Rare Disease Day

Rare Disease Day is all about support. The mission is to reach the millions of people around the world who are living with rare diseases and let them know they’re not alone. It also helps to connect the millions of people who act as caregivers and supporters for those with rare diseases so they, too, can share ideas and encouragement. The overall goal is simple: raise awareness about the global health challenges that rare diseases cause, and harness everyone’s positive creative energy to help find ways to make a difference.

Each year, people with idiopathic pulmonary fibrosis (IPF)—and their families and friends—use Rare Disease Day as a platform to take action. (Learn about IPF.) It’s a great way to get the word out about the disease and the need for more research. Rare Disease Day is held on the last day of February every year.

What Makes a Disease Rare?

In the US, any disease that affects fewer than 200,000 people is considered a rare or orphan disease, according to the Orphan Drug Act of 1983. There are nearly 7,000 diseases that meet this definition, and almost 1 in 10 Americans is affected by one of them—nearly 30 million people in total. IPF is one such disease. People with rare diseases, including those with IPF, often have difficulty getting a proper diagnosis. (Learn how IPF is diagnosed.) They may also have trouble finding information, getting treatment for their condition—if there’s even one available—and getting the support they need. This is why it is so important to raise awareness about these kinds of conditions.

How You Can Get Involved

Rare Disease Day is co-sponsored by the National Organization for Rare Disorders (NORD) and Rare Disease Europe (EURORDIS). These 2 organizations are dedicated to supporting people facing rare diseases around the world. Rare Disease Day was created to promote grassroots efforts to support patients and the people who care for them. There are many ways for individuals, organizations, and companies to participate, and
the organizers encourage everyone who is interested to take part in any way they can—either through online activities or in-person events.

To learn more about the history of Rare Disease Day, and ways you can get involved, visit the official website.