

TEEN TALK PREVENTION

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Practice Prevention to Prevent Problems

As teenagers with bleeding disorders, we have the responsibility to do the best we can to keep ourselves as healthy as possible. It may seem like a lot of bother and something we don't need to worry about because worrying about living healthy is someone else's problem. However, we not only need to lead healthy lives for ourselves but also have a responsibility to do so for our family and friends who care about us. Our families and friends haven't helped us reach our teens just to see us throw away all of their efforts and good practices that have kept us healthy. As teens we need to take charge of our health. If you are still not buying into this idea, maybe thinking about it like this may help. Ask yourself these four questions:

1. What is my main problem or what problem do I want to prevent?
2. What do I need to do?
3. Why is it important for me to do it?
4. What could happen if I don't do anything?

Hopefully, by asking these four questions and thinking about your answers will put the following information into perspective. The NHF wants you to take charge of your life and your health too. The National Hemophilia Foundation (NHF) recognizes the importance of prevention through the *Do the 5*. The NHF National Prevention Program's (NPP) goal is to prevent or reduce the complications of bleeding disorders. NPP's theme *Do the 5* involves these five strategies for living a longer and healthier life with a bleeding disorder:

1. Get an annual comprehensive checkup at a hemophilia treatment center.
2. Get vaccinated – Hepatitis A and B are preventable.
3. Treat bleeds early and adequately.
4. Exercise and maintain a healthy weight to protect your joints.
5. Get tested regularly for blood-borne infections.

The first strategy of the *Do the 5*, attending a hemophilia treatment center (HTC) is extremely important. HTCs are federally funded clinics established in 1975. These sites are where specialized and complete care for bleeding disorders occurs. There are

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four HTC's in Wisconsin: Madison, La Crosse, Green Bay, and Milwaukee. HTC's are economical health care options for people with bleeding disorders. At a HTC, you can be sure you are being seen by someone who is educated and specializes in bleeding disorders. People with bleeding disorders receive specialized medical care along with updates on any new research from doctors who only take care of people with bleeding disorders. According to the Centers for Disease Control and Prevention (CDC), a government agency that monitors and studies health and health care issues, people who regularly attend HTC's at least once a year are 60% less likely to die compared to those who don't. In addition, those who visit HTC's have fewer reported emergency room visits or complications due to a bleeding problem. Another benefit of going to a HTC is the convenience. People with bleeding disorders receive all of their care in one place. There are a range of experts who are willing to help with all the effects of having a bleeding disorder, not just the medical treatments. When you use a HTC, you have the convenience of all the medical experts on bleeding disorders in one building, with one appointment, and one single cost. Having a single cost is also very economical. The cost of care per person with a bleeding disorder in a HTC is 74% less than care outside a HTC. The out-of-pocket expense (what the patient has to pay because insurance doesn't) is also 77% less.

The *Do the 5*'s second strategy, being vaccinated, is also essential. People with bleeding disorders may have more exposure to blood products. Therefore, it is vital that people with bleeding disorders are vaccinated for

Hepatitis A and B. Hepatitis A is spread through fecal-contaminated food or water and usually occurs most often in young adults. Hepatitis B is transmitted in contaminated serum in blood transfusion or by the use of contaminated needles. Both types of hepatitis can be prevented through vaccination. No one wants to sacrifice their health because they didn't take the time to get a few immunizations.

The third strategy of the *Do the 5* is a no brainer. If someone with a bleeding disorder gets a bleed, treat it! Don't wait around because in many cases, the bleed is only going to get worse. It is just common sense to treat any type of injury right away and make sure you take care of yourself afterwards, whether it is a bleed or any medical problem. Ignoring this simple step can result in a lot of unnecessary problems at the time of the bleed and potentially in the future.

Exercising your joints and maintaining a healthy weight, the fourth strategy of the *Do the 5*, is also pretty basic. With or without a bleeding disorder, exercise just makes sense. If you take care of yourself now, your body will thank you later. Even if "later" doesn't matter to you now, exercise is something that also has immediate benefits. You immediately feel better, are doing something "normal" and it is something you can do with friends. (See our Sports Skinny in this issue for some more tips on specific ideas associated with exercise.)

