Global Genes®
Allies in Rare Disease

Rare Disease Day 2024 Media Kit
Driving Awareness, Educating and Advocating

Rare Disease Day, February 29, 2024, is a crucial annual event that brings attention to the challenges faced by individuals living with a rare disease and emphasizes the need for continued research, advocacy, and support. This media kit is designed to assist you in creating awareness during Rare Disease Day and encouraging widespread participation throughout the month of February and beyond.

Educate and Advocate: Social Media

Follow us on social media (@globalgenes) and join in creating awareness.

- **Rare Disease Stats:** Share statistics to raise awareness about rare disease and the unique challenges individuals who live with a rare disease face every day. Reshare our posts, post to your social media, or email to your network. Tag us and use hashtags #CareAboutRare #RareIsNotCommon #RareDiseaseDay **You can download all images here!**
- **ZebraTales:** We want to spotlight the resilience and strength of individuals living with rare diseases, caregivers, and their advocates. We are encouraging individuals to share their personal stories and experiences related to rare diseases. We will be providing a downloadable printout of a zebra tail for people to wear and symbolize their support for rare diseases. We are also encounrating people to craft their own tail for their photos and videos! Participants should share their story and capture photos or videos, tagging @globalgenes and using the hashtags #ZebraTales #CareAboutRare so that we can reshare your contributions and keep the momentum going! **Download your zebra tail here**

Social media samples can be found at the bottom of this document.

Emphasize unity within the rare community:
- **Where can Global Genes be found on February 29? :** Join Global Genes in support of the NIH RARE Disease Day Event and visit our booth on February 29 in Washington D.C. Our staff will be decked in zebra gear and handing out resources and ribbons. At 10:30 am ET, join us and EveryLife Foundation for a coffee reception to meet others within the community. Come visit us!

- **Share Your Event:** Let's show how many events are happening worldwide, in person or virtual. Is your organization hosting an event in February for Rare Disease Day? Promote your events on our website in our [Event Hub](#).

Social Media Samples
- General images and rare disease statistics to share within your social media posts can be found [here](#).
- [#ZebraTales Video](#) to share with your post
- [Downloadable zebra tail print out](#)

Zebra Tales Social Media Posts

1. Celebrate the resilience and strength of rare disease individuals, advocates, and caregivers. @globalgenes #ZebraTales encourages participants to share personal stories and experiences related to rare diseases on social media while sporting their zebra tail (get it?). Post your story and capture photos or videos, tag @globalgenes and use the hashtags #ZebraTales #CareAboutRare so that they can reshare your contributions and keep the momentum going! Don't forget to tag your 2-3 people to participate. Download your [zebra tail print out here](#) or craft your own!

2. Raise awareness for #raredisease by sharing your story. @globalgenes has launched their story telling initiative #ZebraTales encouraging patients, caregivers and advocates to share their rare disease story on social media while wearing a zebra tail. Watch their video here: https://www.youtube.com/watch?v=UvscIjFzfsA then Post your story and capture photos or videos, tag @globalgenes and use the hashtags #ZebraTales #CareAboutRare so that they can reshare your contributions and keep the momentum going! Don't forget to tag your 2-3 people to participate.

3. I am sharing my #ZebraTales as part of @globalgenes initiative to spread awareness through storytelling! I nominate XXXX and XXXX to share their #ZebraTales to keep the momentum going. #CareAboutRare [Download and customize your zebra tail here!](#)

Rare Disease Stat Social Media Posts

1. February 29th is Rare Disease Day! 🦓 Let's shine a light on those facing the challenges of rare diseases by bringing awareness to the unique challenges living with a rare disease brings. Reshare this post to spread awareness and show your solidarity with those living with rare diseases. <add image of one of the stats provided in this folder>

Email Sample

Zebra Tales Awareness

Hi [insert name],

February 29th is Rare Disease Day, but for over 400 million individuals/families, Rare Disease Day is every day. To bring awareness throughout February, Global Genes is spreading awareness through storytelling - #ZebraTales. Participants are encouraged to share their rare disease why (why they work their tail off advocating) and experiences related to rare diseases on social media while sporting their zebra tail (get it?). Download your zebra tail here.

Post your story and capture photos or videos, tag @globalgenes and use the hashtags #ZebraTales #CareAboutRare so that they can reshare your contributions and keep the momentum going! Don't forget to tag your 2-3 people to participate. Visit their World Rare Disease Day webpage for details on how you can support rare disease and share your events. Together, let's make a difference. By spreading awareness and fostering understanding, we contribute to a world where individuals with rare diseases feel seen, heard, and supported.

Thanks, [insert name]

General Awareness

Hi [insert name],

February 29th is Rare Disease Day, but for over 400 million individuals/families, Rare Disease Day is every day. To bring awareness throughout February, we are joining Global Genes to amplify the needs of rare disease. We hope you will join us! Visit their World Rare Disease Day webpage for details on how you can support rare disease and share your

events. Together, let's make a difference. By spreading awareness and fostering understanding, we contribute to a world where individuals with rare diseases feel seen, heard, and supported.

Thanks, [insert name]

For Media:

February 29th is Rare Disease Day, but for over 400 million individuals/families, Rare Disease Day is every day. To bring awareness during throughout February, Global Genes is spreading awareness through storytelling - #ZebraTales. Participants are encouraged to share personal stories and experiences related to rare diseases on social media while sporting a downloadable image of a zebra tail. Stories will be posted on social media through photos or videos, tagging @globalgenes and using the hashtags #ZebraTales #CareAboutRare so that they can reshare contributions and keep the momentum going!

Not able to share a story? Join Global Genes on February 29th in Washington D.C. at the NIH RARE Disease Day Event and visit their booth. Midmorning, there is an open invite for individuals to join them and EveryLife Foundation for a coffee reception to meet others within the community.

Visit their World Rare Disease Day webpage for details on how you can support rare disease and share your events.

Questions? Contact Us
- General questions: Kat Lim, katherine.lim@globalgenes.org
- Global Advocacy Alliance questions: Shelby Carney, Shelby.Carney@globalgenes.org
- Business Development questions: Kathy O'Connor, KathyO@globalgenes.org
- RARE-X Patient Advocacy Organization questions: Katelyn Peters, Katelyn.Peters@globalgenes.org

About Global Genes
Global Genes is a 501(c)(3) nonprofit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of that mission, Global Genes connects, empowers, and inspires the rare disease community to stand up, stand out, and become more effective on their own behalf — helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. Global Genes serves more than 400 million people around the globe, and nearly one in 10 Americans affected by rare

diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact _Global Genes_ at 949-248-RARE or visit the _Resource Hub_.