

## **Program Guide**

---

ECD Global Alliance: Bringing Hope to the Community .....	1
Welcome to the 10th Annual Patient & Family Gathering .....	2
Acknowledgments .....	3
Schedule at a Glance .....	4
Conference Maps.....	5
Patient & Family Gathering Agenda.....	8
Session Details (am) .....	9
Welcome to the Bellvitge & the Patient and Family Gathering.....	9
Overview of Adult Histiocytosis .....	11
Biology of ECD & Current Basic Science Research .....	13
ECD Treatment Options (Current & on the horizon).....	15
ECD Treatment Side Effects.....	17
ECD Clinical Manifestations .....	19
Brain/eye Involvement.....	21
Kidney/Urology Involvement.....	23
Other organ involvement .....	25
Session Details (pm) .....	27
ECD & Concomitant Diseases .....	27
ECD Expert Question and Answer Panel .....	29
Mental and Emotional Health for Patients & Caregivers .....	33
Pain & Fatigue Management .....	35
Staying Active.....	37
Eating Healthy .....	39
ECD Survivorship Management: Question & Answer Panel.....	41
ECD Global Alliance Close and Attendee Evaluation .....	43
ECD Patient & Family Gathering Evaluation Survey .....	45
ECD Global Alliance Resources .....	45

## **ECD Global Alliance: Bringing Hope to the Community**

Dear Attendees of the 2025 ECD Patient & Family Gathering,

On behalf of the Erdheim-Chester Disease Global Alliance (ECDGA) Board of Directors, staff, and community, we warmly welcome you to Barcelona. It is an honor to gather with patients, families, medical professionals, and scientists, all dedicated to improving the lives of those affected by Erdheim-Chester Disease (ECD).

The ECDGA began as a small but determined group of caregivers searching for answers. Since 2008, it has grown into a global network serving over 1050 families across 75 countries. Together, we have built a strong foundation of support, education, advocacy, and research.

This gathering is a valuable opportunity to connect, learn, and share experiences. We hope it provides insights from medical experts, new friendships, and a renewed sense of hope. Our goal is to empower you with knowledge to navigate your ECD journey and advocate for yourself and your loved ones.

Thanks to our dedicated supporters and medical partners, ECDGA has made remarkable progress. We have funded groundbreaking research, identified 41 ECD Care Centers, and united the community in ways that have led to new treatment options for patients worldwide. Most of our programs, including this meeting, are made possible by the generosity of patients and families, ensuring continued advancements in research, education, and patient care.

As we gather in Barcelona, let us celebrate our progress and look forward with hope. Your voice and involvement are powerful, and together, we can drive meaningful change. We also extend our deepest appreciation to the medical professionals and scientists joining us—your expertise is invaluable to advancing ECD research and treatment.

Thank you for being here and for being part of this journey.

With warmest regards on behalf of the ECDGA Board of Directors & Staff,



Kathleen Brewer  
ECDGA President & Founder



Diane Schriener  
ECDGA Vice President

## **Welcome to the 10th Annual Patient & Family Gathering**

Dear Attendees of the 2025 ECD Patient & Family Gathering,

It is my great pleasure to welcome you to Barcelona and to Bellvitge University Hospital for this important gathering. As we come together as patients, caregivers, medical professionals, and scientists, we are reminded of the strength of our shared community and our commitment to improving the lives of those affected by Erdheim-Chester Disease (ECD).

This meeting is a unique opportunity to exchange knowledge, share experiences, and build lasting connections. The more we understand about ECD, the better we can work together to advance research, improve treatment options, and enhance patient care. For patients and families, staying informed is key to navigating this journey with confidence, advocating for the best care, and finding comfort in knowing you are not alone.

I am honored to be part of such a dedicated group of individuals, all working toward a common goal. The collaboration between patients, caregivers, and the medical community is essential to making progress, and gatherings like this serve as a vital foundation for these efforts.

I encourage you to engage, ask questions, and take advantage of the knowledge and support available here. Your voice matters, and together, we can make a difference. Welcome to Barcelona—I look forward to an inspiring and productive meeting.

With warmest regards,



Xavier Solanich, MD, PhD  
Host, 2025 ECD Patient & Family Gathering  
Internal Medicine  
Bellvitge University Hospital, Barcelona, Spain  
ECD Care Center Lead Physician

## **Acknowledgments**

---

### **Sponsor 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' generous sponsorship.

We are also thankful for 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.

