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Twenty-five years ago, a quarter of a century, a small group of people, led by four dedicated founders, came together to form the HFGF. Their purpose was to serve the bleeding disorders community, to provide aid, support, and education to help people navigate the difficulties of life with a bleeding disorder. Each of them had been active previously in the fight for the bleeding disorders community.

They were:

Calvin and Myra Dawson. The late Mr. Dawson was a passionate advocate for those living with bleeding disorders. He suffered himself from hemophilia and was infected with HIV from tainted blood products. He spearheaded a group that brought a successful class-action lawsuit that benefitted many (although not Calvin himself) who had received tainted blood products. He served for two years before his death as the first Executive Director of the HFGF. He, and his wife Myra, who served on the HFGF board for 17 years, worked tirelessly to benefit the bleeding disorders community. Today, Myra Dawson still administers the scholarship fund that bears her husband's name. The fund provides scholarships to Florida residents with bleeding disorders pursuing post-secondary education. If you would like to help grow the fund, go to <http://www.hemophiliaflorida.org/donate.html> and just note under Purpose Scholarship Fund.



Brian and Rhonda McDonald. Brian McDonald was instrumental in funding and organizing the infrastructure, as well as setting goals and direction for the HFGF. He, and wife Rhonda, worked very closely with Calvin Dawson, whom Brian refers to as "an amazing individual," to get the organization off the ground. Brian and Rhonda have always been very involved with the organization, helping establish a factor bank and the Emergency Financial Assistance Fund. Today, they are still organizing and running the single largest fundraising event that benefits the HFGF, the Flight for Tomorrow Golf Tournament, held annually in Tampa.

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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 bleed-
ing disorders and their families
through education, information and
referral services, advocacy and
research.

Disclaimer

The material provided in HFGF
Connections is for your general
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in the practice of medicine. The
HFGF does not recommend partic-
ular treatments for specific indi-
viduals and recommends that you
consult your physician or treatment
center before pursuing any course
of treatment.

Dear Friends,

We really miss everyone and look forward to seeing everyone in person soon. Although we have been fortunate to see everyone virtually...it is sure not the same. We could all use a hug. Hopefully, we will be hugging each other sooner rather than later.

I want to extend a special thank-you to our walk chairs, who took on the task of leading us through 2020's virtual walks. It was a challenge, but they really rose to the occasion. Their leadership and dedication are greatly appreciated.

Co-Champions – Jacksonville Creepy Crawl – Megan and Aaron Tuttle

Co-Champions – Orlando Creepy Crawl – Dawn Solomon, Samantha Nazario and Vilma Negron

Co-Champions – Super Hero Walk – Jennifer Hastie, Montgomerie and Olwyn Hastie

Champion – Gator Clot Trot – Joe Burke

You all are wonderful volunteers – thank you!

Thank you, Rhonda & Brian McDonald for hosting the Annual Flight for Tomorrow Golf Tournament – We had an in-person event that followed CDC guidelines. It was a lot of fun and thanks to the participants' generosity, we were able to raise \$42,500 (net).

Rhonda and Brian are incredible people. Thank you very much for your dedication and support.

We are looking forward to doing in-person events soon, and we are going to begin with our annual family program at SeaWorld. It is June 5, 2021, and we are planning a safe, in-person event that will look a little different, but it will be fun.

I hope everyone has a great 2021, and we look forward to seeing you soon.

Take Care,

Fran

**March is
Bleeding
Disorders
Awareness
Month**



Mark Your Calendars

EVENTS



Teen Program Virtual Escape Room

February 26

Women and Hemophilia (Spanish language)

March 4

Advocacy Day Virtual

March 9 & 10

Clinic to the Kitchen Table Infusing Kids at Home (virtual)

March 11

Micro Bleeds (virtual)

March 18, 2021

Building Connections (virtual)

March 25, 2021

WE ARE GRATEFUL TO OUR VOLUNTEERS AND DONORS THAT SUPPORT
THE HEMOPHILIA FOUNDATION OF GREATER FLORIDA, ESPECIALLY
DURING THIS DIFFICULT TIME

“ THE SMALLEST ACT OF KINDNESS IS WORTH MORE THAN THE
GRANDEST INTENTION.”
OSCAR WILDE



cont'd

Wanda Bedell. Wanda, whose husband Spencer suffered from hemophilia and died in 1989 from HIV acquired from tainted blood products, worked as a vocal and ardent volunteer (her life's work) for the bleeding disorders community. She was asked to serve on the organizing committee that founded Camp Boggy Creek. The first camping session held at Boggy Creek was for children with bleeding disorders. Wanda took over as Executive Director after Calvin's death and affiliated the HFGF

as a chapter of the National Hemophilia Foundation. She served for several years on the HFGF's Board of Directors and refers to her work with the bleeding disorders community as "a labor of love."



