Advocacy, Support, and Resources for the CGD Community

2023 EDITION

Hello, from Horizon Therapeutics! Bringing our chronic granulomatous disease (CGD) community together is a central part of our mission. This newsletter connects you with the CGD community and valuable resources, information, and support that can be helpful along your CGD journey. We are here for you; you are not alone.

Visit the links throughout this newsletter to get more information about support and/or community events provided by each organization. The links provided connect to non-Horizon websites operated by independent parties responsible for their own content, except for Horizon By Your Side.

HORIZON BY your side

Horizon By Your Side provides one-on-one support through a Clinical Nurse Educator (CNE) for those prescribed a Horizon medicine. You can also talk to someone about Horizon By Your Side by calling 1-844-4MY-HBYS (1-844-469-4297).

CGD ASSOCIATION OF AMERICA

CGD Association of America is an independent, nonprofit organization committed to advocating for people living with CGD. Take a look at their blog, resources for families and physicians, and get on the list for Coffee & Community and/or Coffee & Carriers Zoom calls.

IDF Immune Deficiency Foundation

There are over 400 primary immunodeficiencies (PIs), CGD being one of them. The Immune Deficiency Foundation (IDF) is dedicated to empowering those affected by PI through advocacy and education. IDF provides resources and information through their publications, blogs, and newsletters. Find information about living with CGD and check out the Calendar of Events for live and virtual events, support groups, and webinars throughout the year and get involved!

Escape Weekend 2023!

July 21st-23rd, IDF will be hosting an event for teens and young adults.
Register here!

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jm Jeffrey Modell Foundation

The Jeffrey Modell Foundation is a global, nonprofit organization dedicated to making a difference in the lives of families affected by PI. Advocacy and awareness, research, newborn screening, early diagnosis, treatments, and finding possible cures are just some of the Foundation's efforts. Use their immunologist tool to find an expert in your area. Find out more about their Travel Grants and the Roots & Wings patient program.

See more organizations on the next page!

Horizon is dedicated to connecting you and your family with more resources.

HORIZON®

Feeling social? Most of these organizations are on Facebook, Instagram, Twitter, YouTube, and LinkedIn. Like, follow, and get connected!

Remember the Girls is a global community dedicated to connecting, providing resources to, supporting, and advocating for females with X-linked conditions. If you're an X-linked carrier and like podcasts, check out collectively coeXisting.

Angel Aid is an organization that believes in taking care of caregivers and providing emotional support to mothers and families in the rare community. Learn more about their upcoming workshops, retreats, and weekly support groups. Also, **talk to your CNE about getting a Trauma-Less Needle Pokes Kit** through Angel Aid.

The Patient Advocate Foundation addresses obstacles to healthcare access. Get information and help with financial aid, co-pay relief, case management assistance, and more.

National Organization for Rare Disorders (NORD) has been rooted in research, policy, and care, and has remained dedicated to solving challenges and unmet needs for families affected by rare diseases for 40 years. NORD has a wealth of resources, information, and community support, including CGD Patient Assistance Programs, a Rare Disease Database, Centers of Excellence, and mentoring organizations. Interested in starting a rare disease organization? They can help with that, too.

The Center for Chronic Illness is focused on bringing people together to decrease the feelings of isolation, especially when living with a rare, chronic condition. It offers programs and support groups for teens and African Americans living with chronic illnesses, Spanish-speaking women, parenting, and supporting loved ones.

Our Odyssey connects young adults living with rare, chronic conditions with others to help foster community and social support. It provides meetups and programs including a bimonthly Social Meet-Ups Series, a virtual Empower Series workshop, and Topic Specific Virtual Meet-Ups.