

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
- have started or completed at least one 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.

In addition to the main sessions, breakout sessions currently under final consideration include:

1. *What to Expect After Recurrence or Failed Surgery*
2. *Processing Grief*
3. *Managing Your New Hormone Replacement Regimen*
4. *Intimacy and Fertility*
5. *Fitness and Nutrition*
6. *Body Image and Developing Self-Acceptance*
7. *Caregiver Issues*
8. *Adrenal Insufficiency*
9. *New Technologies (including pumps and meters), AI, "There's an App for That"*
10. *Becoming an Advocate – Volunteer, Educational, and Advocacy Opportunities*
11. *Dialogue with the FDA – How to Connect*
12. *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 up to 15 interested patients' stories to use in an edited video that will be shared online.

The conference will be held **October 4-6, 2019**, 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 \$400 per person to put on this event; generous sponsorships and grants subsidize but do not completely cover this expense.

Registration opened Friday, July 12, 2019 to CSRF members. It opened to the larger Cushing's community on Monday, August 19, 2019 and will continue until we have reached room capacity of 120 individuals. We urge you to consider your schedule as soon as possible if you are interested in attending. Registration may be completed using a web form on our website – please e-mail leslie@csrf.net if you are unable to complete the registration survey.

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 11:59pm, after that 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.

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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