### **Event Host**

Xavier Solanich, MD, PhD  
Bellvitge University Hospital  
Barcelona, Spain



### **Planning Committee**


Xavier Solanich, MD, PhD, Bellvitge University Hospital, Barcelona, Spain  
Paul Hendrie, MD, PhD, Fred Hutch, Seattle, WA USA, ECD Global Alliance Board of Directors  
Juvanee Estrada-Veras, MD, ECD Global Alliance Board of Directors  
Diane Schriner, Vice-President ECD Global Alliance Board of Directors  
Belinda Cobb, ECD Global Alliance  
Renita Page, ECD Global Alliance  
Kathleen Brewer, President ECD Global Alliance Board of Directors  
ECD Global Alliance Medical Advisory Board Members  
ECD Patient & Family Members who participated in the planning survey

### **Event Staff & Volunteers**

Ginny Brand	Julie Jones
Kathy Brewer	Lexi Jones
Belinda Cobb	Paul Page
Bill Cobb	Renita Page
Taylor Cobb	Diane Schriner
Dearbhaile Dooley	

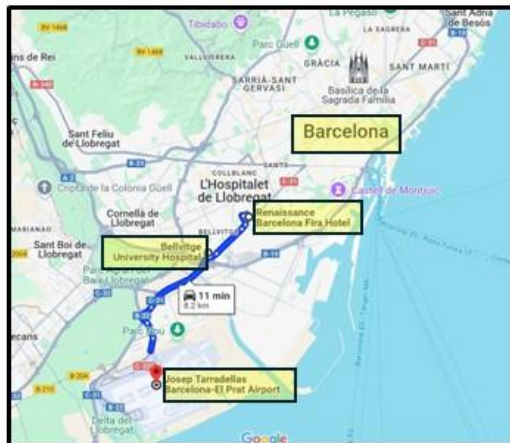
## Schedule at a Glance

Sunday, May 25, 2025   Pre-conference		
5:00 pm – 6:00 pm	Catholic Mass	Renaissance Barcelona Fira; Floor – 1; Room Fira Father Charles Balnaves
Monday, May 26, 2025   Patient & Family Gathering <i>Light breakfast, lunch, and dinner are provided.</i>		
8:00 am – 8:30 am	Registration & Light Breakfast	 Bellvitge University Hospital, Main Building, Street Level, Auditorium
8:30 am – 4:30 pm	Patient & Family Gathering Meeting	Bellvitge University Hospital, Main Building, Street Level, Auditorium
6:00 pm – 8:00 pm	ECD Global Alliance Celebration Dinner	 Renaissance Barcelona Fira; Floor – 1; Room Fira

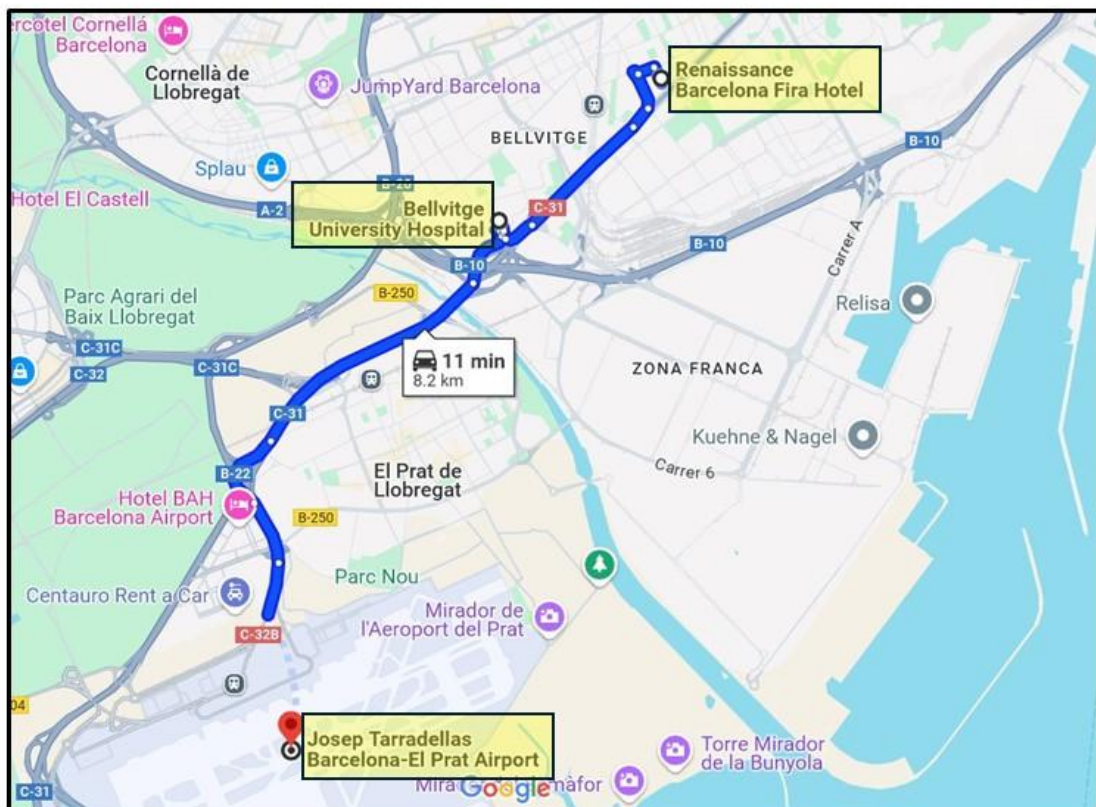
 Volunteers will be in the Renaissance Barcelona Fira hotel lobby from 7 – 7:45 am on May 26 to escort attendees to the hospital via Metro. The estimated travel time 10 minutes. The last escorted group will leave the hotel at 7:45 am. Those with mobility issues may want to consider a taxi or ride-sharing service.

