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Social Worker Corner

## Congratulations to the Calvin Dawson Scholarship Recipients!

Emily Jean Champagne of Bradenton plans to transfer to the University of Central Florida to continue her studies in violin performance. She is currently concertmaster in her college orchestra at State College of Florida, and plays first violin in the Presidential String Quartet at the school. She has worked as a volunteer for the HFGF. Besides practicing her violin, she enjoys listening to classical music and spending time with family and friends.



Rebecca Ann Champagne plans to become a teacher. Rebecca is working to transfer to the University of South Florida from her current school, the State College of Florida at Bradenton where she is pursuing elementary education and is on the Dean's List. She has worked as a volunteer for the HFGF at Camp Boggy Creek. For recreation, she enjoys the beach and shopping.

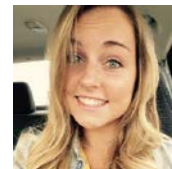
Matthew Kramer hails from Tampa and is in his third year at the University of South Florida studying computer science. He has received the USF Scholars Award and the Florida Medallion Scholars Award. His volunteer activities include the HFGF and an art program for kids at the Tampa Museum of Art. In his free time, he likes drawing, weightlifting, basketball, and playing and designing video games.

Jonathan Lebron is currently attending the University of South Florida as a Music Education major. He started playing baritone saxophone in the seventh grade, played in the marching band, and in senior year was selected to the Florida All State High School Band. He is an advocate for those with bleeding disorders maintaining strong bones and joints through physical activity, swimming from age 5 through high school, participating in Florida State Jr. Olympics and acting as a junior swim coach during summers in the program. Volunteer efforts include being a junior counselor at Camp Boggy Creek, working with many children with chronic medical disorders.



James Patrick Solomon of Clermont is currently studying nursing at Valencia Community College. He plans to pursue an advanced degree and become a Nurse Practitioner. He has received a Nursing Excellence reward and graduated from high school magna cum laude. Meanwhile, his family was recognized as the HFGF Volunteer Family of the Year last year. In addition to volunteering, James enjoys playing guitar, singing, dancing and gaming.

Brooke Taylor Jones of Seminole is transferring this fall to Eckerd College in St. Petersburg from the University of Akron in Ohio. She is seeking a degree in mathematics. On the Dean's List in college, she was a four-year Academic Award recipient and Scholar Athlete in high school. She volunteered at Creekside Animal Clinic and with a program mentoring younger teens. She really loves math!



Duvani Amelia Tejiram of Valrico will study Biomedical Sciences at the University of South Florida in Tampa. In high school, Duvani was an AP Scholar, a member of the National Honor Society and the National Spanish Honor Society and graduated with honors. She has worked as a team captain for the last four years at the American Cancer Society's Relay for Life and has volunteered for the HFGF. Her goal is to continue raising awareness for bleeding disorders while working as a hematologist.

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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,

November is here and with it comes the cooler weather everyone else seems to enjoy—as you may know, I am a summer person. Love the heat and humidity, so will have to pull out the sweaters and jeans and hope we have a short fall.

We had a lot of things happening in October: we had a wonderful Flight for Tomorrow Golf Tournament—more than \$100,000 was raised to support the HFGF. Special thanks go out to Rhonda & Brian McDonald, who are co-chairs and major sponsors for the tournament. We could not have asked for a better day. The golfers, volunteers and the weather were perfect! **SAVE THE DATE for NEXT YEAR: October 23, 2017!**

We just had our annual Creepy Crawl 5k and Walk in Jacksonville and Orlando. We give special thanks to all of our participants, volunteers, individual and corporate donors.

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.

