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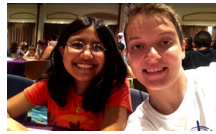
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toll free 800-293-6527  
www.HemophiliaFlorida.org

# 2016

## HFGF Year in Review



### Education Programs

Our education programs, held throughout the state, reached 1,276 people at a cost of \$115,586. Topics included The Affordable Care Act; Tattoos, Gages & Piercings; Women's Tea; Infusion Classes; three Physical Therapy sessions; two Transition (Peds to Adult) sessions; Infusion and Anxiety; and many more.



### Emergency Assistance Fund

The HFGF used \$101,424.00 to help 676 people directly with Dental Care, Medical Appointments, Insurance Assistance, Basic Life Support Issues, Holiday Gift Cards, and Transportation Assistance.



### Scholarship Fund

Eight students received scholarships totaling \$16,000 to fund post-secondary education.



### Camp Spirit Summer Camp Program

One week of camp for children with bleeding disorders was paid for by the HFGF. Sixty campers attended at a cost of \$49,500.



### Family Retreat Weekend

The Family Retreat weekend is an opportunity for families to get together and share information and share experiences. Family Retreat Weekend was rescheduled because of Hurricane Matthew – the HFGF supported the Family Retreat weekend at a cost of \$12,000.



### Professional Education

One of our goals this year was closer collaboration with the Hemophilia Treatment Centers (HTCs) to help provide better care for the bleeding disorders community. We fulfilled that goal by the following:

Holding the inaugural statewide meeting for HTC staff in St. Petersburg. It was attended by 42 professionals.

Hosting a conference for physical therapists from throughout the state. There were 17 professional attendees.



Collaborating on some of our educational programs with the HTCs.

Funding HTC staff attendance at the NHF national meeting and the World Congress both held in Orlando in 2016.

### Staff Participation

The HFGF staff all attended the NHF's national meeting and either attended or volunteered at the World Congress meeting, both held in Orlando.

### Fundraising Events

With the help of our volunteers (We have increased volunteer participation with an outreach program targeting community organizations, sororities and high schools among others.), we held four fundraising walks throughout the state, the Golf Tournament in Tampa and the Evening on Broadway theater event in Orlando.

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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,

Happy NEW YEAR!!! I hope everyone has a healthy and happy 2017.

We have a very special program March 4 at the Florida Aquarium...YOUR MIRACLE, YOUR LIFE,

An inspirational workshop featuring Ali Stroker – the first actress in a wheelchair to be on Broadway, her credits include Glee, The Glee Project and the Broadway production of Spring Awakening and James Stroker, an educator and sports coach in the New Jersey Public Schools. Both speakers will give you the opportunity to open yourself up to explore the new paradigm that is your life and that is the opportunity to dance with adversity and other challenges.

We need volunteers to help us with our advocacy efforts...we need your help to let your congressmen and senators know that if we are repealing the Affordable Care Act that we need the replacement to include

- Pre existing Conditions
- No insurance Caps
- Children can remain on their parents' insurance until they are 26

If you are interested in getting involved, please contact Sandra Davy at [Sandravy@hemophiliaflorida.org](mailto:Sandravy@hemophiliaflorida.org)

We have so many exciting things planned for you...camp, family retreat weekend, camp reunion and recruitment party to name a few. Keep an eye on our calendar; we will have a dates for you soon.

I hope to see everyone before long.

Warmest Regards,

*Fran*



March 8-10, 2017 – Washington Days NHF

March 16, 2017 – Transition Ignition – Gainesville, FL

April 9, 2017 – HFGF BOD MEETING

April 22, 2017 – Gainesville Walk

May 13, 2017 – Tampa Walk

June 22-23 – Nurses, Social Workers and Physical Therapist Conference

July 6-11, 2017 – Camp Spirit Summer Camp



# Walk to Raise Funds for the HFGF and have **FUN in 2017!**

We have two spring walks coming up that you, or you and a team, can participate in to help the bleeding disorders community. We are also still looking for corporate sponsors to support the walks, and each walk needs more volunteers to help make it a success.