## Conference Maps

### Barcelona Map



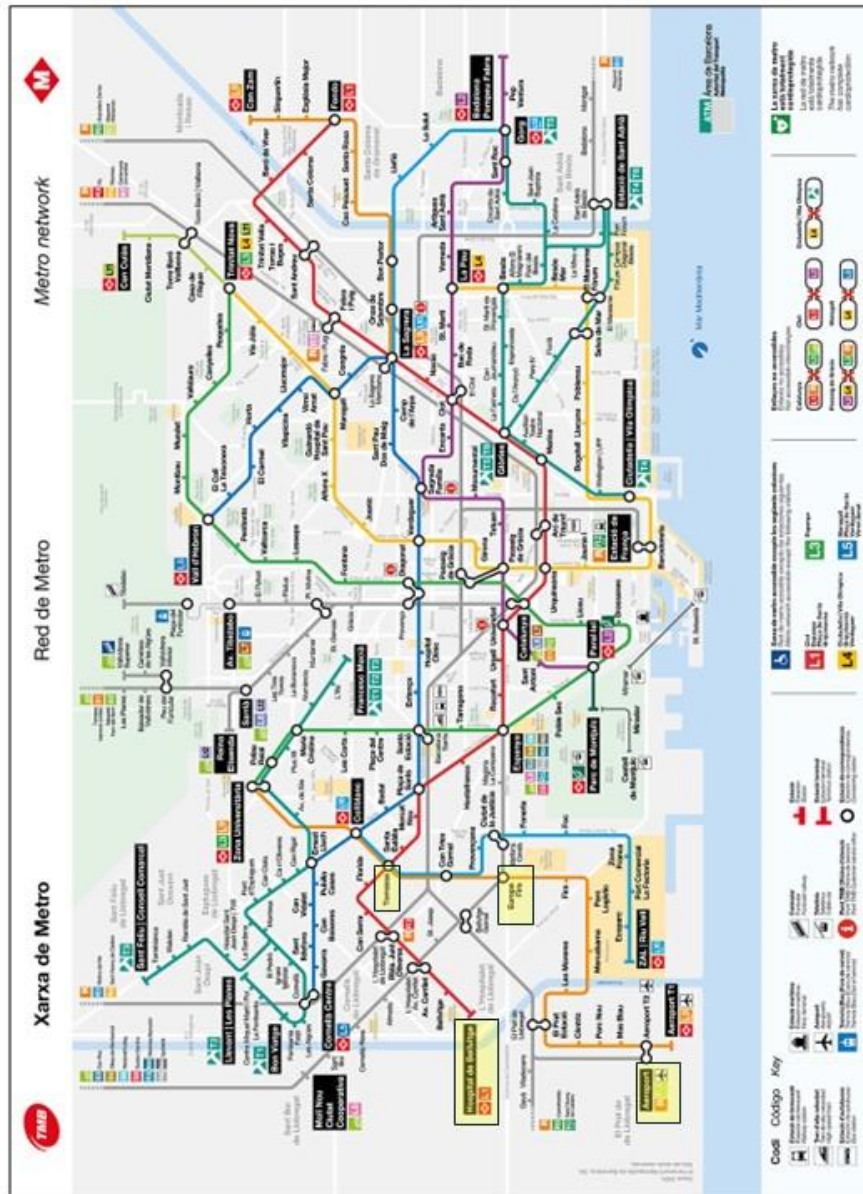
Barcelona Area



Barcelona Airport, Bellvitge Hospital, Renaissance Barcelona Fira Hotel



# Barcelona Metro



## DIRECTIONS

- Airport to Renaissance Hotel - Metro**  
Line 9 to Europa Fira Station
- Hotel to Bellvitge Hospital - Metro**  
Line 9S to Torrassa Station, then  
Line 1 to Hospital Bellvitge
- Hospital to Renaissance Hotel - Metro**  
Line 1 to Torrassa Station, then  
Line 9 to Europa Fira Station

