



FEBRUARY 29

TOOLKIT

Lymphangiomyomatosis (LAM) is just one of the 6000 rare diseases that affect more than 300 million people worldwide. This year, thanks to a generous donor, we will LAMplify, or match any campaign that raises \$1000 for The LAM Foundation on Rare Disease Day. The primary goal of Rare Disease Day is to increase awareness about rare diseases and their impact on the lives of families living with these conditions. This toolkit contains content to help you raise awareness and funds for lymphangiomyomatosis.

CREATE A FUNDRAISING PAGE

Facebook Fundraisers

Create your own Rare Disease Day Facebook Fundraiser. Click [here](#) to get started.

Start your own fundraising team

Utilize The LAM Foundation's fundraising software to create an entire fundraising team! Invite your friends and family members to join you in the Rare Disease Day Challenge. It's easy! Click [here](#) to get started. (ADD LINK)

THINK ABOUT WHO YOU KNOW

Along with friends and family, you have acquaintances, current and former colleagues, fellow alumni, community and religious groups, neighbors, and even businesses you frequent. Share your fundraising link!

Given the opportunity, most people are happy to contribute. Don't hesitate to ask!

HOW TO ASK FOR DONATIONS

Social media channels have made fundraising user-friendly, allowing you to message everyone in your group. You can reinforce this through text, phone, email, or in person. Make sure everyone knows how much this cause means to you.

To help boost your fundraising during the challenge, try these examples of what to say and when to say it:

WEEK 1 – 2/1/24 (Kickoff Day)

Match your donation with the #RareDiseaseDay Challenge!

Email, text, and/or message your donor circle. Make a self-donation to encourage others. Post a link to your online fundraising post/site and let everyone know that no donation is too small.

WEEK 2 – 2/8/24

Reminder: My #RareDiseaseDay fundraiser is underway – join me!

Ask five family members, 10 close friends and four neighbors to each make a \$25 donation. Ask ten members from a house of worship or community group to chip in \$5 each.

WEEK 3 – 2/15/24

Here's a status report on what we need to reach our goal

Reach out to three local businesses you use, like dry cleaners, coffee shops, nail salons, and hair stylists, to give \$25 each.

WEEK 4 – 2/22/22

Last chance to help me double my donation!

This is the last week to make your goal – remind everyone to pitch in so you can get a dollar-for-dollar match for all donations. In other words, almost there!

WEEK 5 – 2/29/24 Rare Disease Day

Its Rare Disease Day! Last day to help me double my donation.

This is the last day to make your goal – remind everyone to pitch in so you can get a dollar-for-dollar match for all donations. In other words, almost there! Share provided graphics to help spread awareness of LAM with a link to your fundraiser.

Week 6 (Thank you, donors!)

We did it! Thank you for making a difference for women with LAM!

Amazing group effort. Thanks to you, we've raised awareness and funds to help the worldwide LAM community. Here's the final tally....

YOUR SOCIAL MEDIA TOOLS

Use or tweak the sample text below and combine it with the graphics (right-click and save the images) to post on any or all your social media channels.

SAMPLE CAMPAIGN TEXT:


Join me for #RareDiseaseDay during February in supporting The LAM Foundation's mission to find a cure for lymphangioleiomyomatosis (LAM), one of 6000 rare diseases worldwide. LAM impacts thousands of women around the world, including [me/my sister/my patients]. We're making progress towards a cure, but we're not quite there yet. Can I count on you? Please consider contributing here to help fund critical research and provide hope to women with LAM. *If I raise \$1000, your donations will be matched dollar-for-dollar.*

LAM FACT GRAPHICS

LYMPHANGIOLEIOMYOMATOSIS
lym • phan • gi • o • lei • o • my • o • ma • to • sis

SYMPTOMS

- shortness of breath (dyspnea)
- chest pain (pleurisy)
- chronic cough
- fatigue
- lung collapse (pneumothorax)
- benign kidney tumors (angiomyolipomas)
- accumulation of fluid called chyle, in chest cavity or abdomen (pleural effusion)


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A BREATH OF HOPE | For more information visit thelamfoundation.org

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PNEUMOTHORAX
(lung collapse)

60%

60% of women living with LAM experience a pneumothorax

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ANGIOMYOLIPOMA
(benign tumors often found in the kidneys)

Angiomyolipomas occur in:

33.33% of women living with sporadic LAM

80-90% of women living with TSC-LAM


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AVERAGE AGE AT DIAGNOSIS

35

The full age range can vary between 13-80+


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FATIGUE

70%

70% of women living with LAM experience fatigue

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PLEURAL EFFUSION
(leakage and accumulation of fluid known as chyle into the chest cavity)

Pleural effusions occur in:

20% of women living with sporadic LAM

<10% of women living with TSC-LAM

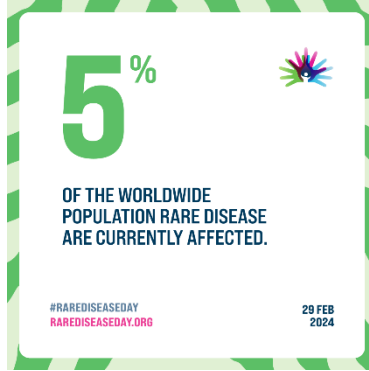
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RARE DISEASE FACT GRAPHICS (via rarediseaseday.org)



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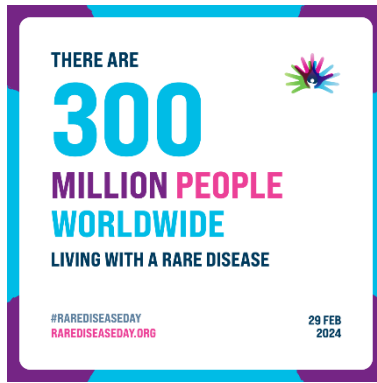
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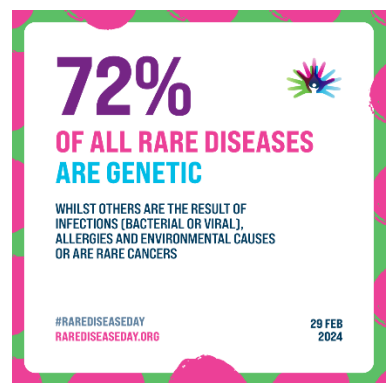
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