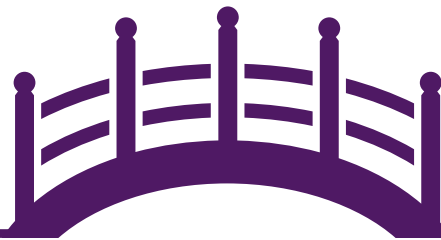


Spinal CSF Leak: Bridging the Gap Between Patients and Providers



Saturday, November 11, 2023



AGENDA

All times listed are Mountain Time

REGISTRATION

7:30–8:15am

WELCOME & INTRODUCTIONS

8:15–8:30am

Dr. Andrew Callen and Andrea Buchanan

SIH: ARRIVING AT A DIAGNOSIS

Patient Talk: Journey to a Diagnosis

8:30–8:40am

Nick Stevens

Provider Talk: Challenges in the Diagnosis of Intracranial Hypotension

8:40–8:50am

Dr. Marius Birlea

Provider Talk: Clinical Mimics of SIH

8:50–9:05am

Dr. Deborah Friedman

Patient Talk: Emotional Lability as a Normal Reaction to Abnormal Circumstances

9:05–9:20am

Dr. John Reiman

Provider Talk: Challenges in the Radiographic Diagnosis of Intracranial Hypotension

9:20–9:35am

Dr. Jessica Houk

Section Q&A

9:35–9:55am

Moderator: Dr. Samantha Petrucci

Break

9:55–10:10am

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**Special Speaker: Navigating CSF Leak Care
When You Are Not at a Major Referral Center** **10:10–10:25am**
Dr. Jill Rau

**Special Speaker: A Clinical Care Model for
Spinal CSF Leaks** **10:25–10:45am**
Dr. Andrew Callen

TREATMENT: PERCUTANEOUS AND SURGICAL

Provider Talk: Epidural Patching 101 **10:45–11:00am**
Dr. Ian Carroll

Patient Talk: Getting A Patch **11:00–11:10am**
Spinal CSF leak patient community members

**Provider Talk: History of Surgical Treatment
of Spinal CSF Leaks** **11:10–11:25am**
Dr. Wouter Schievink

Patient Talk: The Surgical Experience **11:25–11:35am**
Dr. Claudia Perez Sandhu

**Provider Talk: The Scope of Surgery for CSF
Leaks: Concepts, Techniques, and Expectations** **11:35–11:50am**
Dr. Peter Lennarson

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Section Q&A

Moderator: Terri Baker, PA

11:50am–12:10pm

Lunch

12:10–1:20pm

Patient Talk: The View from Here

Spinal CSF leak patient community members

1:20–1:30

POST-TREATMENT: RECOVERY, REBOUND SYMPTOMS, AND POTENTIAL RELAPSE

Provider Talk: What is the Evidence for Post-Patch Care?

Dr. Lalani Carlton-Jones

1:30–1:45pm

Patient Talk: Post-Patch Recovery and RIH

Spinal CSF leak patient community members

1:45–1:55pm

Provider Talk: Rebound Intracranial Hypertension: Clinical Presentation and Treatment

Dr. Prem Subramanian

1:55–2:10pm

Patient Talk: Recovery is a Verb

Jen MacKenzie

2:10–2:25pm

AGENDA

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Provider Talk: The Approach to the Complex Patient 2:25–2:40pm

Dr. Ilene Ruhoy

Patient talk: On Living with a Persistent Leak 2:40–2:55pm

Jodi Ettenberg

Patient voices: Thoughts on Recovery 2:55–3:00pm

Spinal CSF leak patient community members

Section Q&A 3:00–3:20pm

Moderator: Dr. Danielle Wilhour

Break 3:20–3:45pm

Research Updates in Spinal CSF Leaks 3:45–4:00pm

Dr. Ian Carroll

CONCLUSION

Patient Voices: What Doctors Should Know 4:00–4:15pm

Spinal CSF leak patient community members

Q&A 4:15–4:50pm

Moderator: Martha Bond

Closing Remarks 4:50–5:00pm

SPEAKERS

Marius Birlea, MD, FAHS, is an Associate Professor of Neurology Clinical Practice at the University of Colorado School of Medicine, where he is the founding chief of the headache program. He is also the founder of the Colorado Headache Society. He treats patients with any type of head or facial pain disorders, and has a passion for migraine as well as for headaches related to low/high cerebrospinal fluid pressure conditions and to herpes viral infections of the nervous system. He has contributed to research publications in Neurology, including Headache and Neurovirology, and is actively involved in headache advocacy.

Andrea Buchanan, executive director of the Spinal CSF Leak Foundation, is a New York Times bestselling author whose latest book is the novel *Five-Part Invention*. Her memoir *The Beginning of Everything*, about her experience with spinal CSF leak, was a finalist for the 2019 PEN/E.O. Wilson Award for Literary Science Writing. Her other work includes the internationally bestselling *The Daring Book for Girls*, and nine other books.

