

30 APRIL 2026

BIRMINGHAM, ALABAMA, USA

# 11<sup>th</sup> International Erdheim-Chester Disease Patient & Family Gathering

PROGRAM GUIDE



**UAB** MEDICINE®



# Welcome to the 11<sup>th</sup> Annual ECDGA Patient and Family Gathering

## Wi-Fi Information

### **Hilton Downtown Birmingham at UAB**

April 29 and 30

Meet and Greet and Patient and Family Gathering Celebration Dinner

Username: UAB808

Password: UAB808

For guest rooms, enter your last name and room number

### **Heersink Conference Center**

April 30

Patient and Family Gathering



Heersink WIFI  
Directions with  
Screenshots

Step 1: Connect to the “UABStartHere” Network.

Step 2: Open a web browser and navigate to any URL. You will be redirected to a page with options.

Select “Register for Guest Access”

Step 3: Enter your Name, Email Address, accept the terms of use, and click “Register”.

Step 4: You will then receive a registration receipt. This information is also emailed to your email address. Click “Log In” to connect to the network.

## **Program Guide**

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ERDHEIM-CHESTER DISEASE GLOBAL ALLIANCE (ECDGA)  
2026 ANNUAL PATIENT and FAMILY GATHERING

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## **Welcome to the 11th Annual ECDGA Patient and Family Gathering**

### **Birmingham, Alabama**



Jerome Henson  
Executive Director  
ECD Global Alliance



Diane Schriner  
President / Board of Directors  
ECD Global Alliance

Dear friends,

Welcome to Birmingham, Alabama and to the 11th Annual Erdheim-Chester Disease Patient and Family Gathering.

It is truly an honor to be with you. Patients, caregivers, families, and advocates from across the country and around the world are represented here. Each of you brings a story, a strength, and a perspective that makes this community extraordinary. While no one chooses this journey, the way you walk it with courage, resilience, and compassion continues to inspire all of us.

At the ECD Global Alliance, our mission has always been rooted in one simple but powerful belief. No one should face this disease alone. Gatherings like this bring that belief to life. Today, there will be connections formed, knowledge shared, and encouragement gained that can have a lasting impact on your journey.

Today is about you. We want you to leave more informed, connected, and hopeful. Whether it is a conversation with another family, a question answered by a physician, or simply the comfort of being surrounded by people who understand, these moments matter.

I also want to personally thank our physicians, researchers, volunteers, and supporters who have dedicated their time and expertise to make this day possible. Their commitment, combined with your voices, is what continues to move this work forward.

Birmingham is proud to welcome you. My hope is that during your time here, you are surrounded by support, connection, and hope.

Thank you for being here, for trusting us, and for being such an essential part of this community.

With gratitude and respect,



Jerome Henson  
Erdheim-Chester Disease Global Alliance  
Executive Director



Diane Schriner  
Erdheim-Chester Disease Global Alliance  
President of the Board of Directors

## **Welcome to the 11th Annual ECDGA Patient and Family Gathering**

### **Birmingham, Alabama**



**Gaurav Goyal, MD**  
Hematology & Oncology  
University of Alabama at Birmingham School of Medicine  
Birmingham, Alabama, USA

Dear friends,

Welcome to Birmingham for the 11th Annual Erdheim-Chester Disease Global Alliance Patient & Family Gathering. Whether you traveled across the country or joined from nearby, we are truly honored you are here.

Today is about connection, learning, and community. Living with a rare disease can feel isolating; this gathering reminds us that no one walks this path alone. Throughout the day you will hear from clinicians, researchers, and—most importantly—people living with ECD and their loved ones. We have designed the program to be practical and supportive, with opportunities to ask questions, learn about current care, and share experiences that only this community truly understands.

As a physician at the University of Alabama at Birmingham, I am inspired every day by the resilience, generosity, and insight you bring. Your voices continue to shape research priorities and improve the care we deliver. Thank you for trusting us—and for teaching us.

Birmingham's history is rooted in perseverance and progress, and we hope you feel that spirit during your time here. On behalf of the ECD Global Alliance, our volunteers and organizers, and everyone at UAB, thank you for being part of this day.

With warm regards,

A handwritten signature in dark ink that reads "Gaurav Goyal".

Gaurav Goyal, MD  
Associate Professor  
University of Alabama at Birmingham  
Conference Host

## **Special Thanks to this Year's Sponsors**



**Father Charles Balnaves**



### **Sponsors and Volunteers**

This meeting is made possible by our sponsor, Father Charles Balnaves of Melbourne, Australia, who supports this event in memory of his late wife, Tanya. We are grateful for Father Charles' continued, generous sponsorship.

We also appreciate the support of ARUP Laboratories.

We thank all the generous members of the ECDGA community who provide financial support to allow the organization to work on behalf of all those affected by Erdheim-Chester Disease (ECD) worldwide.

In addition, the Patient and Family Gathering would not be possible without community volunteers who give of their time and knowledge so freely to

help all in the community. By working together, we are stronger and we can see the advancements in the management of ECD that brings us all hope.

## Acknowledgments

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### Event Host

Gaurav Goyal, MD  
Hematology & Oncology  
University of Alabama at Birmingham, Birmingham, AL USA

### Planning Committee

Gaurav Goyal, MD, University of Alabama at Birmingham, Birmingham, AL USA  
Matthew Collin, MD, PhD, Newcastle University, United Kingdom  
Paul Hendrie, MD, PhD, Fred Hutch, Seattle, WA USA, ECD Global Alliance Board of Directors  
Kathleen Brewer, Founder, ECD Global Alliance Board of Directors  
Diane Schrinier, President ECD Global Alliance Board of Directors  
Jerome Henson, ECD Global Alliance  
Belinda Cobb, ECD Global Alliance  
Renita Page, ECD Global Alliance  
ECD Global Alliance Medical Advisory Board Members  
ECD Patient & Family Members who participated in the planning survey

