northeast New York, Inc., an organization dedicated to assisting people with various bleeding disorders. They support the bleeding disorder community by means of legislative advocacy and defending the rights of the bleeding disorder community both locally, in New York, and nationally. They were also instrumental in the passing of an important piece of legislation in New

York State, aiding the hemophilia community there.

If the group being advocated for has special health concerns, as is the case for the bleeding disorder community, several other methods of advocacy exist. Organizations can support the funding of research, if it has the potential to improve the quality of life of the group in question. Advocacy groups can also provide support in the treatment and medical care of its members. In many cases, it is also beneficial to train people with disabilities on their rights and how to advocate for themselves. Advocacy groups not only help an individual on a day-to-day basis, but can also provide the foundation of support that will help the individual make continually informed decisions.

The National Hemophilia Foundation, as previously mentioned, is an example of an advocacy group. Like many other advocacy groups, it supports the unique needs of a minority of citizens; in this case, the bleeding disorder community. The bleeding disorder community benefits from advocacy in many ways. Simply informing the public about bleeding disorders is one great way that the NHF helps. Education of the bleeding disorder community is also important. Many people do not know enough about their disease, and as a result make uninformed decisions. The NHF works to educate people and provides a reputable source of information relevant to the bleeding disorder community and the community at large.

Obviously, advocacy groups are created for any number of different causes. But they're all important in maintaining a fair, democratic society by ensuring that the needs of the few are not

# TEEN TALK

ignored by the many. Each organization seems to have its own exact way of going about this, but there are a few common, effective methods of advocacy, like public education, legislative influence, and medical research. If you're part of the bleeding disorder community, you're probably aware of the NHF and its importance as an advocate. But it is also important for the individuals of the bleeding disorder community to actively seek the resources provided by the NHF, to find ways to contribute to the cause, and to act as their own advocates, everyday. The NHF website is [www.hemophilia.org](http://www.hemophilia.org).

## Social Graces

Maybe your friend wants to know about the 'Medic Alert' tag you're wearing, or maybe you watch a stranger in a grocery store asking a paraplegic how they were able to drive there with a wheelchair. Maybe a child who doesn't understand diabetes is upset that their friend doesn't eat cake at her birthday party. Most people aren't familiar with disabilities, whether they involve bleeding disorders, paraplegia, diabetes, or any number of other possibilities. This unfamiliarity is often a source of curiosity, rudeness, and even anger. People aren't aware of even general problems and conditions that face individuals with special conditions or challenges, and are even less knowledgeable when it comes to specific diseases like hemophilia or von Willebrand disease because they aren't always seen on the "outside."

When such a lack of understanding is combined with curiosity, people can ask callous, even rude questions of anyone that seems different, even if it means prying into

your private matters. You probably know what I mean. But maybe, you should take a minute and rethink this scenario and how you might have reacted in the past.

There are generally three reasons why somebody might approach you. Before reacting, step back and try to determine the real motive behind the questions.

- 1) They genuinely care and want to understand and be supportive.
- 2) They feel uncomfortable around anyone who is different and want to cover for it by asking dumb, insensitive questions to shift their awkwardness to you.
- 3) They are just plain rude.

In the first situation, take a deep breath and take the opportunity to educate. Teach them a thing or two. Having some idea beforehand on exactly how much you want to share is important. It is also important to really use the opportunity to key in on the important points you want to make so education really happens. This might take some thought and practice **before** the situation occurs.

In the second situation, it is important not to buy into someone else's attempt to make you feel awkward or uncomfortable. This might be hard to do the first couple of times this scenario happens. However, you really have a lot of choices on how to handle this. One option is to ignore the negative intent of the question, respond to it seriously, and present the educational speech you put together for situation #1. Another option is to move the conversation to some other topic by saying: "Thanks for asking, but I'm really not interested in talking about that right now," or "Thanks for your concern. It would

# TEEN TALK

probably be better to talk about that some other time”.

The third scenario is a no win situation. The person asking the questions probably won't respond to any attempt at education, so that any attempt at that is probably a waste of time. Depending on the situation, it might be best to walk away or move on to other conversations using the examples previously given. You could also think up a catchy response that puts control of the situation back in your court, like “Hey, what's with you? Didn't you eat your Wheaties?”

Sometimes, you need to be your own best advocate. It's your call on how to handle these situations. The key is to think about what you are going to do before it happens and make sure that you feel good at the end.

As soon as somebody realizes that you have something they don't understand or that is different, like hemophilia or von Willebrand disease, it isn't unusual to see people react to your “difference,” show curiosity or just act uncomfortably. They may be uninformed and wonder why you have this, can they get it, and what you can and can't do. Their perception of you is suddenly changed. Of course, this may be human nature. But too often well meaning strangers or friends may begin to ask personally invasive questions. When questioned by strangers, friends, or others, ultimately it is your call on how to handle the situation. Be prepared. Be your own best advocate.

