



THE ECD GLOBAL ALLIANCE IS PROUD TO CONVENE THE

9th International Patient & Family Gathering on Erdheim-Chester Disease



13 -14 April 2024 | Seattle, WA, USA

Program Guide



UW Medicine

Program Guide

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We Come Together to Stop Erdheim-Chester Disease



Kathleen Brewer, M.E.
Founder and President
kathleen@erdheim-chester.org

Dear friends,

It's been nearly fifteen years since we first gathered around a virtual kitchen table to come together on behalf of people living with Erdheim-Chester disease and their family and friends. While there is still much to be done to help those living with ECD, we've built momentum toward a better future for the people in our community and those searching for answers.

Here are just a few milestones that we've crossed together:

1. **Consensus Recommendations for the Evaluation, Diagnosis, and Treatment of Erdheim-Chester disease (2020)**, compiled from real-world practice, insights from people with ECD and their families, and our network of physicians from around the globe.
2. **National Comprehensive Cancer Network (NCCN) Guidelines for Histiocytosis published** to improve the clinical practice of cancer centers treating people with ECD.
3. **Regulatory approval in the United States for two new therapies to treat ECD** to improve the life and longevity of people with ECD.
4. **Opportunities for "citizen scientists" to join in research through the ECD Patient Registry**, hosted in partnership with the Memorial Sloan Kettering Cancer Center.
5. **Development of a multi-nation ECD Care Center Referral Network**, with nearly 40 centers of ECD-knowledgeable professionals around the world available for consultation.
6. **Over \$1.2 million invested in new research on ECD**, supporting a pipeline for early career investigators to engage in the field.
7. **Over 1,500 people with ECD and their families supported** through educational webinars, peer chats, and patient navigation.
8. **Nearly 10 years of in-person, peer learning events including the annual Patient & Family Gathering and the Medical Symposium**, allowing for real-time dialogue between medical professionals, scientists, and the people and families they support.



C. Grace Whiting, J.D.
Chief Executive Officer
grace@erdheim-chester.org

Because of you – your commitment, time, donations, and engagement – we can look back and see how far we've come. What will the future hold next? You tell us. We're ready to keep moving forward on behalf of people living with ECD and their families.

All our best,

A handwritten signature in blue ink that reads "Kathy + Grace".

Welcome to the 9th Annual Patient and Family Gathering



*Paul C. Hendrie, M.D., Ph.D.,
Clinical Professor,
Hematology and Oncology,
University of Washington
School of Medicine, and
Associate Medical Director,
Fred Hutchinson Cancer
Center, Seattle, WA, USA*

Dear friends,

Welcome to my home city, Seattle, Washington for the 9th Annual Patient and Family Gathering, on behalf of the Fred Hutchinson Cancer Center and the University of Washington School of Medicine. We're thrilled to have you!

This meeting is especially important to me for two reasons. First, it's an opportunity for you to find resources and information that you need to ease your ECD journey. Since last fall, I have worked closely with the volunteer planning committee for this event. This committee is comprised of people with ECD and people who are caring for a loved one with ECD – and they have painstakingly planned this program and advised the ECD Global Alliance team about how to design a program with you in mind.

Second, one of the most important tenants in healthcare today is the idea of “person-centered care.” This means that people who are living with this disease are the experts in the lived experience of ECD. By being here, your dialogue with the medical professionals in our community is one way to educate doctors about what it's like to live with ECD. By putting our physicians in the “hot seat,” we give you the chance to ask questions and share your insights. This helps me and my colleagues to do a better job of supporting and caring for people with ECD and their families.

Thank you for taking time to attend this important meeting. I am grateful for the chance to work alongside you.

Sincerely,

A handwritten signature in black ink that reads "Paul C. Hendrie". The signature is written in a cursive, flowing style.

Paul C. Hendrie, MD, PhD
Event Host and Director, ECD Global Alliance Board

Acknowledgments

This meeting was made possible through generous sponsorship from our supporters, including Father Charles Balnaves of Melbourne, Australia, who supports this event in memory of his wife Tanya.

Additionally, this program would not be possible without our community volunteers, individual donors, and other generous supporters, including members like you.

Event Hosts

Paul C. Hendrie, M.D., Ph.D.

Sydney Allen, M.P.A.