### ECDGA Board of Directors



Kathy Brewer  
Founder  
2009-Present  
President 2009-2025



Mohammad( Ishtiaq)  
Chowdhury  
2020-Present  
Treasurer 2022-Present



Juvianee Estrada-Veras, MD  
2013-Present



Joe Fleischhaker  
2024-Present



Janet Froetscher  
2020-Present  
Secretary 2022-Present



Ronald Go, MD  
2025-Present



Paul C. Hendrie, MD, PhD  
2020-Present  
Vice-President 2025-Present



Diane Schrinier  
Treasurer 2019-2022  
Vice-President 2022-2025  
President 2025-Present



David Smyth  
2020-Present

## ECDGA Medical Advisory Board



XinXin Cao, MD



Lorenzo Dagna, MD



Eli L Diamond, MD



Dr. Ronald Go, MD



Gaurav Goyal, MD



Julien Haroche, MD, PhD



Paul C. Hendrie MD, PhD



Razelle Kurzrock, MD, FACP



Oshrat Rokah, PhD



Augusto Vaglio, MD

## ECDGA Staff



Jerome Henson  
Executive Director



Renita Page  
Donor Relations/Database  
Manager



Belinda Cobb  
Patient Navigator

## Event Volunteers & Staff

Kathy Brewer  
Belinda Cobb  
Bill Cobb  
Taylor Cobb  
Jerome Henson  
Karen Henson  
Renita Page  
Paul Page  
Diane Schriener  
Sharon Douglass

## Schedule at a Glance

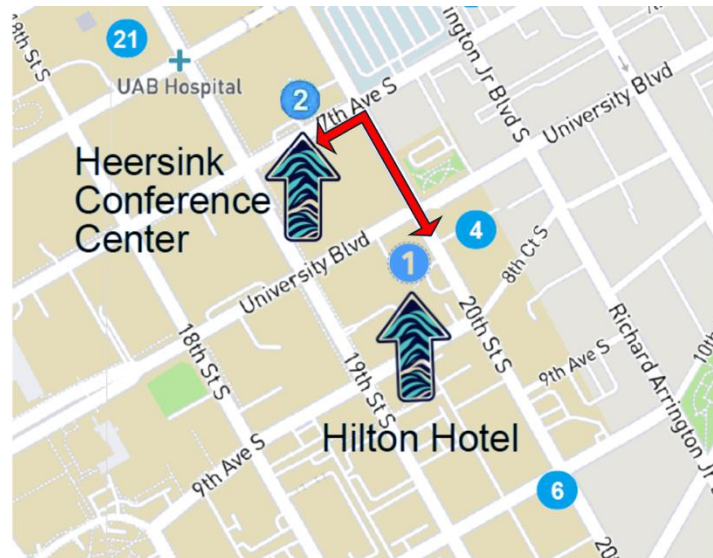
| Wednesday, April 29, 2026   Pre-conference                                                                       |                                           |                                                                                                             |
|------------------------------------------------------------------------------------------------------------------|-------------------------------------------|-------------------------------------------------------------------------------------------------------------|
| 2:00 pm                                                                                                          | Catholic Mass                             | Hilton Birmingham Downtown at UAB;<br>Lobby Level; Cullom Parlor<br>Father Bryan W. Jerabek, JCL            |
| 3:00-5:00 pm                                                                                                     | Meet & Greet                              | Hilton Birmingham Downtown at UAB;<br>Meeting and Event Level (Downstairs<br>from Lobby); Hamilton II       |
| Thursday, April 30, 2026   Patient & Family Gathering<br><i>Light breakfast, lunch, and dinner are provided.</i> |                                           |                                                                                                             |
| 8:00 am –<br>8:30 am                                                                                             | Registration & Light<br>Breakfast         | The Marnix E. Heersink Conference<br>Center<br>Lobby                                                        |
| 8:30 am –<br>4:30 pm                                                                                             | Patient & Family<br>Gathering Meeting     | The Marnix E. Heersink Conference<br>Center<br>Room# 102                                                    |
| 6:00 pm –<br>8:00 pm                                                                                             | ECD Global Alliance<br>Celebration Dinner | Hilton Birmingham Downtown at UAB;<br>Meeting and Event Level (Downstairs<br>from Lobby); Hamilton Ballroom |

Volunteers will be in the Hilton Birmingham Downtown at the UAB hotel lobby from 7 – 7:45 am on April 30, to escort attendees to the Marnix E. Heersink Conference Center. The estimated walking time is 10 minutes. The last escorted group will leave the hotel at 7:45 am. Those with mobility issues may want to consider a taxi or ride-sharing service.

## Conference Maps

Directions to the Heersink School of Medicine Conference Center

- From Hilton front entrance, turn **left on 20<sup>th</sup> St. going north.**
- Walk **two blocks.**
- Turn **left** on 7<sup>th</sup> Ave S
- Turn **right** into the Heersink Conference Center (before the glass skybridge)



### ECDGA Conference

This map is a sample of the amazing things to experience in Birmingham. Please see our website for additional suggestions.

