



LHON Collective Fundraising Toolkit

Hello and welcome to the LHON Collective Fundraising Toolkit!

Thank you for your interest in fundraising to support LHON! Before hosting your fundraiser, take the opportunity to share your story, invite friends and family to join your fundraising efforts, and raise awareness for the LHON Collective.

Everyone's fundraising event is a little different from everyone else's. Ultimately, we share a common goal to raise funds for LHON scientific breakthroughs and provide community support.

Table of Contents

- [First Steps for a Successful Fundraiser](#)
- [How To Use This Toolkit](#)
- [Fundraising Email Templates](#)
- [Social Media Templates](#)
- [Facts about LHON and Initiatives of LHON Collective](#)
- [Fundraising Text Templates](#)

First Steps for a Successful Fundraiser

Set a Fundraising Goal

Consider what you would like to see as your donation goal and set that as your target to meet and, hopefully, surpass.

Decide on your Fundraising Event and how you want to publicize it.

This is the time to decide on the event you want to host and how best to promote it. Email and text messages are personalized and a direct method of outreach. Various social media platforms such as Facebook, Instagram, and TikTok, among others, are also a great resource to share your "why" and get those who care about you excited for your fundraising event.

Make a List

Create a list of friends and family you will want to reach out to. Don't forget to consider your local community leaders, place of worship, gym, schools, and places where you shop or are employed. Many in your community will welcome the opportunity to support your cause and the effort you are putting in for a cause that is important to you.

Stay focused on your reason for hosting your fundraising event. 100% of the funds you raise will benefit future research and patient support for those with LHON.

ARE YOU EXCITED TO JOIN US TO SUPPORT LHON? WE'RE EXCITED YOU'RE JOINING US!

How To Use This Toolkit

Introduction

This toolkit provides support and fundraising guidance for those in our LHON community who would like to host a fundraiser in support of LHON Collective. It includes a set of template emails, texts, social media write-ups, and fundraising possibilities to help guide you towards a successful event.

Use our Templates

You Decide. You can copy and paste our proposed templates or use them as a guide.

Make Your Messages Meaningful

Photos, videos, and graphics tell your story so much better than words alone. When you use these things in addition to your message, you have a greater likelihood of appearing in more people's Facebook, Instagram, and TikTok accounts.

Personalize your Outreach

Emails and texts directly from you make your recipient feel special and important. However, this personal touch can be time-consuming. Consider breaking it up and doing a different batch from your list each day, and your outreach will reach the population you are hoping to include.

Updates are Important Too

Even if someone from your list has already donated, they still enjoy hearing how your fundraising is going and what successes you are experiencing.

Don't Take a Rejection Personally

Everyone's priorities are different, and where their focus is at that point in time may not be in sync with your goals. Don't focus on those who weren't willing to participate with you at this time. There are always other opportunities to pursue.

What you are doing is Important!

Thank you for supporting LHON research and community support. You can do what you have set out to do! Your why is your biggest asset.

Fundraising Email Templates

First Outreach & Invitation to Partner with You

Subject: Exciting Announcement! – I'm hosting an event, and you're invited!

Hi Friends,

I have exciting news to share with you! This {month}, I am hosting {name of event you are hosting} as a fundraiser for LHON Collective. This is an opportunity to help those affected by Leber Hereditary Optic Neuropathy (LHON). I'm looking forward to supporting new research toward a cure for this disease, which causes sudden loss of central vision.

On (Month Day, Year), I invite you to join me in supporting research to ultimately find a cure for people who are affected by this disease, including (Name of your family or friend), who is my motivation and reason to create this fundraiser.

I would love for you to join me, and together we can make a big impact. I want to thank you ahead of time for considering my invitation and I appreciate your partnership. This event is important to me because I believe that a cure is possible for (Name of your family or friend) if we all work together.

