

Fundraising Toolkit



Welcome to the Plasminogen Deficiency Foundation's Fundraising Guide!

Thank you for joining our fundraising effort! Your donations, and those of your personal network, go to support the mission and work of the Plasminogen Deficiency Foundation and all the needs of our community.

This toolkit has everything you need to set up your fundraiser, create your fundraising page, rally your network, and help us raise money for our cause.

We are so honored that you are taking the time to join this critical effort with us. Thank you for being a part of our dedicated, caring community—we couldn't do it without you.

Let's do this!

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Who We Are

The Plasminogen Deficiency Foundation is a 501(c)(3) nonprofit, founded in 2020, whose mission is to improve the lives of patients with plasminogen deficiency (PLGD) by promoting awareness of the disease through education and advocacy, creating a community for those affected by PLGD, supporting research to address the current knowledge gaps in plasminogen deficiency, and supporting development of sustainable treatments.

The success of the Plasminogen Deficiency Foundation to achieve our mission and support our community is due to the generous financial support from PLGD families, friends, and businesses through donations and fundraising events. 100% of donations go directly to the work of the foundation, and the support of our patients. We are grateful for any and all donations and could not do it without you! This toolkit is meant to help in the planning, executing, accounting and acknowledgement of fundraising for your event, to benefit the PLGD Foundation. Everyone can make a difference!

What Is Plasminogen Deficiency

As a PLGD Foundation fundraiser, you have the ability to inform your contacts about Plasminogen Deficiency (PLGD), the work of our PLGD Foundation, and how their donations make a difference.

Symptoms

Symptoms of plasminogen deficiency type 1 (PLGD-1) are due to an accumulation of fibrin, a protein involved in the blood clotting system. Individuals with PLGD-1 have too little of the needed normal plasminogen activity to help regulate and dissolve fibrin once formed.

The most commonly reported symptoms are lesions in the eyes. Other affected organs include the ears, nose, mouth, airways, gastrointestinal and genitourinary tracts, and less commonly, the central nervous system. These abnormal lesions are called “ligneous” because they are “wood-like” in their appearance and can affect the normal function of the involved organ.

Plasminogen deficiency (PLGD) is inherited in an autosomal recessive fashion due to mutations on chromosome 6. Many different mutations have been identified in type I deficiency.

PLGD-1 is a very rare genetic disorder estimated to affect 1.6 per 1 million persons. The true prevalence may be under-estimated because the symptoms can present in a variety of ways to many different types of healthcare providers (ophthalmologists, dentists, ENT physicians, gynecologists, etc), and may not be recognized as a symptom of plasminogen deficiency.

Inheritance and Prevalence

Diagnosis and Treatment

In patients with plasminogen deficiency type 1, blood levels of plasminogen activity are reduced. Diagnosis therefore depends on the development of symptoms followed by blood testing to confirm a deficiency of plasminogen (performed by plasminogen activity and antigen assays). Genetic testing can also help establish the diagnosis in the absence of symptoms.

In June 2021, the FDA approved [Ryplazim](#), the first-ever treatment for patients with plasminogen deficiency. This medication is plasminogen, purified from human plasma, that is given as an infusion into the bloodstream. Ryplazim was found to be safe and effective in a clinical trial of 15 adult and pediatric patients with plasminogen deficiency, and represents a major advancement in the treatment of this rare disorder. It should be considered the first-line treatment for patients with plasminogen deficiency.

Despite the effective treatment available, there are many things that are not well understood about PLGD-1, including how to manage treatments over time, severity categories, and how different activity levels or genetic mutations correlate to symptoms. More research is needed to understand this rare disease.

Host Your Fundraiser

1. Get Inspired

Fundraisers come in all shapes and sizes - you can host an event, or raise funds completely online. There are many creative ways to put your interest and passions to work on behalf of the PLGD community and we'll be here to help you make it easy and fun. Below are several different types of fundraisers - in-person or virtual events and appeals - that have been held to benefit community foundations. You can choose one of these or host something completely new. Use these ideas to find the fundraiser that works best for you!