#### Meeting Locations

- 1 Hilton Birmingham at UAB
- 2 UAB Heersink Conference Center

#### Restaurants

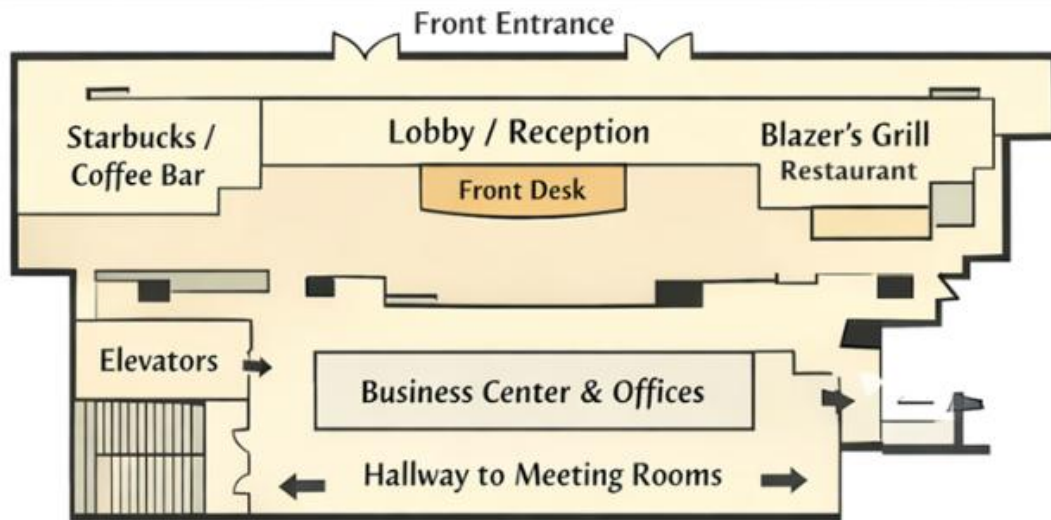
- 3 A's Deli & Grill
- 4 University Tacos and Burritos
- 5 Newk's Eatery Downtown
- 6 Makarios Kabobs & Grill
- 7 Mellow Mushroom - Southside
- 8 Jim N Nick's Bar B Q - Five Points South
- 9 Chez FonFon
- 10 The Fish Market Restaurant - Southside
- 11 The Fennec
- 12 Taziki's Greek Fare - Med Center
- 13 Falafel Cafe
- 14 The Toasted Yolk Cafe
- 15 Hero Doughnuts - Parkside
- 16 Good People Brewing Company
- 17 Ocean
- 18 Tasty Town Greek Restaurant
- 19 The Original Pancake House
- 20 The Red Cat at Railroad Park
- 21 Starbucks Coffee Company

#### Things To Experience

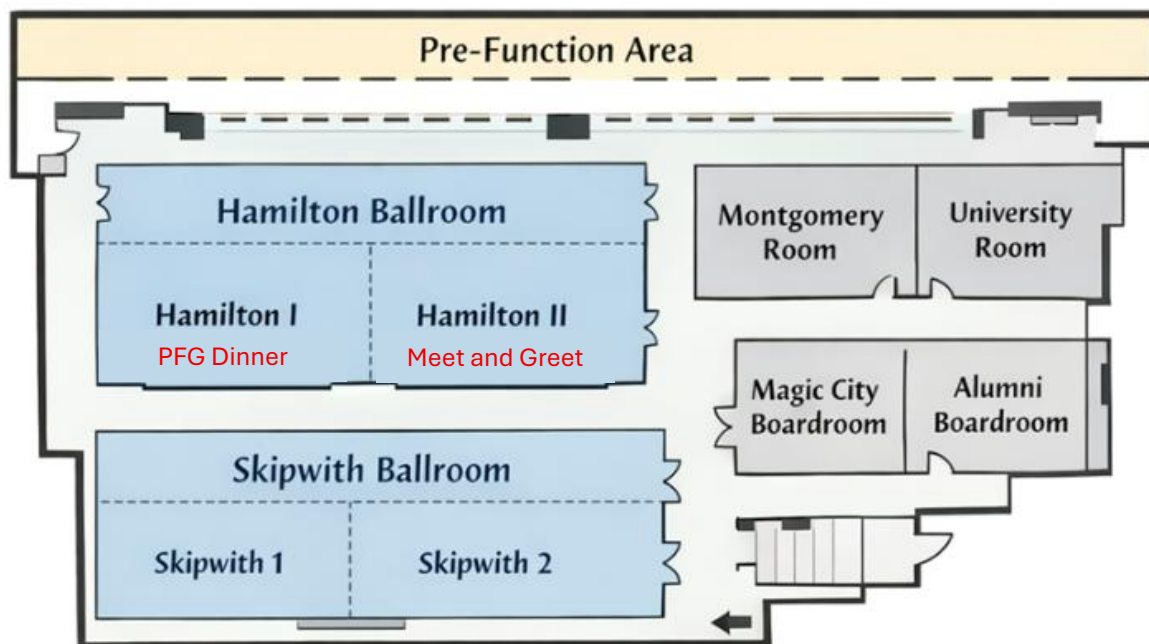
- 22 Railroad Park
- 23 Iron City Birmingham
- 24 Alys Stephens Performing Arts Center
- 25 UAB Campus Recreation
- 26 UAB Visual Arts Gallery Abrams-Engel Institute for the Visual Arts
- 27 Rotary Trail
- 28 Bessie Estell Park Playground



## 1<sup>st</sup> Floor – Lobby Level



## Meeting and Event Level (Downstairs from Lobby)



## Patient & Family Gathering Agenda

| Time     | Subject                                                                                              | Presenter                                                                                                                    |
|----------|------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|
| 8:00 am  | Registration & Light Breakfast                                                                       |                                                                                                                              |
| 8:30 am  | Welcome to Birmingham & The ECD Patient and Family Gathering by the Host & Emcee                     | Gaurav Goyal, MD                                                                                                             |
| 8:45 am  | Manifestations of Histiocytosis in Adults                                                            | Matthew Collin, MD, PhD                                                                                                      |
| 9:00 am  | Histiocytosis at the Cellular Level                                                                  | Astrid van Halteren, PhD                                                                                                     |
| 9:15 am  | ECD/Histio Treatment Options                                                                         | Samuel B. Reynolds, MD                                                                                                       |
| 9:30 am  | Targeted Therapy: The Good, the Bad, and the Unaffordable                                            | Daniel Sokolowski, PharmD                                                                                                    |
| 9:45 am  | Break                                                                                                |                                                                                                                              |
| 10:05 am | Advancing Treatment for Histiocytic Neurodegeneration through Patient Specific Modeling              | Nicole Coufal, MD, PhD                                                                                                       |
| 10:20 am | What Should I Know About ECD Treatment and My Heart? Potential Cardiac Side Effects of ECD Treatment | Carrie Lenneman, MD, MSCI                                                                                                    |
| 10:35 am | ECD on the Brain                                                                                     | Eli Diamond, MD                                                                                                              |
| 10:50 am | Endocrine Manifestations of Erdheim-Chester Disease                                                  | Alexandra Dodd, MD                                                                                                           |
| 11:05 am | ECD Expert Question and Answer Panel                                                                 | Julien Haroche, MD, PhD<br>Eli Diamond, MD<br>Ronald Go, MD<br>Gaurav Goyal, MD (Moderator)                                  |
| 11:45 am | Group Picture                                                                                        |                                                                                                                              |
| Noon     | Lunch (Door Prize Drawing)                                                                           |                                                                                                                              |
| 1:00 pm  | Research Opportunities (Panel Discussion - 5 min each)                                               | Eli Diamond, MD (Registry)<br>Gaurav Goyal, MD (Survivorship)<br>Jithma Abeykoon, MD (CSF1R, ERK)<br>Matthew Collin, MD, PhD |
| 1:20 pm  | ECD Expert Question and Answer Panel (Research)                                                      | Eli Diamond, MD<br>Gaurav Goyal, MD<br>Jithma Abeykoon, MD<br>Matthew Collin, MD, PhD                                        |
| 1:40 pm  | Patient Breakout<br><br>Caregiver Breakout                                                           | Kevin O'Brien, RN, MS-CRNP (stay in Room# 102)<br><br>Sylvia Huang, PhD, MA, MEd, FAAHPM (Room# 201)                         |
| 2:40 pm  | Break                                                                                                |                                                                                                                              |

