



## Chelsea's Hope 2024 Awareness Campaign Fundraiser Toolkit

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## Welcome!

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Thank you for joining our 2024 Chelsea's Hope Awareness Campaign. We are excited to help you fundraise! Your efforts will provide families impacted by Lafora hope for a treatment! All donations will fund the ION283 Safety Study.

**This toolkit contains everything you need to run a successful campaign and achieve your personal fundraising goal. By doing so, you will help Chelsea's Hope reach our collective goal of \$150,000.**

In this document, you will find background on Chelsea's Hope, an outline for success, sample materials, tips, etc. While we have made every effort to make this toolkit as comprehensive as possible, if you need additional information or assistance, the Chelsea's Hope team is also available to help you in any way we can. We want you to reach your goal! We will be checking in with you throughout the campaign, and please feel free to [contact us](#) at any time as well.

## Campaign Overview

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The 2024 Chelsea's Hope Awareness Campaign will run from September 25 – October 9.

**You can [watch this video overview](#) to get started or read the instructions below.**

To start your own fundraising page, go to: <https://givebutter.com/Lafora24>. There, you will scroll down and click either “Join a Team” or “Fundraise.”

In just a few short steps you'll be able to set up your personal fundraising page:

1. You will need to create a Givebutter account.
2. Join an existing team, create your own, or continue without joining.
  - a. The Chelsea's Hope team is for our Board and staff. Other team ideas are your family, community group, or co-workers.
3. Set your fundraising goal under.
4. Tell the story of why you're fundraising.
  - a. We've made it easy by providing a template to help you get started! Feel free to tweak the suggested messages below or write your own to promote your fundraiser in your own style.

Once you launch your fundraising page, you will receive an email that looks like this:

*Subject: Congrats! You've joined Chelsea's Hope Lafora Children Research Fund campaign.*

***View Your Page  
[your link]***

*Learn how to customize your [story](#) and [goal](#).*

## **Share & Edit Your Page**

[Read the guide.](#)

You can click on the link in that email at any time to get back to your fundraising page.

Once your fundraising page is launched, you can edit it (add pictures, change your story, etc) at any time. After you are done editing the page, be sure to click on the blue “Save Page” button to save!

When you click “Share & Manage” on your fundraising page, you can share your link, invite donors, see your supporters, and go back in to edit.

We aim to put the fun in fundraising! We will host a few friendly challenges throughout the month of September to rally our fundraising community. Be sure to pay attention to your emails throughout the month!

Getting started is as easy as [creating your page](#), adding a personal note as to why this is important to you and sending your link out to as many friends and family as possible! From email to social media, don't be shy! The more people you ask, the faster you'll reach your goal. If just 5 people gave you \$20 you'd reach the minimum goal of \$100. Every dollar raised supports our ongoing efforts to support our patients and help advance treatments and a cure for Lafora.

This toolkit includes more details for those who are new to crowdfunding, but for those who understand the process already, feel free to jump right into your page from here!

## **Getting Started!**

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### **The Basics**

If this is your first time managing your own fundraiser, no worries! We have prepared this toolkit to help you. The Chelsea's Hope team is also here to ensure you meet your goal. Below, we go step by step into how to prepare your website and send it out to friends and family for maximum success.

The detailed steps below are to ensure that everyone has all the information needed to feel ready to hit send by the campaign kick-off on September 25<sup>th</sup> (or before if you desire!). However, they are not meant to overwhelm you! The most important thing to remember is to get your story out there to your community, in whatever way is easiest and fastest for you. So, once you personalize your webpage, be sure to share it on social media, send it out via email, text your friends, and you'll be off and running! Read on for a more detailed way to think through this process.

## **Step 1: Personalize Your Website, Tell Your Story**

You should personalize your website with your family's story and a photo. We have provided sample text in the appendix, which you are free to use in its entirety, but we encourage you to think of our sample as a starting point for telling your own story.

## **Step 2: Create Your Prospective Supporter List**

The secret to the success of any fundraising initiative is to tell your story authentically and to as many people as possible.

You'll want to spend some time creating a list of names/emails to whom you will send your personal fundraising page, and then be ready to follow up with this list throughout the campaign as well. Use the "50 names" exercise in the appendix below to help you start gathering at least 50 contacts. And don't stop there! The more people you ask, the faster you'll reach your goal, and the greater impact you'll have on Chelsea's Hope's mission towards treatments and a cure! If 10 people donated just \$25 each to you, you would raise \$250! It's that simple.

Another tip is that starting with a self-donation is a great way to kick-off your campaign, so once you send out messages, you are already "seeded" with some money!

Finally, think about friends and family located anywhere in the country – or the world! There is no geographic limit to who may be excited to help advance this mission.

