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What CAMP Means to Me ...

Here is what campers attending Camp Boggy Creek's medically supervised camping experiences including Camp Spirit (for children 8-16 with bleeding disorders) this summer said about what spending a week at camp meant to them.

- Camp to me is love, trust, faith, courage, and teamwork. It makes me feel like I belong and that it will always be there for me. At camp, there are so many people who can relate to you. Camp is: LOVE and HOME.
- Camp means forming bonds stronger than friends, stronger than even family. The community here is always supportive, loving, and positive. It's one of the greatest treasures in life.
- Camp means love and a place where you feel safe. Camp means everything, camp's my home.
- Camp means that no matter who you are you will always be loved even with every flaw, be better and be yourself.
- This camp means the world to me! I love this place.
- My 2nd home, family.
- Fun and peace to all who come but most of all it's the love that Boggy gives for us to experience and to take with family.
- Everything in this whole world.
- The only place where I looked up at the stars and not wish I was somewhere else.
- Always having a loving family.
- Camp means to me a place I feel that I can be myself and feel safe without being judged by my peers around me. Thank you.
- Camp means being able to make and see new and old friends.

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Published quarterly by
The Hemophilia Foundation of
Greater Florida

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Mission

The mission of the Hemophilia Foundation of Greater Florida is dedicated to improving the quality of life for people with related bleeding disorders and their families through education, information and referral services, advocacy and research.

Disclaimer

The material provided in HFGF Connections is for your general information only. HFGF does not give medical advice or engage in the practice of medicine. The HFGF does not recommend particular treatments for specific individuals and recommends that you consult your physician or treatment center before pursuing any course of treatment.

Hi Everyone,

October was an Exciting Month with the Flight for Tomorrow Invitational Golf Tournament and both the Jacksonville and Orlando Creepy Crawl- what a fun month!!

Congrats to our scholarship award recipients. We are so proud of you, and we wish you the best of luck. You will be a success at anything you do.

It has been two months since Sandra passed away, and we miss her very much. Her birthday is October 1; if you asked me how old she would have been, I could not tell you because she always fibbed about her age and the year she was born. Regardless, we are thinking about you Sandra we wish we could celebrate your birthday with you.

Thanksgiving is around the corner, and we at the HFGF have so much to be thankful for. THANK YOU for supporting the foundation.

We wish you and your family and happy and healthy holiday season.

Warmest Regards,

Fran



November 12

Product Update Tampa

December 2

Holiday Gathering- Gainesville

December 10

Holiday Gathering – Jacksonville

February 17, 2018

Annual Theater Event The Lion King



What camp means to me . . .

cont'd

- Camp is a place where everyone can be themselves and not be judged and that's awesome.
- Camp means that no matter what, we are all family, we are one, united.
- Camp isn't just a place where you go for a week and you just forget it. Camp Boggy Creek is a camp where when you go and you leave you never forget it! This camp will always be in my heart!
- It means LOVE...& a place to ALWAYS feel safe and respected
- My joy, my pride, my inspiration, and my life.
- Camp is a place where I can be myself, and make friendships that last a lifetime, and have so many happy memories here at camp that I will cherish for the rest of my life. There is no place like Boggy, but I hope I can bring the joy I have found here everywhere I go.
- This camp means to me love, kindness and family. That we're all part of the most amazing life changing camp/family!
- Camp means hope, love and knowing that whenever you're here no one can hurt you. Camp is amazing and I couldn't live without it. I never want to leave. I love my friends
- Equality towards others. LOVE! Never forget.
- Camp Boggy Creek is such a wonderful place it is a home away from home and I will always cherish this place in my heart.
- A happy place!

- It means my safe place, my home, my family, loved by everyone around camp.
- It means uniting as one family! Being loved by many.
- Love.
- A true family and real friends.
- It meant hope that no matter how dark it might get, there's always going to be that one thing that makes it all sunny again, whether it be a friend or just someone you meet or a activity you may have done, even a kind word or two. Whatever it may be, you will find that light and when you do, don't let it go, keep it shining for as long as you can.
- Camp is more than just a place, it's home.



- Enjoy the moments you have because they can be gone in a flash. I'm gonna miss you, Boggy. See you later!
- Camp is where my home and family is!
- Camp is my safe place and my home, camp was and is the only reason I am alive today.
- Camp is home.
- Camp means having friends, not being judged for who you are, and having tons of fun with people you care about.

