



Factor Nine News

The Coalition for Hemophilia B Winter 2010

Topics in Hemophilia

- Save the Dates!
- Social Aspects of Hemophilia
Carrier Detection and Education
- “Age 29” Dependent Coverage
Extension
- William N. Drohan Scholarship
Award Announcement
- We remember Maureen Cook
- Industry News
- Mystery of the Missing Sea Lions



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Saturday, March 27th, 2010

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Social Aspects of Hemophilia Carrier Detection and Education

by Dr. David Clark

Hemophilia is as much a social issue as a medical issue. We recently came across two interesting articles that investigated attitudes and communication about carrier testing and education. Carrier detection and education are seen as important for many reasons, the most significant being to ensure adequate care of carrier mothers and their newborn children with hemophilia. (We're writing about "children with hemophilia" because it is becoming more obvious that many women who are carriers actually do have bleeding problems. We'll be writing more about this in future issues.)

An article by Thomas and coworkers surveyed attitudes in the hemophilia community (both A and B) about genetic testing for carriers of hemophilia in the Australian state of Victoria. The investigators interviewed men with hemophilia and fathers of boys with hemophilia, women who knew they were carriers and females relatives of both groups whose carrier status was unknown. The largest difference in

attitudes was between participants who already had a family history of hemophilia and those who became carriers due to sporadic mutations and had no family history. Those with a family history were more likely to express positive experiences, while those with no family history spoke about being overwhelmed by the diagnosis and the scary uncertainty associated with the condition. Participants with a family history of hemophilia had a tendency to adopt a positive attitude and to describe hemophilia as "normal" or even state that they felt "special".

Many participants saw carrier testing as mainly a means of allowing potential carriers to make reproductive choices. That is certainly one aspect, which is welcomed by some but feared by others. Some women and couples didn't want to be faced with such decisions or were concerned about pressure from others once their carrier status was known. Religious beliefs also enter into such decisions. The medical community's main role here is just as a supplier of information.



However, testing also provides valuable information for the medical care of the carrier and any future children. Many carriers do have bleeding problems at times; they actually can have mild, moderate or even severe hemophilia. Knowing that they are a carrier can help simplify diagnoses of possible health problems. It can also help reduce problems during future pregnancy and childbirth. Carriers are at slightly increased risk of miscarriage, which can be managed better if they are aware of the possibility. Measures can also be taken to better protect the baby from trauma during childbirth. A real danger is intracranial hemorrhage, bleeding in the brain, in the newborn, which can cause lifelong mental or neurological problems, or even death.

Interestingly, the men in the survey tended to focus less on the reproductive issues and more on the well-being of their partner, daughter or relative. Men with hemophilia were conflicted though. While they were more likely to see genetic testing as a means of reducing or eliminating the number of people born with a significant genetic disorder, they were usually supportive of their partner's or relative's need to make their own decisions about having children.

The other article by Gregory and coworkers was a similar survey of families with hemophilia in Wales, which concentrated especially on communication about hemophilia to daughters who were carriers or potential carriers. One big difference identified in that study was between women who had brothers with hemophilia and those who had fathers with

hemophilia. Those with hemophiliac brothers tended to be much more involved in the day-to-day issues of living with hemophilia and to be more comfortable about potentially having children with hemophilia.

Interestingly, those who had hemophiliac fathers tended to be shielded more from the issues of living with hemophilia. Some were even teenagers before they knew their fathers were affected. Fathers, being older, tended to have their hemophilia more under control, so there was often less exposure of the children

to the everyday aspects of it. Their wives, the mothers of the carriers, who also tended to be the communicators in the families, usually came from non-hemophiliac families and often reported that they did not feel competent enough to properly educate their daughters.

Many of the parents tended to rely on the clinics and treatment centers to educate their carrier daughters about hemophilia, usually around the time they were tested to determine their carrier status.

However, many of the carrier daughters reported

not really understanding the material presented at the clinics. They got much more from being exposed to it slowly over time in the family environment, based on actual experiences.

Another valuable reason for learning about hemophilia in the context of the family is that this provides a means of transmitting the family's values concerning living with hemophilia. Assurance that hemophilia was something that could be coped with had more authority coming from those who had "been



continued on page 7



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“Age 29” Dependent Coverage Extension

Article courtesy of the Hemophilia Association of New York, www.ins.state.ny.us/health/

On July 29, 2009, Governor David A. Paterson signed into law Chapter 240 of the Laws of 2009, which extends the availability of health insurance coverage to young adults through the age of 29. This expansion will assist young adults who do not have access to employer-sponsored health insurance.

This law is sometimes referred to as the “Age 29” law, because it permits young adults to continue or obtain coverage under a parent’s policy through the age of 29.

The young adult must:

- Be unmarried;
- Be 29 years of age or under;
- Not be insured by or eligible for comprehensive (i.e. medical and hospital) health insurance through his or her own employer;
- Live, work or reside in New York State or the health insurance company’s service area; and
- Not be covered under Medicare.

