

# HISTIO *Patient and Family* SUMMIT

## MEETING PROGRAM



**HILTON MOTIF, SEATTLE, WA  
SEPTEMBER 26-27, 2025**

## SPONSORS

The Histiocytosis Association would like to thank our generous sponsors for the Histo Patient and Family Summit. Without their support, this meeting would not be possible.



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# WELCOME

## Welcome to the Histo Patient and Family Summit

The Histiocytosis Association is honored and excited to welcome you to Seattle - *whether you are in-person or joining us online* - for this unique and meaningful gathering. This Summit is a rare opportunity to bring together patients, families, and some of the world's leading experts in histiocytic disorders - all in one place, united by a shared purpose.

Over the next two days, we hope you'll find valuable educational opportunities, but also something just as important: the chance to connect. Whether it's with others walking a similar path or with professionals who have dedicated their lives to understanding and treating histio, this is a space for learning, support, and community.

We are deeply grateful to our incredible speakers, who have generously volunteered their time and expertise. These physicians, scientists, and experts are not only leaders in their fields - they are compassionate advocates whose commitment to helping patients and families inspires us all. Your presence here means the world to us - thank you for your kind hearts and unwavering commitment.

A heartfelt thank you as well to our sponsors and partners. Your generous support makes this Summit possible. We encourage all attendees to visit their booths and learn more about the important work being done to support the histio community.

We hope these days will leave you informed, inspired, and most of all, connected. May your time here be truly life-changing.

With gratitude,  
The Histiocytosis Association Team

## Histiocytosis Association Team



Jen Silvers  
*Executive Director*



Kristen Nesensohn  
*Director of Community Relations  
and Fundraising*



Danielle Hellick  
*Chief Financial Officer*



Kathy Wisiniewski  
*Histiocyte Society Secretariat*



Peter Yanefski  
*Strategic Communications  
Associate*



Erica Dyer  
*Database Coordinator*



Melinda Atnip  
*Outreach Program  
Coordinator*



Allegra McFadden  
*Fundraising Events  
Coordinator*

# A RARE COMMUNITY

The Histiocytosis Association is a global nonprofit organization, based in Pitman New Jersey, that is dedicated to addressing the unique needs of patients, families, and physicians impacted by histiocytic disorders. Founded in 1986, the Association provides educational and emotional support, raises awareness, and funds research leading to advancements in treatment and cures.

A wide range of resources is easily accessible through the Histiocytosis Association's website, including an interactive physician directory, educational videos and webinars, clinical trial and registry information, and opportunities for peer support. The Association is always available to help - whether by phone or email - to ensure that every patient and family receives the support and guidance they need.



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## BOARD OF TRUSTEES

Want to learn more about the dedicated individuals guiding our mission?

Meet the Histiocytosis Association's Board of Trustees and discover the passion and expertise they bring to supporting patients, families, and research. You can learn more about them [here](#).