- Camp has changed my world and helped me become who I am today. I will never leave camp.



RESERVE YOUR TICKETS NOW!

Tickets are already going fast for the performance at the Dr. Phillips Performing Arts Center on Saturday February 17, 2018.

Your theatre experience will feature orchestra seating, a pre-show reception and silent auction.

Call the **HFGF** Office at **407-629-0000** or **info@Hemophiliaflorida.org** for more information.

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Scholarship Recipients Head Off to School

Meet the 2017 Calvin Dawson Memorial Scholarship recipients.

Emily Jean Champagne of Bradenton is attending the University of Central Florida in Orlando as a music performance major. She plays the violin and hopes to become a member of an orchestra. Her free time includes practicing, listening to classical music and spending time with friends and family.

Rebecca Champagne of Bradenton will be attending the University of South Florida Sarasota/Manatee this fall to study to become a teacher. In addition to her studies, she enjoys spending time babysitting and going to theme parks such as Disney and Universal Studios.

Kyle Ginsberg of Lake Worth is currently finishing his associate's degree at Palm Beach State College. He is planning to continue his schooling to achieve a bachelor's degree in Fine Art (Graphic Art and Design). In addition to his lifelong interest in art, he enjoys music, video games and racing remote controlled cars.

Jacquelyn Hebard of St. Petersburg began her studies in nursing this fall at the University of South Carolina. In her free time, she likes to travel, play volleyball, and spend time with family and friends.

Brooke Jones of Seminole is attending Eckerd College and majoring in mathematics. She plans to become either a medical statistician or a math teacher. In her spare time, she enjoys math puzzles and painting glasses.

Rachel Messer of Ft. Lauderdale plans to study nursing at Florida Gulf Coast University. After suffering from seizures almost her whole life, she underwent brain surgery to remove a lesion and has now been seizure free for six months. Her experience has made her want to help others with medical problems.

Seaira Rose of Lakeland is attending Hillsborough Community College for her Associate degree. She then

wants to transfer to UCF to study Hospitality Management. She loves animals and volunteers at shelters. She also plays music and sings in her free time.

Charlton Sebastian of Jacksonville is majoring in English at the University of North Florida. He loves writing and hopes to make that part of his career.

James Solomon of Clermont is currently studying at the University of Central Florida in Orlando to become a Registered Nurse on the way to his ultimate goal of achieving a Doctorate Nurse Practitioner in order to practice in Hematology Oncology. He enjoys playing guitar and ukulele, as well as video games and basketball.

Amanda Stewart of Tampa will be attending the University of Central Florida in Orlando and studying in their hospitality program. She loves helping people and has founded an organization called Bear Hugs, which collects and distributes new stuffed bears to hospitalized children and their families.



To donate to the Scholarship Fund or to apply for a scholarship (open to Florida residents with bleeding disorders pursuing post-secondary education) see <http://www.hemophiliaflorida.org/scholarships.html>.

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info@hemophiliaflorida.org



HFGF Welcomes Leah Nash to the Staff

Leah Nash has only been with the HFGF for a little more than four months, and she already feels like she is part of the family. With the Jacksonville and Orlando walks, Leah jumped into the role of Development Manager to coordinate and fundraise for the events with our two excellent walk planning committees. "I have felt so welcomed by the HFGF staff, volunteers, and the bleeding disorders community," says Leah.

With 19 years of experience in the Orlando business world, Leah's background is sprinkled with non-profit and association management experience, as well as media, government, and hospitality. She has owned her own company and even taught at Valencia Community College. As both a Rollins College and UCF communications alumnus, her specialties include building partnerships, development, and connecting people.



Leah is a long time member of the Orlando community and her love for her city is evident. In her spare time, Leah loves to attend concerts, art festivals, and eat at local Orlando restaurants with her husband, family, and friends. She even hosts a local radio talk show on WPRK 91.5 FM (wprk.org) on Thursday mornings.

Please welcome Leah to the HFGF staff! Feel free to contact her at leahnash@hemophiliaflorida.org. Leah is looking forward to planning the 2018 walks and being an advocate for the bleeding disorders community.

Research Updates

Alnylam Reports Patient Death in Fitusiran Clinical Study

Alnylam Pharmaceuticals, Inc. has reported on the death of a hemophilia A patient who had been participating in a Phase 2 open label extension study for the company's investigational therapy fitusiran, which is being developed for patients with hemophilia A and B, both with or without inhibitors.