ERDHEIM-CHESTER DISEASE GLOBAL ALLIANCE (ECDGA)  
2026 ANNUAL PATIENT and FAMILY GATHERING

| Time    | Subject                                                                                                              | Presenter                                                                                                                               |
|---------|----------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------|
| 3:00 pm | General Medical Management for ECD                                                                                   | Kevin O'Brien, RN, MS-CRNP                                                                                                              |
| 3:15 pm | Emotional and Cognitive Changes in ECD                                                                               | Sylvia Huang, PhD, MA, MEd, FAAHPM                                                                                                      |
| 3:30 pm | Fatigue and Pain in Erdheim-Chester Disease: Root Causes and Practical Strategies for Energy, Relief, and Resilience | Richard Taylor, PhD, DNP, CRNP, APN-BC                                                                                                  |
| 3:45 pm | Movement is Medicine                                                                                                 | Elizabeth Bohorfoush, DPT                                                                                                               |
| 4:00 pm | Expert Question & Answer Panel                                                                                       | Kevin O'Brien, RN, MS-CRNP<br>Sylvia Huang, PhD, MA, MEd, FAAHPM<br>Richard Taylor, PhD, DNP, CRNP, APN-BC<br>Elizabeth Bohorfoush, DPT |
| 4:20 pm | ECD Global Alliance Close (Door Prize Drawing)                                                                       | Jerome Henson, ECDGA ED                                                                                                                 |

## Session Details (am)

### Welcome to the Birmingham & the Patient and Family Gathering

8:30 am – 8:45 am

**Welcome to the 11th Annual Erdheim-Chester Disease International Conference! Introduction to Birmingham, UAB and the ECD Global Alliance.**

#### **Gaurav Goyal, MD**

Hematology & Oncology  
University of Alabama at Birmingham, Birmingham, AL USA  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Member  
Past Recipient of an ECDGA Grant  
[ggoyal@uabmc.edu](mailto:ggoyal@uabmc.edu)  
+1-205-975-3409



**Dr. Gaurav Goyal, MD** was born and raised in a small town in India. He obtained his medical school diploma from Smt. N.H.L. Municipal Medical College in Ahmedabad, India, followed by an Internal Medicine Residency from Creighton University Medical Center, Omaha, Nebraska, and a Hematology-Oncology Fellowship from the Mayo Clinic, Rochester, Minnesota.

At the Mayo Clinic, he developed a unique focus on histiocytic disorders, including Erdheim-Chester disease, Langerhans cell histiocytosis, and Rosai-Dorfman disease. He conducted multiple studies describing the epidemiology, treatments, and outcomes of patients with histiocytosis and helped establish the first-of-its-kind multidisciplinary Histio-Care Network to improve the practice, education, and research for individuals with histiocytosis. He has led national and international guidelines on the diagnosis and management of these rare disease entities. He was recruited to join the Hematology-Oncology division at the University of Alabama at Birmingham (UAB) as an Assistant Professor in 2019, where he established a histiocytosis program, including an ECD care center.

At UAB, Dr. Goyal continues to conduct multiple research studies in histiocytosis. He launched the Histiocytic Disorder Survivor Study at UAB in partnership with the ECDGA in 2023 to help understand the long-term health problems (health conditions, second cancers, mental health problems, and quality of life) and mortality among individuals with ECD and other histiocytic disorders.

**NOTES** (Please use this space for your notes and reflections.)

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

## Manifestations of Histiocytosis in Adults

8:45 am – 9:00 am

**Learn about the different 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 we once thought they were?**

### **Matthew Collin, MD, PhD**

Hematologist  
Newcastle University, United Kingdom  
ECD Care Center Lead Physician  
Past Recipient of an ECDGA Grant  
[Matthew.collin@newcastle.ac.uk](mailto:Matthew.collin@newcastle.ac.uk)  
+0191 213 8479



**Dr. Matthew Collin**, is a Professor of Hematology at Newcastle University Translational and Clinical Research Institute. He received his medical degree from Oxford University and is a member of the Royal College of Physicians and of Pathologists. He is active in Histiocytosis UK having held multiple leadership roles as well as the Nikolas Symposium and Histiocyte Society. Matthew splits his time between clinical duties and research activities, always searching for ways to better help patients.

**NOTES** (Please use this space for your notes and reflections.)

[illegible]

## Histiocytosis at the Cellular Level

9:00 am – 9:15 am

**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**

### Astrid van Halteren, PhD

Biomedical Scientist  
Erasmus MC University Medical Center Rotterdam,  
The Netherlands  
[a.vanhalteren@erasmusmc.nl](mailto:a.vanhalteren@erasmusmc.nl)



**Astrid van Halteren, PhD**, is a biomedical scientist and certified immunology specialist, serving as research group leader at the Department of Internal Medicine, Erasmus MC University Medical Center Rotterdam, and as co-principal investigator at the Princess Máxima Center for Pediatric Oncology in Utrecht. She has extensive expertise in the hemato-oncology field and has been actively involved in histiocytosis research since 2008.

Dr. van Halteren has served two consecutive terms on the Scientific Committee of the Histiocyte Society and currently holds a member-at-large position on its Board. She is also a member of the Steering Committee of the Nikolas Symposium.