Andrew Callen, MD (Course Director), is an Assistant Professor of Neuroradiology at the University of Colorado School of Medicine, where he is also the Director of the CSF Leak Program. Dr. Callen is also a member of the medical advisory board of the Spinal CSF Leak Foundation.

Ian Carroll, MD, MS, is an Associate Professor of Anesthesia and Pain Medicine and is quadruple-boarded in anesthesia, pain medicine, headache medicine, and addiction medicine. He leads the CSF Leak Program at Stanford University. He is also a member of the medical advisory board of the Spinal CSF Leak Foundation.

Jodi Ettenberg is a former lawyer, a writer, a photographer, and the voice behind the award-winning travel blog Legal Nomads. After sharing stories about travel and food for a decade, she sustained a spinal CSF leak in 2017 that left her disabled. Jodi now writes about curiosity, resilience, and the

SPEAKERS

challenges of big life changes. Her work has been featured in *The New York Times*, *National Geographic*, *BBC Travel*, *CNN*, *The Guardian*, and more. She also sits on the Board of Directors of the Spinal CSF Leak Foundation and recently received a Verywell Health Impact Award for her advocacy work.

Deborah Friedman, MD, MPH, is a Neurologist specializing in Headache Medicine and Neuro-ophthalmology in Dallas, Texas. She was the founding director of the Headache and Facial Pain Program and Cerebrospinal Fluid Dynamics Program at the University of Texas Southwestern Medical Center. She is Board Certified in Neurology and Headache Medicine, and is a Fellow of the American Academy of Neurology, American Headache Society (AHS), American Neurological Association and the North American Neuro-Ophthalmology Society (NANOS). She served on the Board of Directors of AHS is the Treasurer of the Southern Headache Society, was a Past-President of NANOS and was a member of the steering committee for the Idiopathic Intracranial Hypertension Treatment Trial. She has published over 130 articles in peer-reviewed journals and 27 book chapters. Her key interests are intracranial pressure disorders, cluster headache and migraine.

Jessica Houk, MD, is an Assistant Professor of neuroradiology at Duke University Medical Center. She has multiple recent publications on the topic of spontaneous intracranial hypotension (SIH). She has received several teaching awards and currently serves as the medical student and resident representative for the neuroradiology division.

Lalani Carlton Jones, MBBS, practices adult and pediatric neuroradiology at Guy's and St Thomas's neurology service, The Evelina London, and King's College Hospitals. Lalani is an educational program lead for the British Society of Neuroradiologists. She has also founded and directed several national teaching radiology courses, as well as serving as neuroradiology lead for UKIO and the Royal College of Radiologists annual conferences. She

SPEAKERS

holds national teaching roles and has been awarded several prestigious national and international awards and prizes for her work, including the Kings Health Partners Innovation in Education award, British Society of Neuroradiologists Isherwood travelling scholarship, Royal College of Radiologists JRF Trainer of the Year nomination, RCR National Vera Ansell audit prize as well as several conference awards for winning presentations and exhibits including the RSNA (Radiological Society of North America).

Peter Lennarson, MD, received his medical degree from the University of Wisconsin, before completing his residency in Neurological Surgery at the University of Iowa. After serving in the United States Air Force he began his academic career in neurosurgery at the University of Nebraska before moving on to Colorado. Dr Lennarson is currently an Associate Professor of Neurological Surgery at the University of Colorado School of Medicine, Anschutz Medical Campus where he serves as the director of the CU CSF Dynamics Surgical Program as well as the Neurosurgery Trauma Program.

Jen MacKenzie experienced spinal CSF leak symptoms for many years until her leak was found and surgically repaired in early 2023. After volunteering in other capacities, she currently serves as President of the Board of Directors for the Spinal CSF Leak Foundation.

Jill Rau, MD, PhD, is a Headache Neurologist at HonorHealth Neuroscience Institute in Scottsdale, AZ. She completed her headache fellowship and post-doctoral research work at Mayo Clinic Arizona after completing medical school at University of Western Ontario in London, Canada; her PhD in Cell and Molecular Pathology at the University of North Carolina in Chapel Hill; her masters degree in psychology from the University of Canterbury, Christchurch, New Zealand; and her undergraduate degree at Duke University. She is a member of the Spinal CSF Leak Foundation medical advisory board and current chair of the special interest group for CSF Pressure and Volume Disorders at the American Headache Society.

SPEAKERS

John Reiman, PhD, has over 30 years of experience working as a trauma psychotherapist with individuals from all walks of life. After 14 months of life-dismantling symptoms, two CSF venous fistulas were successfully surgically treated in September of 2022.