Fitusiran is a subcutaneous therapy (administered under the skin) that employs small interfering RNA (siRNA) technology to target antithrombin (AT), a liver-generated clotting protein that plays a key role in the regulation of blood clots. siRNA molecules are segments of RNA (ribonucleic acid) that block or "silence" the activity of certain genes through RNA interference, a natural biological process common in plants and mammals. Fitusiran works by silencing the gene responsible for AT, which inhibits the

protein's anticoagulant function. This then compensates for the imbalance caused by deficiencies in other clotting proteins, such as factor VIII (hemophilia A) or factor IX (hemophilia B).

According to the September 7, 2017 press release, Alnylam has halted dosing in all ongoing fitusiran studies to conduct a thorough review of the case. In the meantime, the company has provided some background. While initial findings suggested that the patient had died from subarachnoid hemorrhage, further analysis of CT scans confirmed that the triggering event was, actually, a cerebral venous sinus thrombosis (CVST). A CVST is a blood clot that develops in the venous sinuses of the brain, which prevents blood from draining out. This blood subsequently leaks into the brain tissues, resulting in a hemorrhage. Such an event, albeit rare, is very serious and can result in a stroke.

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Jacksonville Creepy Crawl Raises More Than **\$45,000** for the HFGF

Saturday October 14th was a great day for Halloween costumes and for walking (or running). Team Mason captured the Traveling Walk Trophy for most funds raised by a team, as well as the Team Spirit Award for most walkers. In second place was Team Noah and third place went to Aaron's hemogoblins. Top individual fundraiser was Ashley Ammons.



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Research Updates

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“We are deeply saddened to learn of this patient’s death, and we extend our sympathies to his family,” said Akshay Vaishnav, MD, PhD, Executive Vice President of R&D at Alnylam. “We believe that fitusiran holds great promise as a potential treatment option for patients with hemophilia, and we remain fully committed to its ongoing development. Following further investigation of this safety finding, implementation of a risk mitigation strategy, and alignment with global regulatory authorities, we expect to resume fitusiran dosing in our clinical studies as soon as possible, potentially as early as late 2017, with a goal of advancing this innovative investigational medicine to hemophilia patients in need.”

It is not yet known if this event is directly related to the patient’s treatment with fitusiran. The National Hemophilia Foundation will continue to monitor this case and will provide updates as they become available.

Source: Alnylam press release dated September 7, 2017

Study Yields Important Findings on the Functions of von Willebrand Factor

Researchers at the Boston Children’s Program in Cellular and Molecular Medicine and the Harvard Medical School recently made important discoveries relevant to the functioning of von Willebrand factor (VWF). The study, “Flow-induced Elongation of von Willebrand Factor Precedes Tension-Dependent Activation,” was published online, August 23, 2017, in the journal *Nature Communications*.

Using fluorescent imaging and microfluidic tools, Jiang and his colleagues recreated the blood flow that occurs in humans, particularly the function of VWF within the bloodstream. Through a series of valves, cylinders and tubes, investigators were able to mimic the increase in blood flow that occurs after an injury.

Experiments showed that as the blood flow grew more intense, changes in the shape of VWF would occur. VWF molecules, which are normally rounded and compact, quickly became rapidly elongated in response to the increased tension. Scientists also observed that as VWF elongates it binds with platelets to ensure that a viable blood clot forms. Notably, VWF activates locally at the site of an injury and not in other parts of the body.

“If you can imagine stretching out your arms, and then opening your hands to capture platelets, that’s basically what we are seeing VWF do in response to bleeding,”

said researcher Wesley P. Wong, PhD. “It’s so important that this process occurs only when and where it is needed—this two-step activation process makes that possible.”

While these findings could have future implications for treatment, leading to more novel therapies, they are also scientifically noteworthy. Researchers are no doubt excited to uncover such valuable molecular-level insights on the intricacies of the bloodstream and the mechanisms of VWF.

“This experiment really represents a new platform for seeing and measuring what’s happening in the blood on a molecular level,” said Wong. “Through the use of novel microfluidic technologies that allow us to mimic the body’s vasculature in combination with single-molecule imaging techniques, we are finally able to capture striking images that uncover the mystery of nature’s forces at work in our bodies.” Source: *Genetic Engineering & Biotechnology News*, August 23, 2017



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