

CSR E-NEWSLETTER

BIMONTHLY UPDATES

MARCH - APRIL 2025

Cushing's Awareness Month Turned Into a Party!

For the past several years we've created activities for Cushing's Awareness Month (April), and this year we had the pleasure of formally incorporating some other awareness days into our social media trivia posts: **International Adrenal Diseases Awareness Day** on April 7, **World Hormone Day** on April 24, and **Undiagnosed Day** on April 29. We knew social media would boost participation but did not expect to come in around 400 participants by the end of the month. Thank you!

We are close to finishing tabulation of all the input received throughout the month of questions, and will share it asap.



A Solid Foundation of Trust is Built Over Time, and With Evidence

CSR started in 1995 with one patient who was struggling with a difficult recovery from adrenal surgery. That's the year that the internet was also just "starting up"; the ease with which we can quickly search for something today was a futuristic concept back then. Still, Louise Pace's determination led to a growth of 100 members in the first year, and within three years that number had tripled.

Today we have around 4000 members in our database and approximately 6500 friends on social media. CSR is recognized globally as a leader in patient advocacy and a growing presence in scientific research. Our strong base supports the development of big dreams into reality, and this year we will roll out a one-of-a-kind Patient Registry that will put the power of progress into the hands of patient participants.

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We haven't avoided challenges in the past three decades, of course - funding in the first days was difficult to raise which meant that our Founder paid for many things out of her own pocket. Our earliest partnerships and collaborations were the first of their kind, and all parties involved had to have a little faith that everyone was in it for the right reasons and could carry out what they said they could do. We've always been patient-led, and our leadership has not been immune to recurrence and other hard health and personal surprises. Plus, there's a steep learning curve on this complex and multi-faceted disease!

Today it is thrilling to see normalization of cortisol screening by non-specialists begin to pick up steam, and we aren't far from launching our patient-run global Registry. These two new developments address long-standing unmet needs for a) shorter time to accurate diagnosis and b) a verified source for patient-reported data about the significant "other" variables that cannot be captured in the clinical setting. It's important to have the data come from a scientifically-sound source like a Patient Registry so that it can be used in all research, and it's been no less than 10 years since CSRF first started exploring a role we could play in helping to capture, organize, and share this exact type of data.

There's still so much to be done though. More patients screened means more patients looking for support and resources. We are expanding our capacity right now to accommodate growth and build more. In the last quarter of this year we will share a team of committees we would like to establish, and we will also make space for more Board leadership with demonstrated passion for the mission.

Change can be rough, but there have been many times in three decades where CSRF's leadership

had to act on faith when there was no precedent, and it paid off. That helps me understand the power we collectively hold as a cohesive, motivated community with mutual goals.

Maybe you have a spirit for advocacy and a desire to be a part of our work and mission? Stay tuned as we fully enter our Future Era!


-Leslie Edwin, President


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):

 Saturday, May 24, 11:00am


 Wednesday, June 11, 7:00pm


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

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.

LIST UPDATED MAY 2025

RSVP:

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



May 17 - Orlando, FL

May 31 - Atlanta, GA

June 1 - Washington, DC

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

RECRUITING:

Compensated Market Research Interviews to Gain Understanding of Treatment Choices

We are working with Lagrippe Research to recruit **24 patients** for a 60 minute Zoom interview plus a short task ahead of the call.

Compensation for this project is \$165.

Qualifications:

- US resident 18+
- diagnosed with tumor-source Cushing's (pituitary, adrenal, ectopic)
- currently taking one or more medications to BLOCK or LOWER cortisol (this does not include hydrocortisone, prednisone, or other cortisol replacement medications)
- willing to share contact info and respond quickly
- ready to participate in the next week or two

If you feel this project is right for you, please visit this url to fill out a short pre-qualification and permission to share your information:

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

Your privacy is important to us. Before we agree to assist with recruitment of this type of project, we ensure that personal data collected will not be stored or reused beyond the single project, and that summaries created by the market research firm for their client will be de-identified and never include your personal details.

We also want to emphasize that your story and experience with this rare disease is valuable. We believe when there is a for-profit company asking for it, you should be compensated fairly. Please be cautious and ask who is behind any survey, questionnaire, or sign-up you are offered online.



We are thrilled to finally state with confidence that we are on track for a soft launch of the Registry at our November conference in Phoenix. There's still plenty of work to do to get it across the finish line, but we have submitted our initial set of surveys which was a huge portion of the build.

The surveys are the tools with which we will build our research-ready story in the Registry:

- initial demographics and family history surveys to establish where we come from
- diagnosis and treatment surveys to help differentiate and quantify how we all experienced this disease
- ongoing surveys that will repeat annually to gather datapoints that can be tracked over time to help show trends where better care is warranted
- specialty surveys that go deeper on topics with urgent unanswered questions and unmet needs

It's also an honor to share that we are inviting Mika Armenta, a CSRF member and Cushing's patient with a background in psychology research, to be a Principal Co-Investigator on the Registry. Her commitment to help ask the right questions and honor the entirety of the human experience of Cushing's marked a turning point for us, and we're so lucky to have her!

Another development that will add further value to the Registry is our decision to include pediatric patients via "Legally Authorized Representative". In the beginning we made the decision to exclude these patients because we inaccurately believed that the pediatric cause was beyond our scope, but then another amazing researcher came into our sphere looking for support and resources for their teenage child who had Cushing's before age 10. We pulled the classic "we can do this if you help it happen" move, and it worked! We have had a pediatric expert on our Board for years, so when we asked Meg Keil she agreed to jump in too.

**We will increase our outreach about the Registry in the coming months.
We cannot wait to share it with you, then the world.**



We are moments away from rolling out registration and some agenda highlights for our International Patient Conference being held November 7-8, 2025 at Barrow Neurological Institute in Phoenix, AZ. Get ready to sign up! We're counting the days until we can celebrate 30 years with you.