

Hemophilia HFGF Connections

The Quarterly Newsletter of the HFGF

Spring 2018

Volume 26 Issue 49

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Did You Know?

LION KING

Is a Roaring Success Once Again!

The 16th Annual Evening on Broadway performance of The Lion King on Feb. 17th this year raised more than \$35,000 dollars for the HFGF. Attendees were treated to a reception and charity sale in addition to the production itself.

Thank you very much to our generous sponsors:

Aptevo Therapeutics

Baver

CSL Behring

Novo Nordisk

Pfizer

CVS Caremark

Shire

Octapharma

CVS Craremark

Shire

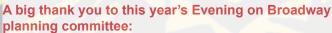
Octapharma











Eileen Gregory

Mendy Hood

Dawn Solomon



Finally, but definitely not least, the HFGF wants to thank all of the donors for the auction items:

4RSmokehouse

Alex and Ani

Bok Tower Gardens

Busch Gardens

Canoe Escape

Club Luma on Park

Community Acupuncture of Orlando Crayola

Experience at the Florida Mall

Dawn Solomon

Dr. Phillips Center for the Performing Arts

Dubsdread Golf Course

Elevate Yoga Center

EO Inn

Ethical Factor

Ethos

Florida Estates Winery

Hooters

Hyatt Regency Jacksonville Riverfront Hotel

JoAnn Brownrigg

Kres Chop House

Medieval Times

Mendy Hood

Morse Museum

Natural Wellness & Chiropractic

Orange County Mayor, Teresa Jacobs

Orlando City Soccer

Orlando Magic Orlando Solar Bears

The Serio Family

Sheraton Orlando North

Sheraton Vistana Villages

Sherri Rojani Ventura Country

Sugar Divas Cakery

Tijuana Flats

Top Golf

Track Shack

Treasure Bay Golf & Tennis

Walt Disney World Resort

Westin Cancun Resort

Westin Los Cabos

Winter Park Scenic Boat Tour

Wonder Works

Zaza New Cuban Diner

toll free 800-293-6527 www.HemophiliaFlorida.org

HFGF Connections Executive Director's Column

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.

Dear Friends,

I hope everyone is doing welll - we are so excited that spring is here--although we do not have cold weather, it is so nice when the sun sets after 8:00 pm.

2018 has been very busy - we have hosted our annual theater event featuring the Broadway production of Lion King and our Annual Gator Clot Trot walk and 5K.

May 19th was our annual Tampa Super Hero walk - Thanks for joining us at Al Lopez park and supporting the bleeding disorders community.

On June 16th, we have a special family program at the Ports of Call. We have a special program planned for "Bring your Parents to the Program," an interactive program for the entire family.

Camp Spirit is around the corner (July 8-13, 2018) at Camp Boggy Creek - if you have not registered for camp, please go to http://www.boggycreek.org/campers/camper-application/ and complete the camp application.

Have a great spring!

Warmest regards, Fran



June 16, 2018 – Annual Family Program at Ports of Call July 8-13, 2018 - Camp Spirit - Summer Camp Program

August 5, 2018 - Family Program - Orlando Pride Game -Orlando Creepy Crawl Kick off

August 26-27, 2018 - Florida State Meeting

October 20, 2018 - Jacksonville Creepy Crawl 5k and walk - Nocatee

October 22, 2018 - Flight For Tomorrow Invitational Golf Tournament

October 27, 2018 - Orlando Creepy Crawl 5 K and Walk-Baldwin Park



Hi Everyone!

My name is Dina Richardson; I am the new Social Worker with HFGF. I wanted to take this opportunity to introduce myself. As the HFGF Social Worker, I am available to help the hemophilia community. I am here to assist when financial constraints are a result of an active bleed and/or hospitalization, assist with obtaining dental services, scholarships, help connecting with community resources, emotional support, and many other services. Please feel free to contact me, I'm here to help! My contact information is dinarichardson@hemophiliaflorida.org and (407) 629-0000. I am very excited to be here and look forward to meeting you all! I know I have very big shoes to fill, as Sandra was a wonderful woman who is sorely missed.