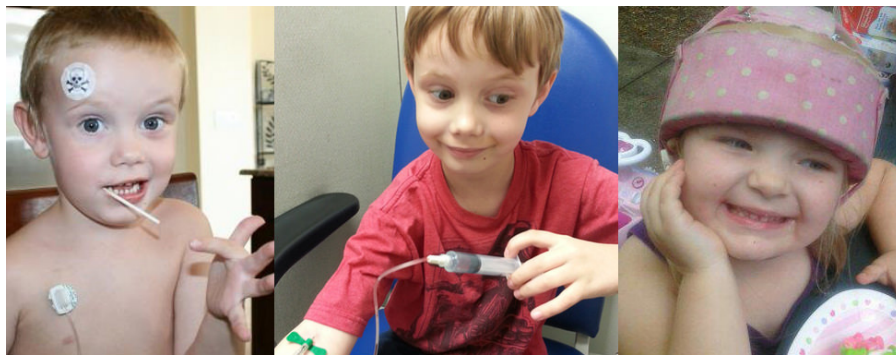
## Gainesville Gator Clot Trot

First, there is the 6th annual Gainesville Gator Clot Trot. Come in your favorite Gator garb to run in the 5K race or to walk in the fun walk. The event will be held Saturday, April 22, 2017 at Depot Park, 200 SE Depot Ave., Gainesville FL 32601. Registration begins at 7 AM; walk and run begin at 8 AM. For more information or to register for the run or walk, see [www.hemophiliaflorida.org/gainesville](http://www.hemophiliaflorida.org/gainesville).



## Tampa Woodstock Walk for Bleeding Disorders

Next up is the very groovy Tampa Woodstock Walk for Bleeding Disorders, to be held Saturday, May 13th, 2017 at Al Lopez Park, 4810 Himes Ave. Wear the most far out hippie costume that you can (there will be a costume contest). Also lots of 60s and 70s music. For more information or to register for the walk, see [www.hemophiliaflorida.org/tampa](http://www.hemophiliaflorida.org/tampa).



# MAKE A DONATION

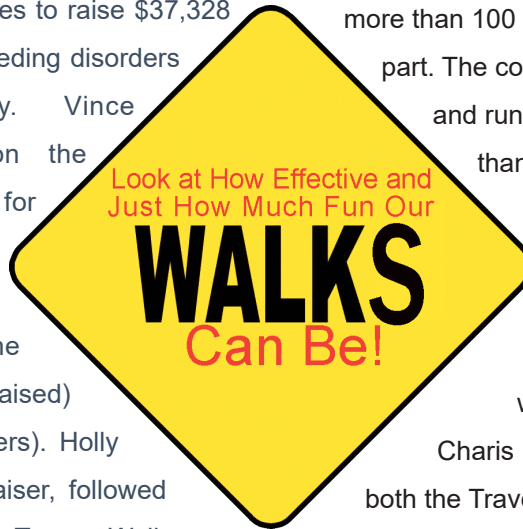
# Jacksonville Creepy Crawl

# Orlando Creepy Crawl



108 runners and 94 walkers joined forces to raise \$37,328 for the bleeding disorders community. Vince Pavic won the 5K race for males and

Robin Potter won for the women. Team Mason captured both the Traveling Walk Trophy (most funds raised) and the Team Spirit award (most walkers). Holly Wright was the top individual fundraiser, followed closely in second place by her mother Tammy Walker. Many thanks to all of our sponsors, who made the event possible.



More than 100 walkers and more than 100 runners took part. The combined walk and run raised more than \$44,500 for the HFGF to use in



support of the bleeding disorders community. The individual 5K race winners were Tony Segreto (Men) and Charis Ivery (Women). Team Hunter captured both the Traveling Walk Trophy (most funds raised) and the Team Spirit Award (most walkers) and Heather Frederick was the individual top fundraiser.



## Silver Sponsors

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- Cottrill's Specialty Pharmacy
- CSL Behring
- Genentech
- Novo Nordisk
- Octapharma
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## Bronze Sponsor

- Superior Biologics
- Mile Sponsor**
- BioRx



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# Research Update

## Potential Therapy Employs Addition by Subtraction Approach



Recent research suggests that a new understanding of furin, a common protein found in most cells, could have therapeutic implications for people with factor VIII deficiency, or hemophilia A. The new findings, “Circumventing Furin Enhances Factor VIII Biological Activity and Ameliorates Bleeding Phenotypes

in Hemophilia Models,” were published October 6, 2016, in the journal JCI (Journal of Clinical Investigation) Insight. The lead investigator of the study was Valder R. Arruda, MD, PhD, a hematology researcher at The Children’s Hospital of Philadelphia. Arruda is also a faculty member of the Perelman School of Medicine at the University of Pennsylvania.

