



# CSRF E-NEWSLETTER

BIMONTHLY UPDATES

JULY-AUGUST 2025

SPECIAL CONFERENCE EDITION

## We Have Several Amazing Initiatives to Share! Please Join Us As We Build a Future of Earlier Diagnosis and Better Support and Education for All

It's been a long time in the making and has required years of blood, sweat, and tears! Our small team has weathered many challenges over three decades, but through it all we have been building, supporting, networking, and looking for opportunities that honor the unique needs and interests of our community.

We are grateful to our members, advisors, supporters, and friends who have answered the call time and again to SPEAK UP, to LISTEN, and to ACT in patients' best interests. We use our authenticity, our stories and experiences to first help ourselves, then look outwards to help others in the present and the future.

CSRF is thrilled to share this pipeline of projects. By this time next year, everything you see below will be live, and it's truly a humbling moment for us, after everything it has taken to get here, today, to know it is our dedication and determination that has given life to all of this, and more.

### CSRF Project Pipeline

#### PROJECT

Determine Need

Network

Plan It

Build It

Rollout

Reduction of Access Barrier:  
Wordly partnership for all languages



New csrf.net website with easier navigation,  
more features



Global Cushing's Patient Registry



International Patient Education Day & 30<sup>th</sup>  
Anniversary Party



"State of the Cushing's Community"  
stakeholder meeting



Reduction of Access Barrier:  
50-state virtual screening w/o bias



Patient Guidebook, a collaborative tool for  
patients & physicians





## REDUCTION OF ACCESS BARRIER: A VIRTUAL PHYSICIAN INITIATIVE TO CREATE AVAILABILITY IN ALL 50 STATES WITH A SCREENING PROTOCOL DEVELOPED BY THE CSRF TEAM

We are finalizing a partnership that will ensure that ALL patients:

- 1) get an appointment within a reasonable amount of time no matter where they live in the US, and it will be covered by their insurance
- 2) get a bias-free initial assessment to collect important clinical data to support the screen and potential diagnosis
- 3) receive the correct screening tests, follow up, and repeat testing and referrals if needed.

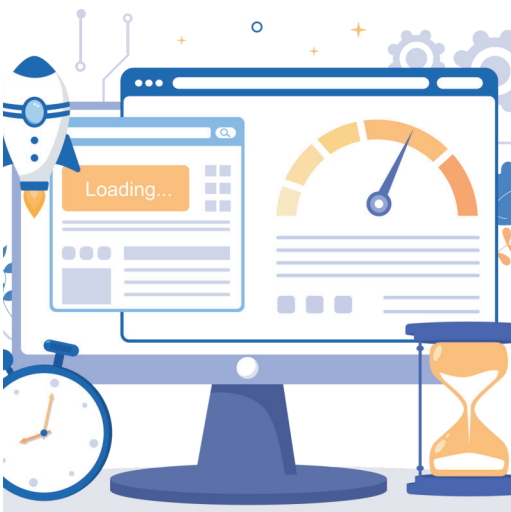
**ROLLOUT FOR ALL 50 STATES: 1<sup>ST</sup> QUARTER 2026 (SOME SOONER!)**



## REDUCTION OF ACCESS BARRIER: AI-DRIVEN REAL-TIME TRANSLATION SERVICES FOR VIRTUAL, RECORDED, AND LIVE PROGRAMMING

CSRF has just signed an 18 month contract with **Wordly** that will allow us to connect with our global peer groups and anyone who speaks something other than English, without the barrier of language comprehension. Our Zoom calls, virtual conferences, and live events will be offered in every language, and participants can speak and respond in their native language because hosts and speakers will have the tool as well. Existing in-house and partner videos can be transcribed to create captions in all languages.

**ROLLOUT: NOW! FIRST BIG PROJECT IS NOV. CONFERENCE**



## NEW CSRF.NET WEBSITE

Slowly but surely we've been updating and transferring files to a new website that will be easier to use and navigate, with new features and guides.

Searches for videos, patient stories, and articles will be streamlined with tags and user-friendly interfacing. Timely lists of upcoming events, activities, and other offerings from CSRF and others will create a more robust rare disease experience for all who visit.

Additional categories will house new offerings such as podcasts and webinars plus links to our new initiatives and information about the Registry.

**ROLLOUT: OCTOBER 2025 IF NOT SOONER**



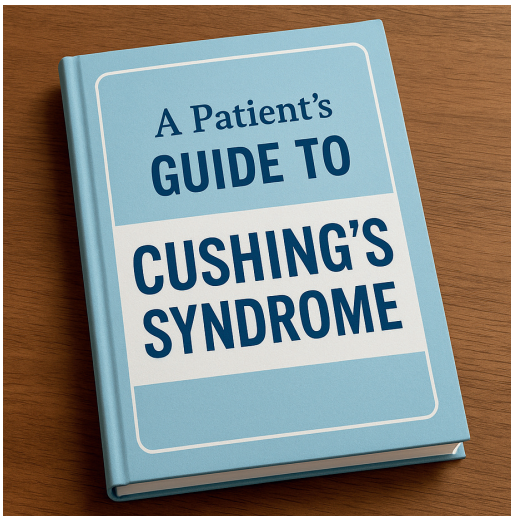


## GLOBAL CUSHING'S PATIENT REGISTRY

CSRF has received funding from the Critical Path Institute for our registry. Over the last 18 months, our team of advocates has worked to determine the right approach to patient-centric research that is heavy on quality of life, elements of wellbeing, and long-term health. As of July 2025, we are rounding the final lap on our build and reaching out to our community for feedback and testing.

We will partner with an entity for consented access to electronic records to verify enrollments, with a bonus that patient participants will also have user-friendly access to their health files, in one place, with tools to summarize and share with providers, at no cost to them and with no risk to their privacy.

**ROLLOUT: NOVEMBER 2025**



## PATIENT GUIDEBOOK

This is one of the most-asked-for resources, and we're working on a draft of a booklet that will cover the spectrum of disease - testing, diagnosis confirmation, heading to treatment, after treatment, long-term care, and many of the "what ifs" that come up because we know this is not always a one-and-done disease. It will also list helpful financial and support resources and programs.

Information will be vetted through patient committee, and clinical data will be reviewed by our Medical Advisory Board to ensure accuracy. Great material from other organizations and entities will be included. There will be no cost for this resource to physicians or patients, and it will be available digitally and in print.

**ROLLOUT: BY 1<sup>ST</sup> QUARTER OF 2026**

## Zoom Support Group for Patients

This group is a safe space for patients to ask questions, get support, and also to BE support for others! Sign up at the url below or visit [csrf.net](https://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, July 19, 11:00am

Wednesday, August 20, 7:00pm

## Caregivers ONLY Zoom Support Group

This group is a safe space for Caregivers to ask questions, learn more about Cushing's, and get help finding resources you need. Sign up via url below or at [csrf.net](https://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, July 20, 7:00pm

Saturday, August 23, 11:00am

YOU, YOUR COLLEAGES, AND  
YOUR PATIENTS ARE INVITED:

# CORTISOL SUMMIT 2025

## NOVEMBER 7-8

HOSTED BY:



WITH CO-HOSTS:



**CONFERENCE LOCATION:**

Barrow Neurological Institute  
2910 N 3<sup>rd</sup> 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>

**CSR.F.NET/CORTISOLSUMMIT2025**