I am originally from South Florida and moved to Orlando a little over two years ago. I completed my master's degree in Social Work at Florida Atlantic University. Prior to coming to HFGF, I provided play therapy to 0-5-year-olds for a year, worked for seven years at a local hospice, and spent the past two years working for private insurance company as an intensive case manager.

I moved up to Orlando in March of 2016 when I got married. Now we have a beautiful bouncing baby boy named Weston who will be one in July, and an adorable dog named Gus.

Help us fundraise for the HFGF and have fun at the same time by joining one of our two remaining walks this year:



















Jacksonville Creepy Crawl October 20, 2018, Nocatee



Orlando Creepy Crawl October 27, 2018, Baldwin Park



Manufacturer Co-Pay Assistance Programs			
Company/Organization	Co-Pay/Co-Insurance Pro- gram Name & Contact Info	Limit total	Notes
Aptevo Therapeutics	IXINITY Savings Program 1-855-494-6489	\$12,000	Must have a valid prescription for IXINITY. Must have commercial insurance. No monthly limits unless limit total is reached. No income requirements. Co-pay program can be used retroactively for up to 12 months.
Bayer	Bayer Access Solutions Kogenate FS Co-pay/Co-insurance Program 1-800-288-8374	\$12,000	Must have a diagnosis of hemophilia A. Assistance is awarded per patient. Multiple members of the same household can apply. Must have private/commercial insurance. No income requirements. Must first contact Bayer Access Solutions.
Biogen	ALPROLIX Co-pay Program 1-855-692-5776 ELOCTATE Co-pay Program 1-855-693-5628	\$12,000	Available to those who use ALPROLIX or ELOCTATE. Must have commercial insurance. Must be treated by licensed doctor in US or Puerto Rico Have a United States pharmacy. Must call number provided for ALPROLIX to enroll or request additional information. Enrollment form available for ELOCTATE via link provided Not responsible for costs associated with administration of therapy, such as office visits, infusion costs, or other professional services.

Manufacturer Co-Pay Assistance Programs cont'd			
Company/Organization	Co-Pay/Co-Insurance Pro- gram Name & Contact Info	Limit total	Notes
CSL Behring	MySource Cost-Share Program 1-800-676-4266	\$12,000 per year	Nust take a CSL Behring eligible product (on-label) for the treatment of von Willebrand disease or hemophilia. Must currently have US-based private insurance that covers your therapy (federally funded program ineligible). Contact My Source Care Coodinator at the number listed to enroll and to obtain further information about the program. Program benefit DOES NOT apply toward out-of-pocket costs for: Physician office visit co-pays. Infusion-related costs or ancillary supplies. Insurance premiums.
Genentech	HEMLIBRA Co-Pay Program 1-844-436-2672	\$15,000	No income requirements. Your enrollment in the program is valid for up to 12 months (You may reapply at the end of 12 months). The program covers the remaining part of your co-pay, up to \$15,000 per year.
			You may be eligible if you: Have been prescribed HEMLIBRA for an FDA-approved indication. Are 18 years of age or older, or have a legal guardian 18 years of age or older to manage the program. Have commercial (private or nongovernmental) insurance. This includes plans available through state and federal health insurance marketplaces. Do not receive support from the Genentech® Access to Care Foundation (GATCF) or any other independent co pay assistance foundations for HEMLIBRA. Are not a government beneficiary and/or participant in a federal or state-funded health insurance program (eg, Medicare, Medicare Advantage, Medigap, Medicaid, VA, DoD or TRICARE). Do not reside in a state where the program is prohibited.