Her research focuses on rare histiocytic disorders, with particular emphasis on molecular and protein profiling of neoplastic histiocytes and their immediate precursors in the blood. A central aim of her work is to understand the process of histiocyte precursor cell generation in the bone marrow and their subsequent differentiation into cells with altered biological features in specific tissues such as bone. In addition, her research team tries to understand why this 'cell-of-origin' occasionally gives rise to clonally related hematologic malignancies. Her long-term goal is to identify alternative therapeutic approaches beyond conventional chemotherapy or targeted inhibitor therapies.

**NOTES** (Please use this space for your notes and reflections.)

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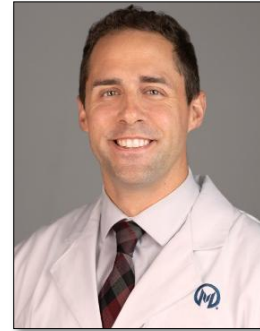
## ECD/Histio Treatment Options (Current & on the horizon)

9:15 am – 9:30 am

**Hear about the current treatment options available to help someone living with ECD.**

### **Samuel B. Reynolds, MD**

Hematologist/Oncologist  
H. Lee Moffitt Cancer Center, Tampa, FL USA  
ECD Care Center Lead Physician  
[Sam.Reynolds@moffitt.org](mailto:Sam.Reynolds@moffitt.org)  
+1-813-745-4673



**Dr. Samuel B. Reynolds, MD** is an Assistant Professor and board-certified hematologist-oncologist at H. Lee Moffitt Cancer Center & Research Institute in Tampa, Florida. He completed his medical degree at the University of South Florida Morsani College of Medicine and went on to complete an Internal Medicine residency, chief residency, and a fellowship in Hematology & Medical Oncology—developing a focus on histiocytic and myeloid neoplasms during his advanced training.

Dr. Reynolds is dedicated to both clinical care and research in hematologic disorders, particularly myeloid and histiocytic neoplasms. His work emphasizes molecular characterization and translational approaches to improve outcomes for patients with these rare and complex diseases. He is affiliated with Moffitt's malignant hematology programs and serves patients at multiple Moffitt campuses, offering both in-person and telehealth consultations.

**NOTES** (Please use this space for your notes and reflections.)

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## Targeted Therapy: The Good, the Bad, and the Unaffordable

9:30 am – 9:45 am

**Overview of targeted treatments for histiocytosis and management of their adverse effects.**

### **Daniel Sokolowski, PharmD**

Pharmacist

University of Alabama at Birmingham, Birmingham, AL USA

[dsokolowski@uabmc.edu](mailto:dsokolowski@uabmc.edu)



**Dr. Daniel Sokolowski, PharmD** is a dedicated pharmacist known for his commitment to high-quality pharmaceutical care and patient advocacy. With a strong foundation in pharmacy practice and healthcare, Daniel brings a passion for optimizing medication therapy and improving health outcomes within his community.

Daniel received his Doctor of Pharmacy at Samford University and his bachelor's degrees in biology and in chemistry from the University of Alabama at Birmingham (UAB). Daniel completed a PGY-1 residency at Indiana University in Indianapolis and PGY-2 in oncology at the University of Louisville.

Daniel's professional journey in pharmacy focuses on clinical excellence and meaningful patient engagement. He has developed expertise in medication management, patient counseling, and collaborative care ensuring that individuals receive safe, effective, and personalized medication guidance. As a healthcare provider, he places a high priority on building trust with patients and working alongside interdisciplinary teams to support patients' quality of life and better outcomes.

Daniel values continuous learning and professional growth, staying current with best practices in pharmacy and patient care. Outside of his clinical role, he supports efforts to educate patients on medication safety and disease management, helping to empower individuals in their health decisions.

**NOTES** (Please use this space for your notes and reflections.)

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## Advancing Treatment for Histiocytic Neurodegeneration Through Patient-Specific Modeling

10:05 am – 10:20 am

**Hear about the importance of patient samples to science, the importance of pilot funding, and where we hope to take it in the future.**

### Nicole Coufal, MD, PhD

Associate Professor of Pediatrics and Neuroscience  
University of California, San Diego, CA USA  
Past Recipient of an ECDGA Grant  
[ncoufal@health.ucsd.edu](mailto:ncoufal@health.ucsd.edu)



**Dr. Nicole Coufal, MD, PhD**, is a board-certified pediatrician and pediatric intensivist at Rady Children's Hospital-San Diego and an associate professor at University of California, San Diego School of Medicine.

She received her medical and doctoral degree in neurosciences at UC San Diego. Thereafter Dr. Coufal continued her training in pediatrics and pediatric critical care at UC San Diego as well as a postdoctoral fellowship at the Salk Institute for Biological Studies.

Dr. Coufal is a physician scientist with training in pediatric critical care and a research interest in neuroimmunology. Her career goal is to bring novel translational therapies to children with rare neurological diseases. The goal of her lab is to understand the contribution of innate immunity to neurodevelopmental and pediatric neurodegenerative disorders. The lab strives to understand the molecular and cellular mechanisms underlying innate immune dysfunction to ultimately identify novel therapeutic targets in currently untreatable pediatric diseases. Her lab utilizes a combination of translational, patient-specific pluripotent stem cells and genome-wide approaches to accomplish these goals.

Dr. Coufal is a fellow of the American Academy of Pediatrics, a member of the Society for Critical Care Medicine and an elected member of the American Society for Clinical Investigation.

**NOTES** (Please use this space for your notes and reflections.)

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## What Should I Know About ECD Treatment and My Heart?

### Potential cardiac side effects of ECD treatment.

10:20 am – 10:35 am

**Discuss common medications used in the treatment of ECD. Review potential cardiac side effects and management strategies of ECD treatment.**

#### **Carrie Lanneman, MD, MSCI**

Professor of Cardiovascular Medicine - Cardio-Oncology  
University of Alabama at Birmingham, Birmingham, AL USA  
[uabcardiologyoncology@uabmc.edu](mailto:uabcardiologyoncology@uabmc.edu)  
+1-205-975-7123



**Carrie Lenneman, MD, MSCI**, is a Professor of Cardiovascular Disease at the University of Alabama at Birmingham (UAB) Heersink School of Medicine, where she directs the Cardio-Oncology Program within the UAB Medicine Cardiovascular Institute. Her work focuses on the cardiovascular health of cancer patients and survivors, with particular emphasis on identifying and managing cardiotoxic effects of cancer therapies and improving cardiovascular outcomes in this population.