Fred Hutchinson Cancer Center, Seattle, WA, USA

University of Washington School of Medicine, Seattle, WA, USA

Patient and Family Gathering Planning Committee, 2023-2024

Ana Valdez

Andy Skaggs

John Schulz

Steve Ban

Event Volunteers

Elizabeth Benavidez

Geoffrey Whiting

Sandra Cooper

Sandy Solis

Shannon Bennich

Sonia Maskas

ECD Global Alliance Team

Kathleen Brewer, M.E, Founder and President

C. Grace Whiting, J.D., CEO

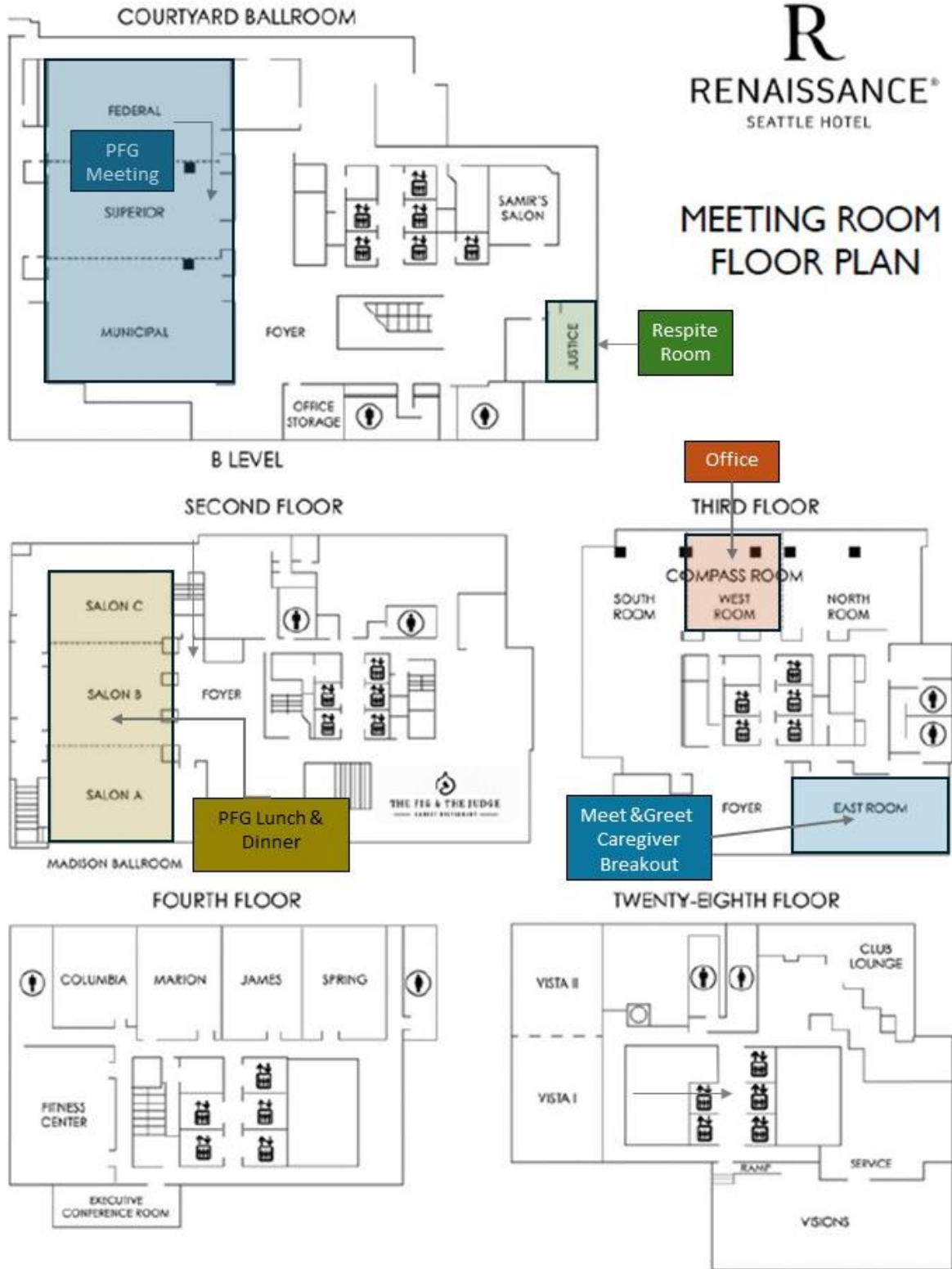
Belinda Cobb, Patient Navigator

Renita Page, Office Manager

Schedule at a Glance

TIME	PRESENTATION	ROOM
SATURDAY, 13 APRIL 2024		
3 – 5 PM	Meet and Greet	2 nd Fl, East
SUNDAY, 14 APRIL 2024		
8:00 AM – 5:00 PM	Registration Opens Respite Room Available	B Level, Foyer B Level, Justice
8:00 AM – 3:30 PM	Information Fair	B Level, Foyer
8:00 AM	Continental Breakfast	B Level, Foyer
8:45 AM	Welcome and Program Overview	B Level, Ballroom
9:00 AM	Overview of ECD Basic Biology	B Level, Ballroom
9:15 AM	Treating Erdheim-Chester Disease	B Level, Ballroom
9:35 AM	Treatment Spotlight: CAR-T and Transplant Therapy	B Level, Ballroom
9:55 AM	Networking Break	B Level, Foyer
10:15 AM	How ECD Impacts the Body’s Organs	B Level, Ballroom
10:40 AM	Tackling Pain and Fatigue in Erdheim-Chester Disease	B Level, Ballroom
11:05 AM	Understanding Integrative Medicine in Cancer Care	B Level, Ballroom
11:25 AM	How Far We’ve Come: An Evolving Research Landscape	B Level, Ballroom
11:40 AM	Break for Group Picture	B Level, Ballroom
12:00 PM	Lunch	2 nd Fl, Madison Ball.
1:05 PM	Living with ECD: A Patient’s Perspective	B Level, Ballroom
1:15 PM	Why Research Matters	B Level, Ballroom
1:35 PM	Question & Answers: Insights from ECD Medical Experts	B Level, Ballroom
2:35 PM	Networking Break	B Level, Foyer
2:50 PM	For Patients: Challenges When Living with ECD	B Level, Ballroom
	For Care Partners: Coping with Caregiving	3 rd Fl, East Room
3:50 PM	Break	B Level, Foyer
4:00 PM	Movement & ECD: How Physical Activity Builds Resilience	B Level, Ballroom
4:20 PM	Unpacking the Pathology Report	B Level, Ballroom
4:35 PM	Program Close and Attendee Evaluation	B Level Ballroom
6:00 PM	Celebration Dinner	2 nd Fl, Madison Ball

