



**THE  
WINNING  
SPIRIT  
NEWSLETTER**  
WINTER 2022

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## Upcoming Events:

### March 4-5

Advocacy Ambassador Retreat with  
Western PA Bleeding Disorders  
Foundation (WPBDF) Bedford  
Springs

### March 8-10

Washington Days

### March 25

Bowling for Bleeding Disorders

### April 13-16

HFA's Annual Symposium

### April 29

Patient Education Day

### May 6

Spring Fling Family Day

### May 19-21 (TBD)

Family Camp

### June 21

EPBDF Annual Meeting

### August 17-19

NHF's Bleeding Disorders Conference

## Hemophilia Treatment Centers



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# REFLECTIONS FROM ALASKA

## From Greta Hayden-Pless

### **CAMP MAGIC: FAMILY CAMP WEEKEND**

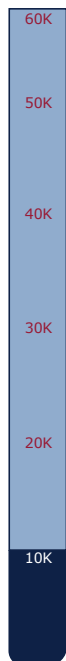
When I think of camp all my memories are surrounded by a special sort of magic that the camp creates. I have seen this magic flow through the memories of everyone who has ever had the chance to attend camp. I've been a camp counselor for several years and I volunteered at camp before that. When I became an intern for Eastern Pennsylvania Bleeding Disorders Foundation to help plan their Family Camp weekend, I was so excited. However, I was also terrified because I wanted to be able to create the camp magic that I knew so well for these families. Staff worked tirelessly making sure everything was planned well, food was catered and the activities planned enjoyed by all ages. I would like to think we succeeded. When we first arrived at Camp Kweebec on a beautiful September weekend, there was a buzz in the air of excitement that increased as we prepped for the arrivals of the families. With the arrival of the families that excitement only continued. Over 40 families attended family camp weekend. They were met upon arrival with a swag bag of family camp weekend shirts, given cabin assignments, and set off to unpack and get ready for the weekend ahead. The first day was filled with a basketball clinic, a carnival, massages for the adults, and a giant inflatable outdoor movie of Avatar. The only downside to the whole weekend turned out to be the one thing we could never control: the weather. While during the day it was sunny and pleasant, the nights dropped in temperature and in cabins with no closed windows, it was a bit chilly. However, we did not let this dampen our spirits or our weekend. The next morning everyone rose to the excitement of color wars; where families were split into different teams to compete against each to see who the color wars champion would be. Color wars consisted of creating a banner and a team

chant, tie dyeing handkerchiefs, and a massive water balloon dodgeball fight. The teams duked it out on the field dipping, dodging, ducking, and dodging water balloons while laughter filled the air. The games wrapped up with a massive game of Simon Says with different team members coming up to be Simon. The judges deliberated over lunch, and it was determined that the red team was in fact the winner this year! The afternoon was filled with lake activities, Bingo, slime creation, and basketball. It was no surprise everyone was ready for the incredible magic show later that night performed by Crescent Circus who came all the way from New Orleans, LA. The jaw-dropping act still leaves me with questions, I have no idea how they did it. We added some of our own magic to the show with our very own hair fairy. We figured the audience could use a little sparkle as well. We ended the night with a dance party, dancing our hearts out on the dance floor, which turned into limbo for a brief moment. This weekend also provided the opportunity to attend a self-infusion clinic, which gave those who are nervous or wanted to learn a chance to gain a bit of independence, or just to gain some practice. We also offered education sessions provided by HFA. All in all, the weekend was filled with laughter, smiles, sparkling hair, and strengthening the bonds within our community. It gave families a chance to come together and learn from one another, but also to feel the support that they are not alone. It created an environment where they were surrounded by people who completely understood what it's like to have or to care for someone who has a bleeding disorder. Most importantly, this weekend gave families a chance to be a family and have fun in a beautiful setting. I would like to think that we created the camp magic that will live in all the families' memories, and hopefully we'll create it again next year.

# ANNUAL CAMPAIGN

Dear Foundation Supporter,

The Board of Directors and Staff at Eastern Pennsylvania Bleeding Disorders Foundation (The Foundation) wish to offer our sincere gratitude for your encouragement in this year of transition. The Foundation is proud to announce that in 2022, we awarded \$36,000 in college and trade school scholarships and over \$20,000 in patient aid. We are thankful you enabled us to provide this support to our local bleeding disorders community, and want you to know what a positive impact you made. Many of our scholarship and aid recipients sent heartfelt, handwritten letters or emails to thank us for our help and compassion, and how it is always provided with dignity. We want to continue to provide funding for our students and community, as it is a critical part of our mission: *The Eastern Pennsylvania Bleeding Disorders Foundation*



*strives to bring together those affected by bleeding disorders in our 41-county coverage area so that we can all feel a sense of connection and support through education, programming, advocacy, and financial assistance.*

Our Annual Campaign goal is to raise \$60,000 by the end of December to be used for patient aid, college and trade school scholarships, and in other ways to directly support our community in 2023.