Until now, scientists understood that among its many roles, furin contributes to coagulation. Factor replacement therapies, including factor VIII (FVIII) in hemophilia A and factor IX (FIX) in hemophilia B, contain amino acids that identify and interact with furin as part of the clotting process. However, Arruda and his team have discovered that while the furin/FIX interaction is a key “clotting-contributor,” furin may not be necessary for a healthy clot to form in people with hemophilia A. They made this discovery by first bioengineering a new variant FVIII protein designed so that it would not interact with furin. They then used that variant in gene therapy experiments in mice with severe hemophilia A, which triggered increased FVIII levels and improved clotting activity in the animals.

Collaborating on the study were investigators from the University of North Carolina (UNC) at Chapel Hill led by Timothy C. Nichols, MD. The UNC team used the same gene therapy on dogs with hemophilia A. They also observed decreased bleeding as a result. In addition, no unwanted immune response occurred from the therapy.

By omitting the furin component, researchers have found a novel way to streamline delivery of the genetic material. “In gene therapy, size matters,” said Arruda. “It’s important to reduce the gene package for FVIII to the smallest effective size.” Deleting the furin-recognition portion both decreases the size of the gene therapy “payload” and enhances its benefits for treating hemophilia A, he added.

Further research is needed before clinical trials in people can be conducted, but the researchers are optimistic about furin’s future. “Because this variant provides more efficient bleeding control than currently available replacement drugs, while avoiding immune reactions, this could address the unmet needs of hemophilia A patients worldwide,” added Arruda. “It may also advance gene therapy for this disorder as well.”

Source: Science Daily, October 17, 2016

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Smile  
they’ll donate to  
The Hemophilia Foundation of  
Greater Florida

*Follow the HFGF on*



Like our page on Facebook: Hemophilia Foundation of Greater Florida or follow us on Twitter @HemophiliaFL or check us out on Instagram.



15<sup>th</sup> Annual

# EVENING ON BROADWAY

*a Sellout Success!*

This year's production, which was great fun for the 135 who attended, was "Wicked" on Jan 28th. The performance included a reception, raffle and silent auction, which raised \$37,000 for the HFGF.

**A warm and heartfelt thank you to our sponsors:**

### Best Play Sponsors

Aptevo Therapeutics  
Biogen  
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Novo Nordisk

### Best Sets and Costumes Sponsors

BioRX  
Octapharma  
Superior Biologics

### Best Actor

Shire

### Reception Sponsor

Pfizer

### Program Graphic Design and Production

John Louis and Diplomat Specialty Infusion Group



**Many thanks also to our event donors:**

- |                             |                          |
|-----------------------------|--------------------------|
| 310 Restaurants             | Panera Bread             |
| 4 Rivers Smokehouse         | San Sebastian Winery     |
| blu on the avenue           | Shake Shack              |
| Bok Tower Gardens           | Spa810                   |
| Bravo/Brio                  | Solomon Family           |
| EO Inn                      | Target                   |
| Ethos Vegan Kitchen         | TooJay's                 |
| Hooters                     | Trader Joes              |
| Hunter's Green Country Club | Tyler Nazario            |
| J McLaughlin                | Vilma Negron             |
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| Morse Museum                | Winter Park Laser & Anti |
| Ocean Prime                 | Aging Center             |
| Orlando City Soccer         | Winter Park Scenic Boat  |
| Orlando Solar Bears         | Tours                    |
| Orlando Magic               | Wonder Works             |



**And, finally but not least, to our volunteers who made the event happen:**

Dawn Solomon  
Pat Solomon  
David Haynes  
Valerie Fetterman  
Denise Young





# Social Work Corner

by Sandra Davy, MSW

## Greetings Everyone!

Its 2017 and to many of us this signals turning the page on the past and moving forward into a new and uplifting direction. Getting a good job, obtaining higher education or career training can open the doors to knowledge about the world around you, independence, and financial advantages. Did you know there are several phenomenal opportunities available for individuals with Bleeding Disorders?

**Fact One.** Federal Government Disability Employment: As the Nation's largest employer, the federal government has a special responsibility to lead by example in including people with disabilities in the workforce.

The federal government is actively recruiting and hiring persons with disabilities. They offer a variety of exciting jobs, competitive salaries, excellent benefits, and opportunities for career advancement.