My goal is to raise \$XX. All proceeds from this event will be donated directly to the LHON Collective. Please join me at the (name of event you are hosting) and have some fun while raising these needed funds!

Thank you again for coming to my event. I'm looking forward to having you join me to support this very important mission.

With gratitude,
(Your Name)

[Letter Template PDF](#)

Fundraising Email Templates: Reminder Email: Second Outreach & Reminder

Subject: Looking forward to our {event you are hosting} to knock out LHON!

Hello,

Next week, we will be gathering together at {name of event you are hosting}. I'm really looking forward to being with you on {Date and time} as we support LHON Collective's mission to accelerate progress toward a cure for Leber Hereditary Optic Neuropathy (LHON) while improving the lives of people living with LHON.

Were you aware that LHON Collective is a volunteer-run organization and 100% of your donation will go directly to the mission of supporting progress in science toward a cure as well as supporting the patient community?

Were you aware that this rare disease is primarily found in the mitochondrial DNA and the danger of losing one's central vision is passed from the mother who carries this mutation to all of her kids?

Together, we will work towards a day when everyone affected with this disease will have it as a distant memory and not a daily challenge they must continue to navigate.

Please reach out to me if you have any questions about our upcoming time together and thank you for taking your time to join me in support of this important mission.

Sincerely,
(Your Name)

Fundraising Email Templates Post-Event Thank You

Subject: Together We Did It!

Thanks for coming to {name of event you hosted}! What a fun time we had together all to support a great cause. Your support really means a lot to me. Thank you.

Together, we raised \$XX to support those affected with legal blindness because of LHON. I appreciate your friendship and support in meeting and exceeding our fundraising goal.

Sincerely,
(Your Name)

P.S. If you were unable to join us and you would still like to donate to this important effort, it's not too late! Visit LHON Collective's [fundraising page](#) and you are invited to join our efforts to make this event even more impactful.

For more information about LHON Collective and other ways to get involved by volunteering or creating your own fundraising program, visit www.lhon.org to learn more.

Fundraising Email Templates: Thank You Notes

Individual Thank You Note to Donors from your Event

Subject: Thank You for supporting my Event that benefited LHON Collective!

Dear {Name of Donor},

Thank you so much for supporting my event, which benefits Leber Hereditary Optic Neuropathy. Your donation of \$XX helped us to raise \$XXX! It was an honor to have your partnership in this successful event. Your generosity is really appreciated.

Together, we have helped to move the science forward towards the return of vision for those who are affected by LHON.

Gratefully,
{Your Name}

Individual Thank You Note to Donor in Honor or Memory of Someone

Subject: Thank You for Such a Meaningful Gift

Dear {Name of Donor},

I wanted to thank you for your caring donation in support of LHON Collective and my event to further their endeavors towards research for a cure.

Your contribution in {honor or memory} of {Person's name in honor or memory of} really touched my heart. I am so grateful to fundraise alongside you for this very meaningful cause.

Your donation of \$XX helped us to raise \$XXX. Together, we have helped to move the science forward to benefit those who are affected by LHON.

Thank you again for your support!

Gratefully,
{Your Name}

Social Media Templates

First Template

My (name of your event) is happening on (date). I'm really looking forward to raising funds to support the critical mission of LHON Collective while also having a great time building community. This event will help the LHON Collective further its mission to promote scientific research towards a cure for this disease. Please join me in supporting this great cause. You can support this event by joining me, or if you can't make it this year, you can visit the website LHON.org and support this effort directly.

#LHONCollective #LHON

Second Template

Were you aware?

LHON Collective is a volunteer-run organization, and 100% of your donation will go directly to the mission of supporting progress in science toward a cure and supporting the patient community. On (date), I am hosting (name of your event) to benefit LHON Collective. I can't wait to have you join me at this fun event, which will support the promotion of science towards a cure and hope for a better future for all affected by LHON.

