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This report includes selected news items from the past week on issues of concern to the bleeding disorders community. It is designed to help keep NHF national and local leadership and staff informed of the latest information from the news media. It will be distributed by email on Thursday of each week, covering important news items from the previous seven days. Subjects covered will include hemophilia, other bleeding disorders, gene therapy, hepatitis, HIV/AIDS, and others.

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April 5, 2018
Isustudentmedia.com (IN)

Give from the Heart, Dance to the Beat – ISU to Host Ninth Annual Dance Marathon

By Jack Gregory

Ninth annual Dance Marathon to be hosted this Saturday to raise money for Riley Hospital for Children patients.

The event will last from noon to around midnight and is being held in the ISU Recreation Center. Last year, the event aimed to raise \$80,000, but that goal was smashed and participants managed to raise \$116,850.99.

This year, it's likely that the university will raise even more money than last as 715 students have already signed up, compared to the 530 that attended last year, with more still registering. According to Lauren LaDow, president of State Dance Marathon here at ISU, student attendance and participation increases every year.

“We have high hopes to raise way more than last year. It is this campus and our dancers that make [Dance Marathon] what it is,” LaDow said.

Students who register for the Marathon will be required to stay on their feet for the duration of the event, whether they're dancing or just standing and taking a break. Dancers raise money through requests for donations, sponsorships and simply by participating.

If you don't want to go alone, invite your friends to register as a team or join a team that's already registered. Those who wish to help out, but can't attend the marathon can still donate either directly to the event or pledge money to one of the dancers. For those students who have registered or are going to register, they can look forward to a night comprised of dancing, games, crafts, food and more into a really fun event that is for a really good cause.

“Without the support and fundraising efforts of every dancer that signs up, we are unable to reach our goals and our organization is so thankful for all the amazing students that support our cause!” LaDow said.

The Dance Marathon started at Indiana University in 1991 to honor Ryan White, a teenager from Kokomo, Indiana who was infected with HIV from a contaminated blood treatment which he normally would receive to treat his hemophilia A.

Due to poor understanding and fear of HIV/AIDS at the time, White was prohibited from returning to school despite the fact that there was no risk of him infecting others. The controversy surrounding him resulted in White being suddenly shot into the national spotlight, appearing on national television, in newspapers and with celebrities, and participating in public benefits for other children with AIDS. After essentially becoming the posterchild for AIDS crisis in America and helping to destigmatize the disease, White died on April 8, 1990, at age 18. The following year, Dance Marathon was formed, as well as many other charities. Since its inception, it has raised over \$28 million as of 2016 and has spread across the state to over 60 different high school and college campuses.

The idea behind this fundraiser is to make sure the children at Riley Hospital and those donations go to a variety of different services to help the hospital's patients, such as funding pediatric research into better ways of treating childhood cancer, diabetes, heart defects, as well as asthma and many other illnesses. It's not all research, though. That money also goes toward good, spacious rooms for the kids to feel comfortable in and support from child life specialists, who help the children and their families cope with their illness and/or disability. Overall, these donations are put to good use towards a good cause.

April 10, 2018

Ranchosantafereview.com (CA)

RSF Rider Wins Championships at Carousel Charity Horse Show

By Karen Billing

Rancho Santa Fe's Henry Reif, 15, recently had a strong showing at the American Saddlebred Association of Arizona's Carousel Charity Horse Show in Scottsdale, Ariz. With horse A Lasting Legacy, Henry was named Junior Exhibitor Five Gaited Champion and Grand Champion; Regal's Promoter and Henry won the Roadster Pony Grand Champion and Open Champion; and Brady and Henry won the Five-Gaited Pleasure Reserve Championship.

Henry, a sophomore at High Bluff Academy in Carmel Valley, began riding horses when he was younger but picked it up again more seriously about three years ago.

"I always liked horses and animals in general and when I went to a new school, none of the sports provided really worked with my medical condition," said Henry, who has **hemophilia**. "I decided to go back to riding and started off really slow."

Henry moved from a small barn that specialized in Peruvian Pasos to Rockridge Farm in Rancho Santa Fe, a barn run by Bill and Debbie Tomin which specializes in American Saddlebreds.

The American Saddlebred is known as the peacock of the horse world, a more "showy and fancy" high-stepping horse. The horse is shown in a saddleseat English saddle or in elegant driving events.

"They have a chess piece look," Henry said. "They're beautiful animals."

Henry was reluctant at first because he wasn't very familiar with the breed but after his first ride with a Saddlebred he was hooked. He now trains at Rockridge three times a week for about two hours a session with head trainer Bill and "awesome" assistant trainer Whitney Anderson.

Debbie Tomin said in addition to the physical skills gained from the challenge of learning to ride a horse, Henry found an added benefit in the trust and relationships that he built with each horse he rode.