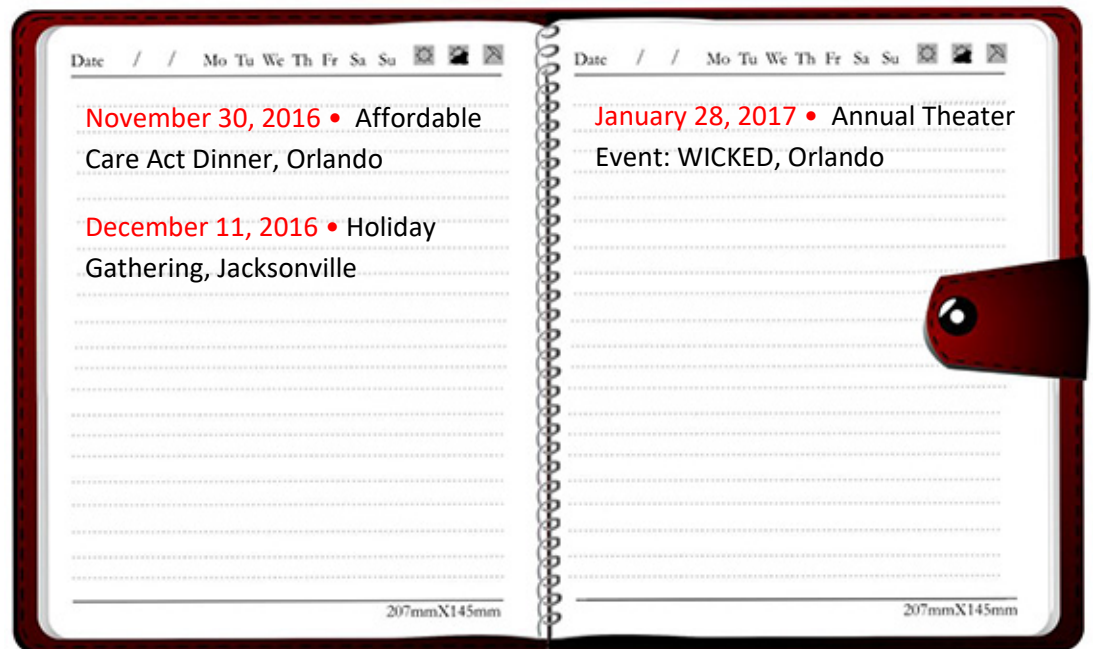
Thanksgiving is around the corner and we at the HFGF have so much to be thankful for. **THANK YOU** for supporting the foundation.

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

Warmest Regards,

*Fran*

## 2016 CALENDAR OF EVENTS





# Flight for Tomorrow Golf Tournament Rises to Great Height



The HFGF's Annual Flight for Tomorrow Golf Tournament was held Monday, October 24<sup>th</sup> at Avila Golf and Country Club in Tampa and raised more than \$100,000 for the HFGF. More than 100 golfers and volunteers were on hand for a round of golf, lunch, cocktails and dinner, and the awards ceremony and auction. A very warm HFGF thank you to our hardworking co-chairs Rhonda and Brian MacDonald.

*Congratulations* to the winning foursome which included Dan Wolfe, Joe Brus, Greg Walker and Jeff Kaufman. Second place foursome: Bobby Capabianco, Gary Redwine. Peter Torey, Barry Cort. Third Place foursome: Brian MacDonald, Joe Pugliese, Ted Langan, Toney Perez. Kudos to all of our other award winners: Long Drive Ladies: Kathy Walterhouse. Long Drive Men: Bob Meheran. Closest to the Pin Hole 5: Bobby Capabianco. Hole 8: Barry Cort. Hole 14: Jeff Kaufman. Hole 17: Gary Redwine. Putting Contest winners: Jeff Beck, Doug Norris, Andy Pack, Les Carroll.

