

LeukoAware[®]

Campaign Toolkit
for Patient Advocacy Organizations



Leukodystrophy Awareness Month

Brought to you by



LeukoAware[©]

September is Leukodystrophy Awareness Month. As we work toward raising awareness for leukodystrophy and supporting those affected by these rare diseases, we believe that collaboration across organizations can strengthen our collective impact.

We invite your organization to join us in elevating our impact by sharing messaging, resources, and cross-promoting, while keeping true to your mission and goals. We truly value the work that you do and believe that together, we can inspire even greater change for the leukodystrophy community throughout Leukodystrophy Awareness month.

This **LeukoAware[©]** campaign toolkit features a variety of assets specially designed to help your organization participate in this collaborative effort to raise leukodystrophy awareness. These resources are designed to make it easy for your organization to get involved while complimenting and aligning with your existing initiatives.

What's included when you join the **LeukoAware[©]** campaign?

Collaboration Recommendations

Suggestions for collaboration, featuring recommended activities and ideas.

Co-branded Content: Customizable graphic templates and poster for creating shared messaging while keeping your organization's branding front and center.

Social Media

Sample posts, and an official hashtag to share across your platforms.

Educational

Infographic and fact sheet to spread knowledge about leukodystrophy.



We are excited to share a variety of ideas and resources to help your organization participate in the **LeukoAware[®]** Campaign while continuing to align with your organizations initiatives.

Host a virtual event

Plan to host a live webinar, educational or Q&A session, and encourage other collaboration with other Leukodystrophy organizations with invitations to co-host or be guest panelist.

Share stories

Feature and share each other's organization stories and testimonials to extend our reach and connect with a broader audience.

LeukoAware[®] Asset Customization

Add your logo, photos and content to the **LeukoAware[®]** assets provided in this document.

Social Media Challenge

Challenge your followers to engage your audiences to join your efforts in raising awareness and share links to assets and resources.

Social Media Takeover

Offer a guest organization or community member to take over your social media channels one day during September.

Pop Quizzes & Polls

Share out polls and quizzes related to Leukodystrophy to educate and engage your community in a fun and interactive way. Utilize the **LeukoAware[®]** fact sheet to create the questions.

Download and Share

Download and share the **LeukoAware[®]** poster and encourage your followers to print and share in their local communities or online.

Advocate

Share information on the importance of advocating for policy changes and research funding and share tools and resources to help become an effective advocate at both the state and federal levels.

LeukoAware® Co-Branded Graphics

The zip folder attached to the email includes .png files of these and other graphics, which you can easily upload into design tools like Canva or Adobe Creative Suite to customize for your organization.



Legal Disclaimer: By participating in this collaborative effort, United Leukodystrophy Foundation grants permission to partner organizations to use and share our LeukoAware copyrighted materials, including but not limited to images, text, and educational resources, strictly for the purposes of raising awareness about leukodystrophy and supporting our joint campaign through our LeukoAware initiative.

Hashtags are used to make it easier for people to join the conversation on social media on a specific topic.

We encourage you to use the hashtag #LeukoAware in addition to your organizations official hashtags when raising awareness throughout the month of September.

Sample Social Posts:

We're excited to partner with The United Leukodystrophy Foundation to raise awareness for leukodystrophy! By combining our efforts, we're elevating our voices and spreading awareness about these rare diseases.

#LeukoAware

September is Leukodystrophy Awareness Month! Inspire others and share your story about how Leukodystrophy has affected you and your family.

#LeukoAware

We're proud to collaborate with [Partner Organization(s)] to share inspiring stories from the leukodystrophy community. Read about [Name] and learn how leukodystrophy has impacted them. #LeukoAware

[include link to blog, or story]

Show Your support and download your LeukoAware badge to add as your profile picture. #LeukoAware

[include LeukoAware* social profile graphic]

In partnership with The United Leukodystrophy Foundation, we're bringing you facts about leukodystrophy. #LeukoAware

#LeukoAware

[include LeukoAware* infographics]

There are many common challenges across the various types of leukodystrophy including difficulties in accessing treatment, the need for lifelong medical care and high expenses, in addition to accessing expert medical professionals.

Together, we have the power to drive change! By joining our voices together, we can advocate for increased funding for leukodystrophy research and the development of life-saving treatments. #LeukoAware

[tag other Leukodystrophy organizations]

LeukoAware

KNOW THE FACTS

Understanding Leukodystrophy



Leukodystrophy is a group of rare, primarily inherited neurological disorders.

Myelin Sheath: Leukodystrophy disrupts the growth or maintenance of myelin, the protective covering around nerve cells in the central nervous system.

Genetic Cause: Most leukodystrophies result from defects in genes responsible for myelin development or maintenance.

Progression: Leukodystrophies tend to worsen throughout the life of a patient.

Over 50 Types of Leukodystrophies: Scientists have identified more than 50 different types of leukodystrophy, with some still unidentified.

Word Origin: The term “leukodystrophy” is derived from Greek, meaning “ill growth of white matter.”

Symptoms: Symptoms of leukodystrophies vary widely due to differences in genetic causes and affected areas of the central nervous system.

Impact: Leukodystrophies affect individuals worldwide, regardless of ethnicity or geographical location.

Advocacy: It's important for those affected by leukodystrophy to advocate by contacting policymakers and supporting legislation that promotes research and access to care.

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Be LeukoAware®

Leukodystrophy is a group of rare, primarily inherited neurological disorders. Scientists have identified more than 50 different types of leukodystrophy, with some still unidentified.

These rare diseases disrupt the growth or maintenance of myelin, the protective covering around nerve cells in the central nervous system.

Symptoms of leukodystrophies vary widely due to differences in genetic causes and affected areas of the central nervous system. The diseases tend to worsen throughout the life of a patient.

What Can You Do?

Make a Donation Today!
Learn more about Leukodystrophy
Get Involved



YOUR LOGO & ORGANIZATION
INFORMATION HERE