"We have watched him gain confidence along with his skills over the years with the horses and his commitment to be one of the country's top juvenile riders," Debbie Tomin said. "His ability to follow directions and execute them with his horses has distinguished him as a quietly confident young man."

In competition, American Saddlebreds walk, trot and canter, and are judged on performance, quality, manners and overall presence.

"It's a little bit of a dance with the horse," Henry said. "You have to figure out how to please the horse and ask nicely with the reins."

A Lasting Legacy, whom Henry calls "Legs" for short, is a stronger horse and a step up from riding Brady.

"He's a really great horse and he has a lot of power," said Henry of Legs.

For his hackney roadster pony, Regal's Promoter or "Mr. P," Henry drives in a cart and in competition is judged on speed while maintaining the horse's form.

As the event is steeped in tradition, riders wear snap-brim hats and long-tailed coats—Henry enjoys designing the look he wears, with efforts made to match the colors of his horses.

The win at Carousel Charity Horse Show was a great way to kick off his first competition of the season—Henry expects to be showing about once a month and he is hoping to build on his success from last year.

Last fall in only his second year of competing, Henry had a great showing at the World Grand Championship in Lexington, Kentucky- he was named the Reserve World Champion in Five Gaited Pleasure with Brady and was third in the world in Junior Exhibitor Roadster Pony with Regal's Promoter.

"For (Rockridge) to have brought me to this point, it's honestly kind of surreal for me to register the fact that I'm second in the world in something," Henry said. "I'm really hoping to go to World Championships again on Legs. That's my goal, to bring him to enough shows and return to Worlds."

April 11, 2018
Businesswire.com

Octapharma USA Grant Supports National Conference for Type 3 von Willebrand Disease Patients

‘Making the Connection’ will be held June 22 – 25 in Palm Beach Gardens, Florida

For the second year in a row, Octapharma USA will serve as the exclusive sponsor of “Making the Connection,” a national conference for patients with Type 3 von Willebrand Disease (VWD).

The conference will be held June 22 – 25 at the PGA National Resort & Spa in Palm Beach Gardens, Florida. For program details and registration, please visit www.vwdconnect.org.

VWD affects up to 1 percent of the U.S. population. Type 3 VWD is the rarest and most severe form of the condition.

“We will bring together patients and their guests with a world class group of physicians and medical professionals in a safe and relaxed environment for making lifetime connections and sharing educational information,” said conference organizer, Jeanette Cesta, President, VWD Connect Foundation. “We thank Octapharma USA for supporting the conference with an educational grant and helping us create a truly special event for the Type 3 VWD community.”

Educational information and other resources will be provided on various medical issues, such as treatment alternatives, joint health, symptoms and diagnosis. Family and professional relationships, challenges of loss and depression, disclosure issues, and positive coping strategies will be among the emotional and social topics on the agenda.

“Octapharma USA is committed to helping patients with chronic illnesses, such as Type 3 VWD, maximize their quality of life,” said Octapharma USA President Flemming Nielsen. “The first conference for Type 3 VWD patients was very well received and we are confident the program this year will build on that success. We are dedicated to programs and products that enable bleeding disorder patients to manage their condition.”

Physicians, healthcare providers specializing in bleeding disorders, geneticists, health educators, nurses, physical therapists, and social workers will be among the many professional resources available to conference attendees. For complete conference information, please visit www.VWDCConnect.org.

About the VWD Connect Foundation

VWD Connect Foundation is a Florida-based non-profit organization created to serve the bleeding disorder community, focusing on severe von Willebrand Disease. It provides education and connection for patients and families, and supports research that will benefit the von Willebrand Disease community.

About the Octapharma Group

Headquartered in Lachen, Switzerland, Octapharma is one of the largest human protein products manufacturers in the world and has been committed to patient care and medical innovation since 1983. Its core business is the development and production of human proteins from human plasma and human cell lines. Octapharma employs approximately 7,600 people worldwide to support the treatment of patients in over 113 countries with products across the following therapeutic areas: Hematology (coagulation disorders), Immunotherapy (immune disorders) and Critical Care. The company's American subsidiary, Octapharma USA, is located in Hoboken, N.J. Octapharma operates two state-of-the-art production sites licensed by the U.S. Food and Drug Administration (FDA), providing a high level of production flexibility. For more information, please visit www.octapharmausa.com.

April 11, 2018
News.tcnj.edu (NJ)

Donna Shaw's Book Traces the Bloodline of Tainted Hemophilia Drugs

In the mid-1990s, TCNJ journalism professor Donna Shaw was browsing through news when she came across a story that would ultimately change the course of her life. In a story about hemophiliacs suing over tainted blood products she recognized the name of the prominent Philadelphia lawyer involved with the case, whom she immediately called.