All of you, through your donations and volunteer efforts, have helped to make the organization's first twenty-five years a success. Here's to the next twenty-five!

**CHANGE THEIR WORLD. CHANGE YOURS.
THIS CHANGES EVERYTHING.**

[BECOME A VOLUNTEER](#)

OR

[DONATE](#)

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VOLUNTEER FOR THE HFGF

**CONTACT US AT 800-293-6527 or
info@hemophiliaflorida.org**

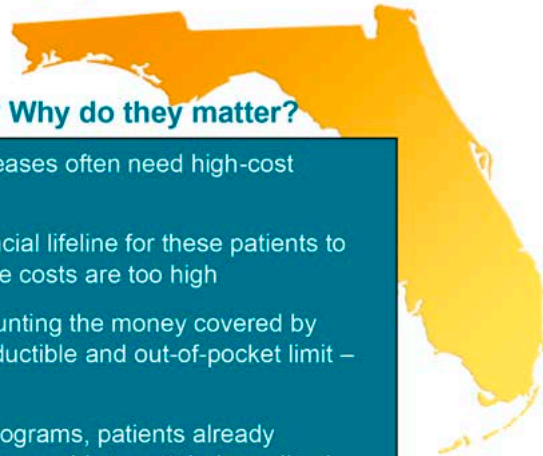


Health Insurance News

Patient Copay Assistance and Copay Accumulators 101

What are Copay Accumulators? Why do they matter?

- Patients with rare, complex and chronic diseases often need high-cost specialty medicines to manage their health
- Copay assistance cards provide a true financial lifeline for these patients to afford their medicines when health insurance costs are too high
- Insurance companies and PBMs are not counting the money covered by copay assistance toward a beneficiary's deductible and out-of-pocket limit – this is a “copay accumulator”
- Without state legislation prohibiting these programs, patients already grappling with severe chronic diseases will be unable to get their medication and put their health at risk



Copay Accumulators in Florida: Patient Impact

- 9/10 Issuers in Florida's 2021 Marketplace have copay accumulator programs
 - Ambetter, AvMed, Bright Health, Florida Blue, Florida Health Care Plan, Health First, Florida Blue HMO, Molina, Oscar
- In 2020, nearly 2 million Floridians enrolled in a Marketplace health plan
- Many Florida patients will be forced to make tough choices between paying for basic necessities and paying for their prescriptions

over 100,000
Lupus patients

45,665
reported with End-
stage Renal Disease

111,000
living with HIV
infection

1000 Hemophilia
patients and more
than 5000 with
bleeding disorders

+1000s more
chronically ill
Floridians with costly
drugs

The Solution: Florida Legislation SB 1078

Insurers and PBMs must apply any amount paid by, or on behalf of, the insured toward the cost sharing responsibility, including: any discount, financial assistance, a manufacturer copay card, a product voucher, or any other reduction in out-of-pocket expenses

The **Florida All Copays Count Alliance** is comprised of locally-based, patient groups that represent millions of Floridians that have serious and chronic conditions, and who rely on high-cost, specialty medications to maintain their health. Copay assistance provides a critical lifeline for these patients.



