

CSRF E-NEWSLETTER

MONTHLY UPDATES

SEPTEMBER 2024



A Cushing's Patient Registry

Patient registries are databases with information and certain medical history in them. Wherever you see your doctors, there is an internal database where patient data is stored and analyzed. If your doctors are at a university hospital, they likely depend on this data to share findings with the broader medical community, and eventually that data can be combined with many other institutions' data for a bigger retroactive study. Most databases like this contain minimal patient quality of life (QoL) data, and it's often collected via short surveys that have been "validated" through repeated use and analysis over the years.

Cushing's is a strange beast with many moving parts that is almost impossible to capture neatly and cleanly, and certainly not without significant contribution from the patients themselves. Due to the nature of this disease, it's imperative to increase understanding of long-term QoL.

CSRF is building a professional patient registry that will be a first of its kind - global, owned by patients, validated through health records where possible, and inclusive even when it isn't.

Our registry is being created in the language and format required for our data to be used by researchers, high level clinicians, drug developers, and device creators. It will be secure to Europe's GDPR levels [1], there will be oversight by an Internal Review Board [2], and NORD [3] will provide technical support.

Participants will be able to see how they compare to others in the registry via graphs and charts of the questions asked. CSRF will host regular planning sessions with members to discuss findings, develop surveys, and create posters and presentations for international conferences.

The most powerful contribution we can make to evidence-based science is **our experience**. We will discuss a new part of the registry each month leading up to our proposed soft launch in February 2025. Are you interested in joining the build? Let us know here:

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

REFERENCES

1. European Data Collection - GDPR
https://www.edps.europa.eu/data-protection/our-work/subjects/health_en (accessed 2024-09-03)
2. Northstar IRB - <https://learningirb.org/> (accessed 2024-09-03)
3. National Organization for Rare Disorder s(NORD) IAMRARE Registry Platform - <https://iamrare.org/> (accessed 2024-09-03)

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):

- ♥ Wednesday, October 16, 7:00pm
- ♥ Saturday, November 23, 11:00am
- ♥ Wednesday, December 18, 7:00pm



Patient Advisory Committee Update

The Patient Advisory Committee has been busy this year, with new members who have been instrumental to projects and programs we couldn't have accomplished without them: a first-ever Mindfulness-A-Thon for Cushing's Awareness Month in April, "One Pager" documents that provide tips and insights for patients beyond the clinical setting, and data clean-up projects to get ready for a new website design, to name a few!

If you would like to learn more about the Committee or discuss joining, please sign up:

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



2024 Upcoming Events

October 19 - Patient Dinner in Washington D.C. sponsored by Sparrow Pharmaceuticals

October 20, 21, 22 - CSRF attending the NORD (National Organization of Rare Disorders) Rare Summit in Washington D.C.

November 8 - Patient Dinner in Palo Alto, CA sponsored by Sparrow Pharmaceuticals

November 9 - Stanford Pituitary Patient Day at the beautiful Stanford Medical Center 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>



CSRF is looking into developing a care package program to send a little encouragement and support to newly diagnosed patients. These packages could contain any variety of fun, useful, cozy, inspirational, and educational items. Each package is meant to remind a new "Cushie" that they are not alone.

What items would have been meaningful to you around the moment of diagnosis? Keep in mind the cost and size for shipping, and let us know your thoughts and ideas!

Email Gretchen at gretchen@csrf.net.