GETTING INVOLVED IN RARE DISEASE DAY 2016

Rare Disease Day takes place on the last day of February each year. The main objective of this day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. Here are three ways to get involved:

Get Social | **Host an Event** | **Share Your Story**

GET SOCIAL

Being active on social media platforms like Facebook and Twitter is a great way to let others know about Rare Disease Day. Make sure to use one of the official hashtags of this year's event: #RareDiseaseDay or #WRDD2016. Below is a sample post highlighting Rare Disease Day 2016 – you can personalize this example and share on your own or your organization's social media channel.

SAMPLE POSTS:

Today is #RareDiseaseDay! There are at least 350 million people around the world who are living with a rare disease.[1] Share the graphic below to show support for rare liver diseases and learn more about rare diseases at http://bit.ly/23wknWb!

1. "RARE Diseases: Facts and Statistics." Global Genes; 2015. Retrieved from https://globalgenes.org/rare-diseases-facts-statistics/

It's #RareDiseaseDay! #DYK 6% to 8% of the EU population[1] & 10% of the US population[2] live with a rare disease? RT to raise awareness!

1. "What is a rare disease?" EURORDIS; 2014. Retrieved from http://www.eurordis.org/content/what-rare-disease
2. "RARE Diseases: Facts and Statistics." Global Genes; 2015. Retrieved from https://globalgenes.org/rare-diseases-facts-statistics/

Included with this guide is a series of graphics to use in your social communications around Rare Disease Day. These graphics have been optimized for Facebook and Twitter – if you decide to use them, please be sure to share the appropriate graphics on their respective social media platforms (i.e. share the PBC Facebook optimized graphic on Facebook; share the rare liver disease Twitter optimized graphic on Twitter). In addition to the graphics, below is a link to a short video created to highlight PBC as a rare liver disease. Feel free to share this video on social media as well.



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Another way to get involved on social media is by participating in the the National Organization for Rare Disorders (NORD) and The American Broadcasting Company (ABC) Tweetchat. It's easy to join – just tweet @rarediseases and @RareDayUS and dive right into the conversation. Marsha Lanes, MS, CGC, NORD's Genetic Counselor & Medical Educator, will be answering questions that come from using the Twitter handles above. In addition to the Tweetchat, signing up for the Rare Disease Day Thunderclap is another simple and effective way to get the word out about rare diseases. On Rare Disease Day, the Thunderclap will simultaneously push out posts on the Facebook and Twitter accounts of everyone who signed up, leading to the topic trending and increasing the reach of the message.

HOST AN EVENT

A great way to showcase your support for Rare Disease Day is to host a local event. Your event can focus on a specific patient or disease, or highlight the full spectrum of the rare disease community. An event is a great way for people living with a rare disease to share their story with others – it is also an opportunity to educate friends, family and community members about different diseases.

If you are unable to host an event, here are some other easy ways to get involved:

- Wear items of clothing to promote rare diseases and raise awareness.
- Distribute flyers about Rare Disease Day.
- Donate to the rare disease charity of your choice.

SHARE YOUR STORY

Let people know why Rare Disease Day is important to YOU by sharing your story, photo or video on the Rare Disease Day website. Sharing your story is a great way to send a message of solidarity and community to the public.

There are many ways to share your story with others. Here are a few examples:

- Write a Facebook post or Tweet to share with your network.
- Take a photo holding a sign stating why you support Rare Disease Day (e.g. Primary Sclerosing Cholangitis is my rare disease).
- Make a video blog of your experience with rare disease.
- Visit http://www.rarediseaseday.org/tell-your-story to upload your story, photo or video.

Keep these helpful tips in mind as you share your story with others:

- Less information is more – keep your story short.
- Get to the heart of the story – what's the most important thing?
- Connect with people – let them know why you care.
- Grab attention – being descriptive can help capture a reader's interest.
- Put your story into context – stats and facts about the rare disease community as whole help make your story relatable.

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