Conference Map



Session Details

Session Name	Welcome and Program Overview
Date and Time	Sunday, 14 April 2024 – 8:45 AM PST
Room	Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level
Description	This session provides an overview of the history of Erdheim-Chester disease and the 9 th Annual Patient and Family Gathering.

Speaker Bios



Paul C. Hendrie, M.D., Ph.D., Clinical Professor, Hematology and Oncology, University of Washington School of Medicine, and Associate Medical Director, Fred Hutchinson Cancer Center, Seattle, WA, USA

Dr. Hendrie is a board-certified hematologist with clinical and research interests in myeloid neoplasms, including histiocyte neoplasms, like Erdheim-Chester disease, systemic mastocytosis, and acute myeloid leukemia. As a physician, Dr. Hendrie leads inpatient oncology service at UWMC, working directly with patients, some of whom participate in clinical trials. Dr. Hendrie joined the ECD Global Alliance community in 2016. He currently serves as a member of the Board of Directors and Chair of the Research Committee.

Dr. Hendrie earned his undergraduate degree from Indiana University Bloomington and his medical degree from Indiana University School of Medicine, where he also completed his residency in internal medicine. He completed a fellowship in hematology at the University of Washington and is board-certified in both hematology and internal medicine.



ECD Care Center
Leader

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**C. Grace Whiting, J.D., CEO,
ECD Global Alliance, Baton Rouge, LA, USA**

Grace joined the ECD Global Alliance in October 2023 after serving as the CEO of the National Academy of Elder Law Attorneys (NAELA) and as President and CEO of the National Alliance for Caregiving (NAC). At NAC, Grace partnered with Global Genes to lead the first-ever policy study of rare disease caregivers. The 2018 study, *Rare Disease Caregiving in America*, captured perspectives from 1,400 friends and family members of people living with rare diseases across 400 conditions. Grace is a frequent public speaker on advocacy and caregiving, and has been a resource for media including the *New York Times*, the *Wall Street Journal*, and C-SPAN, among others.

Grace earned her undergraduate degree from Louisiana State University and her law degree from the University of Memphis Cecil C. Humphreys School of Law. She is a licensed member of the D.C. Bar and lives in Baton Rouge, LA, with her brilliant husband, Geoffrey Whiting, and their cat, Baby.

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Session Name **Overview of ECD Basic Biology**

Date and Time Sunday, 14 April 2024 – 9:00 AM PST

Room Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description This session provides an overview of the basic biology of Erdheim-Chester disease, including existing knowledge and gaps in understanding. The discussion will include current research and clinical trends, and an overview of the types of mutations that may impact a person living with ECD.

Speaker Bio



Ken McClain, M.D., Ph.D., Professor, Pediatrics-Oncology, Baylor College of Medicine, and Physician, Dan L. Duncan Comprehensive Cancer Center, Baylor College of Medicine, Houston, TX, USA

Dr. McClain is a board-certified pediatrician with interests in histiocytic diseases and lymphomas. He is currently a member of the American Society for Hematology, the American Society for Pediatric Hematology/Oncology, and a past president of the Histiocyte Society, among other honors.



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Dr. McClain received his undergraduate degree from Augustana College in Chemistry and Biology, his Ph.D. from the University of Chicago in Pathology and Virology, and M.D. from the University of Chicago Hospitals a year later. He completed a residency at Johns Hopkins in pediatrics, then a post-doc fellowship in molecular biology at the National Institutes of Health. His training in pediatric hematology and oncology was at the University of Minnesota Affiliate Hospitals.

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Session Name

Treating Erdheim-Chester Disease

Date and Time

Sunday, 14 April 2024 – 9:15 AM PST

Room

Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description

This session describes the treatment options available to someone living with Erdheim-Chester disease. The discussion will include an analysis of which treatments have consensus from the medical community and how treatments should be used. The session will also address concerns related to toxicity and reduced effectiveness over time.

Speaker Bio



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Ronald S. Go, M.D., Hematologist, Oncologist, Mayo Clinic, and Professor of Medicine, Division of Hematology, Mayo Foundation for Medical Education and Research, Rochester, MN, USA

Dr. Go is a hematologist/oncologist who investigates the pathogenesis, diagnosis, and treatment of histiocytic disorders such as Erdheim-Chester disease, Rosal-Dorfman disease, and Langerhans cell histiocytosis.