Our Annual Campaign runs from November 1 through December 31. Of course, we welcome donations any time throughout the year. Charitable contributions are tax deductible and you will receive an acknowledgement for your gift.

Any amount is appreciated, and payments can be sent in the following ways:

1. Send check made payable to:

**Eastern PA Bleeding Disorders Foundation**

148 W. State Street Suite 305

Kennett Square, PA 19348

2. GiveButter: Scan QR Code or copy and paste URL: <https://givebutter.com/Annual-gift>



3. Text PatientAid to 53-555

Please follow us on Facebook, Twitter, Instagram and LinkedIn to follow our progress, events, and other important community information.

On behalf of the Board of Directors and Staff at Eastern Pennsylvania Bleeding Disorders Foundation, *thank you*. We look forward to seeing you soon.

Sarah Pilacik

Executive Director

# ADVOCACY



Making Pennsylvania a better place  
for those with Bleeding Disorders.

October 25, 2022

Majority Leader Ward  
Senate Box 203039  
Harrisburg, PA 17120-3039  
Room: 292 Main Capitol

Minority Leader Costa  
Senate Box 203043  
Harrisburg, PA 17120-3043  
Room: 535 Main Capitol

Dear Senate Leaders,

On behalf of both the Western and Eastern Pennsylvania Bleeding Disorders Foundations, we are writing to submit our support for SB 225. In anticipation of the House passing SB 225, we are asking for your support on concurrence.

This legislation will create a quicker, more efficient prior authorization process. The bill also provides a clearer route to request an override from the step therapy process.

Health insurance practices such as prior authorization and step therapy allow insurers to deny a prescribed medication or treatment, requiring patients to try and fail different treatment(s) before approving the original. Additionally, these practices undermine the patient-provider relationship and delay access to needed treatment which may result in worsened symptoms and associated higher healthcare costs.

For patients with bleeding disorders, the current prior authorization process is potentially dangerous. **Any delays for patient access to medication can lead to excess bleeds and serious health complications (permanent joint damage, physical pain, etc.).** As a result, there would also likely be additional clinic visits, extra medication usage, avoidable hospital stays, and of course, overall higher health system costs.

**The bottom line: people with bleeding disorders cannot afford to have their healthcare in jeopardy or any disruptions to therapy.** SB 225 would help prevent potential disruptions to healthcare. We respectfully request your support for this legislation as it moves through the legislative process.

Thank you,

Kara Dornish  
Executive Director  
WPBDF

Sarah Pilacik  
Executive Director  
EPBDF

Find  
Your  
Legislator



Please use this QR Code to Find Your Legislator AND to thank them for their work on the increase in our line item for the state budget!

# ADVOCACY

## HARRISBURG OVERVIEW:

On November 30th, the 2021-22 legislative session officially ended. Any outstanding bills that did not pass through the legislature and get signed into law by the Governor will have to be reintroduced in the upcoming session.

## ELECTIONS

On November 8th, Attorney General Josh Shapiro secured his seat as the next Governor of Pennsylvania with over 56% of the vote; Senator Doug Mastriano (R-Franklin) trailed behind at about 43%. **Shapiro's inauguration is scheduled for January 17th, 2023.**

In addition to the gubernatorial race, all House district seats were up for election as well as half of the Senate districts (even numbered districts). Prior to election day, Republicans held a safe majority in both the House (113-89) and Senate (29-21). **However, for the first time in over a decade, Democrats secured a majority of seats (102) in the House. Republicans lost 12 seats, bringing them down to 101 seats.**

It's important to note that three seats will be vacant when the new session begins:

**Representative Tony DeLuca (D-Allegheny)**  
Passed away on October 9th, 2022.

**Representative Summer Lee (D-Allegheny)**  
Elected to Congress.



**SB 225 WAS SIGNED BY  
THE GOVERNOR. IT HAS  
OFFICIALLY BECOME ACT  
146 OF 2022!**

SB 225 (Phillips-Hill, R-York): Amends Article 21 of the Insurance Company law to provide for prior authorization. Prior authorization is the process that health insurers, Children's Health Insurance Program (CHIP) managed care plans, and Medical Assistance (MA) managed care plans use to grant pre-approval for certain health care services as a condition of payment.