## **Step 3: Write your Email(s)**

Once you have your website ready and a list of who you will send it to, it's time to craft the message. This will likely overlap with your story on your website—that's okay! Your goal is to inspire the reader to click on the link to your website and donate. If they see a similar message once they get there, that only serves to reinforce your messaging overall.

You should plan to send at least three emails throughout the campaign, and more if possible! As you think of how to tell your story in that initial email, think also about how to build on that story over the course of an email series.

We include a sample of how to build your email series in the appendix.

## **Step 4: Plan Your Weekly Outreach**

As you know, people's inboxes are full! Some of your friends will likely want to contribute to your campaign, but your first email will simply get buried in the list. This is the reason we suggest planning at least three emails. If you can send four, even better!

Before the campaign kicks off, plan out your email series and mark your calendar for when you will send each. In between emails, plan to follow up with your closest friends directly via text or phone call. You want to meet your potential supporters wherever they are. This means it's also a good idea to post on social media throughout the campaign—mark your calendar with those plans as well!

### Step 5: Hit Send! Again and Again!

Now you're ready to get your message out to your community! Send emails and post on social media throughout September and October, according to your planned calendar. You'll want to keep track of who has donated to you along the way and thank them with a quick note (email or text) once they give. Be sure to remove those people's emails from your next email ask, so you're not re-asking people who have already given.

You may want to create a second email list of contacts who have donated. Send this "donated" list BCC emails that update them on your progress, express your gratitude, and share the impact of their gifts. You may find that some choose to make a second donation as they get excited about helping you reach your goal, but this should come from thanking them for their impact. Once they've given, you don't need to ask again.

### Step 6: Thank Your Supporters

Once the campaign is over, send one more final thank you to your "donated" list! Let them know the final outcome of your campaign (how much you raised total) and the impact of their collective giving. Invite your supporters to follow Chelsea's Hope on social media to remain part of our work to advance Lafora research.

## Milestones, Rewards & Recognition

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We look forward to celebrating your fundraising success! **All** fundraisers will be recognized on the Chelsea's Hope website. In addition, fundraisers will enjoy extra benefits at each of the following milestones:

- Raise at least \$50 by Monday, September 30<sup>th</sup>: receive a special Chelsea's Hope Button
- Raise at least \$1000 by Wednesday, October 9<sup>th</sup>: receive a Chelsea's Hope t-shirt!
- The top three teams will be highlighted in our October newsletter and on social media

## Frequently Asked Questions

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### What if someone wants to support my campaign but does not want to donate on the website?

Chelsea's Hope accepts donations of all types and sizes! If a donor does not want to give through the website, they are also welcome to send a check.

Please have them write YOUR name on the memo line so we are sure it's attributed to your campaign, and mail to:

Chelsea's Hope  
c/o: Chelsea's Hope 2024 Awareness Campaign  
P.O. Box 348626  
Sacramento, CA 95834

### Can a company/business or foundation support my campaign?

Absolutely! If you have connections to businesses or foundations (including family foundations) who want to fund Chelsea's Hope on your behalf, we encourage you to talk with them about your efforts and the impact Lafora disease is having on patients and their families.

These entities can give directly to your website, or you may connect them with Chelsea's Hope staff to coordinate other ways of transferring their funding. If an application process is required, Chelsea's Hope staff are happy to assist you with those efforts.

### My donor's company will match their gift, will that count toward my total?

Absolutely! We encourage you to remind your donors to check with their companies about matching opportunities, as many corporations offer this (often forgotten) perk to their employees.

If your donor can get their gift matched, ask them to send you an email or screenshot of the confirmation of the match. Send that to [christine@chelseashope.org](mailto:christine@chelseashope.org) and we will be sure to credit your campaign immediately, as the gift itself may take several months to arrive, depending on each corporation's process.

## Appendix Materials

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### Sample Website Set-Up

The below text is a sample of what you may want to insert into the section of your Givebutter page that says: *Tell the story of why you're fundraising. This will appear on your personal page and be visible to any visitors. Don't worry, you can edit this later.*

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Currently, Lafora patients and their families face many challenges. Beyond the initial diagnosis and finding information about the disease, there are no treatments to stop the progression of the disease diagnosed patients face every day.

Chelsea's Hope is working to make life easier for Lafora patients and their families, as well as invest in science that leads to treatments and cures. The first-ever clinical safety study for Lafora disease will begin enrolling patients in the fall of 2024!

<<INSERT PERSONAL STORY AND PICTURES FOR WHY YOU ARE FUNDRAISING HERE>>

Your contribution today will help Chelsea's Hope fund the clinical cost of the safety study and help our entire community change the future for Lafora patients.

Your donation to Chelsea's Hope is fully tax-deductible and brings us a step closer to a cure for this disease. You'll be giving hope to the worldwide Lafora community with your gift.