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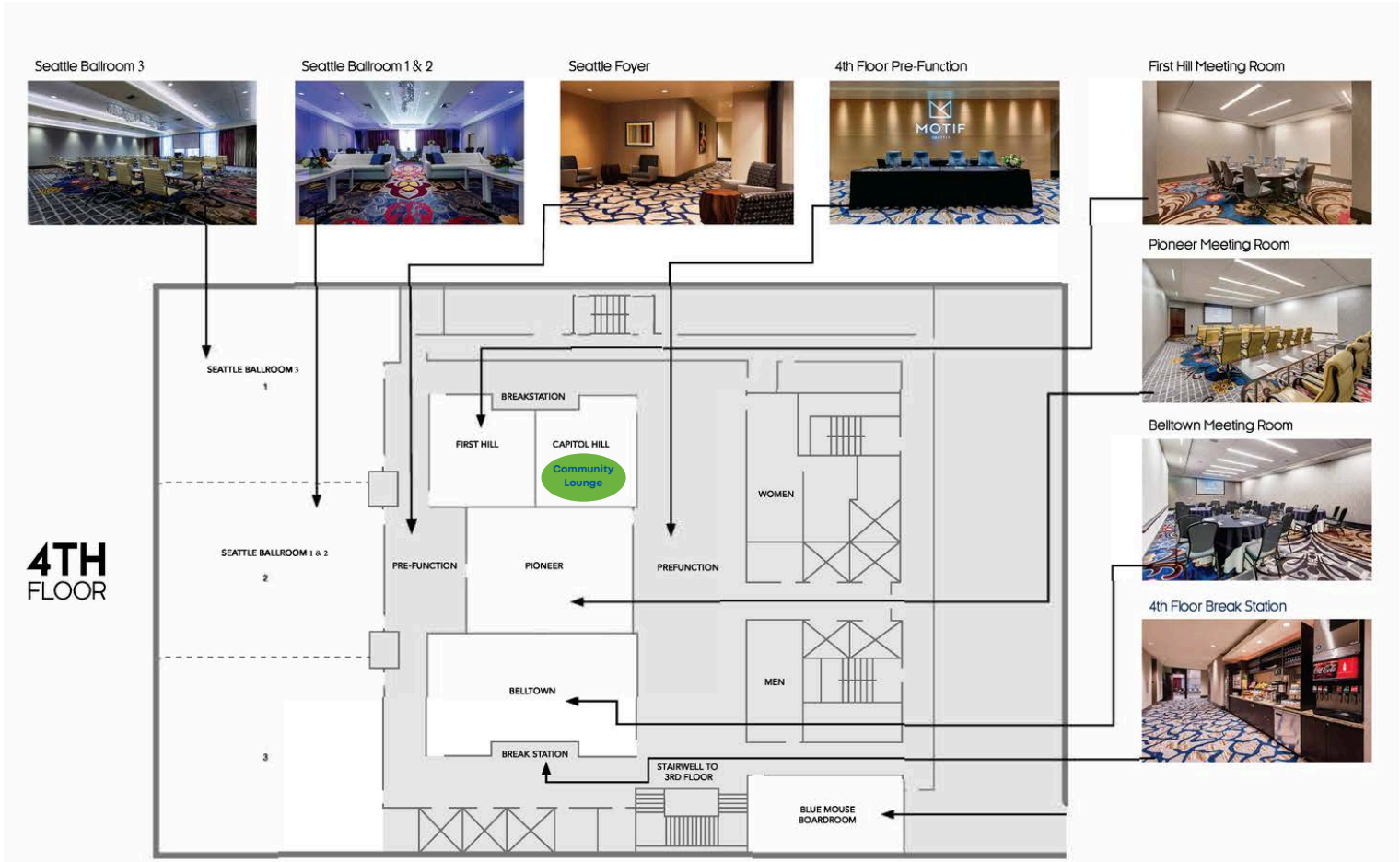
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## SUMMIT MEETING ROOMS

All session rooms are located on the 4<sup>th</sup> floor. Below is a map of the meeting room layout to help you navigate the space. If you need any assistance, staff and volunteers will be available on-site to help guide you.



\*Restrooms are located just off the 4<sup>th</sup> floor Pre-Function foyer.

### 👏 Visit Our Sponsors and Partners (4<sup>th</sup> Floor Pre-Function Foyer)

We are deeply grateful to our Summit sponsors and partners - without their generosity and support, this event and many of our critical programs and resources would not be possible.

Please take a moment during the Summit to stop by their expo booths (*in-person and online*), say hello, and learn more about how they are helping to make a difference in the Histo Community.

## AT-A-GLANCE AGENDA

Full session descriptions begin on page 8 and include details on topics and speakers.