## Also Available

- Uber/Cabify (fastest option)
- Buses

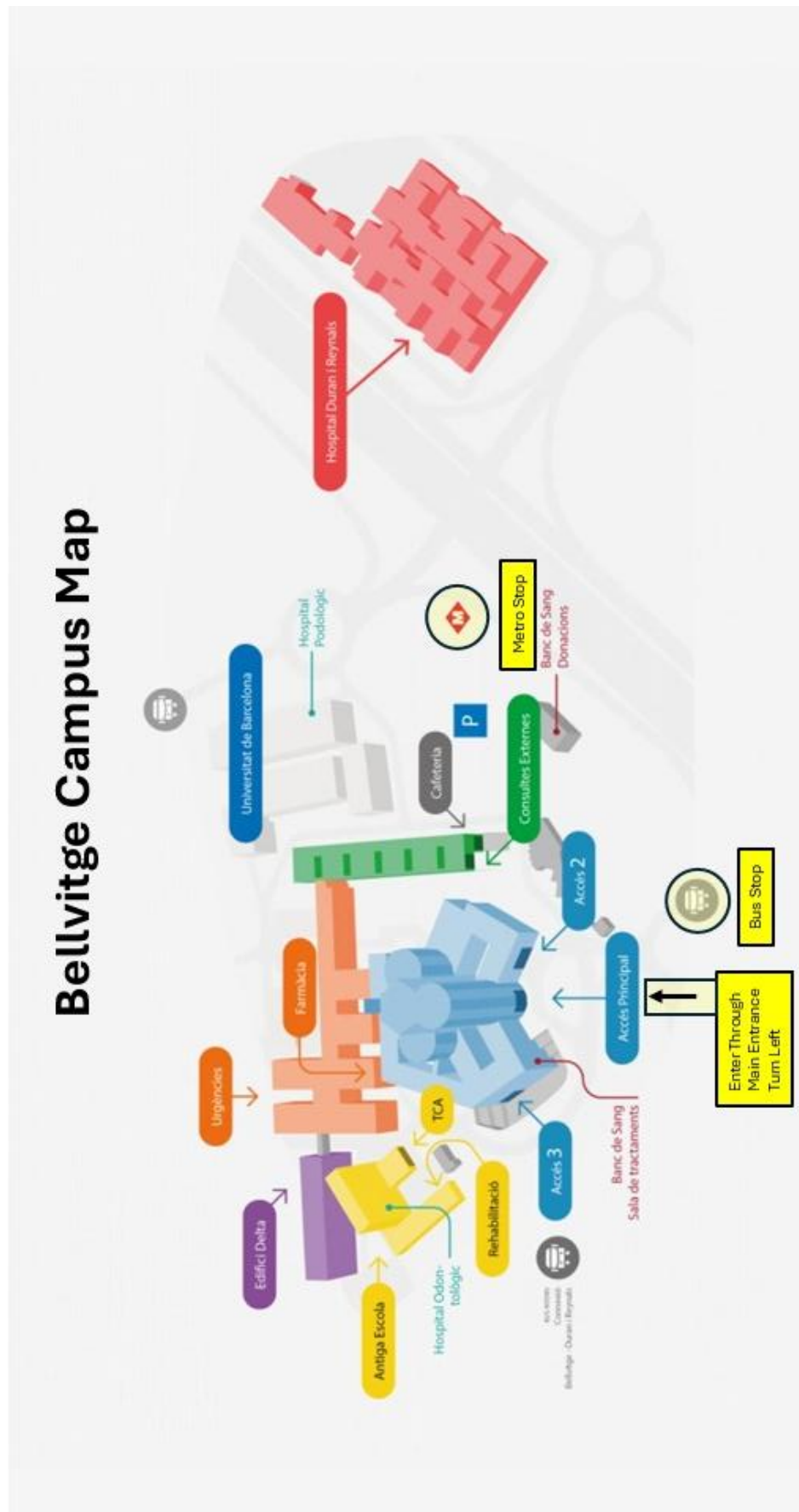
## Metro line runs:

- 5 am - midnight (M-F);
- 5 m - 2 am (S-S)