The law provides two distinct ways in which coverage may be extended: a “young adult” option and a “make available” option. Because both benefits are so different, they are described separately. The “Young Adult” option permits eligible young adults through the age of 29 to continue or obtain coverage through a parent’s group policy.

Insurers will notify employees of this benefit. Employees or their eligible dependents may then elect the benefit and pay the premium, which cannot be more than 100% of the single premium rate.

This benefit, referred to as the “young adult option,” is separate and distinct from the “make-available” requirement. It is called the young adult option benefit because it permits eligible young adults to continue their coverage through a parent’s health insurance coverage once they reach the maximum age of dependency under the policy. Young adults may also elect this coverage when they newly meet the eligibility criteria, such as if they lose eligibility for group health insurance coverage.

Under most individual and many group health insurance coverage, a dependent child loses coverage or “ages off” a parent’s policy when turning 20 years of age, or 23 years of age if attending college.

The “Make Available” option may extend the age of dependency and permit eligible young adults through the age of 29 to remain on a parent’s health insurance coverage in the same manner as dependents who are children.

The law states insurers that issue a policy or contract that provides coverage for dependent children must make available and, if requested by the policy holder/contract holder, extend coverage to qualifying young adults through age 29 as dependents under family coverage.

It is called the “make-available” requirement because insurers are required to make it available at the request of the group or individual policy holder/contract holder.

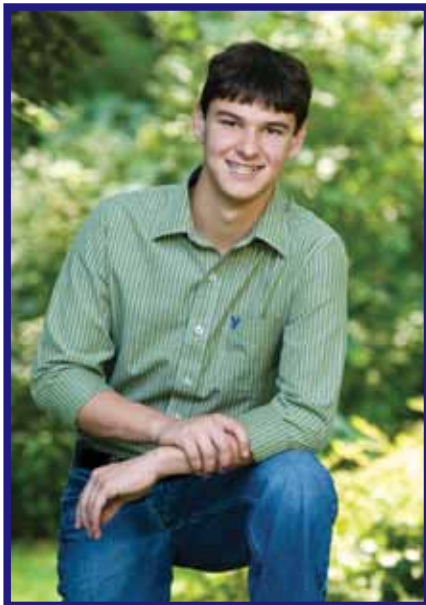
It is important to note that in the case of insurance through an employer or group, the employer or group decides whether to offer this benefit to employees. The young adult does not

continued on page 7

William N. Drohan Scholarship Winners Announced

A special congratulations go out to two siblings, Anna and Anthony Vetter, who were awarded the William N. Drohan Scholarship for the 2010-2011 school year.

Anna Vetter is currently a junior at the University of Illinois in Champaign, majoring in Advertising with a minor in Political Science. She shared with us, “. . . I would like to focus my attention as a volunteer to address some of these issues and help foster public awareness of hemophilia and other bleeding disorders, especially as they relate to women. I hope to accomplish this is by using the skills and insight on the behalf of the bleeding disorder community that I will learn in the course of obtaining an advertising degree. I would find it greatly rewarding to be in a position where I can promote awareness by developing educational materials, plan fundraising events, or even addressing congressional issues regarding insurance coverage and policy direction in order to better the lives of those affected by this often-misunderstood disorder.”



Anthony Vetter is a freshman at University of Illinois in Springfield and is majoring in Business Administration, “My passion is to make sure that though my work, actions, and attitude that the next generation of kids with a bleeding disorder will have someone to look up to, just like I did. When I was young, I had a negative outlook towards my hemophilia because I did not think that anyone felt the same as I did or knew what I was going through. It was at hemophilia camp that I realized there was a group of people who share my experiences. These people are my “blood brothers and sisters.” What we have in common is that we all **live** with hemophilia.”

***Congratulations Anna and Tony.
We at The Coalition for Hemophilia B are all very proud of you!***

“Age 29” Dependent Coverage Extension


continued from page 5

get to make this choice.

The law affects policies or contracts issued, renewed, modified, altered or amended on or after September 1, 2009. For most existing policies, young adults and their parents will be able to access the young adult option once the right attaches to the policy. For most policies, this will happen on the policy's first renewal date on or after September 1, 2009.

You can contact your insurer or group administrator to determine the renewal date. The young adult option must be included with all new policies issued on or after September 1, 2009.

If you are not eligible to make an “Age 29” election, you may be able to elect COBRA/ state continuation coverage for up to 36 months. You would be responsible for up to 102% of the premium. You could consider Healthy NY, which provides reduced-cost coverage to those people meeting eligibility requirements. You may also want to consider Family Health Plus, which provides free coverage to people meeting income and other eligibility requirements.

If you need more information about this law, you can contact the Insurance Department's Consumer Services Bureau at (212) 480-6400 or 1-800-342-3736. 


Social Aspects of Hemophilia Carrier Detection and Education

continued from page 3

there” and had personal experience to draw from.