### Friday, September 26

8:00 - 9:00	Registration Check-In .....	4th Floor Pre-Function
8:00 - 9:00	Breakfast .....	Seattle 3
9:00 - 9:30	Welcome Remarks .....	Seattle 1 & 2
	Keynote: Ana Valdez, Histiocytosis Warrior/Ambassador	
9:30 - 10:10	The Hidden World of Histiocytosis.....	Seattle 1 & 2
10:10 - 10:30	<b>Break/Breakout Transition</b> .....	
		Seattle Foyer
10:30 - 11:00	JXG and RDD .....	Capitol Hill
10:30 - 12:00	Dousing the flames (HLH) .....	Belltown
	Personalizing HLH care	
	HLH: Q & A	
10:30 - 12:00	Do we need a biopsy(LCH).....	Seattle 1 & 2
	Moving Forward: Managing the Lasting Impact of LCH	
	Finding Clues, Finding Cures (LCH)	
	LCH: Q & A	
11:00 - 11:30	Demystifying Erdheim-Chester Disease .....	Pioneer
12:00 - 12:30	Finding Strength in Community .....	Seattle 1 & 2
12:00 - 1:00	Closed Session (Sobi).....	Belltown
12:30 - 1:15	<b>Networking Lunch</b> .....	
		Seattle 3
1:25 - 1:50	What is the Histiocyte Society.....	Seattle 1 & 2
1:25 - 1:50	Pituitary dysfunction(AVP-D/DI) .....	Belltown
1:50 - 2:20	Histiocytosis: Cancer? Disorder? Or Both? .....	Seattle 1 & 2
1:50 - 2:50	 Rare & Resilient: Tools & Strategies.....	Pioneer
	to Cultivate Hope, Community, and Well-Being <i>(For Caregivers)</i>	
1:50 - 2:50	Living with Uncertainty:.....	Capitol Hill
	Coping with Your New Normal <i>(For Patients)</i>	
2:20 - 2:50	Living with Long-Term Effects and Survivorship Care in Pediatric Patients .....	Seattle 1 & 2
2:50 - 3:00	<b>Break</b>	
3:00 - 3:50	Tools to Thrive .....	Seattle 1 & 2
	Mindful Movement, Acupressure, and Health-Promoting Foundations	
3:00 - 4:00	Closed Session (Sobi).....	Belltown
3:50 - 4:00	Day One Closing Remarks.....	Seattle 1 & 2
5:00 - 7:00	 .....	4th Floor Pre-Function
	Hosted by the Histiocytosis Ambassadors	

## AT-A-GLANCE AGENDA

### Saturday, September 27



7:00 - 7:00	Blue Ribbon Run/Walk	
8:00 - 9:00	Registration Check-In	4th Floor Pre-Function
8:00 - 9:00	Breakfast	Seattle 3
9:00 - 9:15	Keynote: Molly Zangrilli, Caregiver/Ambassador	Seattle 1 & 2
9:15 - 10:00	From Beginnings to Breakthroughs Historical perspective on the early days How Hope Gets Funded: The Grant Process Uncovered	Seattle 1 & 2
10:00 - 10:30	Living Beyond Histiocytosis: Understanding Survivorship and Long-Term Health	Seattle 1 & 2
10:30 - 10:45	<b>Break/Breakout Transition</b>	Seattle Foyer
10:45 - 11:45	How Global Efforts Are Fueling Progress	Seattle 1 & 2
10:45 - 11:45	A Whirlwind Tour of HLH: From Discovery to What's Next	Belltown
11:45 - 12:45	Caring for Your Loved One While Caring for Yourself <i>(For Caregivers)</i>	Seattle 1 & 2
11:45 - 12:15	Let's Discuss AVP-D (DI) and its Current and Future Treatments	First Hill
12:15 - 12:45	ECD/RDD/LCH Similarities and Differences	Capitol Hill
12:45 - 1:30	<b>Networking Lunch</b>	Seattle 3
1:30 - 2:00	What Patients Are Telling Us: Insights into Life with Histiocytosis	Seattle 1 & 2
2:00 - 2:30	What happens when LCH cells collect in the brain?	Seattle 1 & 2
2:00 - 2:30	Secondary HLH, MAS, and cytokine storm: what it all means	Capitol Hill
2:00 - 2:30	 Focusing on the Eyes: How Histiocytosis and its Treatments May Impact the Eyes and Vision	First Hill
2:30 - 4:00	Hearing what Matters Most: A Fireside Chat Passion to Purpose: Getting Involved and Community Perspective  Closing Remarks	Seattle 1 & 2
5:00 - ???	Optional Excursion: Mariners vs. Dodgers Game *Pre-purchased ticket holders	Motif Lobby