**Representative Austin Davis (D-Allegheny)**  
Elected as the next Lieutenant Governor.

These three vacancies would bring Democrats back down to 99 seats and bring Republicans temporarily back in the majority with 101 seats. However, it is anticipated that these three seats will be filled by Democrats in a special election in the spring. The House Majority would then likely go back to the Democrats.

**Republicans will continue to hold the majority in the Senate (28-22).** They recently announced their 2023-24 leadership team:

- Senator Kim Ward (Westmoreland)- President Pro Tempore
- Senate Joe Pittman (Indiana)- Majority Leader

- Senator Ryan Aument (Lancaster)- Majority Whip
- Senator Scott Martin (Lancaster)- Majority Appropriations Chair
- Senator Kristin Phillips-Hill (York)- Majority Caucus Chair
- Senator Camera Bartolotta (Washington)- Majority Caucus Secretary

On the Democratic side, the leadership team is comprised of the following members:

- Senator Jay Costa (Allegheny)- Minority Leader
- Senator Tina Tartaglione (Philadelphia)- Minority Caucus Whip
- Senator Vincent Hughes (Philadelphia)- Minority Appropriations Chair
- Wayne D. Fontana (Allegheny)-Minority Caucus Chair
- Maria Collett (Montgomery)-Minority Caucus Secretary

We anticipate a great deal of leadership changes at the Departments of Health and Insurance as well as legislative committee chairmanships, rank-and-file membership, and personnel.

We'll make introductions (either virtually or in-person) with the appropriate government officials, legislators and staff and ensure that they are familiar with the hemophilia community and any legislative concerns.

One of our many roles as your lobbyist is to ensure that you continue to have an active voice in the Capitol and relevant state agencies. This becomes even more critical during transition times!

## LEGISLATION

### Prior Authorization

- SB 225 (Phillips-Hill, R-York): Amends Article 21 of the Insurance Company law to provide for prior authorization. Prior authorization is the process that health insurers, Children's Health Insurance Program (CHIP) managed care plans, and Medical Assistance (MA) managed care plans use to grant pre-approval for certain health care services as a condition of payment.
- Senate Bill 225 would make an electronic

portal with all pre-authorizations and the accompanying paperwork flow into one site. Standardizing the paperwork and expectations will make a more transparent process.

- If insurers question the validity or necessity of the test or treatment, Senate Bill 225 calls for a peer review by a doctor from the specialty in question, not just any physician.
- STATUS: Passed the House and Senate with unanimous support and was signed into law as Act 146 of 2022.

The foundation authored a letter of support, which was circulated to House and Senate leadership.

Many different stakeholders were involved in the negotiation process, including PA Medical Society, Department of Insurance, among others. Congratulations to all!

## BUDGET

We were able to secure a *6% increase* in the hemophilia line item in the 2022-23 budget bill (SB 1100). In addition, we were able to insert language in the fiscal code (HB 1421) to maintain the current funding distribution.

### General Appropriations Language (SB 1100, Page 265)

Section 221. Department of Health  
FOR HEMOPHILIA SERVICES.  
STATE APPROPRIATION..... 1,017,000

### Fiscal Code Language (HB 1421, Page 120)

Section 1726- F.1. Department of Health

7) MONEY APPROPRIATED FOR HEMOPHILIA SERVICES SHALL BE DISTRIBUTED TO GRANTEEES IN THE SAME PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020

Over the next few months, we're going to start our advocacy for the 2023-24 hemophilia line item. We'll advocate with Senate Appropriations Chairmen Martin and Hughes as well as the new House Appropriations Chairs (once they are announced). We'll also request letters of support again from the Senators and Representatives who directly represent the hemophilia treatment centers.

# "THE POWER OF A SINGLE STORY"

## J. Palumbo

In celebration of our nation's bicentennial the Pennsylvania Department of Health published a series of articles citing extraordinary milestones in the healthcare history of our state. Featured were the origins and founding of the Pennsylvania Hemophilia Treatment Program. Pennsylvania was one of the first states to establish such a program and preceded federal support by several years. A close read will reveal the power of a single family's story to change history. It's been fifty years and our combined story is far from over.

113022

**HEMOPHILIA**

Hemophilia is a disease that affects hundreds of Pennsylvania residents. Effective treatment has been developed to permit hemophiliacs to lead reasonably normal lives, but without State financial support only the wealthy could afford proper treatment and care.

The State became involved in helping the plight of hemophiliacs and their families in 1972 when Gov. Milton J. Shapp first learned of the difficulties a Camp Hill family was having in providing money for the treatment of their son, Kevin Marshall. The family had exhausted all private savings and donations and could no longer afford the \$1,000-a-month hemophilia treatments. The family's effort to obtain State aid was turned down by the Department of Public Welfare unless the father quit his job.

