

EASTERN PENNSYLVANIA HEMOPHILIA FOUNDATION



OCTOBER 13, 2019

FUNDRAISING TOOLKIT

Thank you for making a difference in the bleeding disorders community!

By fundraising for the Trick or Trot Walk, you are helping to support medical research and provide financial assistance, education, family programming and advocacy at the state and federal level. **Every cent that you raise goes directly toward creating happier and healthier lives for those affected by hemophilia, von Willebrand disease and other clotting factor deficiencies.**

Check out the resources and tips provided in this toolkit to get started today!

WHY FUNDRAISE FOR THE EASTERN PA HEMOPHILIA FOUNDATION?

OUR MISSION: The Eastern Pennsylvania Hemophilia Foundation supports medical research and provides financial assistance, education, family programming, and advocacy at the state and federal level to benefit local patients with hemophilia, von Willebrand disease and other clotting factor deficiencies.

**College
Scholarships**
\$34,000.00

Advocacy Support
\$54,000.00

**Financial
Assistance**
\$36,000.00

**Community
Events**
\$103,000.00



**Medical
Research
Grants**
\$55,000.00

Total Impact in 2018: \$282,000.00

With your support, in 2019 we can further our mission and expand our total impact for the patients and families in the bleeding disorders community.

Bleeding Disorders

Facts & Figures

- The average cost of treatment for a person with severe hemophilia is approximately \$300,000 per year and can surpass \$1,000,000 if complications occur.
- Approximately 3,000 patients with bleeding disorders receive care at one of the 7 Hemophilia Treatment Centers (HTC) located in the Commonwealth.
- **The 7 treatment centers are:**
 - The Children’s Hospital of Philadelphia
 - The Hemophilia Center of Western Pennsylvania
 - Thomas Jefferson University Hospital
 - Lehigh Valley Hospital
 - Hospital of the University of Pennsylvania
 - Penn State Hershey Medical Center
 - St. Christopher’s Hospital for Children
- CDC studies demonstrate a 40% reduction in mortality and medical complications in patients who receive their care at an HTC compared with those followed by hematologists outside of this network. The overall costs of care are reduced as well.

What is hemophilia?

Hemophilia is an inherited blood disorder. It is due to a deficiency or lack of a specific protein in the blood necessary for proper clotting. The primary symptom of the disorder is chronic, uncontrolled, and often spontaneous bleeding into the joints, muscles, and soft tissue areas of the body. There are three levels of severity – severe, moderate and mild.

What is von Willebrand Disease?

Von Willebrand disease (VWD) is the most common bleeding disorder, affecting between 1% or 2% of the U.S. population. The condition occurs when the von Willebrand factor, a protein that works in unison with factor VIII, is missing or defective. VWD affects both men and women. Symptoms often include frequent nosebleeds, easy bruising and excessive bleeding, particularly following surgery. Like hemophilia, there are three different levels of severity—severe, moderate and mild.

How are bleeding disorders treated?

Hemophilia and related bleeding disorders patients require life-long infusions of expensive clotting factor therapies to replace the missing or deficient proteins in order to prevent life-threatening bleeding.

Due to their biologic nature, clotting factor therapies require specialized storage and handling. Thus, patients cannot access their medications at your traditional neighborhood pharmacy. Instead, medication is provided through specialty pharmacies.

Specialty pharmacies (including hemophilia treatment centers participating in the federal 340B program) usually deliver life-saving clotting factors to patients via mail or other home delivery method and provide a range of support services not offered by traditional pharmacies.

Where do bleeding disorders patients receive care?

Hemophilia and related bleeding disorders patients need access to hematologists and other health care professionals and specialists knowledgeable about hemophilia. Most patients receive care at a federally funded hemophilia treatment center (HTC).

HTCs provide comprehensive care via specially trained multi-disciplinary teams that include hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists, and dentists, among others.

HTCs treat the whole person and the family, through continuous monitoring of all the medical and psychosocial aspects of bleeding disorders, including their physical, emotional, psychological, educational, financial, and vocational factors.

FUNDRAISING TIPS

Whether you are part of a team or not, we need your help now more than ever! **Registration fees cover your entrance into the zoo and all additional donations support the patients and programs of the Eastern PA Hemophilia Foundation.**

Fundraising doesn't have to be intimidating and can be as simple as asking for spare change. Every little bit helps whether you are a solo walker or part of a big team.

Use these ideas to help you fundraise above and beyond your registration fee!

IDEAS FOR EVERYONE

- **Start early.** The sooner you start fundraising, the more time you have to grow your fundraising total.
- **Set your fundraising goal.** Give yourself something to strive for. You would be surprised what you can do!
- **Make a personal donation.** Be the first to show your commitment to the bleeding disorders community by donating first.
- **Start a team.** Ask your friends, family and coworkers to join you in supporting the Eastern Pennsylvania Hemophilia Foundation and the 2019 Trick or Trot Family Walk!
- **Send emails.** This is a great way to share your message and goals. Share your story and include the link to your online fundraising page. Don't be afraid to follow up if people don't respond.
- **Reach out on social media.** Send messages and share your progress. Don't forget to thank your donors as well!
- **Ask about employer matching gifts.** Many companies match their employee's donations. Ask donors if their company will match their gift which will help you raise even more!