Line L1: Torrassa Station - Hospital

Line L9: Airport – Hotel – Torrassa Station





## Patient & Family Gathering Agenda

Time	Subject	Presenter
8:00 am	Registration & Light Breakfast	
8:30 am	Welcome to Bellvitge & The ECD Patient and Family Gathering by the Day's Emcee's	Xavier Solanich, MD, PhD Juvianee Estrada-Veras, MD
8:55 am	Overview of Adult Histiocytosis	Gaurav Goyal, MD
9:15 am	Biology of ECD & Current Basic Science Research	Oshrat HersHKovitz-Rokah, PhD
9:35 am	ECD Treatment Options (Current & on the horizon)	Julien Haroche, MD, PhD
9:55 am	ECD Treatment Side Effects	Pol Cleries Rovira, M. Pharm
10:15 am	Break	
10:35 am	ECD Clinical Manifestations	Jerome Razanamahery, MD
10:50 am	Brain/eye Involvement	Eli Diamond, MD
11:05 am	Kidney/Urology Involvement	Augusto Vaglio, MD, PhD
11:20 am	Other organ involvement	Jithma Abeykoon, MD
11:40 am	Group Picture	
Noon	Lunch	
1:00 pm	ECD & Concomitant Diseases	Francesco Pegoraro, MD
1:20 pm	ECD Expert Question and Answer Panel	Paul Hendrie, MD, PhD Matthew Collin, MD, PhD Eli Diamond, MD Julien Haroche, MD, PhD Xavier Solanich, MD, PhD Augusto Vaglio, MD, PhD
2:20 pm	Mental and Emotional Health for Patients & Caregivers	Laia Ferrer
2:35 pm	Pain & Fatigue Management	Montserrat Olmo Plaza, MD
2:50 pm	Break	
3:10 pm	Staying Active	Mariona Violán, MD
3:25 pm	Eating Healthy	Rafael Lopez Urdiales, MD
3:40 pm	ECD Survivorship Management: Question & Answer Panel	Laia Ferrer Montserrat Olmo Plaza, MD Mariona Violán, MD Rafael Lopez Urdiales, MD
4:00 pm	ECD Global Alliance Close and Attendee Evaluation	Diane Schrinier

## Session Details (am)

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

8:30 am – 8:55 am

**Welcome to the 10th Annual Erdheim-Chester Disease International Conference! Introductions to Barcelona, Bellvitge, and the ECD Global Alliance.**



**Xavier Solanich, MD, PhD**

Internal Medicine

Bellvitge University Hospital, Barcelona, Spain

ECD Care Center Lead Physician

[xsolanich@bellvitgehospital.cat](mailto:xsolanich@bellvitgehospital.cat)

Xavier Solanich, MD, PhD is an internal medicine physician at Bellvitge University Hospital (BUH), where he specializes in the treatment of patients with immunological disorders and rare diseases, including histiocytosis. In addition to his clinical work, he serves as a professor at the University of Barcelona and as principal investigator at the Bellvitge Biomedical Research Institute (IDIBELL). Dr. Solanich has contributed to numerous national and international research projects focused on autoimmune diseases, immunodeficiencies, and other rare disorders.

As the lead physician at the ECD Care Center at BUH, Dr. Solanich oversees the care of patients with ECD, a condition historically viewed as a multisystem inflammatory disorder. Recent breakthroughs in the genetics and immunology of the disease have revolutionized its understanding and treatment, prompting physicians to update and refine their protocols accordingly.

As host of the 10th ECDGA meeting he would like to help physicians stay on top of new research and treatment options and provide the opportunity for European patients and families to contact world experts on the disease.



**Juvianee Estrada-Veras, MD**

Geneticist

Washington, DC USA

ECDGA Board Member

ECDGA Medical Advisory Board Member

Dr. Estrada-Veras is the Head Clinical Geneticist for the MCC and MCCR Clinical Cancer Genetics Program at Walter Reed National Military Medical Center. He is specialty board certified in general pediatrics and Clinical Genetics and Medical Biochemical Genetics.

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 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.

**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.

## Overview of Adult Histiocytosis

8:55 am – 9:15 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 they once were?**



**Gaurav Goyal, MD**

Hematologist

University of Alabama at Birmingham, Birmingham, AL USA

ECD Care Center Lead Physician

ECDGA Medical Advisory Board Member

ggoyal@uabmc.edu

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, 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 Histiocytosis Working Group 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.)

---

---

---

---



## Biology of ECD & Current Basic Science Research

9:15 am – 9:35 am

**Understand the basic biology related to Erdheim-Chester Disease. What does it mean when discussing mutations, and why is this important? What do we still need to learn about ECD, and what current research is happening to help us learn more?**



### **Oshrat HersHKovitz-Rokah, PhD**

Hematology Scientist

Ariel University & Assuta Medical Center, Tel Aviv, Israel

ECD Care Center Scientist

ECDGA Medical Advisory Board Member

oshratr@assuta.co.il

+972-50-679-1939

Dr. Rokah is the head of the Molecular Research Lab at Assuta Medical Center, located in Tel Aviv, Israel. She holds a PhD from the Department of Genetics in the Faculty of Medicine at Tel Aviv University. Dr. Rokah's group were pioneers in studying microRNA expression in Erdheim-Chester Disease, contributing to a better understanding of the molecular mechanisms underlying the development of the disease and opening new avenues for therapeutic treatment. She works in close cooperation with clinical professionals, physicians, and scientists to target real clinical needs and deficiencies. As part of the dedicated clinic at Assuta Medical Center for histiocytic neoplasms, her lab is investigating the role of epigenetic mechanisms in these neoplasms.

