

CSR E-NEWSLETTER

BIMONTHLY UPDATES

MAY-JUNE 2025

Become a Research Partner, Step One: Join a Registry!

A patient registry is a secure platform that collects data on a group of patients defined by a particular condition. They support research, improve quality of care, inform public health, and guide policy.

High-volume academic hospitals have internal registries comprised of their patient list and clinical data related to their treatment. Physicians will often use this data to write articles to share within the scientific community, but the lack of patient input can limit the scope of understanding, especially on issues related to quality of life, elements of well-being, new diagnoses after “cure” or remission, and long-term health.



ERCUSYN.EU

Europe has ERCUSYN, the European Register on Cushing's Syndrome. CSRF Medical Advisory Board member Dr. Elena Valassi is a key team member at ERCUSYN and motivated us several years ago when she said universal healthcare systems helped grow the registry but that the ability to include patient-reported data would allow for so many more avenues to explore. There could be a future where our registries work together to tell more of the story for our European peers!

In the US, our ability to build a unique, validated, IRB-controlled registry “by and for the people” rests on a network of rare disease advocates and educational funding that does not exist anywhere else quite like this. Leading the pack is NORD (National Organization for Rare Disorders), builders of the IAMRARE registry platform we are using.

NORD has listened for more than a decade to IAMRARE users and consistently offers friendly “how to” videos, webinars, and documents. If you would like a 101 on joining a registry, what it looks like once inside, how consent is handled, and lots of other details, please consider joining their webinar on June 12 at 4:00pm EST entitled **Community Conversation: The Living Rare Study.**

[For more information or to register:](https://rarediseases.org/event/community-conversation-the-living-rare-study/)

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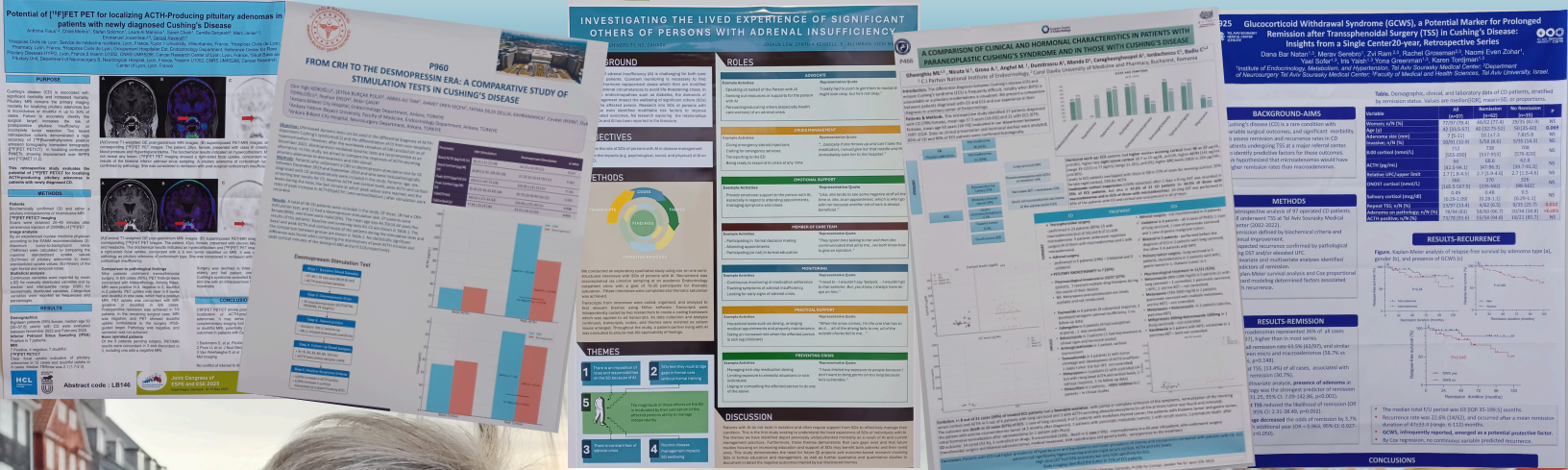
WEBINAR



**LIVING
RARE** Study

**Community Conversation:
The Living Rare Study**

Thursday, June 12 at 4pm ET



European Congress of Endocrinology 2025: Inspiration Across the Pond

May 10-13 in Copenhagen, Denmark was a great place to be if you were looking for new research, unusual studies, and promising discoveries about or related to hypercortisolism. President Leslie Edwin was joined by CSRf Secretary and Pediatrics Lead Meg Keil for this powerhouse of a meeting that combined the European Society of Endocrinology (ESE) with the European Society for Pediatric Endocrinology (ESPE) under one roof.

One of our favorite parts of a large professional conference is the posters: scientists, researchers,

and physicians at all levels of experience share current and late-breaking findings in easy-to-read format. Many times it is a glimpse into ongoing work that will be presented at a later date, and at this meeting in particular it came from all around the world. We will share many of our personal highlights, with summaries in the print newsletter coming next month.

One of the first conversations we had as we were setting up our booth was with two representatives from Hybi (<https://hybi.no/>), an advocacy group out of Norway. It's becoming very clear that there is a strong need for an equity-driven global network of advocacy, research, education, and patient support.....stay tuned!

CORTISOL SUMMIT 2025

NOVEMBER 7-8

HOSTED BY:



WITH CO-HOSTS:



CONFERENCE LOCATION:

Barrow Neurological Institute
2910 N 3rd Ave, Phoenix, AZ 85013

SATURDAY 30th ANNIVERSARY PARTY LOCATION:

2825 W Thomas Rd, Phoenix, AZ 85013
(across the street)



Learn from the Past,
Support and Educate in the Present,
Boldly Contribute to Future Science

EARLY REGISTRATION & ROOM BLOCK ARE OPEN!

<https://www.zeffy.com/ticketing/november-7-8-2025-conference>

Watch CSR social media and member email
for agenda and add-on activities soon.

CSR.NET/CORTISOLSUMMIT2025

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. These dinners are free for you and a guest if you wish to bring one.

LIST UPDATED JUNE 2025

RSVP:

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

June 21 - Chicago, IL

July 12 - San Francisco, CA

August-September TBD - Boston/Plymouth, MA

Late September - Tampa, FL (pending)

October 5 - Anaheim, CA

October 18 - Washington DC

November 5 & 6 - Phoenix, AZ

December TBD - Atlanta, GA

Global Support Calls

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):

♥ Wednesday, June 11, 7:00pm

♥ Saturday, July 19, 11:00am

Caregivers ONLY Support Calls

Please join us for a space where you can ask questions, vent a little, and find resources or information you need to better understand what's going on with your loved one. Sign up at the url below or visit csrf.net (front page middle left); Zoom link will be emailed within 24hrs of the call.

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

Upcoming Call Schedule (All Times Eastern):

♥ Saturday, June 14, 11:00am

♥ Sunday, July 20, 7:00pm



RARE ARTIST

→ **RareArtist.org** ←

The Rare Artist Program celebrates the unique gifts of individuals impacted by rare disease. Now in year 15, this contest is focused on providing a national platform for artists to advocate through **visual artwork, poetry, and music (new for 2025)**. There are a number of awards for top finalists.

Rare Artist 2025 is open for entries June 2nd through July 9th and will accept music as a new medium!