

PROSPECTUS

This year's meeting will delve into the complex challenges beyond "Cushing's 101" faced after successful and unsuccessful surgery / treatment. Currently there is a great need for information for patients, caregivers, and doctors to ensure proper and adequate care during and after the journey. A document will be created with input from attendees and shared widely throughout the medical community. We will also discuss ways to get involved in various aspects of patient advocacy and "unveil" the inner workings of legislation and governmental institutions to determine how to play a part in rare disease decision-making and secure access to safe drugs and devices. Topics have been debated and chosen by a steering committee made up of 34 patients at various stages of recovery and recurrence.

CSRFB invites patients who meet the following criteria:

- confirmed endogenous Cushing's diagnosis – adrenal, pituitary, or ectopic
- at least one completed treatment – surgery, medication, or radiation
- willing to actively participate in sessions and give feedback that will help form a comprehensive document to be shared with the medical community

Each patient may choose to bring up to one caregiver who meets the following criteria:

- truly performs caregiver duties for the patient (i.e. not just an interested friend)
- willing to actively participate in sessions and give feedback

Due to space and cost limitations, this conference is only for qualified patients and caregivers per the above criteria. We apologize for any inconvenience this might present.

Sessions currently under final consideration include:

1. *Self-Care During and After Treatment*
2. *Long-Term Patient Panel (20+ years after treatment)*
3. *What to Expect After Surgery*
4. *What to Expect After Recurrence or Failed Surgery*
5. *Processing Grief*
6. *Physical and Chemical Changes of the Brain and Heart in Cushing's*
7. *Managing Your New Hormone Replacement Regimen*
8. *Intimacy and Fertility*
9. *Medical Therapies Panel*
10. *Fitness and Nutrition*
11. *SSI (Supplemental Security Income) Disability*
12. *Doctor Panel – Centers of Excellence, and What to Do When I Don't Have One*
13. *Body Image and Developing Self-Acceptance*
14. *Bariatric and Skin Surgery*
15. *Neuropsychological Changes – Temporary and Permanent*
16. *Caregiver Issues*
17. *Adrenal Insufficiency*

18. Defining the “New Normal”
19. New Technologies (including pumps and meters), AI, “There’s an App for That”
20. Becoming an Advocate – Volunteer, Educational, and Advocacy Opportunities
21. Dialogue with the FDA – How to Connect
22. Progress Out of Europe

Patients, presenting doctors, and other stakeholders will have several opportunities throughout the weekend to network and share experiences. On Sunday there will be a videographer on site to record interested patients’ stories to use in an edited video that will be shared online.

The conference will be held at the **Emory Conference Center Hotel, 1615 Clifton Road, Atlanta, GA 30329 (emoryconferencecenter.com)**. CSRF has reserved a block of rooms at the hotel as part of the conference package; our rate including all taxes and fees is \$160.00 / night. **Patients wishing to stay at the conference center with the group can book their rooms directly with CSRF.** Priority will be given to attendees who are able to cover the full expense, but a limited number of 50% lodging scholarships may be available. There is no cost to attend the conference including some meals but we do ask you to consider a donation in any amount to help support CSRF. It costs approximately \$350 per person to put on this event; generous sponsorships and grants subsidize but do not completely cover this expense.

Registration opens Friday, July 12, 2019, and continues until we have reached room capacity of 120 individuals. In 2017 we reached capacity less than three weeks after announcing the patient education conference, so we urge you to consider your schedule as soon as possible if you are interested in attending. Registration may be completed using a mail-in form or web form on our website (web form available after Friday, July 19) – please e-mail leslie@csrf.net if you are unable to locate or determine the best format.

Registration confirmations and lodging invoices (if applicable) will be sent via e-mail no more than ten days after receipt of registration. **PLEASE WAIT TO BOOK TRAVEL UNTIL YOU RECEIVE CONFIRMATION OF YOUR REGISTRATION. Lodging payments are refundable through August 23 at midnight, after which they become nonrefundable unless we are able to transfer your reservation to another attendee.**

The final agenda with presenters will be sent to attendees at the end of August along with a list of breakout sessions to choose from for Saturday’s schedule. Information about activities available outside of the conference, transportation details, and other useful facts will be included. If you have questions in the meantime, please direct them to conference organizer Leslie Edwin at leslie@csrf.net.

To join the steering committee to participate in agenda discussions, find the “CSRF Steering Committee” on Facebook. We will finalize topics by the end of July.

If you are interested in sharing your story for the videographer on Sunday, please send a message to leslie@csrf.net for more details.



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