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

---

---

---

---

---

---

---

---





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

9:35 am – 9:55 am

**Hear about the current treatment options available to help someone living with ECD. Which treatments are considered under different circumstances? How are treatments administered and for what length of time? How is dosage determined? What is the lowest level of treatment possible?**



**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

+33 1 42 17 80 37

Dr. Julien Haroche is a professor in internal medicine, at Pitié-Salpêtrière hospital, Paris, France. Since 2003, his main research field is Erdheim-Chester Disease (ECD) upon which he has acquired a world-renowned experience. His other research fields are the other histiocytoses, such as Langerhans cell histiocytosis, mixed histiocytoses (LCH & ECD) and Rosai-Dorfman Disease. He is also interested in vasculitis, systemic lupus and antiphospholipid syndrome. During the past 20 years, he has described most relevant clinical and radiological aspects and increased the awareness of ECD; he has shown that interferon  $\alpha$  was a first line efficient therapy. His team was the first to use targeted therapies in adult patients with histiocytoses in 2012. His group has treated more than 250 patients with targeted therapies.

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

---

---

---

---

---

---

---

---



## ECD Treatment Side Effects

9:55 am – 10:15 am

**Learn about the side effects of the most common ECD treatments. How can someone mitigate these side effects? What should be watched for, and what should be reported?**



**Pol Cleries Rovira, M. Pharm**

Pharmacist

Bellvitge University Hospital

ECD Care Center Pharmacist

pcleries@bellvitgehospital.cat

My name is Pol, and I am a pharmacist with a specialization in hospital pharmacy. Currently, I work in the outpatient pharmacy at Bellvitge Hospital in Barcelona. With over 10 years of experience in the pharmaceutical field, I spent the first half of my career in community pharmacy, addressing a wide range of general health concerns. Today, I focus on the management of patients with immune-mediated diseases, as well as those receiving care for solid organ transplants and pulmonary hypertension.

**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.



## ECD Clinical Manifestations

10:35 am – 10:50 am

**Learn about how ECD can affect someone in general. How likely is it that a particular organ is impacted by ECD? How is impact determined? What should someone living with ECD expect, and what symptoms should be reported to an ECD medical provider?**



**Jerome Razanamahery, MD**

Internal Medicine

Dijon University Hospital, Dijon, France

ECD Care Center Lead Physician

razanamahery.jerome@hotmail.fr

+33 066-030-7447

Jerome Razanamahery is an internal medicine practitioner in the Department of Internal Medicine and Clinical Immunology at Dijon University Hospital. He has led the multidisciplinary effort at Dijon University Hospital to study and treat histiocytic neoplasms. He has established a center of competence for histiocytic disorders recognized by the French Ministry of Health, where we offer comprehensive diagnostic and treatment services for individuals afflicted with histiocytic disorders. His ongoing research endeavors primarily revolve around the study of monocytes in hematological conditions, with a special emphasis on histiocytic disorders.

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

---

---

---

---

---

---

---

---

---

---





## Brain/eye Involvement

10:50 am – 11:05 am

**Understand the impact that ECD can have on the brain and eyes. What do we know today about brain and eye involvement? What are the symptoms to watch for? What research is being done to learn more and better address the impacts?**



**Eli Diamond, MD**

Neuro-oncologist

Memorial Sloan Kettering, New York, NY USA

ECD Care Center Lead Physician

ECDGA Medical Advisory Board Chair

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.

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

---

---

---

---

---



## Kidney/Urology Involvement

11:05 am – 11:20 am

**Hear about possible kidney and urinary system impacts related to ECD. What can be expected if someone living with ECD has kidney/urological involvement? What options are available to manage the impacts?**



**Augusto Vaglio, MD, PhD**

Nephrologist

AOU Meyer, Firenze, Italy

ECD Care Center Lead Physician

ECDGA Medical Advisory Board Member

[augusto.vaglio@virgilio.it](mailto:augusto.vaglio@virgilio.it)

+39 3200265325

Dr. Augusto Vaglio received his medical degree and his post-graduate education in nephrology from the University of Parma. He also did a post-doctoral fellowship in Immunology at Emory University in Atlanta, GA, USA. He is currently at the University of Florence, where he serves as the Director of the Post-graduate fellowship program in nephrology. In addition to his clinical work, he is actively engaged in research to learn more about ANCA-associated vasculitis, retroperitoneal fibrosis and IgG4-related disease, system lupus erythematosus, and Erdheim-Chester Disease. Dr. Vaglio serves on the ECD Global Alliance Medical Advisory Board.