Manuf	acturer Co-Pay As	ssistance	Programs cont'd
Company/Organization	Co-Pay/Co-Insurance Pro- gram Name & Contact Info	Limit total	Notes
Grifols	Factors for Health Patient Support Program 1-844-693-2286 (844-MY-FACTOR)	No limit for in-network Out of network: Will cover \$2,000 of the claim	Pay as little as \$0 for ALPHANATE and Alphanine SD. No monthly or annual maximums. Individual claims exceeding \$2000 will be reviewed for network eligibility. Claims that are in-network will be approved, but those out-of-network may be denied. Prescription is covered up to the patient's annual out of pocket (OOP)maximum. The general OOP maximum limits under the affordable care act are \$6850 (self-only coverage) and \$13,700 (coverage for more than self only). No waiting period; patients may use the offer as soon as they enroll. No income requirements. Annual program enrollment is required. Must have commercial insurance. Patients must have a valid ALPHANATE or AlphaNine SD prescription. Restrictions apply. Helps to cover co-pay and co-insurance costs for ALPHANATE and AlphaNine SD only. It does not cover costs related to physician visits and is not for inpatient use.
Novo Nordisk	Co-pay Assistance Program 1-844-668-6732	\$12,000 per year	Have hemophilia A and have been prescribed an appropriate Novo Nordisk factor treatment; OR Have congenital hemophilia A or B with an inhibitor, congenital FVII deficiency, Glanzmann's thrombasthenia with refractoriness to platelet transfusions, or acquired hemophilia and have been prescribed an appropriate Novo Nordisk factor treatment; OR Have FXIII A-subunit deficiency and have been prescribed an appropriate Novo Nordisk factor treatment; AND Have private/commercial insurance only (state and federal funded programs ineligible)
Octapharma	Octapharma Co-Pay Program 1-800-554-4440	Up to \$12,000 per year for NUWIQ	NUWIQ CoPay Program • Must be receiving treatment with NUWIQ, or have a prescription to begin treatment. • Must have private/commercial insurance or self-pay. • Co-Pay assistance can only be applied to co-payments, deductibles, self-pay, and coinsurance associated with the cost of NUWIQ.

Manufacturer Co-Pay Assistance Programs cont'd			
Company/Organization	Co-Pay/Co-Insurance Pro- gram Name & Contact Info	Limit total	Notes
Octapharma	Octapharma Co-Pay Program 1-800-554-4440	Up to \$6,000 per year for Wilate	Wilate CoPay Program Must currently be using a factor product from Octapharma, or have a prescription to begin therapy. Must have private/commercial insurance. Co-Pay assistance may only be applied to co-payments, deductibles and co-insurance that may be associated with the cost of Octapharma factor products. Co-Pay Assistance Program does not cover costs associated with administration of therapy, such as office visits, infusion costs, or other professional services.
Pfizer	Pfizer Factor Savings Program 1-888-240-9040	\$12,00 per year	Provides co-pay and co-insurance assistance for a Pfizer factor product. Patient financial responsibility of \$10 per month. No financial eligibility requirements. Must have private/commercial health insurance that covers factor.
Shire	Shire's Hemophilia Co-pay Program 1-888-BAX-8379 (1-888-229-8379)		Enrollment can be submitted online or over the phone. Must have commercial insurance. Must use eligible Shire hemophilia products. Eligible patients with private insurance receive up to \$12,000 every 12 months for medication-related co-payment/ co-insurance with retroactive assistance for a date of service within 120 days prior to their co-pay activation date. No income requirements. Adynovate follows FDA guidelines (approved for 12 years of age or older). Program is only valid for residents of the United States, excluding Puerto Rico and other U.S. territories.

^{*}HFA makes every attempt to provide accurate information regarding patient assistance programs and resources. However, since program policies often change, please contact the manufacturer directly for the most updated information. This chart has been updated on March 7, 2018.

For those in the bleeding disorder community who are uninsured, underinsured, or experiencing lapses in insurance coverage, there are also asstance programs to help families facing financial strain get access to factor products.

