



2019 Patient Journey Summit: Defining the “New Normal”

Agenda

Friday, October 4, 2019

- 12:30 – 2:00 pm** Registration, Refreshments, Networking
- 2:00 – 2:15 pm** Welcome, Day One
Leslie Edwin, President, CSRFB
- 2:15 – 3:30 pm** Defining the New Normal; What to Expect After Surgery
Dr. Eliza Geer, Memorial Sloan Kettering Cancer Center, NYC
Dr. Lynnette Nieman, NIH, MD
Dr. Constantine Stratakis, NIH, MD
Blake Heflin, Adrenal Insufficiency United, DC
- 3:45 – 4:45 pm** NIH Programs and a Patient Perspective on the NIH Process
Dr. Lynnette Nieman, NIH, MD
Dr. Constantine Stratakis, NIH, MD
Amy Dahm, CSRFB, DC
- 5:00 – 6:00 pm** Centers of Excellence and What to Do When I Don't Have One, Q&A, Day One Wrap Up, Sponsor Recognition
Dr. Adriana Ioachimescu, Emory University, GA
Dr. Nicholas Tritos, Mass General, MA
Leslie Edwin, CSRFB, GA
- 6:00 pm** Pay-Your-Way Group Dinner Options
On-site restaurant The Club Room or a short walk to variety of restaurants at Emory Point

Saturday, October 5, 2019

- 8:30 – 9:20 am** Breakfast and Networking
- 9:20 – 9:30 am** Welcome, Day Two
Leslie Edwin, President, CSRFB

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Saturday, October 5, 2019

- 9:30 – 10:30 am** Physical and Chemical Changes of the Brain and Heart in Cushing's
Dr. Nelson Oyesiku, Emory University, GA
- 10:30 – 11:30 am** Neuropsychological Changes – Temporary and Permanent
Dr. Suzanne Penna, Emory University, GA
- 11:45 – 1:00 pm** Quality of Life After Cushing's and Realistic Long Term Expectations
Moderator: Dr. Lynnette Nieman, NIH, MD
Dr. Georgianna Eddins, LCP, DC
Dr. Eliza Geer, Memorial Sloan Kettering Cancer Center, NYC
Blake Heflin, Adrenal Insufficiency United, DC
Dawn Herring, MFT, CA
- 1:00 – 2:00 pm** Lunch, with Three *Optional* Roundtable Topics (choose on-site)
-Observations from a Neuroendocrine Physician's Assistant
Lisa Ward, PA-C, Emory University, GA
-Becoming an Advocate, How to Volunteer, and How to Connect with the FDA and Others Who Influence Policy and Legislation
Muriël Marks, WAPO, Netherlands
Leslie Edwin, CSRF, GA
-Making a Drug for a Rare Community
Dr. Nerissa Kreher, CMO, Tiburio Therapeutics, MA
- 2:00 – 3:00 pm** Medical Therapies Panel
Moderator: Dr. Lynnette Nieman, NIH, MD
Dr. Maria Fleseriu, President of Pituitary Society, OHSU, OR
Dr. Eliza Geer, Memorial Sloan Kettering Cancer Center, NYC
Dr. Adriana Ioachimescu, Emory University, GA
Dr. Nicholas Tritos, Mass General, MA
- 3:15 – 3:45 pm** Origin Stories for Three Medical Therapies
Dr. Joe Belanoff, CEO, Corcept Therapeutics
Matthew Pauls, CEO, Strongbridge Biopharma
Jay Welsh, HRA Pharma
- 4:00 – 5:00 pm** Breakout Session One (check your badge for assignments):
Caregivers
Dr. Georgianna Eddins, LCP, DC
Shannon Taylor, Adrenal Insufficiency United, DC
Progress Out of Europe and Around the Globe
Muriël Marks, World Association of Pituitary Organizations, Netherlands
Adrenal Insufficiency: Sick Day Management and Injection Demo
Dr. Margaret Keil, NIH, MD
Processing Grief and Practicing Self-Care
Dawn Herring, MFT, CA

Saturday, October 5, 2019

- 5:00 – 6:00 pm** Breakout Session Two (check your badge for assignments):
- Adrenal Insufficiency: Beyond the 101***
Dr. Margaret Keil, NIH, MD
Blake Heflin, Adrenal Insufficiency United, DC
Shannon Taylor, Adrenal Insufficiency United, DC
- Cushing's Appetite and How Diet Affects Mood and Cognition***
Dr. Eliza Geer, Memorial Sloan Kettering Cancer Center, NYC
- Optimizing Your New Hormone Replacement Regimen***
Dr. Georgiana Dobri, Weill Cornell Medicine, NYC
Dr. Maria Fleseriu, President of Pituitary Society, OHSU, OR
- What to Expect After Recurrence or Failed Surgery***
Dr. Adriana Ioachimescu, Emory University, GA
- 6:00 – 6:30 pm** Conference Wrap Up, Questionnaire
- 6:30 – 10:00 pm** Dinner Social in Wisteria Lanes (onsite private bowling w/ catering)

MAIN CONFERENCE IS FINISHED. SUNDAY IS ONLY FOR OPTIONAL NETWORKING OPPORTUNITIES AND PRE-SET PATIENT VIDEO RECORDING.

Sunday, October 6, 2019

- Patient Video Project** Pre-arranged ahead of conference, will be posted on the csrf.net website and social media by mid-November.
- Optional Networking** Do you want to talk to CSRF about anything? Let us know ahead of the meeting and we will schedule some time on Sunday.

**Thank you for supporting
CSRF!**