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

---

---

---

---

---

---

---

---

---

---



## Other Organ Involvement

11:20 am – 11:40 am

**Learn more about other organs that can be involved with ECD. What regular testing is important and why? What specialists should be seen? What can be done if 'other' organ involvement is found? How likely is it for someone living with ECD to develop involvement in an additional organ after diagnosis?**



**Jithma Abeykoon, MD**

Hematologist

Mayo Clinic, Rochester, MN USA

ECD Care Center Clinician/Investigator

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.

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

---

---

---

---

---

---

---

---





## Session Details (pm)

### ECD & Concomitant Diseases

1:00 pm – 1:20 pm

**Gain knowledge about other blood disorders that some people living with ECD may be at higher risk for developing. What are these diseases? Does treatment change with the development of one of these additional disorders? What research is being done to understand the risk?**



**Francesco Pegoraro, MD**

Hematologist

Meyer Children's, Hospital IRCCS, Florence, Italy

ECD Care Center Clinician/Investigator

pegoraro.fr@gmail.com

+39 055 5662580

Dr. Francesco Pegoraro, 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 several scientific projects focused on histiocytosis and other hematologic conditions.

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 second-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.

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

---

---

---

---



## ECD Expert Question and Answer Panel

1:20 pm – 2:20 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 to ask your questions about ECD in general! [Please note, the panel is unable to provide any personal medical advice during this session.]**

### Moderator:



**Paul Hendrie, MD, PhD**

Hematologist

Fred Hutch, Seattle, WA USA

ECD Care Center Lead Physician

ECDGA Board Member

ECDGA Medical Advisory Board Member

phendrie@uw.edu

+1-206-606-6366

Dr. Paul 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 the 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.

### Panel Members:



**Matthew Collin, MD, PhD**

Hematologist

Newcastle upon Tyne Hospital, Newcastle upon Tyne, England

ECD Care Center Lead Physician

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. Dr. Collin splits his time between clinical duties and research activities, always searching for ways to better help patients.

Panel Members (continued):



**Eli Diamond, MD**  
Neuro-oncologist  
Memorial Sloan Kettering, New York, NY USA  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Chair  
(Bio included in earlier session writeup)



**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  
+33 1 42 17 80 37  
(Bio included in earlier session writeup)



**Xavier Solanich, MD, PhD**  
Internal Medicine  
Bellvitge University Hospital, Barcelona, Spain  
ECD Care Center Lead Physician  
(Bio included in earlier session writeup)



**Augusto Vaglio, MD, PhD**  
Nephrologist  
AOU Meyer, Firenze, Italy  
ECD Care Center Lead Physician  
ECDGA Medical Advisory Board Member  
augusto.vaglio@virgilio.it  
+39 3200265325  
(Bio included in earlier session writeup)

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

---

---

---





## Mental and Emotional Health for Patients & Caregivers

2:20 pm – 2:35 pm

**Hear how emotional support groups are important for patients and their families to feel supported and help alleviate the feeling of being alone. What emotional processes do patients and family members experience when dealing with a complex disease? What actions can be taken to support mental health?**



**Laia Ferrer**

Clinical Psychologist- Psychometricist  
OR Asociación  
laia.psicometri@gmail.com

For five years I have worked to help create an Emotional Support Plan for Spanish-speaking patients and their family members living with ECD and other histiocytic disorders. We have invested in mental and emotional health, offering support and care to pediatric and adult patients and their families.

**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.





## Pain & Fatigue Management

2:35 pm – 2:50 pm

**Learn about ways for those living with ECD to address pain and fatigue. What strategies can be used to manage pain and fatigue? How to talk with your doctor about your pain and fatigue?**



**Montserrat Olmo Plaza, MD**

## Palliative care

ICO (Oncologic Catalan Institute)

L'Hospitalet de Llobregat, Barcelona, Spain

molmo@iconcologia.net

Dr. Olmo is an internal medicine specialist with a Master in palliative care. She has worked for 8 years with HIV-AIDS patients and for the last 15 years has been dedicated to Palliative Care in different settings (Hospital, Hospice, Home care).

Since 2016, she has worked as a palliative care unit staff member at the Catalan Institute of Oncology, attending to outpatients and hospitalized patients.

Dr. Olmo has contributed to medical journal publications and Congress presentations mainly related to patients' symptomatic improvement.