**Buses depart at 5:15**

## SESSION DESCRIPTIONS

Our Summit sessions are designed to educate, empower, and connect. Over the course of the event, you'll hear from inspiring speakers - including leading histio experts, cutting-edge researchers, and individuals personally affected by histiocytic disorders. Each session will dive into a wide range of important topics, covering all forms of histiocytosis with in-depth explanations and updates on the latest advancements in care and research.

From disease-specific education and interactive workshops to advocacy tools and personal stories, there's something for everyone—whether you're newly diagnosed, a longtime caregiver, or simply looking to better understand this complex group of disorders.

### Day One: Friday, September 26

9:30 am - 10:10 am - Seattle 1 & 2

#### **The Hidden World of Histiocytosis-A Peek into the Pathology Lab**

Jennifer Picarsic, MD and Aishwarya Ravindran, MD

The pathology report is the roadmap your doctors use to guide treatment, and understanding what it means can make a big difference. In this session, we'll walk through how histiocytosis is diagnosed under the microscope, what details appear in your report, and why a second opinion with expert pathologists is often pivotal to avoid near misses and ensure the most accurate diagnosis.

10:30 am - 10:50 am - Seattle 1 & 2

#### **Do we need a biopsy in all cases to confirm a histiocytosis diagnosis?**

Astrid Van Halteren, PhD

This talk summarizes how small changes in the genome (mutations) of blood-cell-producing stem cells can lead to the development of histiocytosis. It also highlights how insights from blood analysis can be applied to assess disease activity before and treatment initiation.

10:30 am - 11:00 am - First Hill

#### **JXG and RDD: Symptoms, Treatments and Future Perspectives**

Oussama Abia, MD

This session will review the different clinical forms of juvenile xanthogranuloma (JXG) and Rosai-Dorfman disease (RDD), with emphasis on their distinguishing features. It will also explore diverse treatment strategies, including the potential benefits and challenges of emerging targeted therapies for JXG and RDD.

10:30 am - 11:00 am - Belltown

#### **Dousing the flames: Inhibition of cytokines and cytokine signaling to improve the outcomes for patients with HLH**

Kim Nichols, MD

Dr. Nichols will discuss the biologic mechanisms that drive hemophagocytic lymphohistiocytosis (HLH), with a focus on cytokines – the chemicals secreted by various cells of the body that recruit and activate the immune system. She will also talk about how new drugs that target specific cytokines can be used to treat children and adults with HLH.

## Day One: Friday, September 26

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10:50 am - 11:10 am - Seattle 1 & 2

### **Moving Forward: Managing the Lasting Impact of LCH**

Vasanta Nanduri, MD

Living with LCH doesn't always end when treatment does. This talk will cover the common long-term effects people may face, along with tips and resources to help manage them and support a healthy, full life moving forward.

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11:00 am - 11:30 am - Pioneer

### **Demystifying Erdheim-Chester Disease**

Paul Hendrie, MD, PhD

The objectives of this talk are (1) provide an overview of the presenting symptoms and physical, laboratory and radiographic findings that suggest a diagnosis of Erdheim-Chester disease (ECD), (2) explain the pathology and mutation studies that confirm the diagnosis of ECD, and (3) discuss the rationale for the treatment of ECD.