### We would also like to thank our sponsors.

#### Title Sponsors

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### Finally, the HFGF would like to thank the donors of items for our auction:

Bok Tower Gardens  
Brian and Rhonda MacDonald  
Busch Gardens  
Canoe Escape  
Celebration Golf Club  
Chris and Jaimi Hovan  
Columbia Restaurant  
Cooper's Hawk Winery and Restaurant  
Crayola Experience, Orlando  
Disney  
Florida Estates Winery  
Florida Strawberry Festival  
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Sunny's Restaurants  
Susie Larsen  
Tampa Bay Rays  
Target  
Universal Studios  
Westchase Golf Club



# Good Oral Hygiene and Bleeding Disorders

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By Joanna A. Davis, MD

**People living with bleeding disorders have an extra challenge when it comes to taking care of their teeth and overall good oral hygiene. However, working with your HTC providers and well informed dentists can ensure a lifetime of good oral health.**

It is very hard for families who are living with any chronic medical condition to remember that there is more to life than that condition. For our families, it is most definitely NOT all about Hemophilia or von Willebrand's disease! This means that, in addition to all the specific needs and challenges which are associated with your bleeding disorder, our families have to remember to take care of the "routine" medical responsibilities: immunizations, annual physicals, mammograms, cardiac screening - the list goes on and on.

There is also the "routine" responsibility of ensuring dental health. Regular brushing with a soft brush, twice a day, routine flossing, limiting sugary or very acidic drinks, using an antibacterial mouthwash when appropriate, using fluoride supplements or treatments, and seeing your dentist twice a year should be the "standard of care" for everyone. Having a bleeding disorder does NOT increase the likelihood of developing dental problems. There is, however, an increased chance of gum bleeding, but avoiding proper care (including flossing!) will result in a vicious cycle of gum bleeding: irritation of the gums due to the irritant effect of the blood: further gum irritation: further bleeding, buildup of bacteria, development of cavities...and on and on. Poor brushing/flossing leads to a buildup of plaque or tartar, which causes further gum irritation, more mouth discomfort, gum disease, weakening of the root system of teeth, and the formation of cavities.



Interestingly, the eruption of the baby teeth is usually not associated with bleeding (note, I said "usually"). As the tooth pushes its way up through the gums, there is enough pressure generated to squeeze off the blood vessels along the way, so that there is no blood, or perhaps only a drop, seen when the point of the tooth erupts. If baby teeth are left alone when they become loose, the same pressure effect occurs as the adult teeth push upwards. It is when a child is so excited to have the Tooth Fairy visit that he/she wiggles and pulls at a baby tooth too soon that there may be a lot of unnecessary bleeding.

Certainly, dental procedures, including deep cleaning/scaling, simple extractions, wisdom teeth extractions and root canal procedures, carry a high risk of bleeding if not properly and proactively managed. Mouth trauma of any kind – whether it's the one year old who falls and lacerates his lips/gums/frenula (the thin membranes that attach the underside of the tongue or lips to the surrounding structures), or the active patient who is injured while playing sports, or a person who hits his/her teeth/mouth in an accident will result in excessive bleeding. As overwhelming as this all may seem, preventive dental care is easy to achieve.

It is essential to identify a dentist/oral surgeon who is comfortable with treating people with a bleeding disorder. As our community has learned, there are a lot of health care providers across the board who are not familiar with bleeding disorders, and cannot provide adequate or appropriate care. Dentists are no exception. Ask your HTC staff for recommendations.

For example, at UM, They are fortunate to work with the Hemophilia Foundation of Greater Florida to provide an excellent adult dental program in Miami. Miami Children's Hospital has an experienced team of pediatric dentists, and there are other caregivers in the tri-county area with whom we have worked successfully in the past. As always, it is the team approach which ensures a good outcome.



You are responsible for letting the HTC staff know about upcoming dental visits or procedures. They will speak with the dentist ahead of time to determine what preventive regimen is necessary and appropriate.