EVENTS

Sports Tournaments: Pickleball, Dodgeball, Bowl-a-thons, Golf Tournaments, Basketball Shoot-a-Thons

Sales and Services: Bake Sale; Car wash, Yard sale; Auctions; Bracelet or T-shirt Sales

Parties and Events: Casino night; Concerts; Pub Crawl or Restaurant Partnership; BBQ or Block Party

Contests: Trivia night; Game night; Talent Show

Fitness events: 5K Run/Walk, Half Marathon, Dance Marathon; Obstacle race/Mud run; Cross Fit challenge; Personal Athletic Goals (complete 100 push ups, etc)

Unique social challenges like No Shave November 🙄

APPEALS

PLGD Awareness Day (May)

Giving Tuesday (the Tuesday after Thanksgiving)

Holiday letter or page

Birthday fundraiser (ex: I'm turning 12 and would like to raise \$100 for each year of my life)

Major life milestone ask (graduation, marriage, retirement)

Treatment anniversary

Memorial fund

Corporate Matching Gift Campaigns

2. Create a Personal Fundraising Page

Getting started is easy! We use GiveButter software to help you set up a personalized fundraising page, where you can add your fundraising goal, share your story and the impact that donations will have on you and your loved ones, and then share your fundraising campaign with your network of family and friends.

1

Go to our main campaign page: <https://givebutter.com/fundraisePLGD>

2

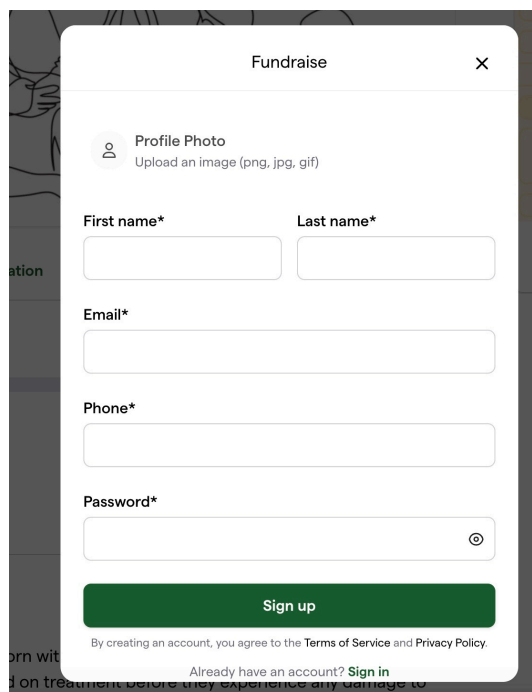
Click the Fundraise button beneath the Progress Bar, in the Team Members section:

Team Members



3

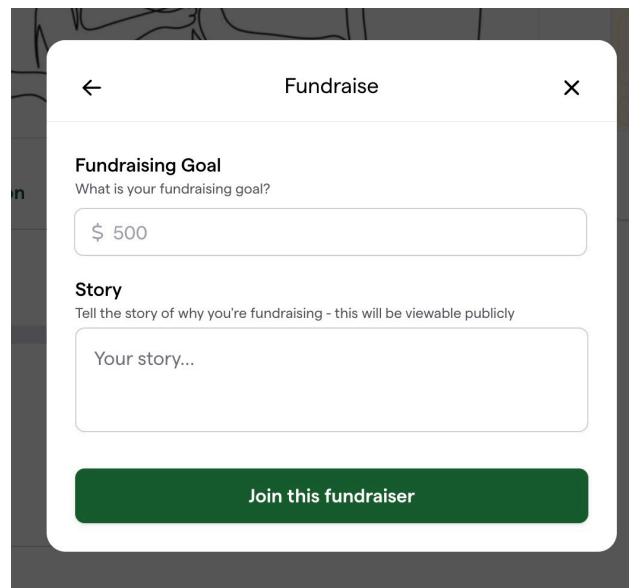
Create an account with GiveButter, or sign in if you already have an account:

A screenshot of a mobile app interface showing a "Fundraise" sign-up form. The form is white with a dark green "Sign up" button at the bottom. It includes fields for "Profile Photo", "First name*", "Last name*", "Email*", "Phone*", and "Password*". At the bottom, there is a link to "Sign in" for existing users. The form is titled "Fundraise" with a close button (X) in the top right corner. Below the "Sign up" button, there is a small line of text: "By creating an account, you agree to the Terms of Service and Privacy Policy." and another line: "Already have an account? Sign in".

