

SEE, KNOW &
UNDERSTAND Danon

Danon Awareness Day Community Toolkit

*Simple ways to raise awareness about
Danon disease in your community*



Danon Awareness Day
October 24

Thank you for supporting Danon Awareness Day in your community.

October 24 is an opportunity to help more people **See, Know & Understand Danon** and shine a light on the signs of Danon disease, the experiences of people and families living with Danon, and the importance of greater awareness, education and research.

This toolkit includes simple resources and ideas to help you get involved, including:

- [Danon disease facts](#) – a shareable overview of Danon and the signs and symptoms to know
- [Social media tips and graphics](#) – ready-to-use content and ideas to help you raise awareness on your social channels
- [Community awareness ideas](#) – simple ways to introduce others to Danon and help start conversations
- [Fundraising ideas](#) – ways to turn your support into action

Choose the activities that feel manageable and meaningful to you. Every action can help.

We'd love to see how you're helping raise awareness!

Tag the Danon Foundation ([@DanonFoundation](#)) on Facebook, Instagram or X. Use [#DanonAwarenessDay](#) so we can celebrate and amplify your efforts.

Thank you for being part of the Danon community and for helping others **See, Know & Understand Danon**.

With gratitude,

Jenny & Amy

**SEE, KNOW &
UNDERSTAND** Danon

 Danon
Foundation

Danon Awareness Day

October 24

Share the Facts about Danon Disease

Help others **See, Know & Understand Danon** with this easy-to-share fact sheet about Danon disease. It provides a quick overview of what Danon is, the signs and symptoms to look for, and why early recognition matters.



[Download the fact sheet](#) from the Danon Awareness Day page and share it with your communities, networks, and social channels to help raise awareness this October.

Take Action on Social Media

Social media can help make Danon more visible. A post can introduce someone to Danon for the first time or spark a conversation. A personal story can help another family feel a sense of community.

You don't need to be an expert – or have a large following – to make a difference.

Here are 3 easy ways you can get active on social to help raise awareness:

1. Engage with our posts

Throughout the month, we will be highlighting facts and stories from the Danon community on our social media channels. Engaging with our content will help us reach more people. We invite you to like and share our posts.

Facebook: [@danonfoundation](#)

Instagram: [@danonfoundation](#)

SEE, KNOW & UNDERSTAND Danon



Danon Awareness Day

October 24

2. Share ready-to-use content

We have created [social media graphics](#), which can be downloaded from our Danon Awareness Day page.

Add your message to help personalize the graphics. Below is draft copy if you prefer to adapt and tailor it.

Sample social post copy

Danon disease is rare, but awareness can help more people recognize the signs, get genetic testing, and understand how to manage the disease.

Help spread the word today. Like or share this post to raise awareness of Danon disease.

Learn more: DanonFoundation.org

#DanonAwarenessDay #DanonDisease #RareDisease

Danon is a rare genetic disease caused by a change in the LAMP2 gene. It can affect how cells recycle waste and can lead to health problems throughout the body.

Because Danon is rare, knowing the basics can be an important first step toward understanding.

Help raise awareness by liking or sharing this post.

Learn more: DanonFoundation.org

#DanonAwarenessDay #DanonDisease #RareDisease

Danon can affect the whole body. Signs may include heart problems, muscle weakness, vision problems, learning challenges, and more.

When multiple symptoms appear together, it's important to recognize the signs and talk to your doctor about Danon.

Like or share this post to help others learn about Danon.

Learn more: DanonFoundation.org

#DanonAwarenessDay #DanonDisease #RareDisease

Danon Awareness Day

October 24

Sample social post copy

Knowing your family history can be an important part of recognizing Danon. A history of heart problems – especially when combined with other signs – may be an important clue.

Like or share this post to help raise awareness of Danon and the importance of genetic testing.

Learn more: DanonFoundation.org

#DanonAwarenessDay #DanonDisease #RareDisease

This Danon Awareness Day, I'm raising awareness of Danon for my family and every family impacted by this rare disease.

Help me spread the word. Like or share this post to raise awareness of Danon disease.

Learn more: DanonFoundation.org

#DanonAwarenessDay #DanonDisease #RareDisease

3. Create your own social content

If you're creating your own social content, you don't have to start from scratch. Here are a few simple ways to get started.