Manufacturer Product Assistance Programs		
Company/Organization	Product Assistance Program Name & Contact Information	
Akorn Pharmaceuticals	Patient Assistance Program: This needs-based program assists patients in accessing Amicar. Programs include copay assistance for patients with commercial insurance coverage and a need based support program for those patients without commercial insurance. These are newly created programs to support your access to the product and reduce copay obligation automatically at participating pharmacies. Click on the link above to locate programs 1-844-202-5909	
Aptevo Therapeutics	IXINITY Patient Assistance Program: For patients who are uninsured or experiencing a lapse in coverage to access treatment. Must meet income requirements. 1-855-494-6489	
Bayer	GAP Coverage Program: Patients who are unemployed or have a loss or lapse in private insurance coverage; connects you to temporary insurance coverage. Patient Assistance Program: Patients who do not have insurance, lack third-party coverage, or have pending Medicaid approval may be eligible to receive Kogenate FS. 1-800-288-8374	
Bioverativ	Factor Access Program: Patients using ALPROLIX or ELOCTATE who have no prescription coverage, are facing a gap in coverage, or have reached their maximum insurance coverage limit, may be eligible to receive product for free. Other restrictions may apply. For ALPROLIX 1-855-692-5776 For ELOCTATE 1-855-693-5628	
CSL Behring	Patient Assistance Program: To be eligible, patients must be underinsured or uninsured. When enrolled, must actively be seeking insurance. Assurance Program: Must currently have private health insurance coverage; this is a certificate program that helps with potential future lapses in private health insurance plans. 1-800-676-4266	
Genentech	GATCF helps people who don't have health insurance. It also helps people who have health insurance but have trouble paying for HEMLIBRA. If you qualify for GATCF, you could receive your medicine for free. For more information, call 877-233-3981 or visit hemlibra.com/access.	
Grifols	Grifols Patient Assistance Program: This program is for patients using ALPHANATE, AlphaNine SD or ProfilNINE who are uninsured or experiencing a temporary lapse of insurance coverage. 1-844-MYFACTOR (1-844-693-2286)	

Assistance Programs
Product Assistance Program Name & Contact Information
1-855-353-7466
Novo Nordisk Product Assistance Program: Provides medication to qualifying applicants at no charge. Eligible patients must have been prescribed a Novo Nordisk product for an indicated condition (check the website for a complete list of eligible conditions), have no insurance coverage, and actively be seeking insurance coverage. Patient must be a documented US resident or on a path to documented status with reasonable likelihood of attaining it. Federal government insurance programs are ineligible. 1-844-668-6732
NUWIQ Free Trial Program allows for up to six (6) doses, or 20,000 IUs, of NUWIQ. A prescription for NUWIQ is required and other restrictions may apply. Wilate Free Trial Program allows for up to 5,000 IUs for Wilate. A prescription for Wilate is required and other restrictions may apply. 1-800-554-4440
Pfizer Patient Assistance Program: Patients must meet income guidelines, which vary by product and household size; have no prescription coverage, or not enough coverage, to pay for their medicine; live in the United States or US territories; and be treated by a health care professional licensed in US/PR 1-844-989-PATH (7284)
Shire Patient Assistance Program: Provides uninsured and financially-eligible patients free product for eligible Shire's hemophilia products. 1-888-229-8379



es/navigating-patient-assistance-programs/.

About Us

The Hemophilia Foundation of Greater Florida is a 501c3 nonprofit organization that has supported the bleeding disorders community throughout the state of Florida since our founding in 1996. For more than 20 years, we have been helping those living with and affected by bleeding disorders live without limits through much needed services and programs.

CONTACT DONATE VOLUNTEER

Our Mission

The Hemophilia Foundation of Greater Florida, a chapter of the National Hemophilia Foundation, has been serving people with bleeding disorders since 1996. We are helping the bleeding disorders community improve their quality of life by offering programs and services to support healthier and more independent lives.

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DID YOU KNOW?

THAT 91% OF OUR FUNDRAISING DOLLARS GO BACK TO THE FLORIDA BLEEDING DISORDERS COMMUNITY? THOSE DOLLARS SEND OUR KIDS TO A MEDICALLY SUPERVISED CAMP, PROVIDE FINANCIAL EMERGENCY ASSISTANCE AND SCHOLARSHIPS, AS WELL AS CONTRIBUTE TO EDUCATIONAL PROGRAMS AND ADVOCACY EFFORTS.

HIGH SCHOOL STUDENTS
EARN COMMUNITY SERVICE HOURS

VOLUNTEER FOR THE HFGF

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