4

Now it's time to personalize your page:

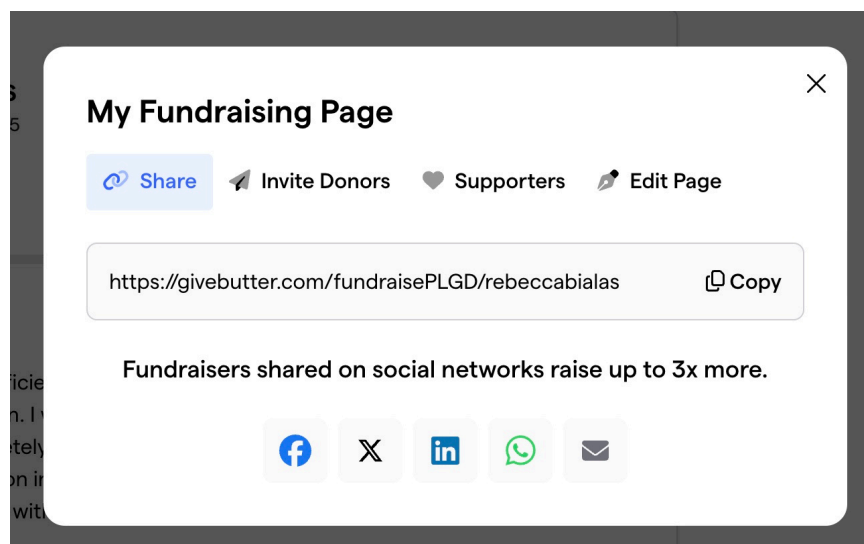
- **Name:** Enter your name to display to all your supporters.
- **Goal:** Set a goal amount that feels attainable for you.
- **Story:** The most important part! Explain your connection to Plasminogen Deficiency, and why donations make a difference to you personally; share your journey with PLGD, or any other details that you think will highlight the important work of the PLGD Foundation.
- **Media:** Add any other photos or videos you'd like to express your passion for the cause!



The screenshot shows a mobile app interface for creating a fundraiser. At the top, there's a back arrow, the title 'Fundraise', and a close 'X' button. Below this is a section titled 'Fundraising Goal' with the prompt 'What is your fundraising goal?'. There's a text input field containing '\$ 500'. Underneath is a section titled 'Story' with the prompt 'Tell the story of why you're fundraising - this will be viewable publicly'. There's a larger text input field with the placeholder 'Your story...'. At the bottom is a green button labeled 'Join this fundraiser'.

5

Share the custom link to your fundraiser campaign – see Forms and Templates, below, for sample scripts to share with your network by email, in person, and on social media. At an in-person event, print and display the QR code (in Forms and Templates, below) to link to our general campaign, and supporters can then donate through your personal fundraising page:



The screenshot shows a mobile app interface for a personal fundraising page. At the top, there's a close 'X' button. Below is the title 'My Fundraising Page'. Underneath are four buttons: 'Share' (with a link icon), 'Invite Donors' (with a location pin icon), 'Supporters' (with a heart icon), and 'Edit Page' (with a pencil icon). Below these is a text box containing the URL 'https://givebutter.com/fundraisePLGD/rebeccabialas' and a 'Copy' button. Underneath is a message: 'Fundraisers shared on social networks raise up to 3x more.' At the bottom are five social media sharing icons: Facebook, X, LinkedIn, WhatsApp, and Email.

When your network makes a donation, it will be credited to your fundraising campaign, so you can see who your supports are:

ncy at th
was able
clear m
providi
PLGD.

\$50
General support for
Foundation activities

\$ OtherUSD

RB

Your support will be credited to:
Rebecca Bialas

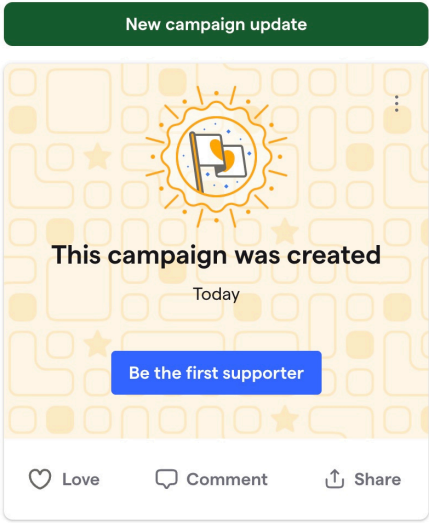
Change

☐ Give in honor/memory

Continue

6

Keep engagement high throughout your fundraiser by posting campaign updates and thanking donors who leave messages on your campaign wall:





3. Get Organized

You've got your idea, and you've set up your personal fundraising page to accept donations. Now its time to plan your event and get organized!