Governor Shapp learned of the situation through news stories early in November of 1972 and arranged for free treatments for Kevin at Hershey Medical Center. Only a month later a bill providing for \$250,000 for hemophilia treatment (ACT 59A) passed the legislature and was signed by Gov. Shapp to provide free State assistance for 800 hemophiliacs in the state.

Hemophilia, for readers unfamiliar with the term, is an inherited disease in which the blood lacks certain clotting factors. Victims are sometimes called "bleeders". The condition lasts throughout one's lifetime—it doesn't go away, nor does it improve. Victims bruise easily, bleed from the kidneys, into joints and into blood excessively when injured and after operations. They know when they are bleeding, experiencing swelling and pain in the area affected.

Not hemophilia centers were established in care for patients. They are located in Philadelphia, Pittsburgh, Allentown, DuBois, Hershey, Harrisburg, Lancaster and Reading. The centers provide evaluation and regulation of registered patients and supply blood products needed by them for blood transfusions. Most of the centers will also train patients or their parents in the techniques for treating themselves, if sufficient medical indication exists for home treatment.

The centers are responsible for determining treatment for patients, be it an outpatient basis, at home, in the emergency room or for a surgical procedure. Most hemophiliacs are

recipients of one of the nine types. However, home treatment is gaining in popularity.

Persons enrolled in the home treatment program have considerably more independence than those who are outpatients. Because of their ability to administer self-treatment, there are fewer visits to the clinics and/or emergency rooms for treatment, more immediate treatment, more self assurance—all resulting in the patient's ability to lead a more independent life in better health, with much less time off from work or school and fewer hospital and doctor bills.

Before the scientific breakthroughs of less than ten years ago, hemophiliacs died at the average age of 11. Then researchers developed a way of isolating the necessary clotting factor to make concentrate of blood plasma clotting factors. HGH hemophiliacs can take the concentrates only when needed to stop bleeding. Moderate or severe hemophiliacs are usually put on regular regimens of the concentrates.

However, some individuals develop inhibitors or antibodies to the concentrates which makes the concentrates relatively ineffective. Other indications are then used in treating these people.

Apart from the possibilities of developing inhibitors, the major problem that has accompanied with the blood product concentrates is the danger of hepatitis. Because large pools of blood donors are required for making the concentrates, it is possible, even with the most sensitive tests and procedures, that the hepatitis virus is present in the concentrates. Though donors are carefully screened, the risk remains high.

The cost to the State for operating the hemophilia program was approximately \$1,450,000 in fiscal year 1974-75.

State funds are used after all other applicable financial sources have been exhausted: private insurance, Federal Title XIX benefits and limited family resources. About 20 percent of those enrolled are required to share part of the cost of concentrates. This share can range from \$50 to \$1,200 a year. About 600 of the approximately 800 hemophiliacs in the state are registered in the State program.

Although hemophiliacs don't usually really bleed to death, slow physical and mental deterioration can take place. Medication helps the body, but psychological support is needed from family, friends and the medical professionals in their day-to-day contact with the hemophiliac.

Pennsylvania's leadership in providing help to hemophilia victims has been cited by the National Hemophilia Association as the best in the nation. The program now serves as a model for more than 600 patients whose medication alone can cost as high as \$12,000 a year.

The director of the state program is Dr. Robert D. Carr. Readers may obtain additional information on the program by writing to Dr. Carr at Pennsylvania Department of Health, P.O. Box 92, Harrisburg, PA 17109.

N.S.F.

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assistance for 800 hemophiliacs in the state.

Hemophilia, for readers unfamiliar with the term, is an inherited disease in which the blood lacks certain clotting factors. Victims are sometimes called "bleeders". The condition lasts throughout one's lifetime—it doesn't go away, nor does it improve. Victims bruise easily, bleed from the kidneys, into joints and also bleed excessively when injured and after operations. They know when they are bleeding, experiencing swelling and pain in the area affected.

Until recently, no treatment was available for such persons, except to splint bleeding joints and rest. This meant time off the job or out of school—which alone marked them as “different”. Chronic bleeding into joints causes severe arthritic crippling, preventing normal usage of limbs. Operations and dental work were out of the question—bleeding complications could result in death.

Act 59A was passed in December, 1972, and implemented in March, 1973—probably faster than any other bill ever passed. Input to the program was received from governmental agencies, the Pennsylvania Affiliates of the National Hemophilia Foundation, interested physicians, patients, and parents of patients.