Health Insurance News

cont'd

Patient Copay Assistance and Copay Accumulators 101

Copay Accumulators: How they work

- Using standard plan design and typical medication costs, the example below demonstrates how a copay accumulator works over the plan year
- The scenarios show how much *more* an insurer collects in payments when a copay accumulator is in a plan, and how a patient could be caught off guard several months into the plan year when the copay assistance has run out
- The bottom line: the insurer collects both the payments made by the patient *and* keeps the payments covered by the copay assistance adding up to a significant amount

- Plan deductible: \$4,600
- ACA annual out-of-pocket maximum: \$8,550
- Cost sharing for specialty tier prescription: 50% *after deductible is met*
- Monthly medication cost: \$1,680
- Manufacturer copay assistance total: \$7,200

Scenario 1: Plan Without a Copay Accumulator Program

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total	Insurer collects
Consumer Pays	\$0	\$0	\$0	\$0	\$0	\$0	\$760	\$590	\$0	\$0	\$0	\$0	\$1,350	\$8,550
Copay Assistance	\$1,680	\$1,680	\$1,240	\$840	\$840	\$840	\$80	\$0	\$0	\$0	\$0	\$0	\$7,200	
Remaining Deductible	\$2,920	\$1,240	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0		

Scenario 2: Plan With a Copay Accumulator Program

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total	Insurer collects
Consumer Pays	\$0	\$0	\$0	\$0	\$1,200	\$1,680	\$1,680	\$40	\$840	\$840	\$840	\$840	\$7,960	\$15,160
Copay Assistance	\$1,680	\$1,680	\$1,680	\$1,680	\$480	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$7,200	
Remaining Deductible	\$4,600	\$4,600	\$4,600	\$4,600	\$3,400	\$1,720	\$40	\$0	\$0	\$0	\$0	\$0		

Deductible is met

Copay assistance limit is met

Out-of-Pocket maximum is met

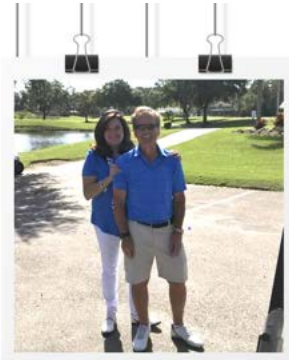


Information is from the Florida All Copays Count Alliance. The Florida All Copays Count Alliance is comprised of locally based, patient groups that represent millions of Floridians who have serious and chronic conditions, and who rely on high-cost, specialty medications to maintain their health. Copay assistance provides a critical lifeline for these patients.



Flight for Tomorrow Golf Tournament

Last year's golf tournament was a little bit different due to the pandemic. Held Monday Oct. 26, 2020, a lovely day for golf, some 60 plus golfers participated with some changes due to Covid-19 including social distancing and following CDC guidelines, along with an outdoor auction and the cancellation of a few of the usual contests. The event was held at East Lake Woodlands Country Club, Oldsmar, Florida. The tournament raised \$42,500 for the HFGF.



We'd like to thank all of our sponsors for helping make the tournament possible:

Title Sponsor

Rhonda and Brian McDonald

Silver Sponsors

Bayer
Novo Nordisk

Bronze Sponsors

CSL Behring
OptumRx, Inc.

Additional thanks go to our auction donors:

Bedgear Pillow
Blossom
Bok Tower Gardens
Bobbie Brown

Kendra Scott Jeweler
PRP Wine International
Rhonda and Brian McDonald

Spirit Airlines
Tampa Bay Buccaneers
Tampa Bay Lightning



2020 Year in Review

This year, as we all know, was not like any other in the history of our lives. That was also true for us at HFGF, and, ultimately, the bleeding disorders community. But we persevered. Early in the year, we had to pivot suddenly to virtual programs learning a new platform that combined Zoom, Webex, and Google.

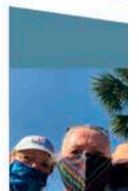
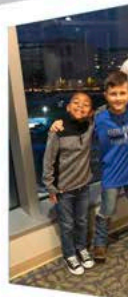
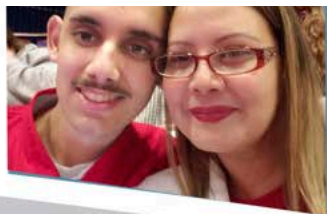
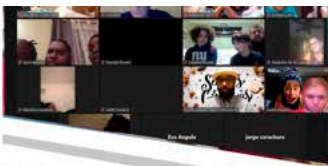
During this time of increased need, the HFGF provided more than \$56,000 in emergency financial assistance for basic life support issues such as rent, light and water bills. The organization also supplied medic alert ids and comfy caps. At holiday time, HFGF gave out more than \$15,000 in holiday gift cards to those in need in the bleeding disorders community. Finally, HFGF awarded more than 13 college scholarships totaling more than \$23,000.