10 DAYS AND 10 WAYS CHALLENGE

Day 1	•Show your commitment! Start by making your own donation of \$25, \$50 or more. Set up your personal fundraising page.
Day 2	•Ask two family members for \$25 each.
Day 3	•Ask a business you frequent to donate \$25.
Day 4	•Ask five coworkers to sponsor you for \$20 each.
Day 5	•Ask your boss for a company contribution of \$100.
Day 6	•Ask five people you know from your hobbies/acitivities to donate \$10; i.e. sports teams, book clubs, gym class etc.
Day 7	•Ask five friends to donate \$20 each.
Day 8	•Turn it around! Ask someone you have supported in the past to support your cause with \$25.
Day 9	•Ask your company if they offer matching gifts.
Day 10	•Do a Facebook fundraiser. Post on social media, people want to support you, you just need to ask!

NEED MORE IDEAS?

Call our office anytime at 484-445-4282

CREATING YOUR TEAM

The first step to a building a successful team is choosing your team captain.

Every Action you take as a team captain falls into one of **four** categories.

Register. Recruit. Raise Funds. Recognize.

Register. Your first step as a team captain is to register and create your team page. Your online team page will allow you and your team to easily track your team's fundraising progress.

Recruit. Spread the word and encourage others to join your team. Send an email to everyone you know asking them to join your team, or give a donation instead.

Raise Funds. The 2019 Trick or Trot Family Walk is a fundraising event, so all team members are encouraged to raise funds online or offline. Help your team members get registered and encourage your members to set up a personal fundraising page where their friends, family, and co-workers can contribute easily to their efforts online.

- **Call the Foundation at any time for help setting up your personal and team page**

Recognize. Recognition of your team members is a MUST for an effective team! Team members who reach certain levels of fundraising may be eligible for special prizes and incentives. Be generous with emails, texts, and calls to let your team know you're proud of their work.

Team Captain Checklist

Get started (3-4 months before the walk)

- Choose your team captain and create your team!
- Name your team something meaningful and creative
- Set your team goals
- Customize your team page
- Set the bar for your team; make the first donation to your team page
- Brainstorm who you would like to recruit
- Invite your recruit list to not only join your team but to donate as well
- Make sure all team members register and join your team during registration
- Have a kick-off meeting
- Check your company's matching gift policy
- Place articles in your company newsletters or intranet site to recruit team members and/or donations
- E-mail your team weekly with fundraising updated and be sure to highlight new team members

Keep up your momentum (1-2 months before the walk)

- Send out fundraising e-mails to ask for donations and remind your team to send out their emails too
- Update the team page with personal stories, photos, and progress
- Distribute flyers to shops and restaurants in your neighborhood
- Host a team fundraising event (see team ideas later in this kit)
- E-mail your team weekly with fundraising updates and recognize your top fundraisers
- Collect team checks and cash. You can send all cash and checks to the office (Victoria Business Center, 1489 Baltimore Pike, Suite 227, Springfield, PA 19064). We will record offline donations on your team page as they come in.
- Order your custom team t-shirts if you're planning on having them

Team Captain Checklist (cont.)

The week before the walk

- Coach all your members to send one more fundraising email
- Register any unregistered new team members
- Email your team all the event details; team meet up location, start time, where to get their team t-shirts, parking, and recognize all your fundraising leaders and anyone who has met the fundraising minimum

Walk day

- Arrive early
- Register any unregistered new team members
- Turn in any donations collected in person at the event
- Take team photos
- Enjoy the day, you did it!
- Post event photos and recognize your team on social media

Immediately after the walk

- Send a thank you note to all of your donors with a team photo from the event
- Send an email to all team members thanking them and send end results of fundraising efforts
- Send follow up emails to those who didn't donate. Share your experience with them and give them one more chance to donate
- Collect and turn in any outstanding pledges
- Send the Foundation any photos you took during the event

IDEAS FOR TEAMS

- **Get organized.** Plan a get-together with your team! A dinner, happy hour or coffee break is a great way to get people involved and to brainstorm.
- **Movie Night.** Host a movie night at your home or local gathering space for friends and family. Make some popcorn/small snacks and ask for a small donation to support the bleeding disorders community.
- **Party with a Purpose.** Invite your friends and their mutual friends over and charge a few dollars for a good cause!
- **Spare change jar.** Ask your work to put out a “change jar” for people to drop in their spare change. You would be surprised how much change can add up! Penny Wars is another great idea. Split your office into teams and see which team pulls the most change!
- **Game Night.** Invite your friends over for a night of games, donations and prizes.
- **Charity night.** Host a charity night at a local restaurant, bar or coffee shop.
- **Write a letter.** A written letter goes a long way! Share your story and who YOU walk for!