Nine hemophilia centers were established to care for patients. They are located in Philadelphia, Pittsburgh, Allentown, Darby, Hershey-Harrisburg, Lancaster and Reading. The centers provide evaluation and reevaluation of registered patients and supply blood products needed by them for blood coagulation. Most of the centers will also train patients or their parents in the techniques for treating themselves, if sufficient medical indication exists for home treatment.

The centers are responsible for determining treatment for patients, be it on an outpatient basis, at home, in the emergency room or for a surgical procedure. Most hemophiliacs are outpatients at one of the nine centers. However, home treatment is gaining in popularity.

Persons enrolled in the home treatment program have considerably more independence than those who are outpatients. Because of their ability to administer self treatment, there are fewer visits to the clinics and/or emergency rooms for treatment, more immediate treatment, more self assurance—all resulting in the patient's ability to lead a more independent life in better health, with much less time off from work or school and fewer hospital and doctor bills.

Before the scientific breakthroughs of less than ten years ago, hemophiliacs died at the average age of 11. Then researchers developed a way of isolating the necessary clotting factors in blood to make concentrates of blood plasma clotting factors. Mild hemophiliacs can take the concentrates only when needed to stop bleeding. Moderate or severe hemophiliacs are usually put on regular regimens of the concentrates.

However, some individuals develop inhibitors or antibodies to the concentrates which makes the concentrates relatively ineffective. Other medications are then used in treating these people.

Aside from the possibilities of developing inhibitors, the major problem thus far associated with the blood products concentrates is the danger of hepatitis. Because large pools of blood donors are required for making the concentrates, it is possible, even with the most sensitive tests and procedures, that the hepatitis virus is present in the concentrates. Though donors are carefully screened, the risk remains high.

The cost to the State for operating the hemophilia program was approximately \$1,480,000 in fiscal year 1974-75.

State funds are used after all other applicable financial sources have been exhausted: private insurance, Federal Title XIX benefits and limited family resources. About 30 percent of those enrolled are required to share part of the cost of concentrates. Their share can range from \$50 to \$1,500 a year. About 600 of the approximately 800 hemophiliacs in the state are registered in the State program.

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Pennsylvania's leadership in providing help to hemophilia victims has been cited by the National Hemophilia Association as the best in the nation. The program now serves as a lifeline for more than 600 patients whose medication alone can run as high as \$12,000 a year.

The director of the state's program is Dr. Robert D. Gens. Readers may obtain additional information on the program by writing to Dr. Gens at: Pennsylvania Department of Health, P.O. Box 90, Harrisburg, PA 17120.

M.S.E.



# ADVENTURE SPORTS

## August 20th

Hershey HTC and EBPBF teamed up to host a wonderful event in August for the community at Adventure Sports. Water, fruit and cookies were donated by Giant, and delicious lunchboxes catered by Dafnos. Although it was a hot day, our community came out - we had over 100 attendees! People enjoyed miniature golfing, cars, and more. We will be at Spooky Nook on September 9, 2023 - the date has already been set! Put it on your calendar now. Thanks to Meredith Getz and Colleen Farrell for their hard work in the planning and preparation for such a successful event.



# ANNUAL GOLF CLASSIC

## September 13th

We were given a beautiful September day to golf at Rivercrest Country Club in Phoenixville, PA. It was exciting to see community members come out, as well as industry representatives and EPBDF Board members. All ages and skill levels played this private course. The day started with lunch and ended with cocktail hour, dinner and awards. Special thank you to CSL Behring for their support of EPBDF, as well as pro golfer Perry Parker for providing a fun competition and many great photos with our golfers. Our goal is to include more community members for 2023 so please be on the lookout for more information and mark your calendars for September 12, 2023!



# ANNUAL MEETING

## October 6th

Though not able to personally compare to other EPBDF Annual Meetings, by all counts the 2022 Meeting was a success! We had over twenty sponsors set up in the beautiful Valley Forge Sheraton as new and old friends greeted each other warmly over appetizers and cocktails. A wonderful dinner followed by remarks from Board president Len Azzarano, a six month summary by Executive Director Sarah Pilacik, and Keynote speaker and new Regional Director, Dr. Nathan Hagstrom from Lehigh Valley Health Network. All Hemophilia Treatment Centers were represented by at least one staff member. We will be back next year at the same location, on June 21, 2023! Please mark your calendars!