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11:00 am - 11:30 am - Belltown

### **Personalizing HLH care: Using new tools to shed light on HLH pathogenesis to improve patient outcomes**

Joseph Rocco, MD

Dr. Rocco will discuss how multiple contributing factors can lead to hemophagocytic lymphohistiocytosis making the clinical evaluation and treatment complex. He will go over new tools including novel biomarkers and translational studies that are helping us identify different forms of HLH which may respond to targeted, personalized treatments to improve clinical outcomes for all those with HLH.

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11:10 am - 11:30 am - Seattle 1 & 2

### **Finding Clues, Finding Cures: How Blood Tests and Clinical Trials Guide LCH Care**

Olive Eckstein, MD

This presentation will explain how blood tests provide valuable clues about LCH and highlight the role of clinical trials in developing improved treatments. Families will gain a clearer understanding of current care and the promise that ongoing research holds for the future.

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11:30 am - 12:00 pm - Belltown

### **HLH: Q & A**

Kim Nichols, MD and Joseph Rocco, MD

Following their presentations on hemophagocytic lymphohistiocytosis (HLH), Dr. Kim Nichols and Dr. Joe Rocco will come together for an open question-and-answer session. This is an opportunity for patients, families, and community members to ask questions, hear expert perspectives, and gain a deeper understanding of HLH—from diagnosis and treatment approaches to ongoing research and future directions in care.

## Day One: Friday, September 26

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11:30 am - 12:00 pm - Seattle 1 & 2

### **LCH: Q & A**

Astrid van Halteren, PhD; Vasanta Nanduri, MD; Olive Eckstein, MD

In this interactive session, Dr. Van Halteren and Dr. Nanduri will address important clinical questions around histiocytosis. Discussion will include when a biopsy is needed to confirm a diagnosis, long-term effects that may arise after LCH treatment, and the role of clinical trials in advancing care. Attendees will have the chance to ask questions directly and learn from the expertise of two leading physicians in the field.

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12:00 pm - 12:30 pm - Seattle 1 & 2

### **Finding Strength in Community: The Power of Peer Support**

Doris Dahdouh, MSW, LSW

In this session, we'll explore the definition and importance of peer support groups, and how connecting with others who share similar experiences can help ease the shock of diagnosis, navigate grief, and adjust to a "new normal." Attendees will learn about the value of being heard and supported, as well as resources and options for finding supportive communities.

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1:25 pm - 1:50 pm - Seattle 1 & 2

### **What is the Histiocyte Society? Everything you will want to know....**

Panel: Kim Nichols, MD; Vasanta Nanduri, MD; Lauren Meyer, MD, PhD; Moderator: Kathy Wisniewski

The Histiocyte Society is a global nonprofit organization of more than 200 physicians and scientists dedicated to advancing knowledge and care for histiocytic disorders. This session will highlight who they are, how they work, and their impact—bringing together clinical and laboratory research to improve understanding, treatment, and outcomes for patients worldwide.

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1:25 pm - 1:50 pm - Belltown

### **Pituitary dysfunction related to histiocytic disorders**

David Werny, MD

This presentation will highlight pituitary dysfunction that can occur with histiocytic disorders, with a particular focus on AVP deficiency (central diabetes insipidus).

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1:50 pm - 2:20 pm - Seattle 1 & 2

### **Histiocytosis: Cancer? Disorder? Or Both?**

Mark Fluchel, MD

This presentation explores the decades-old debate surrounding the question as to whether LCH and other histiocytic disorders are cancers or inflammatory disorders? We will discuss the origins of the debate, the arguments for and against it being considered a cancer, and the implications of having a designation as a "malignancy".

## Day One: Friday, September 26

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1:50 pm - 2:50 pm - Pioneer

### **Rare & Resilient: Tools & Strategies to Cultivate Hope, Community, and Well-Being (VIRTUAL PRESENTATION)**

Amanda Abrenillo-Oliveira, Give an Hour

Living with a rare disease or supporting someone who does touches every part of life, not only physical health. This session creates space to acknowledge the emotional realities of this journey, from grief and uncertainty to moments of resilience and connection. Together, we'll explore practical ways to care for our mental well-being, support one another with empathy, and build a community where hope and healing can grow.