Ilene Ruhoy, MD, PhD, is a board-certified neurologist who focuses on the involvement of connective tissue in neurological disorders. Her PhD is in environmental toxicology. She is the medical director of the Chiari EDS Center at Mount Sinai South.

Claudia Perez Sandhu, MD, is a spinal CSF leak patient and family medicine physician who is also a member of the Spinal CSF Leak Foundation's Patient Advisory Panel for Research. She was born and raised in Mexico, and completed her residency at St. Luke's Hospital in Bethlehem, PA, where her two children were born. Claudia currently lives in California and works for Kaiser Permanente. Now recovered from her spinal CSF leak, she says, "I enjoy watching my kids grow and be part of their lives. As a family we enjoy traveling, watching Marvel movies, and hanging out with our dog."

Wouter Schievink, MD, is a Professor of Neurosurgery, Director of the Cerebrospinal Fluid Leak Program and Director of the Microvascular Neurosurgery Program at Cedars-Sinai in Los Angeles. He has published extensively on intracranial hypotension due to spinal cerebrospinal fluid leak. He is also a Medical Advisory Board member of Spinal CSF Leak Foundation.

Nick Stevens is a 21-year-old person with a CSF Leak. They enjoy things like LARP (Live Action Role Play) and illustration. Nick's leak has affected them since they were 11 years old, and they are still undergoing treatment. They hope to help other patients and doctors with their story.

SPEAKERS

Prem Subramanian, MD, PhD, is the Clifford R. and Janice N. Merrill Endowed Chair in Ophthalmology and is professor of ophthalmology, neurology, and neurosurgery and vice chair for academic affairs at the Sue Anschutz-Rodgers University of Colorado Eye Center/School of Medicine. He is also Adjunct Professor of Surgery at the Uniformed Services University of the Health Sciences. He is President of the North American Neuro-Ophthalmology Society, Vice Chair of the Council of the American Academy of Ophthalmology and member of the AAO Board of Trustees and serves on the Board of Directors of the North American Society of Academic Orbital Surgeons; in addition, he has published over 240 research articles, book chapters, and web-based educational materials and is a dedicated educator in several countries around the world.

MODERATORS

Terri Baker, PA-C, is a certified physician assistant working in the Neurosurgery Spine Department at University of Colorado. She works directly with Dr. Peter Lennarson in consultation, pre/postoperative treatment, and surgical first-assist of spine surgery and CSF leak patients. She is a graduate of Saint Louis University PA Program.

Martha Bond works in oncology clinical research as a Senior Director of Project Management. Martha experienced a spontaneous spinal CSF leak in 2016. After three epidural blood patches and surgery, she has been sealed since 2017. She has gone on to volunteer with the Spinal CSF ILeak Foundation where she currently sits on the board of directors.

Samantha Petrucci, MD, is an Assistant Professor of Neuroradiology at CU Anschutz. She received her MD and PhD in Neuroscience from the University of Illinois followed by Radiology residency and Neuroradiology fellowship at UCSF, where she received extensive training in image-guided spine interventions. She is proud to partner with Dr. Callen to conduct clinical care, minimally invasive spine procedures, and ongoing research efforts through the University of Colorado CSF Leak Program.

Danielle Wilhour, MD, is an Assistant Professor of Neurology at the University of Colorado School of Medicine. After graduating from the University of Pennsylvania, she received her medical degree from Sidney Kimmel Medical School. She completed her Neurology residency and Headache Medicine fellowship at Thomas Jefferson University Hospital. Dr. Wilhour joined the faculty of the University of Colorado in 2019. Her primary interests include non-pharmacologic treatment of headache, spontaneous intracranial hypotension, and headache management during pregnancy. She became Fellowship Director for the Headache section in 2022.

DISCLOSURES

NAME	INELIGIBLE COMPANY	RELATIONSHIP
Andrew Callen	Eli Lilly Pharmaceuticals	Consultant
Lalani Carlton Jones	Radiopaedia	Speaker
Deborah Friedman	Allergan/Abbvie	Advisor, grant support, speaker
	BioDelivery Sciences	Advisor
	International/Collegium	
	Eli Lilly Pharmaceuticals	Advisor, grant support
	Impel NeuroPharma	Advisor, speaker
	Pfizer	Consultant, speaker
	Teva Pharmaceuticals	Advisor
	Zosano Pharma	Advisor, grant support
Prem Subramanian	ACELYRIN	Consultant
	GenSight Biologics	Consultant, independent contractor
	Horizon Therapeutics	Consultant, contractor, researcher
	Immunovant	Independent contractor
	Invex Therapeutics	Consultant, independent contractor
	Kriya Therapeutics	Consultant
	Neurophth Therapeutics	Advisor, independent contractor
	Tourmaline Bio	Advisor, independent contractor
	Viridian Therapeutics	Consultant, independent contractor

All of the relevant financial relationships listed for these individuals have been mitigated.