# 1 WALK

## October 8th

It was a gorgeous fall morning when we arrived to set up for our annual 1Walk at the Elmwood Park Zoo. During registration we provided breakfast snacks and enjoyed the music provided by the DJ. We had over 100 people register for the event including 5 teams. We had a handful of volunteers come out to help, including two of our scholarship recipients who came to hand out our 1Walk T-Shirts. The mornings events opened with an engaging and interactive Animal Meet & Greet followed by announcements and the presentation of gift cards to our 3 highest fundraising teams. The walk started around 9:45 as families and friends set out to enjoy the zoo and the beautiful weather. It was amazing to meet so many community members (some for the first time) and get to know you all a little bit better. We want to give a heartfelt "Thank You" to everyone who came out to support the foundation and we look forward to seeing you at future events. Note: next year, 1Walk will be at a different location in October. We are excited to announce that we are teaming up with NHF and it will be a Unite walk! Stay tuned!



# WOMEN'S RETREAT

## November 3-5th

We kicked off our 2022 Women's Retreat with a pizza dinner and a seasonally inspired craft. We had time to relax, dine with, and engage with our fellow community members while simultaneously using our hands (and brains!) to create a festive craft. Over the course of the weekend we had wonderful speakers, yoga meditation, reiki, food, food, and more food. Some of our attendees were also able to enjoy what Hershey had to offer outside of our scheduled event. Saturday started off with yoga meditation followed by breakfast and the opportunity to meet with nine vendors. Following the foundation welcome we had several guest speakers who presented then facilitated small group discussion. The day ended with yoga mediation, reiki, and dinner. Breakfast started our morning on Sunday which was followed by two more guest speakers and Q&A breakout sessions. All the presentations were informative, engaging, and interactive. We feel so lucky to have such supportive and compassionate female community members and we look forward to seeing you all at our 2023 Women's Retreat - same weekend in November 2023!



# Shared Decision-Making in Hemophilia

*This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Please speak to your treatment team if you have any questions about your/your child's care.*

**This content is brought to you by Pfizer.**

**In shared decision-making, the patient and/or their caregiver collaborates with their health care team. The patient talks about their needs and concerns while the treatment plan is created. Together, the team works to find the best fit for therapies and lifestyle changes that not only takes safety and efficacy into account but also patient preferences and goals.<sup>1</sup>**

## Be a Part of the Team

Patients may find that having a treatment plan tailored to their lifestyle, priorities, and goals can be easier to follow. If the plan doesn't fit into one's lifestyle, it won't offer the best chance at managing hemophilia well. When patients work closely with their health care team and are encouraged to communicate openly about treatment goals, it could lead to an improved quality of life.<sup>2</sup>

The process of shared decision-making in treatment plans does mean that patients need to take some responsibility for their own care. However, being prepared for appointments and clearly discussing the impact of all the available treatment choices could lead to better experiences and outcomes.

## Staying Plugged In

Part of being an empowered patient is being informed about research and advances in new treatments. People who live with hemophilia have choices when it comes to prophylactic, on-demand, and perioperative therapies.

Advances in care and treatments for hemophilia are being made. Maintaining a connection with your care team to ask questions and get information about what options are right for you is key to staying informed. The staff at hemophilia treatment centers and hemophilia advocacy groups are good sources of information on clinical trials, available treatments, and upcoming therapies.

**References:** 1. Nossair F, Thornburg CD. The role of patient and healthcare professionals in the era of new hemophilia treatments in developed and developing countries. *Ther Adv Hematol*. 2018;9(8):239-249. doi:10.1177/2040620718784830 2. Sun HL, McIntosh KA, Squire SJ, et al. Patient powered prophylaxis: a 12-month study of individualized prophylaxis in adults with severe haemophilia A. *Haemophilia*. 2017;23(6):877-883. doi:10.1111/hae.13319

## Taking the Lead

The health care team will often use a patient-centered approach that takes shared decision-making into account. However, in some cases, patients and/or caregivers may need to take a more active role in advocating for themselves and ensuring that their voices are heard.

Connecting with other patients and attending support groups are ways to learn more about how to engage more effectively with the health care team. Pfizer's Patient Affairs Liaisons can also be a source of helpful information on shared decision-making; details on how to contact them can be found at the bottom of this page. Taking the time to understand hemophilia, what treatment options are available, and what one's personal goals (and even family and friends' goals) are will all be a part of preparing for the shared decision-making process.

