Meet Your Hemophilia Treatment Centers

Florida is very lucky to have so many excellent Federally-funded Hemophilia Treatment Centers. We are going to introduce you to their staffs, list their services, and provide information on how to make appointments and who to contact.

All Children’s Hospital
Staff
Hemophilia Treatment Center Director:
Irmel Ayala, MD
Hemophilia Nurse Coordinator:
Mary Ann Cardenas, RN
Social Workers:
Sara Bleattler, MSW • Bryn Dunham, MSW
Physical Therapists:
Kelly Tusha, PT, DPT • Lindsey Watson, PT, DPT, CSCS
Rene van Wieringen, PT, DPT
Clinical Nutritionist:
Emily Ellis, MS,RD, CSP

Clinic hours: Mon-Fri 8:30am -5:00pm
Clinic Locations:
All Children’s Hospital – Outpatient Care Center
Pediatric Hematology/Oncology
601 5th Street South, Suite 302
St. Petersburg, FL 33701
Phone: 727-767-4176
Appointments are the last 2 Thursdays of each month

All Children’s Hospital Specialty Care of Lakeland
3310 Lakeland Hills Blvd.
Lakeland, FL 33805  Phone: 863-802-6600
Appointments are the first Thursday of every even month
Programs:
340-B Program (Section 340-B of the Public Health Service Act legislation)
Educational programs (varies yearly)
For Appointments:
To make an appointment or for any inquiries, please call (727)767-4931 and ask for Mary Ann Cardenas, RN.
We have 24 hour on-call services: (727) 767-4176.
All Children’s Hospital is a member of Johns Hopkins Medicine.

All Children’s Hospital Specialty Care of Tampa
12220 Bruce B. Downs Blvd
Tampa, FL 33612  Phone: 813-631-5001
Appointments are the 3rd Tuesday/4th Wednesday of each month
Clinic hours: Mon-Fri 8:00am-5:00pm
Hemophilia Treatment Centers cont’d on page 4

SAVE THE DATE
01.08.16
Evening on Broadway Theatre Event
Dear Friends,

I hope everyone is enjoying their spring: before we can blink, it is going to be summer (my favorite time of the year).

Congratulations to all of our high school and college kids graduating. We hope all your dreams come true.

We have a great Bullying Program June 6 at the Ports of Call in Orlando. Please contact us if you are interested in participating.

Believe it or not we are hosting two Back to School Programs in June...these programs were designed to teach you about 504s and IEPs. In order to make sure your child has everything ready by August, we have to begin the process in June. This promises to be a great program.

Have you heard the news? We are changing the date of the Holiday Walk to October 25 – in the Halloween spirit, the event is called the Creepy Crawl Benefitting People with Bleeding Disorders. This year we are adding a 5k run along with the walk. If you are interested in getting involved, contact Allison Sullivan at Allisonsullivan@hemophiliaflorida.org.

Please check out our newly designed website for updated programs, information and events.

Have a great spring!

Warmest Regards,

Fran

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**2015 CALENDAR OF EVENTS**
Clot Trotting Is a Success!

On Saturday, April 11, 2015 in Gainesville, 125 walkers took part in the annual HFGF Gator Clot Trot to raise money for the bleeding disorders community. More than $24,000 was raised. A special appearance by Albert, the UF Gator mascot, and the UF Cheerleaders helped to cheer the walkers on.

The Hounds of Heme Team from the adult hemophilia treatment center managed to win both the travelling walk team trophy (for most money raised) and the Spirit Award (for most walkers). Congratulations to all.

We’d like to thank our sponsors for making the event possible:

Accredo Specialty Pharmacy
Bayer
Baxter
Biogen
CSL Behring
Emergent Biosolutions
Pfizer Hemophilia
Novo Nordisk

In-kind Sponsors:

Giggles Photography

The Hounds of Heme
Meet Your Hemophilia Treatment Centers cont’d

Nemours Children’s Specialty Care
(seated: L-R Missy Zippel, Cristin Picciano) (standing: L-R Alex Boddie, Arlyn Jackson, Cynthia Gauger)

Staff
Hemophilia Treatment Center Director: Cynthia Gauger, MD
Clinic Coordinator: Alex Boddie, RN, MSN
Social Worker: Cristin Picciano, LCSW
Physical Therapist: Arlyn Jackson, PT
Data Manager: Elouise Stevens

Clinic Locations:
Nemours Children’s Specialty Care, Jacksonville
807 Children’s Way
Jacksonville, FL 32207
Clinic hours: Monday–Friday, 8 a.m. to 5 p.m
Nemours Children’s Clinic, Pensacola
5153 N. Ninth Ave.
Pensacola, FL 32504
Clinic hours: Mon-Fri 8:00am-5:00pm

Programs:
Comprehensive hemophilia clinics monthly
Individual educational classes for infusion skills
Community programs related to Hemophilia, vonWillebrands Disease and Platelet Disorders

For Appointments:
Hemophilia – contact Alex Boddie, RN, MSN for dates and available times
vonWillebrands Disease – contact Patient Service Specialist at 904-697-3789 for first available appointment with Dr. Cynthia Gauger.
Platelet Disorders - contact Patient Service Specialist at 904-697-3789 for first available appointment with Dr. Cynthia Gauger.