Hiring people with disabilities into federal jobs can be fast and easy. People with disabilities can be appointed to federal jobs non-competitively through a process called Schedule A. Learn how to be considered for federal jobs under the noncompetitive process. Learn the difference between the competitive and non-competitive hiring processes, how to use the Schedule A Authority, and how to conduct a job search in the federal government.

Most federal agencies have a [Selective Placement Program Coordinator](#), a Special Emphasis Program Manager (SEPM) for Employment of Adults with Disabilities, or the equivalent, who helps to recruit, hire and accommodate people with disabilities at that agency.

### Reasonable Accommodations

The federal government may provide you [reasonable accommodation](#) in appropriate cases. Requests are considered on a case-by-case basis.

To find federal jobs for which you can apply, use [USAJOBS](#). This website contains important information for federal agencies to use in recruiting, hiring, and retaining individuals with disabilities and targeted disabilities.

### Selective Placement Background

On July 26, 2010, President Obama issued [Executive Order 13548](#), which provides that the federal government, as the Nation's largest employer, must become a model for the employment of individuals with disabilities. The order directs executive departments and agencies (agencies) to improve their efforts to employ federal workers with disabilities and targeted disabilities through increased recruitment, hiring, and retention of these individuals. This is not only the right thing to do, but it is also good for the government, as it increases the potential pool of highly qualified people from which the federal government draws its talent. Importantly, the Executive Order adopts the goal set forth in [Executive Order 13163](#) of hiring 100,000 people with disabilities into the federal government over 5 years, including individuals with targeted disabilities.

The Executive Order also instructed the Director of the Office of Personnel Management (OPM), in consultation with the Secretary of Labor, the Chair of the Equal Employment Opportunity Commission (EEOC), and the [Director of the Office of Management and Budget \(OMB\)](#), to design model recruitment and hiring strategies for agencies to facilitate their employment of people with disabilities.

In addition to the Executive Order, federal agencies are obligated under the Rehabilitation Act of 1973, as amended to affirmatively employ people with disabilities. The specific requirements of this obligation are spelled out in the [Equal Employment Opportunity Commission Management Directive \(MD\) 715](#). OPM.gov Main Disability Employment - Office of Personnel Management U.S. Office of Personnel Management, 1900 E Street, NW, Washington, DC 20415 [Federal Relay Service](#).



### Corporate Matching

Did you know that many companies will match your tax-deductible donation to the Hemophilia Foundation of Greater Florida? [Click here](#) to check out our list to see if your company has a matching program!



# Social Work Corner *cont'd*

by Sandra Davy, MSW

**Fact Two.** There are 144 schools that offer technological training programs at 199 locations in 78 Florida cities that can lead to technical certificates or associates degrees

Vocational Rehabilitation (VR) is a federal-state program that helps people who have physical or mental disabilities get or keep a job. VR is committed to helping people with disabilities find meaningful careers.

### Florida Vocational Rehabilitation

Florida Vocational Rehabilitation (VR) is a federal-state program that helps people. VR is committed to helping people with disabilities find meaningful careers. Job Placement; Job Coaching; On-the-Job Training; Supported Employment or to help you keep a job. Go to Florida Division of Vocational Rehabilitation: [www.rehabworks.org/](http://www.rehabworks.org/) to download an application or complete an online application. Mail or turn in your application to the nearest VR office. For a list of offices, go to: [www.rehabworks.org](http://www.rehabworks.org) and then click on: "Contact Us," and then select "Directory of Local VR Offices and Vendors" or you may call our toll free number 1-800-451-4327 for more information.

### Tech/Trade Schools in Florida

Technical Certificates give you all the technical training you will need to get to work quickly. A technical certificate is used to get the basic knowledge needed for a chosen profession, and as the first step to an A.S. degree. The following link lists various Florida schools and training programs. [www.tech-schools.us/florida-technical-schools.shtml](http://www.tech-schools.us/florida-technical-schools.shtml)

Moving on to something new and positive is a great way to begin 2017.



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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.



### Use a Search Engine & HFGF Gets a Donation

Do you use Yahoo or Google almost every day? Doesn't everybody? From now on, make [www.good-search.com](http://www.good-search.com) your search engine and every time you search the Web, HFGF will receive a donation; a percentage of the revenues from the site's advertisers. Good Search uses Yahoo search technology so it's reliable and fast. Just go to the site, type HFGF into the "Who do you search for?" box and click the verify button, then conduct your Web search as usual. So, gentlemen, start your search engines and make some money for the HFGF!