The final strategy of the *Do the 5* is very serious. Getting tested for blood borne infections is part of the deal with a bleeding disorder. Ignorance is not bliss. These things can be very serious. By working with your HTC, this is a simple but necessary step. Get tested so you are

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informed about your health. Participate in the UDC at your HTC and you will be able to get free testing and help in an important surveillance project.

Remember information is power. Doing something to help yourself and stay in control of your life and your health is now your responsibility as a teenager. The World Health director-general Lee Jong-wook said, "Improved health care is perhaps humanity's greatest achievement of the last 100 years". *Do the 5!*

For more information on Do the 5 go to www.hemophilia.org/programs/npp/npp.htm.

Prevention and Oral Care

People with bleeding disorders must often deal with a wide variety of physical problems related to their bleeding disorder. In many cases, prevention is the key to maintaining their health. There are the obvious prevention issues related to bleeds such as the NHF's *Do the 5*. There are also more subtle prevention issues that the bleeding disorder community must face on a long-term scale. One issue in particular is oral care for people with bleeding disorders. It is important to maintain a healthy mouth and avoid dental problems by taking preventative measures against oral disease.

Oral diseases not only cause significant bleeding, but they also have the potential to influence your general health. Dental prevention includes two different ideas:

- 1) Preventing disease in the first place.
- 2) Using preventative measures to protect individuals with bleeding disorders when dental

work is needed.

Oral disease occurs when plaque builds up. Plaque occurs when bacteria builds up. Bacteria are created when sugars from food build up in your mouth. Bacteria have the potential to result in tooth decay or tooth loss. These same bacteria can affect the gums and cause bleeding gums. Although bacteria build up, plaque, is the initial cause of gum bleeding, the bleeding is often increased by a bleeding disorder. One major risk for individuals with bleeding disorders occurs during and after dental treatment. Many surgical procedures can result in extensive bleeding that is often difficult to control. Tooth extractions and anesthetic injections are prime examples of how procedures conducted in order to improve dental health can often backfire, creating larger complications if preventative measures are not used before and after the dental work when individuals also have a bleeding disorder.

Fortunately, there are many ways to maintain a healthy mouth. Because we know that plaque causes dental caries or cavities, we can take measures to prevent the accumulation of this substance. Brushing your teeth twice a day for three to five minutes is the single biggest thing you can do to keep your teeth healthy. It is important, though, to choose a toothbrush appropriate for those with bleeding disorders. Hard and medium brushes should be avoided because they can wear down the teeth and gums and are not as effective against plaque. Soft bristle brushes are better. Angled soft brushes are one option that allows access to unreachable areas of the mouth and are a good manual type of toothbrush. Additionally, those with bleeding disorders can benefit from the

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newer “power-brushes” with bristles that rotate or move automatically if you can afford them. This technology can be more effective than regular brushing, and demands less from the joints in the arm, which is another good thing for those with bleeding disorders.

Toothpastes are another important choice. Their purpose is to remove and prevent the formation of plaque in the mouth. Flouride and other desensitizing agents are the important ingredients of toothpastes that prevent oral disease. It is therefore best to choose toothpaste with flouride listed in the ingredients.

For people with bleeding disorders in particular, a mouthwash and flossing are also as important as brushing your teeth and using the right toothpaste. Mouthwashes provide another method of defense against tooth decay and disease that can lead to extensive bleeding. Flossing after meals is another method of reducing the levels of bacteria in the mouth that can lead to tooth decay. Using waxed or easy gliding floss makes flossing easier. It is also important to slide gently down the side of the tooth so you don't create a wound and bleed.

There are lots of other indirect prevention tips that can help you out. If you are playing a physical sport, it is recommended that a mouth guard be used in order to protect the teeth from major blows that could damage or dislodge a tooth. What you eat also affects the health of your teeth. In particular, the frequency with which phosphoric acid and sugars are consumed can affect teeth by speeding up the process of decay. These things can be found in large amounts in sodas. Do we, as teens, really need to drink all that soda? It's something to think about!