Plan your Event

Arrange all the details for your in-person event including location, volunteers, and supplies. Use our Budget Tracker, below, to keep everything organized. Online event? Once you set up your personal fundraising page, you're all set!

Publicize your Event

Spread the word through email, social media, text, and word-of-mouth to your own network of friends, family, and colleagues. Share a heart-felt message about why this matters to you. Reaching out one-to-one is the most effective way to fundraise. We share **sample donation request scripts** for you to personalize below in Forms and Templates.

Keep Track of Donors

Keep track of donors using our **Contact List**, and track any donations from suppliers or businesses with our **In-Kind Donation Form**, if applicable

Make a Donation

Be the first to make a donation to your campaign. Demonstrate to others that you are fundraising for a cause you believe in.

Keep Momentum Going

Continue to reach out to your network throughout your fundraiser, and provide updates along the way like how close you are to reaching your goal. Post on your personal page wall, on social media and via email.

Post-Event Wrap Up

Once your fundraiser is complete, congratulate yourself on your hard work! Your effort makes a difference! See #4 for a complete Post-Event Wrap Up guide.

4. Celebrate your Effort

You did it! Now that your fundraiser is complete, wrap things up with these steps:

- If donations were made directly through your fundraising page, no action is needed! Those donations are tracked and recorded automatically, and all donors receive instant tax receipts.
- Any donations made by check can be submitted to the Plasminogen Deficiency Foundation by mailing them to:
 - 203 Park Bluff Dr N, Chapel Hill, NC 27517
 - Please include a note that these are from your fundraiser! Cash donations should be converted to a check and mailed that way; please do not mail cash!
- One of the most meaningful steps to take next is to send thank you notes to all your donors! All donors will receive a receipt from the PLGD Foundation for tax purposes, but a personalized message from you makes their contribution even more special. Keep it simple and heartfelt, and let them know how much their support means to you and what kind of impact they've helped make.
- Celebrate your event or your campaign's success by posting photos on social media, and sharing them with the Plasminogen Deficiency Foundation. Your success can inspire other families to host a fundraiser of their own!
- And lastly, reflect on your event, what went well, and what you learned. When you're ready, start planning your next event!

Need to Think Things Through? Chat with Us

If you are interested in fundraising, we want to hear from you, and will work with you to:

- Generate ideas for your event
- Answer questions
- Kick-start your planning process
- Assist with set up of your personalized fundraising page
- Provide PLGD Foundation materials as needed
- Help to publicize your event

Contact us at **volunteer@plgd.org** with your idea for your fundraiser, and we will make sure you have all the support and resources you need to get started!

Frequently Asked Questions

How should I collect donations?

Set up your personal fundraising page to easily accept donations using credit cards, PayPal, Venmo, CashApp, bank draft, or even checks! Collect any checks and mail them to our office.

When should I send in donations from my fundraiser?

We encourage fundraisers to send donations as soon as they are collected, but no later than 30 days after your event.

Can I accept the donations on behalf of PLGD Foundation and send one check?

Checks should be made out to PLGD Foundation with your fundraiser written in the memo line. If you write the check, you will receive the tax receipt and not your donors. If donors are expecting to make a tax deductible donation, for any amount over the cost of goods and services, they will not receive it if you write one check.

What if a check is made out to me and not to the PLGD Foundation?

Simply endorse the check with your signature and add "payable to the Plasminogen Deficiency Foundation" underneath your signature, then submit it with the other checks. The donor will receive a tax receipt from the PLGD Foundation.

Can I mail cash?

Please do not send cash. Please convert the cash to a check and make it out to the Plasminogen Deficiency Foundation, with your fundraiser name in the memo line. In this case, please also send the name and contact information of the donor who made the cash donation, so that we can send them a tax receipt and thank them.

What if a business donates goods or services for my event, such as auction items, or a band who donates their time?