Another mission of the HFGF is education. This is usually done at events that offer members of the bleeding disorders community some fun and stress relief, as well as valuable programs. HFGF held one event with the Orlando Magic. After that, education programs,

like most everything else, went virtual. Throughout the year, there were more than twenty programs including infusion classes, virtual teen retreat, virtual family retreat, virtual summer camp, a cooking class, some women and bleeding disorders programs, support groups, Spanish programming, and events like jeopardy and trivia. These programs served more than 1,500 people.

The third leg of our mission is advocacy. HFGF hosted advocacy days in Tallahassee during which we visited legislators to try and pass a step therapy bill with more than twenty-five volunteers participating.

Fundraising becomes even more challenging during a pandemic. Early in the year, the HFGF held two successful events. The inaugural Red Party and the Theater Event featuring Aladdin. With the advent of fall, our annual Flight for Tomorrow Golf Tournament was held near Tampa. The four Walks for 2020 were all virtual. Thank you to all who donated and all who volunteered. Your support is priceless.





Play March Madness with the HFGF!

Join us for the HFGF March Madness pool. Just enter, and you will receive a link so that you can fill out your bracket for college hoops' big show. You will be raising money for the HFGF while having fun. Entry fee is a \$30.00 donation.

There will be prizes awarded for the top three brackets.

Some important dates:

March 14, 2021 Selection Show. Teams are announced after 6 P.M.

March 19, 2021 at 12:15 p.m. ET Pool's Pick Deadline

Tournament Dates included in Pool March 19-April 5, 2021

You can donate and create a bracket entry by going to:

<https://www.hemophiliaflorida.org/hfgfmarchmadness/>



SAVE THE DATE Annual Flight for Tomorrow Invitational Golf Tournament

Monday, October 25, 2021

East Lake Woodland Country Club

1055 E Lake Woodlands Pkwy,
Oldsmar, FL 34677

<http://www.hemophiliaflorida.org/fundraising/golf-tournament/>





Research Update

The First National Patient Satisfaction Survey of U.S. HTC

The federally funded hemophilia treatment center (HTC) network, with its model of a multidisciplinary care team (MDT) and regional infrastructure, has proven itself, over several decades, to be well suited to deliver quality, integrated healthcare to bleeding disorders patients across the U.S. While this system has allowed for various surveillance and data collection projects focused on patient demographics, clinical status, and mortality, it has not, until recently, been leveraged to gauge patient satisfaction on a national level.

The authors of a new paper published in the journal *Haemophilia* posit that patient satisfaction with the delivery of care is an important metric that is associated with treatment adherence and better overall health outcomes. Therefore, a first-of-its kind, nationally uniform and comprehensive patient satisfaction survey (PSS) was conducted and made possible via the coordination of the HTC network's robust regional infrastructure. A steering committee made up of three of the network's regional coordinators initiated and managed the PSS. They were guided by performance standards of the hemophilia program of the U.S. Health Resources and Services Administration (HRSA); the agency provides limited funding to support the eight designated regions that make up the HTC network.

The survey was designed to assess patient demographics, their satisfaction with the HTC's core MDT, plus affiliated clinicians, services, and care processes. The MDT core includes the hematologist, nurse, nurse practitioner, social worker, and the physical therapist. In addition, three fundamental HTC services were rated, including shared decision making and care coordination with both the primary doctor and with other specialists/providers.

Lastly, five key HTC processes were evaluated for patient satisfaction: timeliness of care, ease of getting needed information, ease of understanding how the HTC clinic staff explained things, time spent with clinic staff, and being treated with respect.

All 138 HTCs that were operating in 2014 were invited to

participate in the PSS. The eight regional coordinators of the Network helped facilitate the promotion and dissemination of the survey to HTCs and provided technical assistance to ensure a nationally consistent administration. In February-March 2014 the survey was disseminated to an estimated 28,289 households of patients with which the HTC had a "significant clinical interaction" that same year. The subsequent data collection period through

June of 2015, with the University of Colorado serving as coordinating institution for all data collection and aggregation. To make possible comparisons to other populations, regions were collapsed from eight to four standard regions including West, Midwest, South, and Northeast.