“He said, ‘Are you ready to cover this story for a few years?’ I laughed, but that’s exactly what I ended up doing,” says Shaw, a former business reporter for the Philadelphia Inquirer.

As Shaw launched her investigation of the “dirty blood,” as she puts it, she uncovered a trail of corruption and heartache that has affected thousands of hemophiliacs and their families around the world. Her investigation uncovered that numerous pharmaceutical companies in the 1970s and 80s knowingly distributed tainted blood products, resulting in thousands of hemophiliacs contracting HIV and hepatitis C by using products that were promised to help them.

Soon after Shaw began looking into the topic, she met Eric Weinberg, a New Jersey lawyer who had more HIV-infected hemophilia clients than any other lawyer in the state. The two formed a partnership, sharing information and working together in an attempt to expose the wrongdoings of Big Pharma and to get justice for those affected by the blood.

She, along with Weinberg, went on to write an entire book on the subject, *Blood On Their Hands: How Greedy Companies, Inept Bureaucracy, and Bad Science Killed Thousands of Hemophiliacs*, published in 2017 by Rutgers University Press.

“I wanted people to understand that even when the government has the best intentions, things can go horribly wrong,” she says.

Over the years, Shaw interviewed hundreds of people, both nationally and internationally. More than half of the 17,000 hemophiliacs in America became infected, but there were thousands of others devastated by the tainted blood around the world including in Canada, Ireland, Costa Rica, England, Japan, and France. Hemophilia is generally an inherited disease that affects males, so in some cases, multiple family members were sickened. Shaw gave a voice to as many of them as she could.

Now that the book has been published, Shaw says she is relieved that people can know the whole story.

Ironically, a blood transfusion saved Shaw’s life when she was a child, after a tonsillectomy gone wrong. Her mother also used to work for the National Institutes of Health Bureau of Biologics, a subsequently-renamed federal agency that used to regulate blood products.

“I grew up hanging out at NIH after school,” says Shaw. “I thought those people were gods and heroes, and for the most part, I still do. But now I’m a little wiser.”

Donna Shaw has received three nominations for a Pulitzer Prize, including for her work on the HIV-hemophilia tragedy.

April 11, 2018
Hemophilianewstoday.com

Exercise Approach Called Programmed Sports Therapy Can Help Hemophilia Patients, Study Suggests

By Alice Melão

Exercise can be an important part of recovering from hemophilia and continuing to keep a handle on it, according to a German review of previous research.

The study, "[Programmed Sports Therapy \(PST\) in People with Haemophilia \(PwH\) — Sports Therapy Model for Rare Diseases](#)," appeared in the Orphanet Journal of Rare Diseases.

Dr. Thomas Hilberg's article focused on the importance of sports and other kinds of exercise in the treatment of people with hemophilia. And the article championed an exercise approach that the University of Wuppertal professor calls programmed sports therapy.

Before the development of clotting factors that could counter hemophilia bleeding episodes, doctors recommended that people with the disease limit their physical activity. The fear was that a sports injury would trigger bleeding.

Scientists have since concluded that inactivity can be more harmful than exercising in certain diseases, including hemophilia.

Hemophilia can damage the body. One manifestation of this is muscle weakness that can lead to joint damage. In addition, having to be immobile after a bleeding episode can contribute to loss of muscle tone and strength, and tendon atrophy.

Previous studies have shown that people with hemophilia have less muscular coordination and more balance problems than healthy people, whether or not they have joint damage.

Hilberg said physical rehabilitation after a hemophilia episode "should not only focus on the muscle atrophy after bleeding," but also on what can happen from not using the body.

Exercise should be viewed as more than a way to keep active and have fun, but as a therapy component, he said. It can help people with hemophilia improve both their physical situation and mobility after a bleeding episode, he said.

Those who work with hemophilia patients have developed a concept called programmed sports therapy. It is designed to help patients manage their condition while giving them the benefits of sports therapy in a supervised environment.

Programmed sports therapy works toward five goals:

- Enhancing body awareness and coordination.
- Improving joint movement.
- Regulating muscle tone.

- Improving muscle strength and coordination.
- Increasing endurance.

The program combines work at sports therapy camps, including theoretical and practical training, with individual and group training at home or in fitness centers. Because people have different symptoms and disease manifestations, an exercise regimen needs to be personalized, Hilberg said.

He said the overarching goal is to “bring the training to the trainee and not the other way round.”

Hilberg has been involved in 35 sports therapy camps in Germany and Switzerland for 18 years. They “are helpful in the development of personal competence of people with hemophilia” and pose little risk of complications, he said.

Programmed sports training “can also be helpful in other rare diseases,” he added.