Non-cash gifts are tax-deductible, as long as the gift benefits the PLGD Foundation 100%. You or the donor should fill out the "In-Kind Donation" Form (see below under Forms and Templates). We will send our IRS 501c3 determination if the company donating the gift requests it. We will also acknowledge the in-kind gift as long as the form is filled out and returned to us.

What about accepting donations on Facebook?

The benefits of raising funds through Facebook are convenience and waived transaction fees. The downside is that the PLGD Foundation does not receive any donor information once the money is processed, meaning your donors will not get a thank you letter or tax receipt. This also means we have no way of connecting money that comes through Facebook to your family.

We want to make items for our fundraiser. Can we use the PLGD Foundation logo?

If you'd like to include our logo on any materials, please contact us at volunteer@plgd.org so that we can get you the appropriate version. We also ask that you send us the proof of any materials before printing so that we may approve.

How are donors acknowledged?

Donors who give any amount online automatically get a thank you and tax receipt emailed to them. The PLGD Foundation will recognize all tax-deductible donations and will track all donations for which we receive complete information.

I want to have an event that carries some risk; do I need waivers?

If you are planning a 'high-risk' event (where alcohol is present or a sporting event where injuries may occur), your insurance company can advise what permits and waivers might be needed. The PLGD Foundation does not assume any risk for community fundraiser events.

What if I want to fundraise as a team?

We can help you with that! Contact us at volunteer@plgd.org and we can get you all set up!

I have more questions. Who should I call?

The PLGD Foundation team is here to help you through every step of your event. Contact us at volunteer@plgd.org. We look forward to helping you!

Thank you for considering organizing a community fundraiser to support the Plasminogen Deficiency Foundation! Planning and hosting a community fundraiser is very personally fulfilling, and has a meaningful impact on the lives of those living with PLGD. Thank you for being part of our growing community of fundraisers who are working together to support and improve the lives of patients everywhere living with plasminogen deficiency!



Forms and Templates

Scripts for Asking for Donations:

Below are best practices and sample language for “making the ask” to your social network to help you reach your fundraising goal.

💡 **Pro tip:** Sharing an update at least every five days can make your campaign up to three times more successful!

1. Email 📧

Use email to share your individual campaign link with friends and family and encourage them to contribute. Use the template language below to share your connection to the Plasminogen Deficiency Foundation, and include any photos or videos you’d like to express your passion for the cause!

Keep in mind: Personalized messages make a big difference! Instead of cc’ing a long list of contacts, you might consider copying and pasting your message into individual emails to make the ask more personal and direct.

Sample emails:

Launch day

Subject line: I’m raising **[\$Amount]** for **[Cause]**: Can you help me reach my goal?

Body of email:

Hi **[Name]**,

I hope you're doing well! I'm reaching out because I'd love your support for a cause I know we both care a lot about.

[Provide language here about the need in your community and your organization’s mission].

This issue is meaningful to me because **[Share any personal connection you want to make or feelings about the cause]**.

I’m joining the Plasminogen Deficiency Foundation to help raise enough to **[What specifically the funds will be used for]**.

My personal goal is to raise **[\$Amount]** by **[Date]**. Would you consider donating to my campaign? A contribution of **[Provide example of an amount and impact, e.g., \$50 will sponsor five nights of shelter and care for one child]**.

To make a donation, simply visit **[Your fundraising page URL]**.

Thank you for your support—it means a lot!

Take care,

[Your name]

Reminder (If they haven't already donated, forward your first email and change the subject line so they have all of the info in one thread.)

Subject line: I'm so close to my goal! Can you help me reach the finish line?

Body of email:

Hi **[Name]**,

I'm raising funds for the Plasminogen Deficiency Foundation because **[Provide language here about your organization's vision]**.

I'm **[\$Amount]** away from hitting my goal of **[\$Amount]** by **[Date]**. Can you make a donation to help me cross the finish line? You can contribute any amount right here: **[Your fundraising page URL]**.

I really appreciate your time. Let me know if you have any questions about the campaign!

Thanks,

[Your name]

Thank you (Send an individual, personalized thank you email to everyone who donates to your campaign! A handwritten letter is also a nice touch, too, if you have mailing addresses.)

Subject line: Thank you so much, **[Name]**!

Body of email:

Dear **[Name]**,

Thank you for making a donation to my campaign for the Plasminogen Deficiency Foundation!

Thanks to your generosity, I've been able to raise **[\$Total amount]**—every dollar going directly to **[What specifically the funds will be used for]**.