Since 2017, he has led the Mayo Clinic Histiocytosis Working Group, a multidisciplinary and dedicated team of physicians treating histiocytic disorders. Besides histiocytic disorders, Dr. Go's clinical and research interest include thrombotic microangiopathies, immune cytopenias, and monoclonal gammopathy of undetermined significance. He also performs health outcomes research in hematologic malignancies.

Dr. Go leads an ECD Care Center at the Mayo Clinic including a multidisciplinary Histiocyte Working Group. This group meets monthly to discuss every case being studied within the collaborative tumor board.

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Session Name	Treatment Spotlight: CAR-T and Transplant Therapy
Date and Time	Sunday, 14 April 2024 – 9:35 AM PST
Room	Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level
Description	This session will provide an overview of CAR-T therapy and transplant therapies for people living with ECD. Dr. Appelbaum will review the biology of bone marrow transplant and efforts to distill the impact of transplant for immune function modulation. By the end of the talk, attendees will understand the process of bone marrow transplant, be informed of risks and potential benefits of this lifesaving treatment, and anticipate some of the innovations and challenges anticipated for engineered designer cell therapies including CAR-T cell therapies.

Speaker Bio



Jacob Appelbaum, M.D., Ph.D., Assistant Member, Fred Hutchinson Cancer Center and Assistant Professor, Hematology and Oncology University of Washington School of Medicine, Seattle, WA, USA

Dr. Appelbaum is a physician and researcher with clinical practices in hematologic malignancies, non-malignant hematology, acute myeloid leukemia (AML), and other myeloid malignancies. He is board-certified in hematology and internal medicine. He has specialized in AML and other myeloid malignancies that result in the abnormal production of cells in bone marrow and blood.

In his current work, Dr. Appelbaum is studying how to bring cellular immunotherapies such as chimeric antigen receptor (CAR) T-cell therapy to patients with AML. This method directs a person's T-cells, a type of immune system cell, to target and eliminate cancer.

Dr. Appelbaum received his undergraduate degree in Biology and Chemistry from Amherst College. He earned his Ph.D. in Cell Biology from Yale University and his M.D. from Yale School of Medicine. After completing his residency from the University of California, San Francisco, in Internal Medicine, Dr. Appelbaum completed a fellowship at the Fred Hutchinson Cancer Research Center in Hematology-Oncology.

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Session Name How ECD Impacts the Body’s Organs

Date and Time

Sunday, 14 April 2024 – 10:15 AM PST

Room

Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description

This session will discuss the impact of ECD on the body’s organ systems. Topics for discussion include identifying which organs ECD can affect, how involvement is determined, and what symptoms should be reported to a medical provider.

Speaker Bios



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Eli L. Diamond, M.Phil., M.D., Neuro-Oncologist, Memorial Sloan Kettering Cancer Center, New York, NY, USA

Dr. Diamond 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.



Francesco Pegoraro, M.D., Histiocytosis Clinic, Meyer Children's Hospital IRCCS, Florence, Italy

Dr. Francesco Pegoraro, M.D., is a clinical researcher and pediatrician specializing in Erdheim-Chester disease and other histiocytic disorders at Meyer Children's Hospital IRCCS in Florence, Italy. Dr. Pegoraro earned his medical degree from the University of Turin, Italy. He subsequently completed his residency in pediatrics at Meyer Children's University Hospital in Florence. During his residency, he joined the Histiocytosis clinic, caring for adults and children affected by Erdheim-Chester disease and other histiocytic disorders, and he actively participated in numerous scientific projects focused on histiocytosis. Currently, Dr. Pegoraro is a part-time Medical Doctor at the Department of Hematology and Oncology. Additionally, he is pursuing a Ph.D. at the University of Florence, Italy, as a first-year student. His doctoral research is dedicated to elucidating the genetic predisposition underlying histiocytosis, with the aim of expanding our understanding of this complex disease.

Session Name **Understanding Integrative Medicine in Cancer Care**
Date and Time Sunday, 14 April 2024 – 11:05 AM PST
Room Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level
Description This session will provide an overview of integrative medicine, what it is, how it can help improve care for ECD, and what options patients might have.
Speaker Bio



Blake Langley, N.D., LAc, Staff Scientist, Fred Hutchinson Cancer Center, Seattle, WA, USA

Dr. Langley is a staff scientist at the sole WWAMI region NCI-designated comprehensive cancer center investigating the impact of lifestyle, behavioral, dietary, and mind-body interventions on symptom burden and quality of life in cancer treatment and survivorship. He is a licensed naturopathic doctor and acupuncturist in Washington. As a researcher, Dr. Langley has examined how integrative medicine can benefit oncology patients.

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Session Name **How Far We Have Come: An Evolving Research Landscape**

Date and Time Sunday, 14 April 2024 – 11:25 AM PST

Room Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description This session will provide an overview of ECD-related research and highlight recent accomplishments in understanding the science of ECD. The discussion will include an overview of how important collaborative research is, and what can be learned when research institutions, people living with ECD, and their families work together.