## Available Decision Tools

In the management of hemophilia, there are multiple therapies available. This is good from the aspect of patient choice, but it also means that putting together a plan takes more thought and effort.<sup>1</sup> There may not be a clear-cut path to developing the "best" plan. This is why patient choice and comparing how options align with lifestyle and preferences becomes important. Researchers and patient advocacy groups have developed tools that can help health care providers and patients work together to decide on a plan.<sup>1</sup> Some of these include:

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- National Hemophilia Foundation: Products Licensed in the US, at [www.pfi.sr/hemophilia-products](http://www.pfi.sr/hemophilia-products)
- Hemophilia Federation of America Dateline Federation, at: [www.pfi.sr/hemophilia-spring](http://www.pfi.sr/hemophilia-spring)



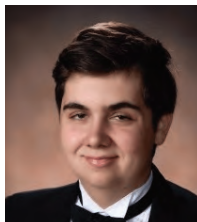
Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

**Visit [www.pfizerpal.com](http://www.pfizerpal.com) to connect with your Patient Affairs Liaison.**

# CONGRATULATIONS

## 2022-2023 Scholarship Recipients

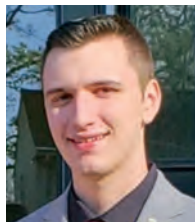
EPBDF is thrilled to award college scholarships to each of the talented students below.



**Kristian Azzarano**  
Sophomore  
Rochester Institute of  
Technology



**Nickolas Azzarano**  
Junior  
Rochester Institute of  
Technology



**Matthew Bayer**  
Junior  
Thomas Jefferson  
University



**Caleb DeFrank**  
Freshman  
Alvernia University



**Isaac Heilman**  
Freshman  
Saint Joseph's University



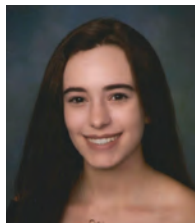
**Kataryna Iannuzzi**  
Junior  
Rowan College at  
Burlington County



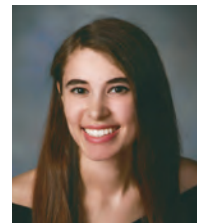
**Michael Iannuzzi**  
Junior  
Rowan College at  
Burlington County



**Rylee Knepper**  
Junior  
Lancaster Bible College



**Justine Lampe**  
Sophomore  
Indiana University



**Nadine Lampe**  
Senior  
University of Southern  
California



**Elisa Macera**  
Senior  
University of Delaware



**Ainsely McFarland**  
Freshman  
Loyola University



**Noah Penica**  
Freshman  
Penn State University



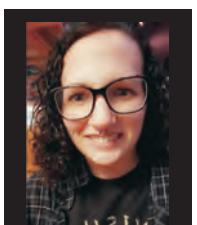
**Jose Perez**  
Freshman  
Community College of  
Philadelphia



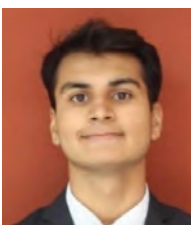
**Tori Robbins**  
Senior  
Stockton University



**Dylan Rooney**  
Senior  
The Catholic University of  
America



**Victoria Selinsky**  
Senior  
YTI Career Institute  
Lancaster



**Tejas Sharma**  
Junior  
Villanova University

# Dedication and Personal Support

**Your Pfizer Patient Affairs Liaison** is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



## Annie Sukhnandan

NY Metro, NJ, E. PA

[annie.sukhnandan@pfizer.com](mailto:annie.sukhnandan@pfizer.com)

**O:** 347-757-0922

*"I've been a passionate and dedicated advocate for the rare disease community for over 16 years."*

### My work is guided by:

#### Compassion

Listening to your needs and addressing questions and concerns that you may have

#### Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

#### Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

*We wish you a season filled with peace and hope, good health and joy. Thank you for your support and encouragement!*

*We will see you in 2023!*

*Greta, Sarah, & Lisa*

*Eastern PA Bleeding Disorders Foundation*



# INGREDIENTS FOR SALT DOUGH ORNAMENTS



You'll only need flour, salt and water to make your ornaments. We do recommend sealing them when they are finished painting. You can seal with either a mod podge or a clear glaze spray.

## How Long to Knead Salt Dough

You will definitely need some elbow grease to knead your salt dough. We like to knead for at least 10 minutes to thoroughly mix the dough. Once you start mixing the dough it will be very dry and flaky. Just keep kneading until it turns into a dough-like consistency. If you find it too dry, add a little more water. If it's still a little sticky, add a little more flour.

## Baking Temperature for Salt Dough

We like to bake our salt dough ornaments at a very low temperature. This helps to reduce any puffing you may encounter when baking. If you raise the temperature and notice puffing simply dial back the temperature again.

You'll need to bake for a long duration when baking at a low temperature. You can also air dry for 24 hours and then bake which helps reduce the baking time required. We do recommend some baking in the oven to ensure all moisture is removed from the ornaments.

## What Paint to Use for Salt Dough Ornaments?

We prefer to paint with acrylic paint. For an even brighter ornament, find a glossy acrylic paint. This will give the ornament a little bit of sheen.