University of Florida
Staff
Hemophilia Treatment Center Director: Tung Wynn, MD
Adult Medical Director: Anita Rajasekhar, MD, MS
Adult Hematology Nurse: Alicia Guth, RN
Pediatric Hematology Nurse: Anne Dove, RN
Adult Social Worker: Victoria Pearson, MSW
Pediatric Social Worker: Jennifer Larson, MSW

Clinic Locations:
Department of Medicine
Adult Hemophilia
P.O. Box 100277
Gainesville, FL 32610

Pediatric Hematology/Oncology
P.O. Box 100296
Gainesville, FL 32610

Programs:
Monthly hemophilia clinics

For Appointments:
Adult: Call 352 265-0725 until end of June. Then, new number is 352-265-8199.
Pediatric: 352-273-9120

Hemophilia Treatment Centers cont’d on page 5

When you shop with Amazon.com Smile they’ll donate to The Hemophilia Foundation of Greater Florida
Meet Your Hemophilia Treatment Centers cont’d

St. Joseph’s Hospital – Hemophilia Treatment Center

Staff
Medical Director: Erin Cockrell, DO
Adult Hematologist: Bruce Hough, MD
Hemophilia Nurse Coordinator: Sara Nixon, RN, BSN
Hemophilia Nurse Coordinator: Lisette Sanchez, RN, BSN
Hemophilia Nurse Coordinator: Megan Dobbins, RN, BSN
Social Worker: Margaret Rosa, M.S.W
Physical Therapist: Tracey Dause, M.S.P.T

Clinic Location:
St. Joseph’s Hospital - HTC
3001 West Dr. Martin Luther King Jr. Blvd.
Tampa, Florida 33607
Comprehensive clinic is held the 2nd Wed. of each month
Clinic hours: Mon-Fri 8am-4:30pm

Programs:
Comprehensive onsite multidisciplinary care for adults and pediatric patients
HTC 340B Factor Program (Section 340-B of the Public Health Service Act legislation)
Comprehensive education and outreach to schools, home visits and to the community
HTC drug trials and research
Provide genetic education, testing and counseling

For Appointments:
To make an appointment, please call 813-321-6820.

New Date, New Location, New Name for Fundraising Walks

Creepy Crawl New Name for Orlando Fundraising Walk
The former Reindeer Clot Trot has changed its name and date. This year the event will take place on
October 25, 2015 and be called the Creepy Crawl (in honor of Halloween). But the object is the same: to
raise money to support the bleeding disorders community. So turn out and walk with us at Harbor
Park at Baldwin Park in Orlando.

Register yourself or a whole team of walkers (great fun) at our website:
http://www.hemophiliaflorida.org/.

Creepy Crawl
for Bleeding Disorders
October 25, 2015
Harbor Park
Orlando, FL

Turkey Clot Trot Moves to New Date and Location
The Jacksonville Turkey Clot Trot will be held
November 7, 2015 at the
Welcome Center at Ponte Vedra on Nocatee Center Way. Register yourself or a whole team of walkers
(great fun) at our website: http://www.hemophiliaflorida.org/.

Hemophilia Treatment Centers cont’d on page 6
University of Miami Miller School of Medicine
Hemophilia Treatment Center

Meet Your Hemophilia Treatment Centers cont’d

Staff

Director, Special Coagulation Lab: David Andrews, MD
Medical Director, Pediatric Program: Joanna A. Davis, MD
Medical Director, Adult Program: Thomas Harrington, MD
Pediatric Hematologist: Fernando Corrales-Medina, MD
Nurse Practitioner, Adult Program; Pediatric Hematologist:
Maya Smith, MSN, ARNP
Nurse Coordinator, Pediatric & Adult Programs: Maria Santaella, RN, MSN
Program Development: Patrice Bravo, LCSW
Clinical Social Worker/Psychotherapist: Annalise Guerra, MSW
Clinical 340B Program Coordinator: Magaly Gonzalez
Clinical Research Coordinator: Leandro Pisani
Secretary/Outreach Assistant: Mindi Valancy

Programs:
Monthly comprehensive pediatric and adult hemophilia clinics.

340B Program, a federal program that provides clotting factor to many patients at significantly reduced prices.