Speaker Bio



**Juvianee I. Estrada-Veras, M.D.,
Board of Directors, ECD Global Alliance**

Dr. Estrada-Veras is currently Head Clinical Geneticist for the MCC and MCCR Clinical Cancer Genetics Program at Walter Reed National Military Medical Center, serving both the clinical cancer genetics and research cancer genetics needs per MCCR vision and direction. He is specialty board certified in general pediatrics by the American Board of Pediatrics, as well as Clinical Genetics and Medical Biochemical Genetics by the American board of Medical Genetics and Genomics.

Dr. Estrada-Veras' interests are the diagnosis and treatment of inborn errors of metabolism in children as well as other genetic disorders. Previous research interest include inborn errors of metabolism and non-Langerhans cell histiocytic disorders, especially Erdheim-Chester disease. Dr. Estrada-Veras was a collaborator with the NIH study, "Clinical and Basic Investigation into Erdheim-Chester Disease" and "Dabrafenib and Trametinib Trial for Treating Patients With Erdheim-Chester Disease and BRAF Mutation."

Dr. Estrada-Veras has received several awards for his outstanding medical care, including the Genome Recognition of Employee Accomplishments and Talents (G.R.E.A.T.) from the NIH-NHGRI. In 2016, he received the Distinguished Alumnus Award from his medical school as recognition of his research efforts for rare diseases at NHGRI/NIH. Most recent, in 2021 he received the Associate Master Clinician Award from Walter Reed NMMC / USUHS – NSAB for his performance in clinical care at WRNMMC.

Dr. Estrada-Veras earned his M.D., Magna Cum Laude, from the Instituto Tecnológico de Santo Domingo in the Dominican Republic. He completed residency training in pediatrics at the State University of New York Health Science Center and University Hospital in Brooklyn, NY. Following this, he joined the NIH Medical Genetics and Genomic Medicine training program at the National Human Genome Research Institute (NHGRI) where he completed residency training in clinical genetics and fellowship training in medical biochemical genetics.

Session Name

Why Research Matters

Date and Time

Sunday, 14 April 2024 – 1:15 PM PST

Room

Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description

This session will cover why research is so important to the clinical practice of caring for people living with ECD. The discussion will also provide updates on emerging research trends in the field, including the ECD Survivorship study and other major findings in the histiocytosis community.

Speaker Bio



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Gaurav Goyal, M.D., Hematology-Oncology, University of Alabama at Birmingham, Birmingham, AL, USA

Dr. Goyal 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. He completed his residency in Internal Medicine from Creighton University Medical Center, Omaha, Nebraska. During his residency, he developed a special interest in hematology-oncology and completed a fellowship in the same from the Mayo Clinic.

During his time at the Mayo Clinic, he developed a unique focus in a rare group of blood diseases called 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 led to the establishment of the first of its kind multidisciplinary Histiocytosis Working Group. He has led national and international guidelines on the diagnosis and management of these rare disease entities. He was subsequently recruited to join the Hematology-Oncology division at University of Alabama at Birmingham as an Assistant Professor in 2019.

Dr. Goyal established the histiocytosis program after moving to UAB and expanded the Histiocytosis Working Group to include members from UAB. He continues to conduct clinical, translational, and outcomes research in histiocytosis at his current position. He has additionally developed a special interest in survivorship research with ongoing projects evaluating the burden of morbidity and mortality among individuals with histiocytic disorders.

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Session Name	Question & Answers: Insights from ECD Medical Experts
Date and Time	Sunday, 14 April 2024 – 1:35 PM PST
Room	Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level
Description	This is an open Question and Answer discussion with ECD Medical experts. Come with your questions and insights!

Speaker Bio



Moderator

Paul C. Hendrie, M.D., Ph.D., Clinical Professor, Hematology and Oncology, University of Washington School of Medicine, and Assoc. Medical Director, Fred Hutchinson Cancer Center, Seattle, WA, USA

Please see Dr. Hendrie's full bio on page 9.



Eli L. Diamond, M.Phil., M.D., Neuro-Oncologist, Memorial Sloan Kettering Cancer Center, New York, NY, USA

Please see Dr. Diamond's full bio on page 17.



Ronald S. Go, M.D., Hematologist, Oncologist, Mayo Clinic, and Professor of Medicine, Division of Hematology, Mayo Foundation for Medical Education and Research, Rochester, MN, USA

Please see Dr. Go's full bio on page 13.



Jithma Abeykoon, M.D., Hematology - Oncology, Mayo Clinic, Rochester MN, USA

Jithma Abeykoon, MD, is an Assistant Professor of Hematology and Medical Oncology in the division of Hematology at Mayo Clinic, MN. Abeykoon's research interest is to study rare blood cancers such as lymphoma, plasma cell disorders, and histiocytic malignancies such as Erdheim-Chester Disease (ECD). As a young clinician investigator, his aim is to better understand and delineate disease biology, characteristics, and clinical outcomes of patients with these rare malignancies, with a focus on identifying new treatment strategies and biomarkers. Dr. Abeykoon's ultimate goal is to deliver passionate care for patients while conducting research to advance science and discover new treatment strategies for patients with these rare cancers.

