

## PFG Agenda for Birmingham April 30, 2026

Emcees: Gaurav Goyal, MD & Matthew Collin, MD, PhD

Time	Allocated minutes (510 min total)	Presentation Subject Possibilities (Actual Titles to be Provided by Presenters)	Presenter	Session Description
8:00 AM	30	Registration & Light Breakfast		
8:30 AM	15	Welcome to Birmingham & PFG Meeting	Gaurav Goyal, MD	Welcome to the 11th Annual Erdheim-Chester Disease International Conference! Introductions to Birmingham, UAB and the ECD Global Alliance.
8:45 AM	15	Manifestations of histiocytosis in adults	Matthew Collin, MD, PhD	Learn about the difference types of adult histiocytic disorders. How are they different? How are they the same? What have we learned recently that makes us believe they are more alike than they once were.
9:00 AM	15	Histiocytosis at the Cellular Level	Astrid van Halteren, PhD	This presentation will zoom into the different cell types which can be found in the bone marrow, blood and tissues of patients diagnosed with histiocytosis
9:15 AM	15	ECD/Histio Treatment Options	Sam Reynolds, MD	ECD/Histio Treatment Options (Current & on the horizon)
9:30 AM	15	Tagreted Therapy: The Good, the Bad, and the Unaffordable	Daniel Sokolowski, PharmD	Overview of targeted treatments for histiocytosis and management of their adverse effects.
9:45 AM	20	Break	N/A	
10:05 AM	15	Advancing treatment for histiocytic neurodegeneration through patient specific modeling	Nicole Coufal, MD, PhD	The importance of patient samples to the science, and the importance of pilot funding and where we hope to take it in the future.
10:20 AM	15	What should I know about ECD Treatment and My Heart? Potential cardiac side effects of ECD treatment.	Carrie Lenneman, MD, MSCI	Discuss common medication used in treatment of ECD. Review potential cardiac side effects and management strategies of ECD treatment.
10:35 AM	15	ECD on the Brain	Eli Diamond, MD	Discussion of ECD effects on the brain.
10:50 AM	15	Endocrine Manifestations of Erdheim-Chester Disease	Alexandra Dodd, MD	Understand endocrine manifestations of ECD including effects on the pituitary gland. Understand the treatments for endocrine disorders related to ECD.
11:05 AM	40	Expert Q&A	Julien Haroche, MD, PhD Eli Diamond, MD Ronald Go, MD Gaurav Goyal, MD (Moderator)	Ask your questions and hear the answers from ECD Medical experts. Hear up-to-date answers from those who are doing ECD research.
11:45 AM	15	Pictures	N/A	
12:00 – 1:00pm	60	Lunch	N/A	
1:00 PM	20	Research Opportunities (Panel Discussion - 5 min each)	Eli Diamond, MD (Registry) Gaurav Goyal, MD (Survivorship) Jithma Abeykoon, MD (CSF1R, ERK) Matthew Collins, MD, PhD	Hear the answers from ECD Medical experts about the open research opportunities. Hear up-to-date answers from those who are doing ECD research.
1:20 PM	20	Expert Question & Answer Panel	Gaurav Goyal, MD Eli Diamond, MD Jithma Abeykoon, MD Matthew Collins, MD, PhD	Ask your questions and hear the answers from ECD Medical experts. Hear up-to-date answers from those who are doing ECD research. Don't be shy, ask your questions about ECD in general! [Please note, the panel is unable to provide any personal medical advise during this session.]

1:40 PM	60	Breakout Sessions	Kevin O'Brien, RN, MS-CRNP (patients) Sylvia Huang, PhD, MA, MEd, FAAHPM (Caregivers)	Breakout Session: - Patients: Personal Challenges in Living with Erdheim-Chester Disease - Caregivers & Family: Addressing YOUR Emotional Needs
2:40 PM	20	Break	N/A	
3:00 PM	15	General medical management for ECD	Kevin O'Brien, RN, MS-CRNP	Highlighting the importance of managing ongoing general medical problems. For example, hypertension, diabetes, weight, cholesterol levels, etc. These uncontrolled medical problems can compound overall disease burden.
3:15 PM	15	Emotional and Cognitive Changes in ECD	Sylvia Huang, PhD, MA, MEd, FAAHPM	Living with Erdheim-Chester Disease can bring emotional, cognitive, and fatigue-related changes that are real and often invisible. This session offers understanding, reassurance, and practical guidance to help patients and families make sense of these experiences. Participants will learn about supportive strategies and resources that promote resilience, wellbeing, and hope.
3:30 PM	15	Fatigue and Pain in Erdheim-Chester Disease: Root Causes and Practical Strategies for Energy, Relief, and Resilience	Richard Taylor, PhD, DNP, CRNP, APN-BC	This session is designed to empower patients and caregivers by unpacking the root causes of fatigue and pain in Erdheim-Chester Disease (ECD).  The goal is to offer meaningful, evidence-informed tools to reduce suffering, build resilience, and improve energy, mobility, and quality of life.
3:45 PM	15	Movement is Medicine	Elizabeth Bohorfoush, DPT	Patients and caregivers receive guidance through gentle, low-level exercises to help reduce pain, build strength, improve posture, and encourage activity.
4:00 PM	20	Expert Question & Answer Panel	Kevin O'Brien, RN, MS-CRNP Sylvia Huang, PhD, MA, MEd, FAAHPM Richard Taylor, PhD, DNP, CRNP, APN-BC Elizabeth Bohorfoush, DPT	Ask your questions and hear the answers from the experts. Don't be shy, ask your questions! [Please note, the panel is unable to provide any personal medical advice during this session.]
4:20 PM	10	ECDGA Close	Jerome Henson, ED (ECDGA)	Learn more about the ECD Global Alliance. Hear why the organization was created and what has been accomplished as a result. Learn how the organization is able to do its work and how you can become more involved in improving the lives of all who have been impacted by Erdheim-Chester Disease.