Chelsea's Hope is helping to change the future through clinical trials. Patients will be monitored closely, allowing doctors to better understand disease progression and clinical biomarkers, advancing diagnostic and treatment guidelines. As treatment development accelerates, we can more quickly translate those advancements to families so that our loved ones with Lafora disease get the most appropriate treatment and care.

## Designs You Can Use

Our [Awareness folder](#) has images in multiple languages that you can share via text, email, or social media. They are great to raise awareness!

We regularly update the folder.

## Sample Social Media Templates

### *For Lafora Body Disease Day*

This #LaforaBodyDiseaseDay, we ask you to spread the word, educate, and most importantly, donate to help fund the ION283 safety study—paving the way for potential treatment breakthroughs.

Lafora disease is a degenerative neurological condition affecting children. It is terminal, and there is no cure. Perfectly healthy children first show symptoms in their early teens and typically die within 10 years.

Let's make a difference and fight for a future where no child has to suffer from Lafora Disease: [Link to donate] #FightLafora

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Today, October 1st, I am creating awareness for #LaforaBodyDiseaseDay. Join us in the fight to treat Lafora disease by donating to fund the ION283 safety study. Learn more about how you can help: [Link to donate]

#FightLafora

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This #LaforaBodyDiseaseDay, we're asking for your support to help fund the ION283 safety study, a critical step toward finding a cure. No child should have to face their own death. Let's make a difference together. 💜

Visit us at [Link to donate] to learn more and donate.

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Learn about #LaforaDisease this #LaforaBodyDiseaseDay. It's an ultra-rare degenerative neurological condition affecting children. Symptoms present in perfectly healthy teens, leading to epilepsy, childhood dementia, cognitive decline, and death within 10 years.

Chelsea's Hope is dedicated to fighting Lafora disease head-on. Help us fund the ION283 safety study and bring hope to these families. [Link to donate] #FightLafora

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Share how you #FightLafora today! Every share, every like, and every conversation counts. Let's make Lafora disease visible and support the warriors battling it daily. ❤️

This #LaforaBodyDiseaseDay, your donation can help fund the ION283 safety study, a key step toward finding a cure. No amount is too small in the fight to save lives. [Link to donate]

### **LinkedIn**

I am excited to share that I am raising funds for Chelsea's Hope Awareness Campaign, supporting the global Lafora community and all their patients! My goal is to raise (insert goal) by October 9th -- please consider donating to my fundraising page here: [Insert your personal fundraising webpage url](#)

### **Facebook**

I'm excited to share that I'm fundraising for Chelsea's Hope Awareness Campaign. This campaign will help provide Lafora patients and their families with support as they face this ultra-rare disease. My goal is to raise at least \$GOAL during the campaign!

These funds will go to ensure that Chelsea's Hope can advance science and treatments for the Lafora community, which has not been done before. The safety study will be the first-ever trial of treatments for patients in need! If you're able to support my efforts, please visit my campaign website to make your contribution: [Insert your personal fundraising webpage url](#)

*\*Important for Facebook: do not start a Facebook fundraiser through the Facebook platform, rather, share your Givebutter personal URL in each of your fundraising posts\**

### **Twitter/X**

I'm joining @Chelseashopela1 to support their rare disease community! Will you join me? My goal is to raise \$GOAL by October 9th to help families diagnosed with Lafora disease. Donate & join the movement: [Insert your personal fundraising webpage url](#)

### **Additional Post Suggestions For Ongoing Communication:**

Imagine you are one of 200 families worldwide that are diagnosed with a rare disease and you have no answers or treatments for the fatal disorder that your child has. This is the experience of the families who receive an Lafora diagnosis for their child. But Chelsea's Hope is here to help! This amazing organization provides patients with information, helps connect them with other patients, and provides ongoing support to the entire Lafora community. That's why I'm supporting Chelsea's Hope and fundraising to provide research and hope for this community! Support at [Insert your personal fundraising webpage url](#)

By coming together as a community, we are leading the charge in educating, advocating and finding answers for Lafora disease. Our patient community has many needs; and

we need a treatment to help our community ASAP. Chelsea's Hope provides education and information to help us inform those surrounding our family throughout this diagnostic journey. When you contribute to my efforts ([Insert your personal fundraising webpage url](#)), Chelsea's Hope will use your donation to invest in the advancements of a treatment and cure to help improve the quality of life for families living with this rare disease!

## Sample Email Templates

The best emails are ones that tell your unique story about why being involved with Chelsea's Hope is important to you, thus inspiring your community to get involved in this movement. Our samples offer a model for a three-email series, where you fill in the details for your personal story.

### Email #1

Dear friends,

I've joined [Chelsea's Hope](#) and I am excited to share this work with you! Chelsea's Hope is improving the lives of children and families impacted by Lafora disease, which is a severe, rare, and fatal form of epilepsy. This is a disease that is typically not known at birth, and a seemingly healthy child starts to suffer from it later in life.