Dr. Lenneman earned her medical degree from the Medical University of South Carolina and completed her internal medicine residency and cardiology fellowship at Vanderbilt University, where she also served as Chief Cardiology Fellow and completed a Master of Science in Clinical Investigation. She started her professional career in cardio-oncology research during fellowship and later served as Director of Cardio-Oncology and Associate Program Director for the Cardiology Fellowship Program at the University of Louisville before joining UAB in 2017 to establish and expand the cardio-oncology program.

At UAB, Dr. Lenneman's program has been recognized for clinical excellence, earning Gold status certification from the International Society of Cardio-Oncology, and she remains actively involved in clinical care, research, and education. Her research interests include predictors of cardiotoxicity in cancer patients, the cardiac and vascular effects of cancer immunotherapies, and interventions—including lifestyle strategies—to improve heart health in cancer survivors.

**NOTES** (Please use this space for your notes and reflections.)

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## ECD on the Brain

10:35 am – 10:50 am

### Discussion of ECD effects on the brain.

#### Eli Diamond, MD

Neuro-Oncologist  
Memorial Sloan Kettering Cancer Center (MSKCC), New York, NY USA  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Chair  
Past Recipient of an ECDGA Grant  
[Diamone1@mskcc.org](mailto:Diamone1@mskcc.org)  
+1-212-610-0243



**Dr. Eli Diamond, MD**, is a neuro-oncologist who specializes in the care of patients with ECD and other histiocytosis, as well as brain tumors and neurologic complications of cancer. He conducts and has conducted several research studies for patients with ECD, including the vemurafenib trial, the cobimetinib trial, a study looking for gene mutations in ECD tumors, a study to improve ECD biopsies, and a study about ECD and the brain. He is a longtime supporter of the ECD Global Alliance, where he Chairs the Medical Advisory Board. He is also the co-founder of the global ECD Patient Registry which empowers people living with ECD to join in research.

Dr. Diamond received his undergraduate degree from Harvard University and his Masters in Philosophy from the University of Cambridge in the United Kingdom. He earned his M.D. from the Albert Einstein College of Medicine of Yeshiva University and completed his residency in neurology at Brigham and Women's Hospital/Massachusetts General Hospital. He is board-certified in neurology and neuro-oncology and completed his fellowship in neuro-oncology at MSKCC.

**NOTES** (Please use this space for your notes and reflections.)

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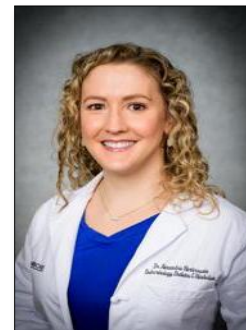
## Endocrine Manifestations of Erdheim-Chester Disease

10:50 am – 11:05 am

**Understand endocrine manifestations of ECD including effects on the pituitary gland.  
Understand the treatments for endocrine disorders related to ECD.**

### Alexandra Dodd, MD

Assistant Professor – Endocrinology, Diabetes & Metabolism  
University of Alabama at Birmingham, Birmingham, AL USA  
[amartirossian@uabmc.edu](mailto:amartirossian@uabmc.edu)



**Dr. Alexandra Dodd, M.D.** is an Assistant Professor of Medicine in the Division of Endocrinology, Diabetes & Metabolism at the University of Alabama at Birmingham (UAB), where she also serves as Medical Director of Ambulatory Services for the division. She is a board-certified endocrinologist and internist with clinical expertise in general endocrinology and specialized interests in pituitary disorders, diabetes, lipid metabolism, and complex endocrine diseases.

Dr. Dodd earned her medical degree from the University of Texas Medical Branch School of Medicine in Galveston and completed her internal medicine residency at UAB. She went on to pursue fellowship training in Endocrinology, Diabetes, and Metabolism through the Washington University/Barnes-Jewish Hospital/St. Louis Children's Hospital Consortium. Her academic and clinical work includes managing a broad range of endocrine conditions, from metabolic disorders to adrenal and pituitary disease, and she frequently participates in multidisciplinary care, including UAB's interdisciplinary pituitary clinic.

In addition to her clinical responsibilities, Dr. Dodd is actively involved in teaching and continuing medical education, presenting at conferences such as the UAB Endocrinology Update and UAB Endocrinology Grand Rounds, and contributing to the training of medical students, residents, and fellows.

**NOTES** (Please use this space for your notes and reflections.)

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## ECD Expert Question and Answer Panel

11:05 am – 11:45 am

**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 to ask your questions about ECD in general! [Please note, the panel is unable to provide any personal medical advice during this session.]**

### **Gaurav Goyal, MD**

Hematology & Oncology  
University of Alabama at Birmingham, Birmingham, AL USA  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Member  
[ggoyal@uabmc.edu](mailto:ggoyal@uabmc.edu)  
+1-205-975-3409



### **Julien Haroche, MD, PhD**

Internal Medicine  
Hôpital Pitié-Salpêtrière, Paris, France  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Member  
[julien.haroche@aphp.fr](mailto:julien.haroche@aphp.fr)  
+33 1-42-17-80-37



### **Eli Diamond, MD**

Neuro-Oncologist  
Memorial Sloan Kettering Cancer Center (MSKCC), New York, NY  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Chair  
[Diamone1@mskcc.org](mailto:Diamone1@mskcc.org)  
+1-212-610-0243



### **Ronald S. Go, MD**

Hematologist, Oncologist  
Mayo Clinic, Rochester, MN USA  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Member  
ECDGA Board of Directors  
[Go.ronald@mayo.edu](mailto:Go.ronald@mayo.edu)



**NOTES** (Please use this space for your notes and reflections.)

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## Session Details (pm)

### Research Opportunities (Panel Discussion - 5 min each)

1:00 pm – 1:20 pm

**Hear the answers from ECD Medical experts about the open research opportunities. Hear up-to-date answers from those who are doing ECD research.**

