The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Affiliated with Children's Hospital Colorado and University of Colorado Hospital

The Zika Virus and Plasma Products



The Zika virus has been all over the news in the past month or so with fears of the spread of the disease into the United States. While the virus and symptoms appear to have only mild effects on normal, healthy people, infection in pregnant mothers appears to be linked to birth defects in babies. Those with hemophilia and other bleeding disorders may have fears that the Zika virus will make its way into the blood supply and thus contaminate the plasma based pharmaceutical products they use.

Those fears are understandable and justified, but as far as we know, the likelihood of contamination is very low. These are a few things that we do know about Zika.

The World Health Organization has declared Zika virus to be a "public health emergency of international concern." This is because they estimate that up to 4 million people could be affected by the virus this year. There is potential for the disease to spread worldwide, which is why they and many health organizations in various countries are acting now to encourage a coordinated international response and prevent the spread of the disease.

Because the disease has been linked to severe birth defects, travel warnings have been issued to pregnant women to avoid countries where the virus is active.

Transmission of the Zika virus appears to be primarily via blood, which is why there is concern for those exposed to the mosquitoes in the areas where the virus is active. It appears the virus can also be spread from a mother to child around the time of birth, but this is extremely rare. It is also documented that the virus can be spread through blood transfusions or sexual contact, though this also appears to be very rare.

The fact that the Zika virus can be transmitted through blood has led the Red Cross and other international blood authorities, to recommend a 28 day blood donation deferral for those who have visited affected countries to avoid the virus in the blood supply. The 28 day delay is considered long enough for a visitor to an affected country and who contracted the virus, with or without symptoms, to clear their blood system of the virus. This is a similar deferral recommendation as for those who have visited countries that could expose travelers to dengue fever.

As some products for bleeding disorders are plasma derived it is also important to note that indications from medical researchers appear to show that the virus would very likely be inactivated and removed by current viral inactivation and removal techniques already used in the manufacturing of those products. Similar viruses are also eliminated through these processes and there are no signs that the Zika virus would respond differently.

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HTC PATIENT SPOTLIGHT: EVERY DAY ELIJAH



Photo: Jennifer Warren

Every day patients come in to our center and amaze us as they overcome challenges to achieve their dreams, learning to

adapt to living with a chronic bleeding disorder. Every day those of us who get to work with them are inspired by their strength and resiliency. Elijah Warren is one of those patients and has become known among friends as ED, for "Every Day" Elijah for his daily dedication to overcome the challenges that he faces with hemophilia.

Elijah was born with severe hemophilia and there are many obstacles that must be overcome in managing the bleeds, the pain and the unique difficulties that a bleeding disorder brings. Told by his doctors that swimming was the sport best suited to keep his body strong, Elijah began swimming at age seven and has been darting through the lanes ever since. Elijah, who lives in Parker,



Photo: Michael Lein

Colorado, swims for Regis Jesuit High School and has a love for the sport that shows in his speed in the water.

Elijah's goal is to make the US Olympic Swim team and someday bring home an Olympic medal, a high bar for anyone, but his perseverance is putting him within reach. At only 16 years old he is currently training to reach the Olympic team trials. The competition is fierce, but his coach believes it is a possibility for Elijah if he continues his dedication and training. In the past several years he has continued to improve his times as he competes and has enjoyed the support of many along the way. He has three younger sisters who are his biggest fans, and spend many hours cheering him on. His parents, Brandon and Jennifer are devoted, and at least one of them is always at Elijah's meets.

When he was ten, Elijah broke a bone in his arm, and though it healed, at 13 he developed Osteochondritis Dissecans or OCD. This is a joint



Photo: Jennifer Warren

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Though this led to surgery and forced him to sit out most of his swimming season that year, he still posted improved times even though he couldn't compete the full season. Elijah looked to other athletes who have come back from injuries as his heroes, giving him hope to work hard in rehab and persevere after setbacks.

Our center cheers this remarkable young man when he visits with Dr. Wang and his team, working together to try and keep Elijah healthy and able to compete on such a high level. Our Pharmacy has helped his family navigate changes in health insurance and have worked to make sure he has all his factor products as he heads to out-of-state meets.

Elijah trains year round, but his swimming season for Regis Jesuit High School is starting in March and his goal is to make the time to qualify for the Olympic Trials, which will be held in late June and early July 2016. While he and his coach are not expecting him to make the team for Rio, he is working toward making qualifying times for a future chance at Olympic competition.

Elijah balances early morning and afternoon practices and still is able to maintain a 4.0 GPA at Regis with a rigorous academic schedule, and has dreams beyond Olympic gold. He already has his sights set on working as a physical therapist, athletic trainer or possibly study sports medicine. Elijah loves watching sports on television, especially basketball and football, enjoys music, spending time with friends and occasionally shooting hoops. Hemophilia can cause Elijah to miss practices or meets but he has learned to take extra time to ease back into training.