---

## **Sports Skinny: Disabled Actor**

Historically, it has always been hard for disabled athletes to find ways to

participate in sports and other necessarily physical activities. Even with the help of advocacy groups, a large burden is placed on the individual to find ways to maintain the lifestyle they desire. That's why Hugh Farrington's career as an athlete and actor is so impressive; particularly in the way, he has become his own advocate, refusing to sacrifice his lifestyle for his disability.

Hugh Farrington has been wheelchair bound since the 1960s, after a plane crash crushed his lower spine. However, as a competitive former high school and college athlete, and as a U.S. Navy pilot, Farrington was not ready to give up his active lifestyle. He began competing in, and winning, athletic competitions for the disabled. Farrington also began acting, first in television, gaining notoriety as the tough detective Lt. Pete O'Brian on T.J. Hooker. He has also worked in film, most notably in *The Terminator*, all the while bound to his wheelchair.

His disability did not stop Farrington from living a meaningful life. He continued to be a remarkable, competitive athlete, did well in the physically demanding world of professional acting, and even flew regularly in a special, hand-controlled airplane.

I'm a teenager, and I have a bleeding disorder, so I know it can be hard to do all the things you want to do and not let your condition interfere with your interests and activities. It's hard to make sacrifices to accommodate a disability, whatever it may be. Farrington undoubtedly went through this too. But he found ways to live healthily and happily. He took care of himself, and still did the things he loved doing. As you face challenges with your condition, remember that you too can

# TEEN TALK

live an active, physical, fulfilling life, and keep your condition from controlling you. Hugh Farrington created his own opportunities and lifestyle, in spite of, or maybe due to his challenges. He was his own best advocate. You too can act as your own advocate, by making informed, positive decisions, leading to an active life on your own terms.

---

## Links

In this issue of Teen Talk, we reviewed the Disability Resource's Monthly Guide on the internet at [www.disabilityresources.org/index.html](http://www.disabilityresources.org/index.html). Disability Resources, Inc. is a nonprofit organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live a full and independent life. This organization serves thousands of individuals with disabilities through a massive network of service providers and consumers. In order to reach many people with disabilities as cost effectively as possible, the organization utilizes libraries, disability organizations, independent living centers, and the internet to promote their message. They also have an extensive database of disability-related resources in order to perform customized searches, and an [on-line guide](#) to disability resources on the internet.

This site would be a great starting point if you are looking for **basic** information on many types of disabilities and associated resources. All the information on this site is focused on disabilities and includes information on upcoming conferences, FAQs, and has a topic, state, and web site of the week.

This web site gives you great information on disability resources and can easily get you in contact with the right group of individuals that can help you. There is an extensive variety and quantity of information. On the homepage, there are browse options, resources, contact information, and recent or upcoming events and updates related to disabilities. For every topic included on this web site, there were links that led to even more information.

One problem that was encountered was the fact that sometimes the web site was hard to navigate through. There was a very good search engine but sometimes there was too much going on in the web site. Something would catch my eye and five minutes later, I would be somewhere completely different than I intended. Lots of information is packed on one page and it doesn't seem organized. When searching under the key word hemophilia, there were three hits, one of which was the National Hemophilia Foundation's web site! All of these hits provided detailed information on disability information. When trying to search for von Willebrand Disease, there were zero hits. When searching under platelet disorders, no results came up. In general, the web site has lots of general information on more common conditions and not always many specifics. However, since the goal is to be a starting point for a large and diverse group, the main goal of the site may be met.

When topics were found, the reading level was at an understandable level. Few pictures or other graphics were found any where on this site. This site is good because there is something here for everyone. Any teen, a science geek or not, would enjoy looking and

# TEEN TALK

reading this web site, as long as they stayed focused and don't get distracted by all the options. However, the site does help the individual who wants to find information on simple prevention tips in an organized setting and is willing to spend some time searching.

The Disability Resource's Monthly Guide web site seems to focus on many types of disabilities with lots of links. Overall, the site is a good starting point in a search for disability resources and provides some assurance since it is a nonprofit group. The pages are not very well organized and laid out. This site is a good place to start a resource search for options based on your personal situation. You can't advocate for yourself if you don't know your options!

Overall rating: Good

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

## Legislative Column

### Legislative Article

This issue of Teen Talk focuses on advocacy, which in one form can involve government and our legislative leaders. It is important to understand our government and who our leaders are, in order to be informed about issues important to our community and those issues requiring advocacy. Because our leaders speak for all of us, we need to be

informed voters. This way, we can indirectly and directly take part of the advocacy process.

In this legislative column, we will focus on legislative leaders in Wisconsin. Their position and contact information follows.