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1:50 pm - 2:50 pm - First Hill

### **Living with Uncertainty: Coping with Your New Normal**

Doris Dahdouh, MSW, LSW

Patients will come together in a supportive space to discuss the emotional challenges of living with uncertainty after diagnosis. This session will provide tools and strategies for coping with frustration, discouragement, and limitations, while also offering ways to find grace and resilience when daily life feels difficult.

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2:20 pm - 2:50 pm - Seattle 1 & 2

### **Long-Term Effects and Survivorship Care in Pediatric Patients with Histiocytic Disorders**

Scott Baker, MD

This session will focus on issues that long-term survivors of histiocytic disorders may face as result of treatment side effects or conditions related to the disease itself. Surveillance for late effects and preventative strategies will also be discussed.

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3:00 pm - 3:50 pm - Seattle 1 & 2

### **Tools to Thrive: Mindful Movement, Acupressure, and Health-Promoting Foundations**

Blake Langley, ND

This session will include two movement activities (qigong and acupressure) in addition to practical takeaways for promoting well-being. Attendees will be invited to a seated or standing activity focused on intentional body movement and breath work, acupressure on select points commonly recommend to patients, and a brief lecture on key ways to promote a healthy diet and lifestyle.

## Day Two: Saturday, September 27

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9:15 am - 10:00 am - Seattle 1 & 2

### **From Beginnings to Breakthroughs**

#### **Historical perspective on the early days-formation and partnerships**

Stephan Ladisch, MD

Discover how the Histiocytosis Association began as a grassroots effort and grew into a global community. Learn how its partnership with the Histiocyte Society united patients, families, and researchers to advance care and find a cure.

#### **How Hope Gets Funded: The Grant Process Uncovered**

Eli Diamond, MD

Go behind the scenes of how hope turns into action. This session explores how the partnership between the Histiocytosis Association and the Histiocyte Society laid the foundation for funding impactful research. You'll learn how the grant process works—from proposal submission to review - and how it continues to support innovative science driving progress in histiocytic disorders.

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10:00 am - 10:30 am - Seattle 1 & 2

### **Living Beyond Histiocytosis: Understanding Survivorship and Long-Term Health**

Gaurav Goyal, MD

This presentation explores the journey of living with and beyond histiocytosis—a rare group of diseases that often go undiagnosed for years. You'll learn how advances in diagnosis and treatment have improved survival, but also how little we know about what comes after. Dr. Goyal highlights the invisible struggles many patients face—chronic pain, fatigue, emotional challenges, and the risk of other health conditions. You'll hear about a new research effort aimed at understanding these long-term effects and improving care for survivors. Whether you're a patient, caregiver, or family member, this talk is about acknowledging the challenges, sharing hope, and inviting you to be part of the journey toward answers.

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10:45 am - 11:45 am - Seattle 1 & 2

### **How Global Efforts Are Fueling Progress**

Fernando Gotz (CHiPs), Milen Minkov, MD, PhD (ECHO), Sara Hastings (NACHO);

Patient Advocacy Group representative(s)

In this session, we'll learn about inspiring initiatives from around the world that are helping shape a global movement for histio. From collaboration to innovation, these efforts are powering progress and bringing hope to patients and families everywhere.

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11:45 am - 12:45 pm - Belltown

### **A Whirlwind Tour of HLH: From Discovery to What's Next**

Michael Jordan, MD

This session will explore how our understanding of HLH has developed, the priorities shaping future research, and ways you can play a role in advancing knowledge. We'll look at the journey from early insights to today's progress—and how each of us can help move the field forward.

## Day Two: Saturday, September 27

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11:45 am - 12:45 pm - Seattle 1 & 2

### **Caring for Your Loved One While Caring for Yourself**

Doris Dahdouh, MSW, LSW

This session is dedicated to caregivers navigating the complex emotions and responsibilities that come with supporting someone with a histio diagnosis. We'll explore practical ways to balance appointments, daily routines, and emotional well-being, while also acknowledging the caregiver's own feelings, needs, and self-care.