Infusion 101 - An award-winning educational workshop led by the medical team which focuses on providing hands-on infusion instruction while addressing difficult feelings that may accompany the task of learning to infuse. Next workshop scheduled for June 8.

Hemophilia Lunch and Learn Series - An accredited traveling educational series that focuses on providing medical professionals in the ER setting an overview of the signs, symptoms and treatment of hemophilia.

For Appointments:
Pediatric: 305 243-5302 Option 3
Adult: Call either Jackson Memorial Hospital 305 585 6226 or 305 243 6102 Option 2.

Clinic Locations:
Pediatric Clinic
Sylvester Comprehensive Cancer Center
"Alex's Place"
1475 NW 12th Avenue, C130
Miami, Florida 33136
Clinic hours: Mon-Fri 8:30am-5:00pm

Adult Clinic
1611 NW 12th Avenue ACCW-3C
Miami, Florida 33136
Clinic hours: Mon-Fri 8:00am-5:00pm
University of South Florida Saba Center for Bleeding Disorders

Staff
Director of Division of Hematology/Oncology: Damian Laber, M.D., FACP
Hematology/Oncology: Nathan Visweshwar, M.D., FRCPC
Clinical Coordinator: Rukshana R. Azam, MBBS
Medical Social Worker: Stacey Terry, BSW
Office Administrator: Monique Johnson

Clinic Location:
Carol & Frank Morsani Center
13330 USF Laurel Dr.
Tampa, FL 33612

Programs:
Comprehensive care for adult patients affected by bleeding disorders including Hemophilia A and B, Von Willebrands disease, and other Hematological disorders.

Our services range from medical treatment, counseling and support, to pharmacy services for clotting-factor replacement including a 340-B program (Section 340-B of the Public Health Service Act legislation).

We also provide ongoing support for our patients and their families through educational activities outside of the clinic.

For Appointments: 813 974-3725

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

Springtime takes us into an amazing seasonal period, with the focus on rejuvenation of mind/body, and learning about key bleeding disorders resources that include educational programs covering initial chronic disease diagnosis issues, pain management, self-infusion, transitioning to young adulthood, utilizing services offered by the Hemophilia Treatment Centers, engaging in sports & exercise safely, employment & educational pursuits and alternatives, coming to terms with the concept of change, bullying, positive nutritional options, inner self-improvement, financial planning, parents empowering parents support group, and self-care maintenance.

From January 2015 thru May 7, 2015 HFGF presented the following programs: ACA Marketplace Enrollment, Genetics, How to Make a Great Impression, Infusion 101, Joint Bleeds and, most recently, Financial Planning/Understanding Insurance and Vocational Rehabilitation. This year, HFGF expanded programming is to include cities such as Pensacola, Kissimmee with plans to present educational programming in Sarasota and Melbourne soon. Make sure HFGF has your current email address, physical address, and phone/cell numbers so that you will be aware of upcoming programs and their locations. Also check our website (www.hemophiliaflorida.org) for information and events or call 800-293-6527, the HFGF office.

The Affordable Care Act Marketplace open enrollment period ended on April 30, 2015. However, you can still get coverage two ways:

If you have certain life changes—like having a baby, getting married, or losing health coverage—you may qualify for a Special Enrollment Period. If you do, you can enroll in a Marketplace plan outside the annual Open Enrollment period. Learn about Special Enrollment Periods by going to www.HealthCare.gov.

You may be able to enroll in coverage through Medicaid and the Children’s Health Insurance Program (CHIP). There’s no limited enrollment period for these programs, which provide free or low-cost health coverage to millions of Americans. You can apply any time. If you qualify, you can enroll immediately any time of year. Learn how to apply for Medicaid and CHIP by going to InsureKidsNow.gov | 1-877-Kids-Now for the websites below or call (1-877-543-7669):

- Florida Department of Children and Families (DCF)
- KidCare Program Information
- Apply for Florida KidCare
- Healthy Kids Program Information
- Apply for Healthy Kids

If none of these options works for you, you can enroll in 2016 health coverage during the next Open Enrollment period. The Open Enrollment period for 2016 is November 1, 2015 to January 31, 2016.

Remember: If you don’t have qualifying health insurance coverage in 2015, you must either pay a fee or have a health coverage exemption. The fee for 2015 is higher than it was in 2014.

The fee for not having coverage in 2015

If you don’t have coverage in 2015, you’ll pay the higher of these two amounts:

- 2% of your yearly household income. (Only the amount of income above the tax filing threshold, about $10,150 for an individual, is used to calculate the penalty.) The maximum penalty is the national average premium for a bronze plan.

- $325 per person for the year ($162.50 per child under 18). The maximum penalty per family using this method is $975.

