



CSR Share. Aid. Care.
CUSHING'S SUPPORT & RESEARCH FOUNDATION

CSR E-NEWSLETTER

MONTHLY UPDATES

OCTOBER 2024

Who Can Join the CSR Patient Registry?

How many different names for Cushing's have you heard? Various terms are used by our doctors and researchers to describe high cortisol based on its origin - Cushing's Disease for pituitary, Cushing's Syndrome and Mild Autonomous Cortisol Secretion (MACS) for adrenal, Non-Neoplastic Hypercortisolemia or Pseudo for high cortisol without a tumor source, and Exogenous for the kind that can come from medications.

The differences in cause, treatment, prognosis, gaps in existing knowledge, and long-term care led us to a decision to focus on tumor-source Cushing's in our registry. Targeted studies to explore the unique needs within the pseudo/non-neoplastic and exogenous communities are areas we can revisit in the future with the skills we're developing as we build this registry.

But that's just for the registry! CSR supports ALL people with symptomatic high cortisol, regardless of the type. Validation and peer connection can help in our journeys when we feel helpless, unheard, and unseen. Serving patients in this capacity will always be our first job.



"There is no knowledge that is not power."

– Ralph Waldo Emerson



A Critical Need for Diversity

The registry is a tool to tell stories that are currently not shared in the medical community, and sometimes even in patient spaces. It's imperative to include all cultural, geographic, ethnic, "non-white American female" patient populations so that we and the medical community can recognize the different ways this disease affects ALL of us. Achieving this is not going to be an easy task because there is justified mistrust of the process of medical research, perceptions of exclusion, wildly differing access and equity issues, and even doctor mischaracterizations that "people like you just don't get this disease" to overcome. CSR is committed to developing and maintaining relationships with patients and advocates who prioritize correcting these roadblocks. How can you help?

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/2024CSRFSupportcalls>

Upcoming Call Schedule (All Times Eastern):

♥ Saturday, November 23, 11:00am

♥ Wednesday, December 18, 7:00pm



Patient Advisory Committee Update

The Patient Advisory Committee is in full swing! To give you a taste of what we do, our current undertaking involves writing a volunteer handbook, updating data for our website and researching information online for a variety of projects that just takes time. Also, for the creative thinkers out there, what ideas do you have to help raise awareness of CSRF on social media?

Sign up to learn more about the Committee:

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

Would you like to join us to advocate for patient needs at a professional conference in 2025? Check the schedule below for a city near you and send us an email! leslie@csrf.net

DATE	2025 PROFESSIONAL CONFERENCES AT WHICH WE WILL EXHIBIT / NETWORK	LOCATION
May 10-13	European Congress of Endocrinology (ECE) joint conference with Paediatric Endocrinology (ESPE)	Copenhagen, Denmark
May 15-17	American Association of Clinical Endocrinologists (AACE)	Orlando, FL
May 16-18	American College of Obstetrics and Gynecology (ACOG)	Minneapolis, MN
June 17-22	American Association of Nurse Practitioners (AANP)	San Diego, CA
July 10-17	The Endocrine Society (ENDO) + Pituitary Society	San Francisco, CA
July 31 - Aug 2	National Conference for Family Medicine Residents and Medical Students (AAFP)	Kansas City, MO
Aug 8-11	ADCES (diabetes care and educators)	Phoenix, AZ
Oct 5-9	Family Medicine Experience (AAFP)	Anaheim, CA

Remaining 2024 Events

November 8 - Patient Dinner in Palo Alto, CA

November 9 - Stanford Pituitary Patient Day followed by an onsite dinner hosted by CSRF

TO RSVP for one of the dinners:

<https://surveymonkey.com/r/2024patientdinners>

For more info on Stanford Patient Day:

<https://www.eventbrite.com/e/753505203347>