## How to Seal Salt Dough Ornaments

Once you are done, don't forget to seal with either mod podge or a clear glaze spray. We like this spray for a durable finish. Adults should do the spraying and always follow directions of the product chosen. Sealing the final ornaments will help stop them from cracking in a few years.

## Are Salt Dough Ornaments Safe for Pets?

No. Please keep all salt dough ornaments away from pets. If you plan on hanging on your Christmas tree, place high enough that any pets will not be able to reach them. Due to the salt content in the dough, the ornaments can be toxic to pets if they consume them. They are not toxic if touched so if you want to get a paw print ornament done that is fine.

## Ingredients for Salt Dough Ornaments

- 4 cups flour
- 1 cup salt
- 1.5 cups warm water (maybe a little more)
- Ornament Cookie Cutter
- Acrylic Paint
- Glitter

- Clear Glue
- Gold Twine
- Clear glaze spray or mod podge

## How to Make Salt Dough Ornaments

1. Preheat your oven to 250 degrees Fahrenheit. Adults will need to do the baking part, but kids can help decorate!
2. Combine your flour, salt and water and mix. Knead for 5-10 minutes or until your dough is soft. If your dough is too dry, add a tablespoon of water at a time. If your dough is too sticky, add a little bit of flour back in.  
Tip: Add extra flour to your kneading surface, rolling pin and cookie cutters to help stop the ornaments and dough from sticking.
3. Once you're done kneading, roll out the dough to about 1/2 cm thickness. If you make your ornaments thicker, they will take much longer to bake. We recommend thinner ornaments to reduce baking time.
4. Using your ornament cookie cutter, cut out your shapes from your dough. Use a smaller circle cookie cutter to cut out the center of some of your ornaments. To make a hole for adding twine in, use a straw.
5. Bake for 2 hours at 250 degrees Fahrenheit.  
If you find your ornaments are still a little doughy on the bottom, put them back in for another hour. If they are still not dried through after this you can leave them to air dry overnight on a cookie drying rack. Check them in the morning and if they need to still dry out more, you can place them back in the oven for another hour.  
The baking time will vary greatly depending on the size and thickness of your ornaments. Larger ornaments will take longer whereas smaller ornaments will take less time. To reduce baking time, you can also let them air dry for a day before baking.  
Tip: To avoid puffing, make sure your ornaments are not too thick and your temperature is low (250 degrees Fahrenheit)
6. Once cool and completely dried, paint with acrylic paint. We used gold acrylic paint for the tops of the ornaments.
7. You'll want to seal your ornaments before adding your glitter. Make sure your ornaments are completely dried through before sealing. Spray with a clear glaze spray (adults only) or finish with mod podge.
8. Now add clear glue on top of your ornament and shake glitter on top until you fill the ornament with glitter. For the photo versions we just put a few lines of glitter across the ornament.
9. Glue a photo to the back of the ornament. We would recommend hot glue (adults should do this part) to ensure the photo stays if using a laminated or a real photo. If printing photos from your computer you can use regular glue.
10. Once you're done, add your gold twine for hanging them on the tree.

# APPRECIATING GRETA

On behalf of the Foundation, we would like to extend our heartfelt gratitude and appreciation to Greta for her investment and expertise as she both interned and worked for us since July. Greta has taught us so much about the bleeding disorders community. She has jumped right in (literally and figuratively) with passion and dedication and has done so much for not only Family Camp, but many other events. She even made a Zoom appearance at our Women's Retreat to be on a panel. It would be impossible to list all Greta has done for EPBDF, and her work has been critical to the success of this year. We look forward to collaborating with Greta as the years go on. She is always welcome as both an expert intern and a beautiful soul.



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## NEW CONTACT INFORMATION?

If you have an updated address,  
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please send to  
[info@hemophiliasupport.org](mailto:info@hemophiliasupport.org).

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Eastern PA Bleeding Disorders Foundation  
Liberty Place at Kennett Square  
148 W. State Street, Suite 305  
Kennett Square, PA 19348

## IN SEARCH OF:

**PA DENTISTS/ORAL SURGEONS  
WHO KNOW HOW TO TREAT  
PEOPLE WITH BLEEDING  
DISORDERS, AND DO IT WELL.**



**OR**

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DISORDERS FOUNDATIONS ARE  
CREATING A LIST OF THESE  
PROVIDERS SO THAT WE CAN HELP  
OTHERS WHO NEED IT.

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CHAPTER IF YOU HAVE A REFERRAL,  
CLICK ON THE LINK, OR SCAN THE QR  
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