In addition to potentially needing an infusion on the day of the visit, your Hemophilia Treatment Center may prescribe Amicar® (aminoepsiloncaproic acid). This is a medication that stabilizes clots which form in the mouth. Factor prevents bleeding or allows for the formation of healthy clots after an injury (like dental work). Clots which form in the mouth not only start to break down because of the natural process of fibrinolysis (fancy word for clot breakdown), but are also weakened by the digestive enzymes which are released from the salivary glands. Our mouths think that a clot is like a piece of meat: salivary enzymes are produced to start the process of digestion once the clot forms. Not sure what this is? Have you ever felt your mouth “water” when you smell something really delicious? The “water” is actually the salivary digestive enzymes, released automatically when your body anticipates eating something. Amicar® helps to block the effect of both the regular breakdown process and the clot “digestion”. Your HTC provider will determine how much factor/Amicar® should be used, and on what schedule, depending on the procedure. However, there needs to be time to have the discussions, make the arrangements for extra factor, for Amicar®, for an overnight admission to the hospital if necessary. Please give your HTC adequate notice that you are having wisdom teeth extractions done. If you wait until a day or two before that will result in delaying the procedure until it can be done safely. Your dental provider should be able, along with your HTC staff and PCP, to address your questions and concerns, and to help you develop a safe and effective oral hygiene plan. There are no contraindications to routine dental treatments for members of the bleeding disorders community. Preventive dentistry is essential!

### **The World Federation Recommends:**

For patients with hemophilia, dental care and mouth hygiene are imperative. Daily brushing and flossing with regular visits to the dentist are necessary to prevent gum disease and build-up of dental tartar, which will increase bleeding tendency and accelerated decay. If dental hygiene is neglected, a vicious cycle of increasing gum disease and bleeding that will prevent or scare you away from brushing and flossing will be generated. Prevention is everything! In compliance with the guidelines of the World Federation of Hemophilia, we recommend the following:

- Brush twice daily with fluoride toothpaste.
- Use a toothbrush with medium texture bristles.
- Use interdental cleaning aids, such as floss, tape, and interdental brushes to prevent cavities.
- Use mouth rinses containing antibacterial and astringent ingredients such as chlorhexidine gluconate.
- Limit the consumption of foods and drinks with high sugar or acid contents. Three exposures per day, with meals, is the recommended maximum.
- See your dentist regularly, ideally every 6 months.

### **Further Information and Education:**

- Download the “Information for the Dentist” form on the Baxter Website created specifically for people with bleeding disorders. The form was created by Melissa A. Kennell, DDS, a general dentist in Gilford, New Hampshire, who has a son with severe hemophilia A.
- Read CSL Behring dental care publications.
- The World Federation of Hemophilia’s (WHF’s) Dental Committee published “Guidelines for Dental Treatment of Patients With inherited Bleeding Disorders” in 2006 (Treatment of Hemophilia Monograph No. 40). It is written by dentists for dentists and does not provide specific guidelines regarding doses of factor concentrates.
- WHF published “Oral Care for People with Hemophilia or a Hereditary Bleeding Tendency” in 2008 (Treatment of Hemophilia Monograph No. 27).
- View the American Academy of Pediatric Dentistry’s “Policy on the Dental Home.”
- Read “Insurance and Dental Procedures,” HemAware September/October 2003.

This issue we are featuring 25-year-old Brett Palaschak. Brett has severe hemophilia A, which has shaped the course of his life in several ways. The primary one of those is his work.

Brett is a graduate of and researcher at the University of Florida. His research program, which is affiliated with the College of Medicine, has the goal of trying to develop a viral vector that can carry a specific gene that affects a clotting factor, such as factor 8 for hemophilia A. Recently, Brett was third author on a paper for the Journal of Molecular Therapy Methods of Clinical Development called “Potential for Cellular Stress Response to Therapeutic Factor VIII Expansion from AAV Vector.”



Brett does this work because he says that there is “a great need in the community for better therapies that I have seen firsthand.” Also, because “in less fortunate countries [an individual with a bleeding disorder] could develop a bleed and because the treatment is so expensive could die.”

Brett has done a lot of volunteer work with the HFGF at walks and other events, as well as being a camp counselor at Camp Warren Jyrch for Bleeding Disorders in Illinois. In his free time, he likes to play video games and go to Florida theme Parks with his wife when he is not interacting with his two dogs, Australian Shepherd crosses that he rescued.