The overall participation rate for HTCs was high as 133 out of 138 centers (96.4%) opted into the survey. In sum, 5006 individuals who received care from a center in 2014 completed the PSS, representing a 17.7% national response rate. At 29.2%, females represented almost a third of the participants, the majority of which were White, non-Hispanic. A look at participants grouped by age shows a fairly even breakdown amongst the groups, while there were significant differences in partic-

ipation levels amongst the four geographic regions with 42.1% (2109) from the Midwest, 27.9% (1398) from the Northeast, 19.0% (952) from the West and 10.9% (547) from the Southeast. The majority of the respondents, 3,106 (62%) had hemophilia, 1299 (25.9%) had von Willebrand disease (VWD), and 601 (12.0%) reported diagnosis as "other," "unknown" or did not specify. Overall, those with a severe hemophilia and type 3 severe von Willebrand disease represented 29.4%, of respondents, while those with a moderate bleeding disorder, including VWD type 2 or moderate hemophilia accounted for 17.8% of participants. Those with a mild bleeding disorder (VWD type 1 or mild hemophilia) comprised the largest group at 32.8%.

By virtually all measures, results of the PSS suggest consistently high levels of satisfaction with HTCs amongst the more than 5,000 respondents. Overall, 94.2%-97.9%





Research Update

cont'd

reporting responded that they were 'always' or 'usually' (A/U) satisfied with the overall care they received at their center. Participants also rated highly their satisfaction with members of their HTC's core MDT, including the hematologist, nurses, nurse practitioners, social workers, and physical therapists (PTs). A national breakdown by member showed that 97.3% of respondents were A/U satisfied with the hematologist, 97.0% with the HTC nurse and nurse practitioner (combined), 95.1% with the social worker and 95.6% with the PT.

HTC care processes considered integral to PSS also scored very well nationally, with more than 95% of respondent's A/U satisfied with each of the five processes. These included timeliness of care (94.9%); ease of getting needed information (95.0%); ease of understanding how the HTC clinic staff explained things (97.3%); time spent with clinic staff (97.0%); and being treated with respect (98.0%). On a regional level, A/U satisfaction for each of the five care processes was at least 91.2%.

The survey also reflected well on transition issues nationally. Of respondents aged 12-17 years, 90.2% reported being A/U satisfied with how their HTC talked about how to care for their bleeding disorder as they became adults. Similarly, 92.8% of adolescents were A/U satisfied with how their HTC encouraged them to become more independent in managing their bleeding disorder.

The authors point to this initiative's success as a "proof of concept" in the far-reaching utility of a regional infrastructure to deliver meaning and impactful national assessments now and in the future.

"This HTC PSS initiative provides new national data, reducing evidence gaps in quantifying the extent to which patients value the different healthcare professionals on the integrated HTC team, HTC services, processes and overall care. These high levels of patient satisfaction were articulated regardless of patient diagnoses, severity of disease, gender, race or ethnicity, or geographic location, and pose several implications," explained the authors. "First, these data indicate that patients highly value the HTC multidisciplinary team approach."

While the authors do acknowledge limitations, including an imbalance in regional representation, the take home message remains the same; there exists a strong correlation between patient satisfaction and quality of care. Further, such PSS data may be employed in various advocacy efforts, to engage payers, and ensure the viability of the HTC Network.

"The high level of patient satisfaction documented in this inaugural national survey of the US HTC Network's ambulatory services has several important policy implications. Specifically, in the United States, access to HTC care must be guaranteed," conclude the authors. "All payers must include HTCs in their networks to maintain high-quality patient care."

Riske B, Shearer R, Baker J. Patient Satisfaction with US Hemophilia Treatment Center Care, Teams and Services: The First National Survey. Haemophilia. 23 October 2020.

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The Hemophilia Foundation of
Greater Florida



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A new year brings new hope that things will return to at least a semblance of pre-pandemic normal. Our walks have new dates, a new location in one case, and are scheduled to be live events. So, make a note of the one or more that you plan to participate in:

**Gator Clot Trot – August 7
Veterans Park, Gainesville**



**Jacksonville Creepy Crawl- October 23, 2021
Nocatee Community, Ponte Vedra**



**Super Hero Walk- September 25, 2021
Vinoy Park St. Petersburg**



**Orlando Creepy Crawl – October 30, 2021
Baldwin Park, Orlando**