Chelsea's Hope resources to families to help them navigate this journey. This year, the Lafora community is coming together to fund a clinical safety study to help our community get answers and more understanding of the biomarkers and disease progression. This will help us advance diagnostic and treatment guidelines. This is huge for an international community with currently less than 200 people worldwide diagnosed.

[\[Insert personal story about Chelsea's Hope/Lafora disease and why you are helping to raise awareness for it\]](#).

My goal is to raise \$XX to help the Lafora community as part of the 2024 Awareness Campaign. Will you help me reach my goal with a donation to my personal fundraising page today [\[Insert link\]](#)?

If you have any questions about Lafora disease or my experience with the community (or how to donate to my campaign) please feel free to be in touch anytime. I love being able to share my passion about supporting Chelsea's Hope families and helping to find a cure!

Sincerely,  
NAME

### Email #2

Dear friends,

A few weeks ago I sent you a note to share information about [Chelsea's Hope](#) and my fundraiser [\[insert personal link\]](#) for the 2024 Awareness Campaign.

Did you know that there is no cure for Lafora disease? [\[Insert personal story and why you are helping to raise awareness of Lafora disease\]](#).

That is why I am so passionate about participating in the 2024 awareness campaign this year. We need a treatment! Will you help me reach my goal of raising \$[GOAL](#) so that I can help Chelsea's Hope fund research and their clinical study to help provide answers for this community? Giving is easy! Just click here for my personal website [\[link to website\]](#).

Thank you again for supporting me! You are helping create hope for the Chelsea's Hope community through this gift. I look forward to sharing updates with you as I continue my journey to raise awareness for Lafora disease!

Sincerely,  
NAME

### **Email #3**

Dear friends,

These are the final days of my Chelsea's Hope 2024 Awareness Campaign [\[Link to page\]](#) and I am hoping you can help me cross the finish line!

My goal is to raise \$[GOAL](#) by October 9th, and I'm only [AMOUNT](#) away!

With your gift of any size today, I know that we will hit this goal. Your support means to the world to me as I continue to support and raise awareness for a rare disease that [\[insert connection here\]](#). Chelsea's Hope will use your money to support the safety study to help bring treatments and a cure to the community. Together we are part of a movement that is helping to provide families with answers and advance medical research!

Sincerely,  
NAME

### **50 contacts - Building Your Outreach List**

Are you wondering who to ask for a donation? Here's a quick way to jog your memory of people who might consider supporting you! This list isn't exhaustive but rather an exercise to help you consider all the different groups of people you could ask to support your efforts. By all means, don't stop at 50 – the more people you ask the quicker you'll reach your goals! Grab a pen and start writing. You'll be surprised by how quickly your list grows!

- 5 relatives
- 5 friends from high school
- 5 friends from college
- 5 current co-workers
- 5 former co-workers
- 5 neighbors
- 5 members of a social organization
- 5 people you do business with (salon, mechanic, trainer, etc)
- 5 people who have invited you to a gathering
- 5 friends through your partner, children, parents, etc (friend of a friend!)

### More about Chelsea's Hope Awareness Campaign

In September 2024, Chelsea's Hope is raising \$75,000 to provide families with the tools they need to stay up to date on medical treatment options, to advocate for better medical care and experiences in the community, and to think about their healthcare treatments in a holistic manner.

Throughout the month, we ask patient families to get involved, share their photos and their stories to raise awareness for this rare disease. We hope that our small but mighty voices throughout this month will help reach new families who may just be starting their journey and not yet realize that this community exists to help.

The more details you can share about your Lafora journey as you tell your story, the better! Here are some of our favorite resources to share when introducing the disease and Chelsea's Hope to new people. Please feel free to use them in your fundraising materials this month as well!

- [The Chelsea's Hope Story](#)
  - o We believe in our combined power to impact and accelerate Lafora science to change patients' lives. Chelsea's Hope is a non-profit that connects other families, funds research and advocates for patients.
- [What is Lafora Disease?](#)
  - o Lafora disease is a rare genetic disorder that is a severe form of epilepsy. It's most commonly known by mutations in one of two genes: EMP2A and EMP2B. Most patients are unaware they have the disease until they begin having seizures around adolescence. Eventually, they can have difficulty walking, eating, talking, childhood dementia, decline, ataxia and intractable seizures. There currently is no cure.
- [Share Family Stories](#)
  - o Meet Lafora warriors from around the world and learn their stories. They are who we raise awareness for on Lafora Body Disease Day. We hope for treatments to help our children.

**You can tag us on:**

- Facebook: @chelseashopelaforacure
- Instagram: @chelseashopelaforacure
- TikTok: @chelseashopelaforacure
- Threads: @chelseashopelaforacure
- Twitter: @Chelseashopela1
- LinkedIn: Chelsea's Hope Lafora Children Research Fund