## Something **WICKED** This Way Comes



Join HFGF’s annual Evening on Broadway for the national touring company production of *Wicked* on Saturday January 28, 2017 at the Dr. Phillips Center for the Performing Arts in Orlando. You will enjoy great seats and a pre-show reception and silent auction. Tickets are available now for \$135 each from the HFGF office at 407-629-0000. Call and reserve yours today!



# Gainesville Clot Trot Raises More Than \$27,000

On Saturday, September 24th, walkers gathered at Tioga Town Center for the annual Gator Clot Trot Fun Walk. They were joined by 69 runners for the inaugural 5K run. This year's walk and run raised \$27,800 for the HFGF. That money will be used to send children with bleeding disorders to camp; build HFGF's Emergency Assistance Fund for those with bleeding disorders; and fund medic alert bracelets and helmets.

Julius Gylys won first place for male runners and Kourtney Oliver came in first for female runners. Congratulations to Team E-Man's Ethan Howick for taking home the Traveling Walk Trophy and the award for Top Individual Fundraiser. Ethan raised \$2,175 for HFGF. Congratulations are also in order to Dr. Tung Wynn and UF's Team Peds Clinic for taking home the Champions in Action award for raising \$1,560 and the Most Team Spirit award. Next year, the Gainesville walk will be move back to the spring, so save the date for APRIL 22, 2017



- We want to give a very special thanks to our **Corporate Sponsors:**
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  - Biogen
  - BioRX
  - Cottrill's Pharmacy Inc.
  - CSL Behring
  - Novo Nordisk
  - Octapharma
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- In-kind Sponsors**
- Aairius DJ
  - Entertainment
  - Florida Health of Alachua County
  - Gainesville Health and Fitness
  - Piesanos Stone Fired Pizza
  - Tioga Town Center
  - Town of Tioga

**Save the date!**  
**6th Annual Gator Clot Trot**  
**April 22, 2017**  
**Location TBD**





## Greetings, everyone!

The fall season is here, and once again, it's time to either enroll in a health plan for the 1<sup>st</sup> time, enroll in a *different/new* health plan, renew, enroll in a Medicare health plan/Medicare Supplemental plan, or enroll in Children's Health Insurance Program (CHIP), *MediKids*, *Florida Healthy Kids*, *Children's Medical Services Managed Care Plan (CMS)*, or *Medicaid*. Below you will find the deadline dates, plan information, and websites for each of the above mentioned health care plans.

### 1. Marketplace deadlines for 2017 health insurance

You can get quick answers about keeping or changing plans for 2017 and [Preview 2017 plans and prices right now](#) by going to: <https://www.healthcare.gov/>

- Enroll October 30 through November 15, 2016 for health insurance effective December 1, 2016.
- Open Enrollment for 2017 health plans starts November 1, 2016.
- November 1, 2016: Official Open Enrollment starts—first day you can enroll, re-enroll, or change a 2017 insurance plan through the Health Insurance Marketplace. Coverage can start as soon as January 1, 2017.
- December 15, 2016: Last day to enroll in or change plans for coverage to start January 1, 2017.
- January 1, 2017: 2017 coverage starts for those who enroll or change plans by December 15.
- January 31, 2017: Last day to enroll in or change a 2017 health plan. After this date, you can enroll or change plans only if you qualify for a [Special Enrollment Period](#) (Go to [Healthcare.gov](#) for Special Enrollment information).



#### Important information to know:

- If you have job-based insurance: You can buy a Marketplace plan, but you'll pay full price unless your job-based insurance doesn't meet certain standards. Most job-based plans do.
- If you have Medicare: You can't switch to Marketplace insurance, use a Marketplace plan as a supplement, or buy a Marketplace dental plan.