You can support this cause when you join me at the event or go directly to the website [LHON.org](https://lhon.org) to support those with LHON today. #LHONCollective #LHON

Third Template

Are you ready to join me at (name of your event) next week? I hope so! Planning this event has already brought me closer to my mission of honoring (name of family member or friend affected by LHON) and supporting others also affected by LHON vision loss.

Together, we can reach our fundraising goal! Your support is really important at any level. Donate at the event or click the link to donate directly to lhon.org. #LHONCollective #LHON

Fourth Template: (Pro Tip - Tag Those Who Supported You and Personalize Your Message!)

Fundraising Update and Thank You!

#Gratitude! We reached our goal of \$XX to support @LHONCollective. A special thank you to @XX (tag people who donated). So far, we have raised \$XX. I would still love your support. Click the link below to visit [LHON.org](https://lhon.org) to donate directly towards the goal of ending blindness caused by LHON. #LHONCollective #LHON

Facts about LHON and Initiatives of LHON Collective

Facts and information to share with your community about LHON Collective

- More than 100 people in the U.S. and thousands more globally become affected by LHON each year.
- People who experience vision loss due to LHON typically lose their central vision first in one eye and then, within a few months, in the other eye.
- LHON is caused by a mitochondrial genetic mutation that is passed from a mother to all of her children.

- LHON affects men and women at any age.
- In males, vision loss most commonly appears between the ages of 12 and 26.
- Gene therapy is currently being tried as a treatment method for those affected by LHON vision loss.
- Mitochondrial gene editing is a promising future treatment for those with LHON.
- Volunteers make up the base of supporting the LHON community and working as patient advocates to further the science towards finding a cure for LHON.
- Many Zoom events covering various topics of interest to the LHON community are conducted each year.
- There are a variety of social media groups that offer support and information from regional, demographic, and interest-based perspectives.
- LHON Collective collaborates with RARE-X at Global Genes to capture patient data in a medical registry that can be shared with researchers interested in LHON.
- LHON Collective has partnered with the Milken Institute to conduct a landscape analysis and identify the most promising science to focus on for strategic investment in scientific progress.
- To learn more about the initiatives LHON Collective is undertaking, please visit the website at www.LHON.org

Social Media Posts for Fundraising Events

Day of Your Fundraising Event

The (name of your event) is happening today! Looking forward to supporting this great cause with many of you, my family and friends. Together, our support will be a step to be proud of to support scientific progress towards a cure for LHON!

Thank you Message

Pro Tip: Personalize your comments and don't forget to tag your supporters! Review the examples here.

We did it! We all came together and successfully supported LHON Collective! I am proud of what we accomplished and had so much fun hosting an event that was successful and meaningful to my family. Thank you so much for coming together to have a good time and support a cure for LHON! We raised a total of \$XX, and if you still want to participate in this year's successful event, visit LHON Collective's website at LHON.org and give directly to benefit those affected by LHON!

Fundraising Text Templates

Introduction of Upcoming Event

Hi (Name of Invited Donor), Big news! I'm hosting a/an (name of event) to support LHON Collective. I hope you can come, and I would appreciate any support towards this important research. My goal is

\$XX. The event is on (Date) at (Time). Please join me for a fun get-together that will benefit an important cause. Thank you! #LHONCollective #LHON

One Week before the event

It's almost time to get together at the (name of event)! I'm looking forward to having you join me to benefit LHON research and community support. Thank you for joining me to support the fight for a cure. I look forward to seeing you soon! #LHONCollective #LHON

After the Event

We had a very successful event. Together, we honored (name of family or loved one affected by LHON) and promoted research towards a cure for people who are affected by LHON. On top of all the funds we raised, the event was a fun time to be together, working on a shared mission. I look forward to you joining me at (name of your event) next year to continue our great work. If you know someone who would still like to support this effort this year, please feel free to share this text. They can visit LHON Collective's [fundraising page](#) and are invited to join our efforts to make this event even more impactful! #LHONCollective #LHON