**Rare Disease Day Social Media Toolkit**

***Before Rare Disease Day February 28th***

1. Join us on **#RareDiseaseDay (Feb 28)** to stand in solidarity with the **30 million Americans** living with rare diseases. Let’s make rare visible! #LeukoAware #RareDiseaseDay #ShowYourStripes
2. The zebra is the mascot for rare disease patients because, in medicine, zebras represent uncommon answers. With 1 in 10 Americans affected by a rare disease, awareness is crucial! On February 28 it’s #RareDiseaseDay and we ask you to join INSERT YOUR ORGANIZATION NAME and show your stripes for all those affected leukodystrophy and all those impacted by rare disease!  
   #LeukoAware #RareDiseaseDay #ShowYourStripes
3. February 28 is **#RareDiseaseDay**, let’s advocate for better research, treatments, and support for those impacted. Join us and spread awareness on this global day of awareness for rare diseases! #LeukoAware #RareDiseaseDay #ShowYourStripes

***On Rare Disease Day February 28th***

1. 🦓 **Leukodystrophy is rare.** It affects **1 in 7,633 live births** and is one of over **10,000+ rare diseases**. In the U.S., a disease is considered rare if it affects fewer than **200,000 people**, yet rare diseases collectively impacts **approximately** **30 million Americans and over 300 million people worldwide**. #LeukoAware #RareDiseaseDay #ShowYourStripes
2. Leukodystrophy is a rare disease and many struggle with access to specialists, treatment, care and support. They are not alone, **approximately** **30 million Americans** live with a rare disease and face very similar challenges! #LeukoAware #RareDiseaseDay #ShowYourStripes
3. Scientists have identified more than 50 different types of leukodystrophy, with some still unidentified. #LeukoAware #RareDiseaseDay #ShowYourStripes
4. Leukodystrophy is a **group of rare, inherited neurological disorders** that affect the **myelin sheath**, the protective layer around nerve cells. It’s one of **over 10,000 known rare diseases**, yet fewer than **5%** have an FDA-approved treatment.  
   #LeukoAware #RareDiseaseDay #ShowYourStripes
5. 🦓 **1 in 7,633 live births** is affected by leukodystrophy.  
   🦓 **1 in 10 Americans** lives with a rare disease.  
   🦓 **15 million U.S. children** have a rare disease, and tragically, **30% won’t see their 5th birthday**.  
   Advocacy matters! Support research, access to care, and policy change to improve lives. #LeukoAware #RareDiseaseDay #ShowYourStripes
6. It’s important for those affected by leukodystrophy to advocate by contacting policymakers and supporting legislation that promotes research and access to care. #LeukoAware #RareDiseaseDay #ShowYourStripes
7. There are over 50 types of leukodystrophy, and they are part of the 10,000 known rare diseases affecting over 300 million people worldwide. This #RareDiseaseDay we raise awareness for all navigating a rare disease diagnosis. #LeukoAware #RareDiseaseDay #ShowYourStripes
8. Leukodystrophy is a group of rare, primarily inherited neurological disorders. Scientists have identified more than 50 different types of leukodystrophy, with some still unidentified. #LeukoAware #RareDiseaseDay #ShowYourStripes
9. Today is **#RareDiseaseDay**, let’s raise awareness and advocate for research! Share who you #**ShowYourStripes** for and stand in solidarity with all those impacted by rare disease. #LeukoAware #RareDiseaseDay #ShowYourStripes
10. Today we #ShowYourStripes for the 1 in 7633 people affected by leukodystrophy and the 1 in 10 Americans affected by other rare diseases. #LeukoAware #RareDiseaseDay #ShowYourStripes
11. Let’s amplify **rare disease voices** through raising awareness and advocacy! For those affected by leukodystrophy what are some challenges you face navigating this rare disease? #LeukoAware #RareDiseaseDay #ShowYourStripes
12. Living with **leukodystrophy** or any **rare disease** comes with overwhelming challenges beyond the diagnosis itself. Many patients and families face:

* **Isolation**, feeling alone in a world that doesn’t understand their disease.
* **Limited access to care** with few specialists, long travel distances, and little to no treatment options.
* **Financial Burdens** – Medical costs for rare diseases total **$400 billion annually**, comparable to cancer and Alzheimer’s. Many families struggle with ongoing care, therapies, and adaptive equipment.

#LeukoAware #RareDiseaseDay

For more information and resources about Rare Disease Day please visit <RareDiseaseDay.us> (U.S. site powered by NORD) or <rarediseaseday.org> (Global site).

*This toolkit was developed and provided by the United Leukodystrophy Foundation.*