Besides these basics, there are special considerations for the bleeding disorder community in regards to the prevention of oral disease. Informing and educating your dentist about the nature of your condition often helps to make dental procedures run more smoothly and safely. When dealing with a dentist or other dental practitioner, people with bleeding disorders need to work closely with their physician in order to insure a safe treatment plan. Developing treatment plans with a dentist and someone with knowledge of the bleeding disorder before a dental procedure happens is essential. An in-depth assessment of the teeth is a good idea for 12 to 13 year olds, as a way of planning for future problems related to overcrowding such as extractions, braces, and pulling wisdom teeth. Tell your dentist the type and severity of your bleeding disorder, if you have an inhibitor, if you take any medications or need to pretreat. When working with an orthodontist, it is important to communicate with them about your bleeding disorder, just as it is important to communicate with a dentist. Developing a plan with a hematologist is wise in this situation as well. Additionally, when using anesthetics, it is best to avoid deep injections if possible, which could result in heavy bleeding.

There are many benefits for the bleeding disorder community to maintaining a high level of dental health. Prevention is key, and includes brushing regularly with the right type of toothbrush, using mouthwash and dental floss, as well as scheduling regular dental check ups. In addition, you should educate your dentist or orthodontist and work with a hematologist to develop any necessary

treatment plans *before* a dental procedure. Watching your diet and taking other preventative measures, such as using a mouth guard, are other ways of avoiding injury to your mouth and teeth. It's up to you-prevention and planning is easy if you take control of your health including your mouth and teeth.

Sports Skinny-Preventing Injuries in Joints through Exercise

The National Hemophilia Foundation, or NHF, has released a list of five ways to increase fitness and decrease joint injuries through *Do the 5*. One of the *Do the 5e* involves exercising to strengthen joints and reduce joint damage. The Centers for Disease Control and Prevention reports that almost half of young Americans do not routinely exercise.

Strong muscles can do a lot to protect the joints. This is reassuring, considering that 80% of people with hemophilia have joint complications. Continued low impact aerobic activity is one of the best ways to develop strong muscles. The American Heart Association recommends about thirty minutes daily of moderate, sustained activity. The keys to receiving the benefits of exercising to strengthen your joints include:

- Evaluating what if any exercise you currently do
- Determining how hard you need to work
- Following sports recommendations for people with bleeding disorders

-Fitting exercise into your everyday life to strengthen your joints and muscles

Most of these goals can be accomplished relatively easily by assessing what level of fitness you wish to attain and how much your exercise habits must change in order to do so. If you do this and make sure to avoid the more physically damaging sports (football, hockey, wrestling, etc.) you are already on your way to increased fitness.

Many times, however, it is difficult for people to find the time, every day, to do the exercise required to reach a healthy level of fitness that can benefit the joints. There are a few strategies to incorporate exercise into your daily routine without sacrificing other major aspects of your life. With the help of a physical therapist or other health professional, you can determine your current joint motion, and with the appropriate preparation, you can choose activities that you find interesting and enjoyable. Professionals can even work with you to create a routine that specifically addresses current weaknesses and that can help avoid injuries. Another way of effectively integrating exercise into your life is by getting a friend or family member to exercise with you, making the experience more enjoyable. Of course, the rewards of strengthening your muscles through a routine exercise program usually out way the time commitment anyways. Strong joints that last into your old age and general good health are worth a few hours of exercise a week.

Preventative exercise focusing on strengthening your joints is one of the best ways to protect your joints, not to mention the other benefits of good health

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(such as the decreased chance of strokes, heart disease, and high blood pressure, among others). By developing a plan to add an exercise routine to your weekly schedule, you can create long-lasting changes in your body that will protect your joints.

Links

In this issue of Teen Talk, we reviewed the U.S. Preventive Services Task Force's web site at www.ahrq.gov/clinic/uspstfix.htm. The task force is part of the Health and Human Services Department (HHS) and its purpose is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. This site would be a great starting point if you were looking for basic information on health prevention. All the information on this site is focused on health prevention and included information on research findings, public health preparedness, and consumer information. This web site gives you great information on new prevention recommendations, upcoming events, the U.S. Prevention Services Task Force meetings, as well as a list of topics related to prevention.

