



CSRF SUPPORTS RARE DISEASE DAY

28 FEB
2025

rarediseaseday.org

#RareDiseaseDay

CSRF E-NEWSLETTER MONTHLY UPDATES JANUARY-FEBRUARY 2025

It's Rare Disease Day (Week)!

Rare Disease Day was created by Rare Diseases Europe (EURORDIS) in 2008 as an internationally recognized day and initiative. Its goal is to raise awareness, generate support, and advocate for care and treatments for the 300 million people globally, including 30 million Americans (about half of whom are children), who are living with a rare disease. Rare Disease Day takes place each year on the last day of February.

The National Organization for Rare Disorders (NORD) also creates annual themed campaigns to encourage all of us living with rare diseases to share this experience with others. For 2025, NORD has created a **#ShowYourStripes** social media campaign. The zebra serves as a mascot for rare disease patients because medical professionals have historically been told that when they “hear hoofbeats” they should expect a common horse, not a less common zebra.

We now know that 1 in 10 people in the U.S. have a rare disease. Will you help us recognize Rare Disease Day 2025 on social media by wearing or featuring zebra print in profile photos and/or using any of the available frames, posts, and graphics provided by EURORDIS and NORD?

Check us out on Facebook or Instagram and feel free to share our posts, or create your own! Don't forget to use the four themed hashtags for this awareness day:

[#ShowYourStripes](#)

[#CSRF](#)

[#RareDiseaseDay](#)

[#CushingsAwareness](#)

EURORDIS resources in 15 languages:

<https://www.eurordis.org/rare-disease-day/>

NORD resources (look for social media toolkit):

<https://rarediseases.org/rare-disease-day/>

CSRF Facebook:

<https://www.facebook.com/CSRF.net>

CSRF Instagram:

<https://www.instagram.com/csrfcommunity/>



Zoom Support Group for Patients

Please join us if you have questions or need support, and also if you have the spoons to BE the support for others! Sign up at the url below or visit csrf.net (front page upper left).

Zoom link will be emailed within 24hrs of the call.

<https://surveymonkey.com/r/2025CSRFSupportcalls>

Upcoming Call Schedule (All Times Eastern):

- ♥ Saturday, March 15, 11:00am
- ♥ Wednesday, April 16, 7:00pm
- ♥ Saturday, May 24, 11:00am
- ♥ Wednesday, June 11, 7:00pm

Caregivers ONLY Zoom Support Group

This group is a safe space for Caregivers to find support as they give support. Ask questions, learn more about Cushing's, and get help finding resources you need. Sign up via url below or at csrf.net (front page upper left).

Zoom link will be emailed within 24hrs of the call.

<https://surveymonkey.com/r/CSRFCaregiverCalls>

Upcoming Call Schedule (All Times Eastern):

- ♥ Sunday, March 16, 7:00pm
- ♥ Saturday, April 12, 11:00am
- ♥ Sunday, May 4, 7:00pm
- ♥ Saturday, June 14, 11:00am

2025 Patient DINNER SERIES



Community Dinner in Newport Beach, CA 2/4/2025

SAVE THE DATE if we're coming to a city near you! We'd love to break bread with you.

RSVP:

<https://www.surveymonkey.com/r/2025dinners>

March 30 - San Diego, CA

April TBD - Atlanta, GA

May 10-13 - Copenhagen, Denmark

May 17 - Orlando, FL

June 1 - Washington, DC (pending)

June 14 - Tampa, FL (pending)

June 21 - Chicago, IL

July 12 - San Francisco, CA

August-September TBD - Boston/Plymouth, MA

October 4 - Anaheim, CA

October 18 - Washington DC

November 5 & 6 - Phoenix, AZ

December TBA - Atlanta, GA

Cushing's Registry Updates



We've been building our Global Cushing's Registry for a little over a year now, and we are thrilled to share that we see the light at the end of the tunnel! This journey has been bumpy and frustrating at times, but when I take my feelings out of it and really look at what we're doing, I'm amazed. Everyone putting their heart, soul, blood, sweat, and tears into this project, was a **patient** first. That is why this is going to be successful - **we are the missing link to progress**, and we can't wait until it is ready to enroll Participant #00001!

The past 6-8 months have been fully focused on the development of our initial set of surveys. When a participant joins the registry, they will verify their diagnosis and answer some health and background questions in starter questionnaires:

- Participant Profile
- Getting Started & Diagnosis
- Demographics
- Family & Lifestyle

Following those, the next surveys will look at signs and symptoms of Cushing's, quality of life topics, measures of well-being, and additional medical data specific to your Cushing's journey.

Some of these initial surveys will ask general questions, example "Did you have sleep problems

during Cushing's?" We know there's a lot more to the complex sleep issues we have, but our first step is to establish the areas where there's majority rule, and **then** do detailed studies.

A big goal for the registry is longevity and engagement - we want Participants to know its value and stay connected over time. Enrolling, answering the first set of surveys, and then never logging in again defeats the purpose! Annual and semi-annual surveys create data points that can help with healthcare conversations, or just for you to see your progress in areas as you heal from surgery. In other surveys, once finished, you will be able to access graphs and charts showing where you stand in comparison with others in the registry. Anonymously, of course!

Future study capabilities are possibly the most exciting part - game-changing confirmations and discoveries within the registry become studies that lead to education and action. From this point on, we don't wait for someone, somewhere to notice and do something. We are here, with a state-of-the-art research tool that doubles as a validator of everything we experience in Cushing's. Stay tuned for more in next month's e-news and a big spread in our print publication!

-LESLIE EDWIN, PRESIDENT

Advocate

WITH YOUR EXPERIENCE:

TWO COMPENSATED PROJECTS FOR YOU TO CONSIDER



Patient/Caregiver Leadership Council

One of our supporters is forming a Patient Leadership Council (PLC) to give patients a “seat at the table.” Members review and discuss a variety of topics, and their input helps the company make clinical trial design decisions.

Scope of work is four video conference calls per year and perhaps one in-person meeting if needed. Members of the PLC may renew their annual contract for one additional year if desired.

Participation Requirements:

- Diagnosed with Cushing’s Syndrome, or the spouse/caregiver of someone diagnosed.
- Willingness to provide open, honest, and constructive feedback and input.
- Comfort speaking in a small group setting.
- Ability to participate via video conferencing on camera from a computer or tablet.
- United States citizen or permanent resident.
- Not currently engaged in an advisory role with a pharmaceutical company.

**Interested? Email Leslie:
leslie@csrf.net**



Medscape Video: Looking for Three Patients

The organization **Same but Different** specializes in films and photography capturing rare diseases and disability. They are creating a short film for Medscape focused on patient voice in Cushing’s Syndrome: diagnosis, impact on life, and importance of treatment options. The film will be used to educate healthcare professionals on the importance of keeping patient needs at the forefront of treatment.

Ideally, the three people they want to interview:

- had difficult-to-control type 2 diabetes before Cushing’s diagnosis
- tried more than one treatment or medication to get the diabetes under control, possibly even being told they are not being compliant
- ultimately received a diagnosis of Cushing’s Syndrome as the underlying cause of the diabetes.

**Check out Same but Different on the web at
www.samebutdifferentcic.org.uk**

**Interested? Email Producer
Ceridwen Hughes:
ceri@samebutdifferentcic.org.uk**