All of the other planners, faculty, or individuals in control of content for this educational activity have no relevant financial relationship(s) to disclose with ineligible companies.

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- At the end of the course, please go to this link to take the evaluation survey. You **MUST** complete the survey before **5 pm on November 27** to get credit and claim your certificate.



<https://www.surveymonkey.com/r/SpinalCSFLeaks>

- Your CME certificate will be emailed by Thursday, November 30.

**The Spinal CSF Leak Foundation
would like to thank all of today's speakers
and moderators, including the following
patients from our extended community
who so kindly shared their thoughts with us:**

Amber

Amy

Anna A.

Anna F.

Asia

Aubrey

Bonnie

Donna

Eva

Emma

Judith

Lee

Lillie

Melanie B.

Melanie L.

Meri

Michael

Michal

Pam

Penelope

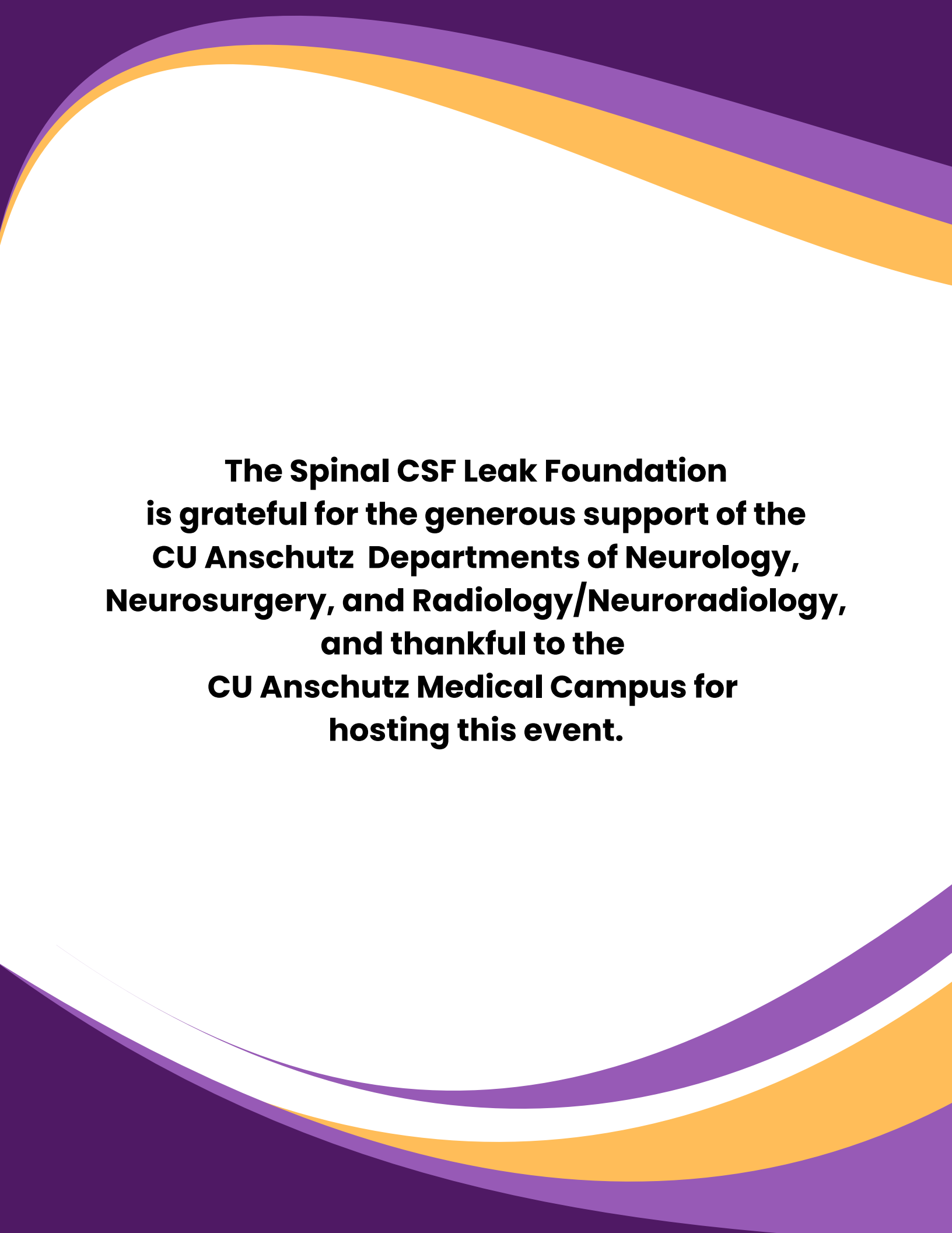
Sara

Sarah

Shelley B.

Shelley S.

Theresa



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