There is an extensive variety and quantity of information. On the homepage, there are browse options, resources, contact information, and recent studies and updates related to health prevention. For every topic included on this web site, there was at least a half page or more of information plus other links leading to even more information or studies.

One glaring problem that was encountered was the fact there was no search engine. Instead there was a list titled "A to Z". To use this list, you

needed to know your specific topic and be willing to manually search for it alphabetically. We tried looking under H for hemophilia and had 10 hits. Of these hits, only a few provided detailed information on prevention. When trying to search for von Willebrand Disease, we came up with 0 hits. When we tried looking for platelet disorders, about 5 results came up but only a couple had to do with prevention. In general, the "A to Z" list was hard to use and took a lot of time while providing only mixed results.

When topics were found, the reading level was at an understandable level. Few pictures or other graphics were found anywhere on this site. For those teens who are into the science of health prevention, this is *not* a good site for you. 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 U.S. Preventive Services Task Force's web site seems to focus on basic prevention ideas with lots of links. Overall, the site is a good starting point in a search on health prevention and provides some assurance of accuracy since it is a government site. It is very well organized and laid out with the exception of a good search engine. This site is a good place to start a life of prevention and increase your awareness!

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

Overall rating: Good

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The Government's Family History Initiative

The Office of the Surgeon General under the leadership of the U.S. Surgeon General, Richard H. Carmona, M.D., M.P.H., along with the U.S. Department of Health and Human Services, National Human Genome Research Institute, Center for Disease Control and Prevention, the Agency for Healthcare Research and Quality, and The Health Resources and Services Administration, have begun a Family Health History Initiative. This initiative is aimed at increasing awareness of the health issues that run in families. By having families participate in the Family History Initiative, individual family members may be diagnosed for certain diseases more easily. In addition, they will have the potential to predict the diseases that an individual may be at risk for, before they occur.

Because many diseases are hereditary and can run in families, health care professionals believe this initiative will help to watch for, try to prevent, or allow diagnose of early health problems in new generations of a family. By being aware of health problems your family has faced, you can determine what types of issues you may have to deal with and what preventative strategies you might be able to utilize. Among the most common hereditary disorders in families are heart disease, cancer, and diabetes. In addition, for members of the bleeding community, a family history is especially important to help identify others in your family who may have had a bleeding disorder, what type, and how they responded to treatment as well as genetic factors

associated with the bleeding disorder. By creating a family history, you may be able to anticipate the problems you may face and prevent some of them from happening or becoming as severe.

The Surgeon General has even declared a family history day. The first annual National Family History day took place in 2004 on Thanksgiving. To further aid Americans in learning more about their family's history, the Department of Health and Human Services has set up a website, www.hhs.gov/familyhistory/, with more details and information as well as a family history tool to help individuals have an awareness of possible diseases for which they may be at risk. It includes a link to download a free program that helps keep track of your family history, as well as answers to questions you may have about the significance of having a comprehensive family health history.

Quickie Quizlet

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

1. Which of these is not part of the *Do the 5*?
 - a. See your regular doctor every 6 months to prevent bleeds.
 - b. Get an annual comprehensive checkup at a hemophilia treatment center.
 - c. Get vaccinated – Hepatitis A and B are preventable.
 - d. Treat bleeds early and adequately.
 - e. Exercise and maintain a healthy weight to protect your joints.

- f. Get tested regularly for blood-borne infections.
2. True or False: The U.S. Preventive Task Force's web site is a good place to start looking for preventive information.
3. True or False: An electric toothbrush is easier on your joints and is much better for your teeth than a manual toothbrush.
4. The Centers for Disease Control and Prevention believes that what percentage of young people go without the proper exercise?
5. A benefit to tracking your family history is:
 - a. To learn more about your family's culture
 - b. That individual family members may be diagnosed for certain diseases more easily
 - c. To learn about the changes in health care through many years

Answers:

1. A
2. T
3. T
4. About half or 50%
5. B

Guest Corner

Teen Talk is still looking for a guest columnist for the next issue! If you write and send us a publishable article on 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> with the subject line "Teen Talk"!

**Don't
Forget to
Look for
Our Next
Issue of
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