IDEAS FOR CORPORATE TEAMS

- **Collect extra change.** Ask coworkers if they can spare some change by placing a jar in a common area.
- **Prize drawing.** Request a \$10 donation from your coworkers for a chance to be entered into a drawing for gift cards, parking spaces, corporate tickets, etc.
- **Host a casual/jeans day.** An extra “jeans day” is a great way to get some donations! Ask for a small donation in exchange for a chance to dress down to work.
- **Pie in the face event.** Make a donation for a chance to pie someone! A sweet way to support our community.
- **Create an in-house raffle or auction.** Procure or donate items for an in-house fundraiser.
- **Create friendly competition.** Offer a prize to motivate your team members to contribute more to your team total!

Tips BEFORE Your Fundraiser

1. Choose Your Time

- Give yourself plenty of time to plan, prepare and ask for donations. We recommend a timeline no more than 3 months before the fundraiser and no less than 2 weeks before. This creates an urgency for people to give to your fundraiser without giving a tight deadline.

2. Set an Achievable Goal

- \$40 provides a Medic Alert bracelet for a patient in need. \$30 provides a child with a comfy cap. Creating a goal that revolves around direct impact can be extremely helpful. A goal also gives you a reason to update your audience and follow up with them after they have donated.

3. Approve all Collateral

- Please share any marketing materials with the office to ensure appropriate use of our logo. We will also market your fundraiser to our database!

Tips DURING your Fundraiser

1. Be the First to Donate

- Encourage others to donate by making the first donation yourself. Make your donation the same amount you are hoping to receive from your supporters so you can ask them to match your donation.

2. Share

- Spread the word via email, social media and personal phone calls. Ask your friends and family to share too! You can hit a wide audience in a short amount of time. Tag us on social media and we will share as well!

3. Ask!

- Don't feel shy to ask. Often times people are honored to be included in your fundraiser. Many people plan on donating but simply forget - follow up and encourage donations early.

4. Document Your Event

- Involve your donors by taking photos, sharing stories and getting quotes from participants. Your event may even end up in our newsletter!

Social Media Guide

Social Media is changing the world every day. One of the best tools for your fundraiser is utilizing social media. Whether you're hosting an event, managing a fundraising page or even doing a social media fundraiser, sharing what you are doing and why will help get others involved. Here are a few tips to help you utilize social media for your fundraiser!



FACEBOOK

- Create a Facebook event and select friends to attend. This can be a great tool to keep track of those attending and the interest in your event. Ask friends and family to share the event with their network.
- Share your personal fundraising page with a link that donors can use to access your page.
- Let others know your “Why”
- Share your personal story!
- Thank donors by giving them a shout-out.
- Tag us so we can share!

SAMPLE POST

- **The Eastern PA Hemophilia Foundation helps our community in important ways such as providing scholarships and financial assistance. Please join me in raising money for the 2019 Trick or Trot Family Walk! To join my team or to donate, please go to:**
<http://runsignup.com/kimboskrew>



TWITTER

- Introduce your fundraiser to your followers; briefly explain why you are doing the #TrickorTrotFamilyWalk
- Share a link to your personal fundraising page so that they can learn more about your event
- Tweet before, during and after your event. Keep your supporters updated on your planning process, goal updates and a recap after!
- Remember to include @hemophilia_epc and #TrickorTrotFamilyWalk in your tweets so we can share!

SAMPLE TWEETS

- **When you're a Kimbo's Krew Walker, you never walk alone. Walk the #TrickorTrotFamilyWalk with us this October @hemophilia_epc.**
<http://runsignup/kimboskrew>



INSTAGRAM

- Take photos of your fundraiser!
- Include links to your personal fundraising page in your post
- Tag us @hemophilia_epc and we will share!

FREQUENTLY ASKED QUESTIONS

When are donations due and how can I get check/cash donations on my page?

We accept donations all the way through the Trick or Trot event, in fact a lot of donations are received day of or a little after. If you receive checks or cash as donations, let us know and we can manually add it to your team page.

Will a donor receive a tax deduction letter for their donation? If the donation was made directly to your team page, the donor should automatically receive a receipt through their email. If you receive a donation in hand or for some reason an online donor did not receive a letter, let us know and we will be happy to create a letter and mail it.

I need tax identification information to request a fundraiser at a local business, where can I find that? Contact us! We are happy to provide the necessary paperwork and work with you to make the fundraiser successful! We can also share your event and even attend if possible.

Will the staff from Eastern Pennsylvania Hemophilia Foundation be at my fundraiser? While we wish we could be at every fundraiser to support our community, we cannot guarantee Foundation staff presence. Please let us know as soon as possible the date of your fundraiser and we will make every effort to have someone there if the date is available.

We're here to help you.

If you have any questions not answered above, please don't hesitate to contact Kat Kocsi at katk@hemophiliasupport.org or 484-445-4282