11:45 am - 12:15 pm - First Hill

### **Let's Discuss AVP-D (DI) and its Current and Future Treatments (In-Person Only)**

Nadine McDonnell

Please come and share your experience and insights with AVP-D (DI).

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12:15 pm - 12:45 pm - First Hill

### **ECD/RDD/LCH - Similarities and Differences**

Ron Go, MD

This talk will review the clinical presentation of the three major adult histiocytic neoplasms, highlighting their distinguishing features and impact on patients. It will also discuss the indications, goals, and therapeutic approaches to treatment, offering insights into current strategies and considerations for optimal care.

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1:30 pm - 2:00 pm - Seattle 1 & 2

### **What Patients Are Telling Us: Insights into Life with Histiocytosis**

Eli Diamond, MD

This talk will highlight what has been learned from patient-reported outcomes (PROs) in histiocytosis, including findings from the MSK Registry and other PRO studies. It will explore symptoms, unmet needs, and quality of life, while shedding light on the challenges patients face and what truly matters to them in daily life.

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2:00 pm - 2:30 pm - Seattle 1 & 2

### **What happens when LCH cells collect in the brain?**

Kenneth McClain, MD, PhD

LCH cells circulating in the blood escape from blood vessels into the brain. These cells may cause masses (tumors), MRI changes in the cerebellum (or other parts), and in rare cases lead to symptoms (balance and speech problems or tremors). Having brain MRI changes is NOT neurodegeneration.

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2:00 pm - 2:30 pm - Capitol Hill **(VIRTUAL PRESENTATION)**

### **Focusing on the Eyes: How Histiocytosis and its Treatments May Impact the Eyes and Vision**

Jasmine Francis, MD

A patient-friendly look at the potential impact of histiocytosis and its therapies on vision, with guidance on prevention, symptoms, and care.

## Day Two: Saturday, September 27

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2:00 pm - 2:30 pm - First Hill

### **Secondary HLH, MAS, and cytokine storm: what it all means from the rheumatologist's perspective**

Ed Behrens, MD

Children can have what looks like primary HLH and yet not have any evidence that the typical genetic problems are present. This often happens when other immune or rheumatologic symptoms are involved and can go by many different and confusing names. The talk will explain what all the names and acronyms mean and how patients with these problems are both similar, yet importantly distinct from primary HLH.

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2:30 pm - 3:00 pm - Seattle 1 & 2

### **Hearing what Matters Most: a Fireside Chat with Executive Director, Jen Silvers**

Jen Silvers, Histiocytosis Association

This session is all about you - the patients, families, and community members at the heart of our mission. Join Executive Director Jen Silvers for an informal fireside chat focused on listening and learning from your experiences. What matters most to you? What do you need? What should we know? Come share your voice, your story, and your perspective as we continue building a stronger Histo Community - together.

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3:00 pm - 3:50 pm - Seattle 1 & 2

### **Passion to Purpose: Community Perspective**

- **How to Get Involved:** Melinda Atnip - Outreach Coordinator/Caregiver
- **Advocacy and Awareness:** Nate Milam - Histo Warrior/Ambassador
- **Fundraising: Mark and Robin Ross** - Caregivers/Ambassadors

Join us for Passion to Purpose: How to Get Involved, a closing session where three community members share how their personal histio journeys turned into opportunities to give back. You'll hear how small steps of involvement can grow into something bigger—creating connection, hope, and impact. Come be inspired and discover practical ways you too can get involved and make a difference.