#### Eli Diamond, MD

Neuro-Oncologist  
Memorial Sloan Kettering Cancer Center (MSKCC), New York, NY  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Chair  
[Diamone1@mskcc.org](mailto:Diamone1@mskcc.org)  
+1-212-610-0243



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Hematology & Oncology  
University of Alabama at Birmingham, Birmingham, AL USA  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Member  
[ggoyal@uabmc.edu](mailto:ggoyal@uabmc.edu)  
+1-205-975-3409



#### Jithma Abeykoon, MD

Hematologist  
Mayo Clinic, Rochester, MN USA  
ECD Care Center Clinician/Investigator  
[Abeykoon.Jithma@Mayo.edu](mailto:Abeykoon.Jithma@Mayo.edu)  
+1-507-284-2511



#### Matthew Collin, MD, PhD

Hematologist  
Newcastle University, Newcastle upon Tyne, United Kingdom  
ECD Care Center Lead Physician  
[Matthew.collin@newcastle.ac.uk](mailto:Matthew.collin@newcastle.ac.uk)  
+0191 213 8479



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## ECD Expert Question and Answer Panel (Research)

1:20 pm – 1:40 pm

**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 advice during this session.]**

### Eli Diamond, MD

Neuro-Oncologist  
Memorial Sloan Kettering Cancer Center (MSKCC), New York, NY  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Chair  
[Diamone1@mskcc.org](mailto:Diamone1@mskcc.org)  
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University of Alabama at Birmingham, Birmingham, AL USA  
ECD Care Center Lead Physician  
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[ggoyal@uabmc.edu](mailto:ggoyal@uabmc.edu)  
+1-205-975-3409



### Jithma Abeykoon, MD

Hematologist  
Mayo Clinic, Rochester, MN USA  
ECD Care Center Clinician/Investigator  
[Abeykoon.Jithma@Mayo.edu](mailto:Abeykoon.Jithma@Mayo.edu)  
+1-507-284-2511



### Matthew Collin, MD, PhD

Hematologist  
Newcastle University, Newcastle upon Tyne, United Kingdom  
ECD Care Center Lead Physician  
[Matthew.collin@newcastle.ac.uk](mailto:Matthew.collin@newcastle.ac.uk)  
+0191 213 8479



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## Patient / Caregiver Breakout Sessions

1:40 pm – 2:40 pm

**This breakout session will allow patients and caregivers to hear helpful information about their role in living with ECD, and provide time for each group to discuss their unique perspectives and connect with others who may be experiencing similar situations.**

### Patient Breakout Session (room #102)

#### Kevin O'Brien, RN, MSN-CRNP

Adult Nurse Practitioner, Clinical Investigator  
Genome Research Institute, National Institutes of Health,  
Bethesda, MD USA

[obrienke@mail.nih.gov](mailto:obrienke@mail.nih.gov)

+1-301-412-7694



### Caregiver Breakout Session (Room #201)

#### Sylvia Huang, PhD, MA, MEd, FAAHPM

Clinical Psychologist  
University of Alabama at Birmingham, Birmingham, AL USA

[chhuang@uabmc.edu](mailto:chhuang@uabmc.edu)



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## General Medical Management for ECD

3:00 pm – 3:15 pm

**This session will highlight 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.**

### **Kevin O'Brien, RN, MSN-CRNP**

Adult Nurse Practitioner, Clinical Investigator  
Genome Research Institute, National Institutes of Health,  
Bethesda, MD USA  
[obrienke@mail.nih.gov](mailto:obrienke@mail.nih.gov)  
+1-301-412-7694



**Kevin O'Brien, RN, MSN-CRNP**, is an Adult Nurse Practitioner and Clinical Investigator affiliated with the National Institutes of Health (NIH) in Bethesda, Maryland. At NIH, he practices as an advanced nurse clinician in the Clinical Center and within the National Human Genome Research Institute's (NHGRI) Office of the Clinical Director, where he provides comprehensive adult care and participates in clinical research and patient-centered care initiatives that support translational biomedical studies and genomic medicine programs.

With a strong background in nursing and advanced clinical practice, Kevin specializes in adult patient assessment, management of complex health conditions, and interdisciplinary coordination across research and clinical teams. He applies evidence-based practice to enhance care delivery within the NIH's unique research-integrated care environment, collaborating with clinicians, investigators, and support staff to ensure high-quality care for research participants.

Kevin contributes to NIH's mission of advancing human health through scientific discovery and clinical excellence. In this role, he supports studies and clinical protocols that integrate nursing practice with cutting-edge biomedical research — including work involving rare diseases and genomic studies — and helps translate research findings into practical health outcomes.

Before joining NIH, Kevin completed rigorous clinical and academic training in nursing and advanced practice, earning credentials that underpin his expertise in adult health and complex care coordination. His work reflects a commitment to patient-centered care within federally sponsored research and clinical innovation at one of the nation's leading medical research institutions.

**NOTES** (Please use this space for your notes and reflections.)

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## Emotional and Cognitive Changes in ECD

3:15 pm – 3:30 pm

**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.**

### **Sylvia Huang, PhD, MA, MEd, FAAHPM**

Associate Professor / Clinical Psychologist  
University of Alabama at Birmingham, Birmingham, AL USA  
[chhuang@uabmc.edu](mailto:chhuang@uabmc.edu)



**Dr. Sylvia Huang, PhD, MA, MEd** earned her PhD in Clinical Psychology from the University of Alabama and completed her postdoctoral fellowship in Palliative Psychology and Psycho-oncology at UAB, where she now leads innovative clinical and training programs focused on psychosocial care for individuals facing serious and rare illnesses.

In her clinical work, Dr. Huang provides counseling to patients and families navigating the emotional, psychological, and relational impact of illness and leads the Psycho-Oncology Distress Screening and Management Program at UAB Medicine. Her work focuses on improving access to high-quality psychosocial care, advancing interprofessional education, and supporting both patients and caregivers across the illness trajectory.

Dr. Huang serves as Principal Investigator of the Psychosocial Oncology Training Academy (POTA), which trains healthcare professionals to better integrate psychosocial support into medical care. Her work reflects a deep commitment to helping patients and families feel supported, understood, and less alone.