Start Small

- Share one Danon fact
- Share why you support the Danon community
- Invite one person to learn more about Danon
- Like, comment on, or share another community member's post

Keep it Simple

You don't need a long post to make an impact. Try:

- Focusing on one idea per post
- Writing the way you naturally speak
- Pairing your message with a photo, video or Danon Awareness Day graphic
- Inviting people to learn more, share your post, or start a conversation

Danon Awareness Day

October 24

Share Your Story

Personal stories can help others understand what living with Danon means. If you're comfortable, you might share:

- What you wish more people knew about Danon
- How Danon has affected you or your family
- A moment that changed the way you understood Danon
- What awareness means to you
- Why you're supporting Danon Awareness Day
- What you hope will change in the future

Protect Your Peace

Sharing online can be empowering, but it can also bring questions, opinions or attention you didn't expect. Only share what you feel comfortable with and give yourself permission to set boundaries. It's okay to:

- Take a break from social media
- Turn off comments or notifications
- Limit who can see your posts
- Decide not to answer personal questions
- Share only the parts of your experience you're comfortable making public
- Keep your awareness efforts separate from your personal account

Remember: You decide what to share. You never have to disclose more than what feels right for you.

If you find yourself needing additional guidance or support, Danon Foundation offers [resources](#) designed to help you stay informed, feel connected, and access care when you need it.

Tag Us!

Help more people find Danon Awareness Day content by using the official hashtag and tagging the Danon Foundation.

#DanonAwarenessDay

@DanonFoundation on Facebook, Instagram and X

Danon Awareness Day

October 24

Bring Danon Awareness into Your Community

There are other ways to bring awareness to Danon disease beyond social media. We've outlined some ideas below. Choose one that fits your time, interests, and comfort level.

Start a Conversation

- Share the [Danon fact sheet](#) with a friend, family member or coworker
- Refer someone to the Danon Foundation to learn more about Danon disease
- Tell someone why Danon Awareness Day matters to you

Get your Community Involved

- Ask permission to display or distribute the [Danon fact sheet](#) at places in your community, such as:
 - Libraries
 - Community centers
 - Schools
 - Local businesses
 - Community events
- Ask a local business you know to support Danon Awareness Day. A personal connection can make the conversation easier. The business might:
 - Display the [Danon fact sheet](#)
 - Share an awareness message with customers
 - Make a donation
- Ask a team, class, club or community group for 5-10 minutes to introduce Danon disease and explain why awareness matters
 - A simple conversation can be the beginning of greater understanding
 - Refer to the [Danon fact sheet](#) for messages that may help you get started

Reach Out to Local Media

- Consider writing a letter to the editor about why Danon awareness matters
- You can share your personal perspective, explain why Danon deserves greater recognition, and invite your community to learn more
- Refer to the [Danon fact sheet](#) for messages that may help you get started

Danon Awareness Day

October 24

Turn Awareness into Action

Fundraising is one way to turn Danon Awareness Day into action. Whether you organize an event, start a fundraiser, or ask others to get involved, your efforts can help bring people together and raise awareness of Danon.

Find an Idea that Works for You

Fundraising doesn't have to be complicated. Consider an activity that brings together your friends, family, coworkers or community. Keep it simple. Choose something you enjoy and invite others to be a part of it.

Ideas include:

- Host a potluck
- Organize a game night
- Plan an activity (examples: bowling night, craft night)
- Hold a bake sale
- Organize a restaurant fundraiser
- Plan a community walk or other activity
- Create a birthday fundraiser

Turn Your Idea into a Fundraiser

Once you have an idea, you can turn it into a fundraiser. You don't need a big event to make a difference. A small gathering, personal fundraising goal or community activity can be a meaningful way to raise awareness and support the Danon Foundation.

Here are a few ways to get started:

- **Ask for a donation** – invite your guests to make a donation in support of the Danon Foundation. You can suggest an amount or simply let people give what they can
- **Sell something** – for a bake sale or craft night, set a price for items or invite people to make to donation in exchange for what you've created
- **Ask for sponsorship** – a local business may be willing to donate money, food, supplies or services to help make your event possible

Talk to Your Employer about Matching Gifts

Some employers match charitable donations made by their employees. Check with your employer's HR department to see whether a matching-gift program is available.

Danon Awareness Day

October 24

Turn Awareness into Action

Create a Facebook Fundraiser

A Facebook fundraiser can give friends and family an easy way to support your efforts and help raise awareness of Danon disease.

To get started:

- Share why Danon matters to you
- Set a fundraising goal
- Invite friends and family to participate
- Share your fundraiser on your social channels to help spread the word

Donate!

Your generous gift helps fund advocacy, support and research for Danon disease.

Thank you for your support.



Danon Awareness Day
October 24

Your Voice Can Help Make Danon Visible

Awareness starts with real people sharing information, experiences, and stories.

Your voice can:

- Help someone feel part of a community
- Help others better understand Danon disease
- Encourage conversations about diagnosis and care
- Bring greater visibility to people and families living with Danon
- Support continued education, advocacy and research
- Help build a stronger Danon community

You don't need a large audience or a perfect plan.

Share a post. Start a conversation. Tell your story. Invite someone to learn.

Whatever action you choose, thank you for helping people **See, Know & Understand Danon.**

Together, we can make Danon more visible.