Session Name

For Patients: Challenges When Living with ECD

Date and Time

Sunday, 14 April 2024 – 2:50 PM

Room

Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description

This session is for people who are living with ECD and will include a discussion on stress management techniques, how to practice self-care, and how to manage personal challenges when living with the disease.

Speaker Bios



Kevin O'Brien, RN, MS-CRNP, Nurse Practitioner, Clinical Investigator, Genome Research Institute, National Institutes of Health, Bethesda, MD, USA

Kevin O'Brien is a nurse practitioner and clinical investigator at the National Human Genome Research Institute of the National Institutes of Health in Bethesda, MD.

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Session Name

For Care Partners: Coping with Caregiving

Date and Time

Sunday, 14 April 2024 – 2:50 PM

Room

Renaissance Seattle Hotel, Room: 3rd Floor, East Room

Description

This session is for those who care for someone living with ECD. The discussion will focus on managing the complicated emotions of caring for someone with a chronic disease, including addressing depression, anxiety, grief, or stress related to care responsibilities.

Speaker Bios



Laura C. Polacek, Ph.D., Postdoctoral Fellow, VA Boston Healthcare System, Boston, MA, USA

Laura C. Polacek, Ph.D., is a Geropsychology Fellow at VA Boston Healthcare System where she supports older adult Veterans and their caregivers as they cope with chronic and life-limiting illnesses, including cancer, dementia, chronic obstructive pulmonary disease, and end-stage renal disease. She completed her doctorate in clinical psychology at Fordham University, during which she trained in numerous medical systems, including Memorial Sloan Kettering Cancer Center, New York University School of Medicine, and Long Island Jewish Medical Center.

She has provided care across a variety of settings, including outpatient, long-term care, and Veterans' homes, and she has treated a range of mental health concerns, including depression, anxiety, grief, and posttraumatic stress disorder. Her research focuses on end-of-life communication and the development, implementation, and dissemination of novel psychotherapies for patients with cancer and their caregivers.

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Session Name **Movement & ECD: How Physical Activity Builds Resilience**

Date and Time Sunday, 14 April 2024 – 4:00 PM

Room Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description This session will focus on the role that physical activity, rehabilitation, and exercise can play in improving physical function and symptoms of ECD. Ongoing research about factors that influence physical and psychological resilience will be highlighted as well as the need for an individualized rehab approach.

Speaker Bios



Hanna Hunter, M.D., Assistant Professor | UW Medicine, Department of Rehabilitation Medicine, and Medical Director | Cancer Rehabilitation, Fred Hutchinson Cancer Center

Hanna Hunter, M.D., is a board-certified physician in physical medicine & rehabilitation. She is the Medical Director of Cancer Rehabilitation at the Fred Hutchinson Cancer Center and is an Assistant Professor in the Department of Rehabilitation Medicine at the UW School of Medicine. She graduated from Rutgers New Jersey Medical School prior to her residency at New York Presbyterian Hospital – Columbia/Cornell. She completed a fellowship in Cancer Rehabilitation at Memorial Sloan Kettering Cancer Center prior to moving to Seattle.

Dr. Hunter works closely with an interdisciplinary team of physical, occupational, speech, and lymphedema therapists to develop holistic and personalized rehabilitation plans for individuals with chronic illness. She specializes in the diagnosis and treatment of musculoskeletal and neurologic changes that can occur from cancer and its treatment. Dr. Hunter’s scholarly interests focus on improving mobility and fitness prior to, during, and after cancer treatment.

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Session Name

Unpacking the Pathology Report

Date and Time

Sunday, 14 April 2024 – 4:20 PM

Room

Renaissance Seattle Hotel, Room: Courtyard Ballroom, B Level

Description

This session will focus on understanding pathology and its role in diagnosing someone with ECD. The presentation will include an overview of the pathology report and how to interpret it, as well as what questions to ask the provider and how to get additional information as needed.

Speaker Bios



Aishwarya Ravindran, M.D., Assistant Professor of Pathology, Division of Laboratory Medicine-Hematopathology, Department of Pathology, The University of Alabama at Birmingham, AL, USA

Dr. Aishwarya Ravindran is a consultant Hematopathologist at the University of Alabama at Birmingham (UAB) and an Associate Scientist in Cancer Control and Population Science at the O’Neal Comprehensive Cancer Center at UAB. She received her MBBS from Stanley Medical College in India. Subsequently, she pursued her research fellowship in Hematology, followed by a residency in Anatomic/Clinical Pathology and a fellowship in Hematopathology at the Mayo Clinic in Rochester, Minnesota. While training at the Mayo Clinic, she developed a special interest in studying rare diseases, specifically histiocytic/dendritic cell neoplasms.