Sporadic carriers, those with no family history, had the hardest time. They usually only found out after the birth of an affected child. They and their families usually had no existing knowledge of hemophilia and tended to see this as a real tragedy. The mothers often had great feelings of grief and guilt that they had done this to their child. (Although not addressed in this article, spontaneous genetic mutations causing hemophilia often come from the father during sperm production, so the father of the sporadic carrier, the grandfather of the newborn with hemophilia, is often the actual source of the mutation.) The researchers point out, however, that “in many cases there were positive outcomes, with family relationships

assuming a particular closeness and intensity as a result of the diagnosis.”

There is much more in both articles than we can cover here. Also, the authors were careful to point out that these were non-random samplings of attitudes that don't necessarily represent the views of the entire hemophilia community. However, as we continue to recognize that hemophilia is not just a medical condition that only affects only men but something that affects the quality of life for entire families, we can do a better job providing the education and support they need. 

Gregory M, Boddington P, Dimond R, Atkinson P, Clarke A, Collins P, Communicating about haemophilia within the family: the importance of context and experience. *Haemophilia*, 13(2), 189-198, 2007.

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As we keep Maureen Cook close in our hearts, minds, and prayers, we thought we would share with you one of our favorite pictures of her as she enjoyed herself at her son's wedding a few years ago.

Maureen, we miss you dearly.



Maureen Cook
April 6, 1961 - December 2, 2009

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Industry News

Inspiration Biopharmaceuticals and Ipsen form Partnership

Inspiration Biopharmaceuticals (Laguna Niguel, CA) has formed a partnership with Ipsen Group (Paris, France) to develop Inspiration's recombinant factor IX, IB1001, for treatment of hemophilia B and Ipsen's recombinant porcine factor VIII, OBI-1, for treatment of hemophilia A patients with inhibitors. The partnership will help Inspiration continue the clinical development of IB1001, which has shown good results in Phases I and II. Phase III clinical studies for IB1001 are scheduled to begin in 2010. Inspiration will also continue development of its recombinant FVIIa product for treatment of hemophilia A and B patients with inhibitors and its recombinant FVIII product for treatment of hemophilia A. Inspiration's rFVIIa product is scheduled to begin clinical studies in 2011. According to the press release from the two companies, their partnership will "create a world leading hemophilia franchise."



Biogen Idec and Biovitrum begin Phase III Study of rFIXFc



Biogen Idec (Cambridge, MA) and Biovitrum (Stockholm, Sweden) have announced that they have started the Phase III clinical trial for their long-acting recombinant factor IX product, rFIXFc, after good results in their initial Phase I/IIa study. The Phase III study, called the B LONG study, will evaluate the safety, efficacy and pharmacokinetics of rFIXFc in about 75 hemophilia B patients. It is the first long-acting FIX product to enter clinical studies. They will evaluate different dosing regimens as well as on-demand use and use in surgery. rFIXFc is a recombinant factor IX protein attached to a recombinant Fc immunoglobulin fragment. As reported in the Autumn 2008 issue of Factor IX News, the attached Fc fragment is designed to increase the half-life of factor IX in the circulation, leading to less frequently needed infusions for patients, especially those on prophylaxis. The results for their initial Phase I/IIa study will be presented publicly at the WFH meeting in Buenos Aires in July, 2010. The companies are also developing a long-acting recombinant factor VIII product, rFVIIIc, which has just entered Phase I/IIa clinical studies.

Pfizer Acquires Wyeth

On October 15, 2009, Pfizer completed its acquisition of Wyeth after approval by shareholders and all required regulatory bodies. Wyeth, the manufacturer of BeneFIX, became a wholly-owned subsidiary of Pfizer.



Mystery of the Missing Sea Lions of San Francisco is Solved!

In our last issue of Factor Nine News we shared an interesting story with you about the Sea Lions that live at Pier 39 in San Francisco, California. Last November, after living at the pier for over 20 years, the Sea Lions suddenly vanished, baffling both magicians and scientists.

We thought this would be of interest to many of our readers who, while attending the National Hemophilia Foundation conference last fall, had the opportunity to visit the famous Sea Lions during their trip.



Well, mystery solved! The Sea Lions have migrated toward Monterey Bay (118 miles from San Francisco). Monterey Bay is teeming with herring. The disappearing act was really a testimony to the resilience of

animals and the magic of nature. Experts at Marine Mammal Center don't think this is the last they will see of the Sea Lions, they believe the Sea Lions will come back to Pier 39 in Spring in time for Tourist Season!

Reference: www.Care2.com



Factor Nine Santa would like to give a heartfelt ***“Thank you”*** to all of the wonderful people that so generously gave to the Santa Fund this past holiday season. The Coalition for Hemophilia B was very happy and proud to be able to make the holidays a little bit brighter for 45 children!

For back issues of **Factor Nine Newsletter** or for more information on research, please call or write to:
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