**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.



## Staying Active

3:10 pm – 3:25 pm

**Hear from a leading expert in exercise. Why is exercise important for a patient? Why is it important for a caregiver? What kind of exercise is recommended for someone living with ECD? How can exercise be made fun? What should be considered regarding safety?**



**Mariona Violán, MD**

Professor of Physical Education and Sports Sciences Degree  
INEFC UB Campus, Barcelona  
Sports Departments. Generalitat of Catalonia  
Catalan Society of Sports Medicine

Dr. Mariona Violán is a physician and specialist in Sports Medicine based in Barcelona, Spain. She earned her medical degree and specialization in Sports Medicine from Barcelona University.

As the Coordinator of Health and Physical Activity Promotion Programs at the Sports Department of the Generalitat de Catalunya, Dr. Violán leads initiatives promoting exercise for public health. She is also an Associate Professor at the Faculty of Physical Activity and Sports Sciences (INEFC), Barcelona University, where she educates future professionals in sports medicine.

In addition to her academic and public health roles, Dr. Violán serves as President of the Societat Catalana de Medicina de l'Esport, contributing to advancements in sports medicine and health promotion in Catalonia.

Her leadership in research, education, and policy development continues to enhance the role of physical activity in healthcare, improving public health outcomes.

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

---

---

---

---

---



## Eating Healthy

3:25 pm – 3:40 pm

**Understand what foods can help you feel your best. Are there any foods that will provide energy? Should someone living with ECD follow a general healthy diet or is there something specific that should be included/excluded from the diet? Does that change based on treatments?**



**Rafael Lopez Urdiales, MD**

Endocrinologist

Bellvitge University Hospital, Barcelona, Spain

ECD Care Center Clinician

rafaellopez@bellvitgehospital.cat

Dr. R. López Urdiales is an accomplished endocrinologist specialized in Nutrition, with 20 years of experience at Bellvitge University Hospital. After completing medical studies at the prestigious universities of Granada (Spain) and Padova (Italy), he pursued specialization in Endocrinology and Nutrition at Bellvitge University Hospital. He is a firm believer in the fundamental principle that access to medical nutrition is a basic human right. Dr. R. López Urdiales expertise and passion for nutritional care have made him a valuable asset in managing the nutritional needs of patients with complex conditions. As an invited speaker at this international Erdheim-Chester Disease convention, Dr. R. López Urdiales looks forward to sharing his insights and contributing to the ongoing dialogue on nutritional management in general health and in rare diseases.

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

---

---

---

---

---

---

---

---

---

---



## ECD Survivorship Management: Question & Answer Panel

3:40 pm – 4:00 pm

**Ask your questions related to mental health, pain and fatigue, staying active, and eating healthy. Because these subjects can all be interrelated, asking a question about one, might bring comments from other panel members about 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.**



**Laia Ferrer**

Clinical Psychologist- Psychomotricist

OR Asociación

laia.psicomotri@gmail.com

(Bio included in earlier session writeup)



**Montserrat Olmo Plaza, MD**

Palliative care

Oncologic Catalan Institute

L' Hospitalet de Llobregat, Barcelona, Spain

molmo@iconcologia.net

(Bio included in earlier session writeup)



**Mariona Violán, MD**

Professor of Physical Education and Sports Sciences Degree

INEFC UB Campus, Barcelona

Sports Departments. Generalitat of Catalonia

Catalan Society of Sports Medicine

(Bio included in earlier session writeup)



**Rafael Lopez Urdiales, MD**

Endocrinologist

Bellvitge University Hospital, Barcelona, Spain

ECD Care Center Clinician

rafaellopez@bellvitgehospital.cat

(Bio included in earlier session writeup)



**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.

## ECD Global Alliance Close and Attendee Evaluation

4:00 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.**



**Diane Schriner**

ECDGA Board Vice-President

Diane.Schriner@Erdheim-Chester.org

Diane graduated from Sienna Heights University in 2003 with a Bachelor of Business Administration, Accounting Major. Diane is currently employed at LECO Corporation in St. Joseph Michigan as a Senior Accountant and as an Executive Assistant to the President. She has a 32-year-old son named Denzil and a 12-year-old granddaughter named Magnolia. She lives in Michigan with her husband, Scott, who was diagnosed with ECD in 2016. In her free time, Diane enjoys playing Texas Hold-Em Poker, spending time with her husband and her family, traveling, and spoiling her granddaughter.

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

[illegible]



## **ECD Patient & Family Gathering Evaluation Survey**

The ECD Global Alliance wants to know what you thought of the meeting. Your input will help us to serve you better in the future. Please take this online, multi-lingual survey. Thank you!



---

## **ECD Global Alliance Resources**



ECD Global Alliance Website



Join the ECD Global Alliance



Download ECD Brochures



Find ECD Care Centers



Support the ECDGA