Her research analyzes the phenotypic and genotypic correlates in these neoplasms and integration into clinical practice. She has published numerous peer-reviewed scientific articles and was also a recipient of the Mayo Clinic Dr. Hobart K.B. Allebach Fellowship award and the American Society of Clinical Pathology - 40 Under 40 Honoree for outstanding contributions to the field of pathology. As an active member of the multidisciplinary Mayo Clinic - UAB Histiocytosis Working Group, she aims to improve awareness about these rare disorders.

Notes

Please use this space for your notes and reflections.

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If You Need a Break: The Respite Room

Sometimes, when attending an information-rich meeting such as this one, you may need a break in a quiet, tranquil space. It could be that you need some time to process the information you are hearing, or that you want a private space to reflect on something that may be challenging to learn about.

Our Respite Room is a quiet space on the B Level in the Justice Room in case you need a moment to yourself. If you need someone to talk to, please check in with the Registration Desk and one of our volunteers will come to assist.

Help and Resources

Leukemia & Lymphoma Society (LLS)

<https://www.lls.org/>



**On-Site
Exhibitor**

The Leukemia & Lymphoma Society® (LLS) is the world's largest voluntary (nonprofit) health organization dedicated to funding blood cancer research, support, and advocacy. LLS funds lifesaving blood cancer research around the world, provides free information and support services, and is the voice for all blood cancer patients seeking access to quality, affordable, coordinated care. Speak one-on-one with an LLS Information Specialist who can assist you through cancer treatment, financial and social challenges, and give accurate, up-to-date disease, treatment, and support information. For more information, please visit www.LLS.org/PatientSupport.

Fred Hutchinson Cancer Center

<https://www.fredHutchinson.org/en.html>



**On-Site
Exhibitor**

Fred Hutchinson Cancer Center unites comprehensive care and advanced research to provide the latest cancer treatment options and accelerate discoveries that prevent, treat, and defeat cancer and infectious diseases worldwide.

Fred Hutchinson Cancer Center - Cook for Your Life

<https://www.cookforyourlife.org/>



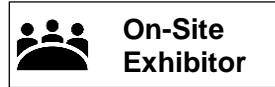
**On-Site
Exhibitor**

Cook for Your Life was founded in 2007 by three-time cancer survivor Ann Ogden Gaffney, who founded a non-profit in New York City providing free in-person classes to cancer patients and survivors. Ann's classes eventually became the extensive online resource found at Cook for Your Life, offering healthy recipes and nutrition tips to people touched by cancer all around the world. Acquired by Fred Hutchinson in 2019, Cook for Your Life offers an ever-expanding collection of recipes, instructional cooking videos, and science-based nutrition and health information in both English and Spanish – all adhering to standards established by the Academy of Nutrition and Dietetics. Backed by research and clinical trials, teams at Fred Hutchinson are using this global platform as a powerful tool to advance research on diet, cancer prevention, and survivorship. The Cook for Your Life team is committed to reaching people wherever they are and strives to be an inclusive, multicultural resource that everyone can use, with the ultimate goal of helping millions of people worldwide live their best lives.

For Residents of the U.S.

Angel Flight West

<https://angelflightwest.org>



Angel Flight West delivers health and hope using donated flights to serve those with healthcare or other compelling human needs. In the air, Angel Flight West links volunteer pilots and commercial airlines with people whose non-emergency health needs require air transportation to access care. On the ground, volunteer drivers, earth angels, ferry passengers to and from their departure and destination airports. Angel Flight West provides air transportation within and across: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, Oregon, Utah, Washington, and Wyoming. For a full list of Angel Flight services in the United States, please visit <http://www.angelflightamerica.org/aboutus.html>.

U.S. Social Security Administration

<https://www.ssa.gov/>



The Social Security Administration administers social security benefits in the United States, including Social Security Disability Insurance and the Representative Payee Program. Our colleague will provide help with Social Security benefits to include:

- Filing or appealing for Social Security Disability Benefits
- Retirement
- Survivors benefits

U.S. Centers for Medicare & Medicaid Services (CMS)

<https://www.cms.gov/>

The Centers for Medicare & Medicaid Services (CMS) is the federal agency that provides health coverage to more than 160 million through Medicare, Medicaid, the Children's Health Insurance Program, and the Health Insurance Marketplace. CMS works in partnership with the entire healthcare community to improve quality, equity, and outcomes in the healthcare system.

Patient Advocate Foundation (PAF)

<https://www.patientadvocate.org/>

The Patient Advocate Foundation is a national non-profit organization that offers free, one-on-one assistance to patients and families to help them solve real-life problems related to a serious health condition. Services include help with insurance navigation, enrollment, education, appeals, and prior authorizations; support for financial issues related to medical or cost-of-living expenses; screening and enrollment in available safety net programs; and disability education and enrollment.

American Cancer Society

<https://www.cancer.org/support-programs-and-services.html>

The American Cancer Society offers programs and services to help you during and after cancer treatment. In addition, ACS provides resources for families and friends who may be caring for someone with cancer at <https://www.cancer.org/cancer/caregivers.html>.