#### What you pay for insurance depends on your income—and you'll probably save

Your savings depend on your expected household income for the year. Over 8 in 10 people who apply are eligible to save, and most can find plans for between \$50 and \$100 per month (after accounting for their premium tax credit). You may qualify for a [premium tax credit](#) that lowers your monthly insurance bill, and for extra savings on out-of-pocket costs like [deductibles](#) and [copayments](#). The plans are offered by private insurance companies with a range of prices and features. All plans cover:

- [Essential health benefits](#)  
[Pre-existing conditions](#), including pregnancy  
[Preventive care](#)

You can [add dental](#), but you don't have to. You can't buy a dental plan unless you enroll in a health plan.





## 2. Children’s Health Insurance Program (CHIP), MediKids, Florida Healthy Kids, Children’s Medical Services Managed Care Plan (CMS), Medicaid health care plans

**Children’s Medical Services Managed Care Plan**  
Birth through 18 with special health care needs

**Florida Healthy Kids**  
From 5 years through 18 years

**MediKids**  
From 1 year through 4 years

The above health care plans provide free or low-cost coverage to millions of people and families with limited income, disabilities, and some other situations.

To apply online go to:  
<https://www.healthcare.gov/>

Applying is easy! It takes approximately 6 weeks to process a complete application. Coverage only begins after your child's eligibility has been determined and the first month's premium has been received, if required.

Medicaid Ages: For children coverage is from birth to 18 years old.

Individuals may apply any time for assistance online at: <http://www.myflorida.com/accessflorida/>. Additional information about Medicaid for low-income families is available in the Family-Related Medicaid Fact Sheet. Information regarding income limits can be found on the Family-Related Medicaid Income Limits Chart.

Medicaid provides medical coverage to low-income individuals and families. The state and federal government share the cost of the Medicaid program. Medicaid services in Florida are administered by the Agency for Health Care Administration. Medicaid eligibility in Florida is determined either by the Department of Children and Families (DCF) or the Social Security Administration (for SSI recipients).

### DCF determines Medicaid eligibility for:

- Parents and caretakers relatives of children
- Children
- Pregnant women
- Former Foster Care Individuals
- Non-citizens with medical emergencies

Aged or disabled individuals not currently receiving Supplemental Security Income (SSI)

### 3. Medicare Open Enrollment for 2017 For additional information or to apply go to the Medicare.gov – Official Site <https://www.medicare.gov>

#### Medicare Important information & Dates:

During this annual enrollment period (AEP) you can:

- You can switch from Original Medicare to Medicare Advantage, or vice versa.
- You can also switch from one Medicare Advantage plan to another, or from one Medicare Part D (prescription drug) plan to another.
- And if you didn’t enroll in a Medicare Part D plan when you were first eligible, you can do so during the general open enrollment, although a late enrollment penalty may apply.
- If you want to enroll in a Medicare Advantage plan, you must meet some basic criteria.
- You must be enrolled in Medicare Part A and B.
- You must live in the plan’s service area.

#### Auto-renewal

If you’re already enrolled in a Medicare Part D prescription plan or a Medicare Advantage Plan, and you *don’t want to make changes* to your coverage for 2017, you don’t need to do anything during open enrollment, assuming your current plan will still be available in 2017. If your plan is being discontinued and isn’t eligible for renewal, you will receive a non-renewal notice from your carrier prior to open enrollment. If you don’t, it means that you can keep your plan without doing anything during open enrollment.



## Changing Medicare Advantage coverage after the AEP

Between January 1 and February 14 each year, if you are enrolled in a Medicare Advantage plan, you can leave your plan and return to original Medicare. You cannot switch to another Advantage plan unless you have a circumstance that affords you a Special Enrollment Period.

After you leave your plan, you will have until February 14 to enroll in a Part D plan that will begin the first day of the following month that you enroll.

## Enrolling in Original Medicare

If you didn't sign up for Medicare A and B when you were first eligible, you have a chance to do so each year from January 1 to March 31, with coverage effective July 1. You may be subject to a late enrollment penalty, however. For Medicare Part B, the penalty is an additional 10 percent of the premium for each 12-month period that you were eligible but not enrolled.

Let 2017 be the year you become informed about your health care options

Sandra

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## OUR LOCATION

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Winter Park, FL 32789

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