**NOTES** (Please use this space for your notes and reflections.)

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## **Fatigue and Pain in Erdheim-Chester Disease: Root Causes and Practical Strategies for Energy, Relief, and Resilience**

3:30 pm – 3:45 pm

**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.**

### **Richard Taylor, PhD, DNP, CRNP, APN-BC**

Assistant Professor/Associate Scientist –Palliative and Supportive Care  
University of Alabama at Birmingham, Birmingham, AL USA

[rtaylor@uabmc.edu](mailto:rtaylor@uabmc.edu)

+1-205-996-6419



**Dr. Richard Taylor, Ph.D., DNP, CRNP, ANP-BC**, is an Assistant Professor in the UAB School of Medicine, Department of Gerontology, Geriatrics, and Palliative Care, and a board-certified adult nurse practitioner with clinical expertise in oncology, gerontology, and palliative and supportive care for seriously ill adults. He is actively involved in both the academic and clinical missions of UAB, combining patient-centered practice with teaching and research.

Dr. Taylor earned his Bachelor of Science in Nursing (BSN) from UAB, his Master of Nursing from the University of California, San Francisco, a Post-Master's Adult Nurse Practitioner certificate, Doctor of Nursing Practice (DNP), and Ph.D. in Nursing from the University of Alabama at Birmingham. His educational journey reflects a deep commitment to advancing nursing practice and improving care for patients with serious illness across the lifespan, particularly in underserved populations.

In his clinical role, Dr. Taylor provides compassionate, evidence-based care in palliative medicine and supportive care settings, focusing on symptom management, especially cancer-related pain and fatigue, holistic patient support, and interprofessional collaboration to enhance quality of life for patients and families facing complex health challenges. He is known for his thoughtful approach, integrating clinical expertise with empathy and dignity for those he serves.

As an educator, Dr. Taylor teaches and mentors graduate learners, preparing the next generation to meet contemporary health care needs with skill and compassion. His academic contributions also include research and scholarship that advance understanding of life-space mobility in older cancer survivors and patient outcomes in oncology, gerontology, and palliative care contexts.

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## **Movement is Medicine**

3:45 pm – 4:00 pm

**Patients and caregivers will receive guidance through gentle, low-level exercises to help reduce pain, build strength, improve posture, and encourage activity.**

### **Elizabeth Bohorfoush, DPT**

Physical Therapist  
University of Alabama at Birmingham, Birmingham, AL USA  
[ebohorfoush@uabmc.edu](mailto:ebohorfoush@uabmc.edu)  
+1-205-801-8624



**Elizabeth Bohorfoush, DPT**, is a Doctor of Physical Therapy serving patients at the Supportive Care Clinic at the Whitaker Clinic of UAB Hospital in Birmingham, Alabama. She specializes in physical therapy with a focus on improving mobility, reducing pain, and enhancing functional strength for adult and geriatric populations.

Dr. Bohorfoush earned her Doctor of Physical Therapy degree from the University of St. Augustine for Health Sciences, graduating in 2003, and is licensed through the Alabama Board of Physical Therapy. Her clinical interest areas include exercise and cancer rehabilitation, management of scar tissue through manual therapy, and addressing radiation-induced fibrosis.

Known for her compassionate and skilled care, Dr. Bohorfoush works closely with patients to design individualized therapeutic programs that support pain relief, strength improvement, and enhanced quality of life. Her practice emphasizes patient education and active participation in recovery and long-term physical wellness.

Dr. Bohorfoush is recognized for her commitment to supportive care within the UAB Health System and for helping patients navigate the physical challenges associated with chronic conditions and complex treatment histories.

**NOTES** (Please use this space for your notes and reflections.)

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## Expert Question & Answer Panel

4:00 pm – 4:20 pm

**Ask your questions related to general medical management, emotional and cognitive changes, pain and fatigue, and staying active. Because these subjects can be interrelated, asking a question about one might prompt comments from other panel members on how another activity can help. Address your questions to any one of the panelists and learn if one of the other panelists might be able to surprise you with additional information.**

### **Kevin O'Brien, RN, MSN-CRNP**

Adult Nurse Practitioner, Clinical Investigator  
Genome Research Institute, National Institutes of Health,  
Bethesda, MD USA  
[obrienke@mail.nih.gov](mailto:obrienke@mail.nih.gov)  
+1-301-412-7694



### **Sylvia Huang, PhD, MA, MEd, FAAHPM**

Clinical Psychologist  
University of Alabama at Birmingham, Birmingham, AL USA  
[chhuang@uabmc.edu](mailto:chhuang@uabmc.edu)



### **Richard Taylor, PhD, DNP, CRNP, APN-BC**

Palliative and Supportive Care  
University of Alabama at Birmingham, Birmingham, AL USA  
[rtaylor@uabmc.edu](mailto:rtaylor@uabmc.edu)  
+1-205-996-6419



### **Elizabeth Bohorfoush, DPT**

Physical Therapy  
University of Alabama at Birmingham, Birmingham, AL USA  
[ebohorfoush@uabmc.edu](mailto:ebohorfoush@uabmc.edu)  
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## ECD Global Alliance Close

4:20 pm – 4:30 pm

**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.**

### Jerome Henson

Executive Director  
Erdheim-Chester Disease Global Alliance, DeRidder, LA USA  
[Jerome.Henson@Erdheim-Chester.org](mailto:Jerome.Henson@Erdheim-Chester.org)  
+1-318-491-2403



**Jerome Henson, Executive Director**, has more than 30 years of leadership experience in education, having served as a teacher, principal, and curriculum supervisor throughout his distinguished career. Jerome enjoys spending time outdoors hunting, working on woodworking projects, and, most importantly, spending time with his family. He and his wife share two daughters, a son-in-law, and a granddaughter.

“I am honored to join the Erdheim-Chester Disease Global Alliance and to serve a community that demonstrates such strength, resilience, and compassion”. I look forward to working alongside patients, families, volunteers, and supporters to continue advancing the important work of ECDGA.”

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## **ECD Global Alliance Resources**



ECD Global Alliance Website



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