U.S. Department of Veterans Affairs

<https://www.va.gov/>

For former members of the U.S. military, the VA offers healthcare and other supports. In addition, the VA offers a comprehensive program for those who care for a Veteran at

<https://www.va.gov/COMMUNITYCARE/programs/caregiver/index.asp>.

National Organization of Rare Disorders

<https://rarediseases.org/>

NORD advances practical, meaningful, and enduring change so people with rare diseases can live their fullest and best lives. They work to elevate care, advance research, and drive policy in a purposeful and holistic manner to lift up the rare disease community.

Everylife Foundation for Rare Disease

<https://everylifefoundation.org/>

The Everylife Foundation for Rare Disease is an advocacy organization which works to empower the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

Rare Disease Diversity Coalition

<https://www.rarediseasediversity.org/>

Black Women's Health Imperative launched the Rare Disease Diversity Coalition™ (RDDC™) to address the extraordinary challenges faced by underserved populations with rare diseases. The Coalition brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to alleviate the disproportionate burden of rare diseases on historically marginalized populations.

Global Resources

The Histiocytosis Association (HA)

<https://histio.org/>

The Histiocytosis Association (HA) is a global nonprofit organization dedicated to supporting patients, families, and healthcare providers impacted by all histiocytic disorders. Programs and services offered by the HA include an international physician directory, up to date information on each histiocytic disorder, regional meetings, virtual education sessions, peer to peer support groups, grief support groups, awareness activities, advocacy, and a wide range of resources from partners around the world. In addition, the HA provides direct support to the medical community acting as Secretariat and long-standing partner for the Histiocyte Society and by funding research projects via seed grants offered through their Annual Research Program. For questions and support, reach out to the team at +1 856-589-6606 or info@histio.org, or visit their website at www.histio.org.

Global Genes

<https://globalgenes.org/>

Global Genes provides a globally connected community for people living with rare disease and their families. They are committed to providing information, resources, and connections to all communities affected by rare diseases and offer an annual meeting as well as other resources to help.

Rare Disease International

<https://www.rarediseasesinternational.org/>

Rare Diseases International (RDI) is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI advocates for rare diseases as an international public health priority and has more than 90 member organizations from 46 countries.

International Alliance of Patient Organizations (IAPO)


<https://www.iapo.org.uk/>

IAPO is a unique global alliance representing patients of all nations across all disease areas and promoting patient-centered healthcare across the world.

International Alliance of Carer Organizations (IACO)


<https://internationalcarers.org/>

IACO members are working collaboratively and independently to raise awareness of carers, identify and disseminate best practices and enhance carer well-being. Once seen as a personal and private matter in family life, unpaid caregiving has become one of the most important social and economic policy issues worldwide.




Looking for help with ECD? Get involved!

Join a Virtual Chat!




Chats include Peer-to-Peer Chats, Caregiver Chats, Grief Chats.

We also have chats in Spanish, French, Italian, German, and regional chats such as people living in Australia and New Zealand.




SCAN ME

Find an ECD-knowledgeable medical professional.




Our Care Center doctors treat people with ECD.

We have nearly 40 ECD Care Centers around the world.




SCAN ME

Connect with our Patient Navigator.



Belinda Cobb
belinda@erdheim-chester.org

Join our private Facebook group for people with ECD and their friends or family.



SCAN ME

Patient Assistance Programs

These resources are designed to help people get access to needed medication, especially if they cannot afford the medication prescribed by their doctors.

Leukemia & Lymphoma Society (LLS) - Acute Myeloid Leukemia (AML)

Co-Pay Assistance Program

<https://www.lls.org/support-resources/financial-support/co-pay-assistance-program>

Provides up to \$4,000 per patient including those with Erdheim-Chester disease to remove the barriers patients face in accessing care.

Genentech Patient Foundation

<https://www.gene.com/patients/patient-foundation>

The Genentech Patient Foundation gives free Genentech medicine to people who don't have insurance coverage or who have financial concerns. For a full list of participating medicines, visit

<https://www.gene.com/patients/patient-foundation/our-participating-medicines>.

Genentech Patient Assistance Programs for Zelboraf (vemurafenib)

<https://www.genentech-access.com/hcp/brands/zelboraf/find-patient-assistance.html>

Genentech Patient Assistance Programs for Cotellic (cobimetinib)

<https://www.genentech-access.com/hcp/brands/cotellic/find-patient-assistance.html>

Genentech Patient Assistance Programs for Actemra (tocilizumab)

<https://www.genentech-access.com/hcp/brands/actemra.html>

Novartis Patient Assistance Foundation

Enrollment offers assistance for the use of Mekinist (trametinib) and Tafinlar (dabrafenib).

For US Patients

<https://www.novartis.com/us-en/patients-and-caregivers/patient-assistance/patient-assistance-foundation-enrollment>

Oncology Support

<https://www.novartis.com/us-en/healthcare-professionals/novartis-patient-support-oncology>

KINERET® On TRACK™

<https://www.kineretrx.com/>

This program provides assistance with prescription delivery, insurance, and reimbursement; and answers to some of their Kineret-related questions.

For additional resources, please visit <https://erdheim-chester.org/resources/>.