The fee for not having coverage in 2014

If you didn’t have coverage in 2014, you’ll pay the higher of these two amounts:

- 1% of your yearly household income. (Only the amount of income above the tax filing threshold, about $10,150 for an individual, is used to calculate the penalty.) The maximum penalty is the national average premium for a bronze plan.

- $95 per person for the year ($47.50 per child under 18). The maximum penalty per family using this method is $285.

**You can find all of the above information and answers to health insurance questions by going to www.HealthCare.gov and placing your question in the website’s Search Box.**
Gene Therapy Study in Dogs Shows Markedly Lower Bleeding Rates

In a recently published paper, an international team of researchers report effectively administering gene therapy to three dogs with hemophilia B in an ongoing study. The report, “Liver-Directed Lentiviral Gene Therapy in a Dog Model of Hemophilia B,” was published March 4, 2015, in the journal Science Translational Medicine. The lead author of the paper was Luigi Naldini, MD, PhD, director of the San Raffaele Telethon Institute for Gene Therapy at the San Raffaele Scientific Institute in Milan, Italy.

The three dogs in the study were administered the gene therapy either through direct injection into the liver, a primary source of clotting factor protein production, or intravenously. The therapy was housed in repurposed retroviruses called lentiviral vectors. These vectors act as vehicles, carrying customized genetic material to elicit the production of factor IX (FIX). One advantage in using lentiviruses is that a majority of patients do not generate antibodies to this type of vector, avoiding an immune response that would otherwise render the treatment ineffective. Another benefit of using lentiviral vectors is their large size, enabling them to deliver greater concentrations of the FIX gene, resulting in a more optimal therapeutic effect.

Three years after administering the treatment, Naldini and his colleagues report significant symptomatic improvement. Prior to receiving the therapy, the dogs experienced approximately five spontaneous bleeds per year. In contrast, in the three years since receiving therapy, the dogs have averaged 0 to 1 bleed per year. This notable decrease in spontaneous bleeding events was achieved because the gene therapy boosted FIX generation in the dogs from virtually 0 to 1%-3%. This seemingly modest increase was enough to dramatically lower bleeding rates.

“The result was stunning,” said Timothy Nichols, MD, director of the Francis Owen Blood Research Laboratory at the University of North Carolina School of Medicine and co-senior author of the paper. “Just a small amount of new factor IX necessary for proper clotting produced a major reduction in bleeding events. It was extraordinarily powerful.”

Investigators have also reported no harmful side effects. Safety being a primary concern, Naldini and his team performed additional studies in types of mice that are more likely to develop complications from lentiviruses, such as malignancies. No hazardous responses to the therapy were reported. “Considering the mouse model data and the absence of detectable genotoxicity during long-term expression in the hemophilia B dogs, the lentiviral vectors have a very encouraging safety profile in this case,” said Nichols.

Ideally, Naldini, Nichols and their team would like to increase FIX production to 5%-10% to essentially eradicate spontaneous bleeding in patients with hemophilia B. To reach this endpoint, several years of additional investigation, including larger animal studies and eventual human clinical trials, will need to occur.

Source: ScienceDaily, March 12, 2015
I can’t believe it’s May and almost time for summer!!!! Kids out of school, vacations, days at the beach, and Florida heat. This summer, the Hemophilia Foundation of Greater Florida will be offering some fun summer programs. In June, we will be having our Back to School program. We will be bringing in Don Molter, MSEd who is a career counselor with the Indiana Hemophilia and Thrombosis Center. He will be talking all about the 504 and IEP plans for school. Remember, summer is the best time to start planning for the 2015-2016 school year. Get your educational in-services scheduled with your school early. Communication is the key to a successful school year. We will also be offering a lunch-and-learn series of programs throughout the summer. These interactive programs will be offered in different areas of the state and will be a fun way to get out of the heat and learn something new. We will have fun topics like traveling with a bleeding disorder and healthy living. Remember, Camp Spirit is July 6-11th. It’s OK to feel a little nervous and scared about camp. To be honest, I am a little nervous and scared about camp, but I am also excited about meeting new friends, fishing and roasting marshmallows. Camp is a fun way to meet new friends, try new activities and learn to self-infuse. I look forward to seeing everyone sometime this summer. Remember to wear sunscreen, stay cool and always travel with your factor and supplies. Please feel free to call me if you have any questions about camp, summer programs, or school in-services. Have a safe and fun summer.

Summer Travel Tips:

1. Know how many doses of factor you will need for your trip and pack accordingly.
2. Wear your Medic Alert bracelet or necklace.
3. Have a travel letter to take with you. Get your travel letter from your Hemophilia Treatment Center or Hematologist.
4. Never pack factor in checked luggage. Always bring your factor and supplies in your carryon bag.
5. RELAX and HAVE FUN.

Check out www.stepsforliving.hemophilia.org for more information on traveling with a bleeding disorder.