The HTC applauds Elijah in his quest for excellence in swimming and know he can achieve his goals. You can



Photo: Michael Lein

follow Elijah's progress on Twitter, his account is @EWarren88 and the Regis High School swimming team account is @RJHSBDSwimDive. The school also posts meet results during the season (March-May) on their website.

Every Day Elijah, thank you for being a great example to others with bleeding disorders and good luck as you swim!

ZIKA (FROM PAGE 1)

The Plasma Protein Therapeutics Association (PPTA) and the American Association of Blood Banks (AABB) have both released statements concerning the safety of plasma related products as it regards to the Zika Virus. Both organizations suggest that it is highly unlikely that Zika will be transmitted through products derived from blood. They indicate that the recommended deferral of 28 days before donating blood after visiting affected countries is expected to be an effective method of eliminating the virus from being passed on through transfusions or plasma derived products.

We have posted articles from the World Federation of Hemophilia, the National Hemophilia Foundation, the Hemophilia Federation of America and the National Institutes of Health and will continue to update our website and social media as news pertaining to the virus is released. Resources for answers to any questions on the Zika virus are available through any of their websites, as well as the Centers for Disease Control and Prevention.

Please feel free to speak with your doctor if you have any concerns about any of the products that are recommended for your care.

Find direct links to all the articles we used as resources for this article at our website by going to:

www.medschool.ucdenver.edu/htc

Find the RESOURCES tab, then the NEWSLETTER tab and click on the CURRENT DIGITAL NEWSLETTER link and find the February 2016 Newsletter. Links are in the main article.

IMPORTANT UPDATE!

Our After Hours Pharmacy contact info has changed.

For emergency factor after hours-Please call our regular pharmacy number:

303-724-0168

SCHOLARSHIPS



It may be only February but it is already time to start thinking about scholarships for the 2016-2017 school year. If you are a graduating High School Senior, or already in college and are looking for financial assistance, you may want to take a look at our scholarship page. Parents with growing teens, you also might want to take a peek as to your child's options in coming years.

The NHF, HFA, pharmaceutical companies, and various memorial scholarships offer amounts from \$150 to \$7000 toward gaining a college, vocational or technical degree. Trying to navigate some of the sites just to apply can sometimes be cumbersome; even websites dedicated to scholarships can be slow, hard to navigate, or out of date.

We hope to make it a little less frustrating to search for what you need and have provided a list of the scholarships we've found for those with bleeding disorders at our website. We've listed them by the due date of the application, and each has a brief synopsis so you know what each one is for. Each scholarship is different but we tried to link to the website page with the best information for you to proceed.

Most of the scholarships we have listed are for those with a bleeding disorder and several are also for family members of those with bleeding disorders. While they each have their own requirements, due dates and varied amounts, it is worth looking into if you are headed to school in near future.

We strive to maintain our website's accuracy, so if a link is broken or inaccurate, we apologize and welcome your feedback to improve this as a resource. We will do our best to post reminders on social media when these scholarships will come due, so like our Facebook page and follow us on Twitter for updates. Questions or feedback please email: HTC.Newsletter@ucdenver.edu

Find our scholarship list by going to www.medschool.ucdenver.edu/htc and find our RESOURCES tab and the CHILDREN & TEENS page.

RECENT HEADLINES

These are a few of the headlines that we've recently featured on our home page.

We maintain a Newsroom page at our website with a list of the news we feel may be of interest to our patients and families. To see more head to: www.medschool.ucdenver.edu/htc then find the RESOURCES tab, and go to the NEWSROOM page.

NHF, CDC and Others Update Actions Being Taken to Keep Blood Supply Safe from Zika

Gene Therapy Research Shows Potential for Long Lasting Treatment

FDA Approves Zepatier to Treat Chronic Hepatitis C Genotypes 1 and 4

Gilead Faces Scrutiny, Lawsuits Over Pricing of Treatments for AIDS and Hepatitis C

Hemophilia Patients' Dual Roles Create Ethical Quandary

UPCOMING EVENTS

Feb 19-21: RMHBDA Education Weekend

Feb 25-27: NHF Washington Days

March is Bleeding Disorders Awareness Month

Mar 5: NHF CO –Social Factor Denver **Apr 8-10:** NHF Colorado Education Dayz

Apr 17: World Hemophilia Day

May 29-31: NHF CO Family Camp-

Allenspark, CO

June 6-8: Outreach Clinic-Billings, MT

Jul 8-10: Mile High Camp Leadership Pre-Retreat-Rocky Mountain Village

Jul 10-15: Mile High Summer Camp-Rocky Mountain Village

July 21-23: NHF Annual Meeting-Orlando, FL

July 24-28: WFH World Congress-Orlando,

See more at our Events Page on our website: www.medschool.ucdenver.edu/htc find RESOURCES tab, go to EVENTS

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100 Aurora, CO 80045

Clinic Main: 303-724-0724 or toll free at 888-297-0724 Pharmacy Main: 303-724-0168 or toll free at 888-724-7427

Web page:

http://medschool.ucdenver.edu/htc

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