It means so much to me that you contributed. Thank you for helping to make a difference!

[Your name]

2. Social media 🌟

Take your message even further with social media posts. Contact us if you need logos or graphics from our library to share and customize the sample text below for your captions.

Sample social media posts:

Launch day:

Did you know that **[language here about the need in your community]**?

I'm raising **[\$Goal amount]** for the Plasminogen Deficiency Foundation because I believe **[Provide language here about your organization's vision]**.

Please consider making a donation to help me reach my goal: **[Link to your personal campaign page]** Thank you!

[Provide hashtags]

5 days in:

I've already raised **[\$Amount]** but I need YOUR support to reach my goal for the Plasminogen Deficiency Foundation! Please help me get to **[\$Goal amount]** by **[Date]**.

With your help, we can make **[What specifically the funds will be used for]** possible.

Donate here: **[Link to your personal campaign page]**. Thank you!

[Provide hashtags]

Almost there:

I'm just **[\$Amount]** away from my fundraising goal!

A contribution of **[Provide example of an amount and an impact, e.g., \$50 will sponsor five nights of shelter and care for one child]**.

Please chip in to help me reach my goal by **[Date]**: **[Link to your personal campaign page]**. Thank you!

[Provide hashtags]

Thank you (Get permission to tag friends who have donated!):

Wow—I am blown away by the support of my friends and family who chipped in to raise funds for my campaign on behalf of the Plasminogen Deficiency Foundation!

Shout out to **[Tag individuals]** for helping me reach **[\$Total amount]**!

Thanks to your support, we'll be able to **[What specifically the funds will be used for]**.

Haven't had a chance to contribute yet? It's not too late! **[Link to your personal campaign page]**.

[Provide hashtags]

3. Texting 📱

Connect with your supporters right on their phones with text messages that include a brief note and a direct link to your campaign!

Sample Text Messages:

Launch day

Hi **[Name]**! I'm raising **[\$Goal amount]** for the Plasminogen Deficiency Foundation to support **[What specifically the funds will be used for]**. Can you make a donation to help me reach my goal of **[\$Goal amount]** by **[Date]**? Thank you! **[Link to your personal campaign page]**

Reminder (If they haven't already donated!)

Hi **[Name]**! I'm just **[\$Amount]** away from my fundraising goal! A gift of **[Provide example of an amount and an impact, e.g., \$50 will sponsor five nights of shelter and care for one child]**.

Please consider chipping in to help me reach my goal by **[Date]**! **[Link to your personal campaign page]** Thank you!

Thank you

[Name]—Thank you so much for making a donation to my campaign! I appreciate you so much. Thanks to your generosity, we will be able to **[What specifically the funds will be used for]**. Thank you for making a difference with me!

4. Individual conversations 🍷

Whether you're on the phone or having an in-person conversation over coffee, direct asks are one of the most impactful ways to help you reach your fundraising goal.

Sample talking points:

I wanted to see if you'd be interested in supporting a cause I know we both care a lot about.

[Provide sample language here about the need in your community and your organization's mission.]

I'm joining the Plasminogen Deficiency Foundation to help raise enough to **[What specifically the funds will be used for]**.

My personal goal is to raise **[\$Amount]** by **[Date]**.

Would you be willing to make a donation to my campaign? A contribution of **[Provide example of an amount and an impact, e.g., \$50 will sponsor five nights of shelter and care for one child]**.

Any amount you can give would mean the world to me.

If they say yes: Thank you so much! I can text you a direct link to the fundraising campaign. Would it be okay if I gave you a shoutout on social media?

[Send an email or text after your conversation that says "Thank you again!" and attach the link to your campaign page.]

If they say no or aren't sure: I completely understand. May I send you the link to the campaign page so you can learn more?

[Collect their email address, say thanks, etc.]

Contact List

Budget Sheet

Sponsorship Request Letter

QR Code:



In Kind Donation Form

PLASMINOGEN DEFICIENCY FOUNDATION

Address: 203 Park Bluff Dr N, Chapel Hill, NC 27517

Email: contact@plgd.org

Website: www.plasminogendeficiency.org

The Plasminogen Deficiency Foundation gratefully acknowledges the Indiana Hemophilia and Thrombosis Center and The Chordoma Foundation for their assistance in the development of this Toolkit.