- The Governor of Wisconsin is James Doyle. He was elected in 2002 and his term expires in 2007. Doyle grew up in a politically active family living in Madison, Wisconsin. Previously he was our attorney general.
  - If you would like to contact James Doyle his web site and phone number are: [www.wisgov.state.wi.us](http://www.wisgov.state.wi.us) and 608-266-1212.
- The Attorney General of Wisconsin is Peg Lautenschlager.
  - To contact the Attorney General, the e-mail and phone number are: [webmaster@doj.state.wi.us](mailto:webmaster@doj.state.wi.us) and 608-266-1221
- Wisconsin's Senior Senator is democrat named Herb Kohl. He was elected in 1998 and his seat comes up in 2006. He is on the Senate Health and Human Services Committee, which creates and reviews important health concerns and policies.
  - If you would like to contact Herb Kohl his web site and phone number are: [www.kohl.senate.gov](http://www.kohl.senate.gov) and 202-224-5653.
- The Secretary of Health and Human Services is Mike Leavitt.
- Wisconsin's Junior Senator is a democrat named Russell Feingold. He was elected in 1992 and his seat is up in 2010. He is not on the Health and Human Services committees but is still an important voice for all Wisconsinites. He is on the Aging,

# TEEN TALK

Budget, Foreign Relations, and Judiciary committees. Recently, he has been in the spotlight regarding the Patriot Act.

- If you would like to contact Russell Feingold, his web site and phone number are: [www.feingold.senate.gov](http://www.feingold.senate.gov) and 202-224-5323.

Wisconsin has eight districts each run by an individual person.

1. Wisconsin's First District: Paul Ryan
  - a. He is the representative for the Janesville, Kenosha, and Racine areas.
  - b. Contact Information: [www.house.gov/ryan](http://www.house.gov/ryan) and 202-225-3031
2. Wisconsin's Second District: Tammy Baldwin
  - a. She is the representative for the Beloit and Madison areas.
  - b. Contact Information: [www.tammybaldwin.house.gov](http://www.tammybaldwin.house.gov) and 202-225-2906
3. Wisconsin's Third District: Ron Kind
  - a. He is the representative for the Eau Claire and La Crosse areas.
  - b. Contact Information: [www.house.gov/kind](http://www.house.gov/kind) and 202-225-5506
4. Wisconsin's Fourth District: Gwen Moore
  - a. He is the representative for the Milwaukee area.
  - b. Contact Information: [www.house.gov/gwenmoore](http://www.house.gov/gwenmoore) and 202-225-4572
5. Wisconsin's Fifth District: Jim Sensenbrenner
  - a. He is the representative for the Brookfield area.
  - b. Contact Information: [www.house.gov/sensenbrenner](http://www.house.gov/sensenbrenner) and 202-225-5101
6. Wisconsin's Sixth District: Tom Petri
  - a. He is the representative for the Fond du Lac and Oshkosh areas.
  - b. Contact Information: [www.house.gov/petri](http://www.house.gov/petri) and 202-225-2476
7. Wisconsin's Seventh District: David Obey
  - a. He is the representative for the Superior and Wausau areas.
  - b. Contact Information: [www.obey.house.gov](http://www.obey.house.gov) and 202-225-3365
8. Wisconsin's Eighth District: Mark Green
  - a. He is the representative for the Appleton and Green Bay areas.
  - b. Contact Information: [www.house.gov/markgreen](http://www.house.gov/markgreen) and 202-225-5665

---

## Quickie Quizlet

Check out our quiz section and see what you can remember!

1. Give three examples of advocacy groups.
2. Hugh Farrington is most known for his role in what TV show?
3. Come up with your own strategy for dealing with rude questions relating to your disability.
4. What does Disability Resources Inc. do and what is their purpose?

# TEEN TALK

---

5. Who is Peg Lautenschlager?
- Governor of Wisconsin
  - Secretary of the Health and Human Services Committee
  - Attorney General of Wisconsin

**Answers:**

- NAACP, Greenpeace, and NHF
- T.J. Hooker
- Answers may vary
- Disability Resources, Inc. is a nonprofit organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live a full and independent life.
- C

---

## **Guest Corner**

Teen Talk is still looking for a guest columnist for the next issue! If you write and send us a publishable article concerning Advocacy, you could receive ten dollars! The article can be a story, idea, opinion, or tip! Be creative, it's up to you! The article needs to be well written and polished so we can easily put it in our newsletter. Also, limit your article to 500 words, please. So get those pens out and start writing! You can send those publishable articles to Ali and Derick Stace-Naughton at [pjstacen@wisc.edu](mailto:pjstacen@wisc.edu) with the subject line "Teen Talk"!

Don't Forget to  
Look for Our  
Next Issue of  
Teen Talk on  
Planning your  
Future with a  
Bleeding  
Disorder!