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## SUMMIT SPEAKERS

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**OUSSAMA ABLA, MD** - *Hospital for Sick Children, Toronto, Canada*

**AMANDA ABRENILLO-OLIVEIRA** - **Give an Hour**

**SCOTT BAKER, MD** - *Fred Hutchinson Cancer Center, Seattle, WA*

**EDWARD BEHRENS, MD** - *Children's Hospital of Philadelphia, Philadelphia, PA*

**DORIS DAHDOUH, MSW, LSW** - *New York, NY*

**ELI DIAMOND, MD** - *Memorial Sloan Kettering, New York, NY*

**OLIVE ECKSTEIN, MD** - *Texas Children's Hospital, Houston, TX*

**MARK FLUCHEL, MD** - *Seattle Children's Hospital, Seattle, WA*

**RONALD GO, MD** - *Mayo Clinic, Rochester, MN*

**FERNANDO GOTZ** - *OR Asociacion, Barcelona, Spain*

**GAURAV GOYAL, MD** - *University of Alabama at Birmingham, Birmingham, AL*

**ASTRID VAN HALTEREN, PHD** - *Erasmus Medical Center, Rotterdam, The Netherlands*

**SARA HASTINGS** - *National Consortium for Histiocytosis, Memphis, TN*

**PAUL HENDRIE, MD, PHD** - *Fred Hutchinson Cancer Center, Seattle, WA*

**MICHAEL JORDAN, MD** - *Cincinnati Children's Hospital, Cincinnati, OH*

**STEPHAN LADISCH, MD** - *Children's National Hospital, Washington, DC*

**BLAKE LANGLEY, ND, LAC** - *Fred Hutchinson Cancer Center, Seattle, WA*

**KENNETH MCCLAIN, MD, PHD** - *Texas Children's Hospital, Houston, TX*

**MILEN MINKOV, MD, PHD** - *St. Anna Children's Hospital, Vienna, Austria*

**VASANTA NANDURI, MD** - *Watford General Hospital, Watford, UK*

**KIM NICHOLS, MD** - *St. Jude Children's Research Hospital, Memphis, TN*

**JENNIFER PICARSIC, MD** - *Children's Hospital of Pittsburgh, Pittsburgh, PA*

**AISHWARYA RAVINDRAN, MD** - *University of Alabama at Birmingham, Birmingham, AL*

**JOSEPH ROCCO, MD** - *National Institutes of Health (NIH), Bethesda, MD*

**DAVID WERNY, MD** - *Seattle Children's Hospital, Seattle, WA*

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## GET TO KNOW THE SPEAKERS

We asked our speakers a few questions to help you get to know them on a more personal level - what drew them to histio, what keeps them inspired, and a bit about who they are outside of their work. We hope these snapshots help you feel more connected to the amazing people behind the sessions.



**Oussama Abla, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I was intrigued by the mysterious biology of histiocytic disorders, and wanted to get involved in improving the cure rates and enhancing the quality of life of patients with histiocytosis.

**What's something your patients might be surprised to learn about you?**

Fun fact: I am not a handy man and don't even know how to hold a hammer; my wife does all the fixing around the house.

**If you weren't in medicine, what career do you think you'd have pursued?**

A culinary Chef.



**Amanda  
Abrenillo-Oliviera**

**What inspired you to get involved in this line of work?**

My education was in psychology and conflict management, so I've always been drawn to mental health and well-being. My volunteer work leading workshops for communities affected by violence and trauma was especially impactful, and I felt right at home when I found a place at Give an Hour to connect with people and help them find support to heal and grow.

**What's something people might be surprised to learn about you?**

I come from a rural town in the Northwest Georgia mountains, and attended a very small elementary school with multiple grades in each classroom and wood-burning stoves to heat the building. We explored science with hands-on experiments, utilized antique tools for history lessons, and spent recess in the woods behind our playground. It was such a unique experience, and I'm still connected to the friends I made all those years ago...

**If you weren't doing this work, what path or passion do you think you'd be pursuing instead?**

I would be writing books - sharing my own story to help others find hope has always been my dream!



**Scott Baker, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

One of the first patients that I took care of during my pediatric hematology/oncology fellowship was a baby with HLH. At that time, we knew almost nothing about the disease but I found it fascinating and challenging.

**What's something your patients might be surprised to learn about you?**

I am in the process of joining the US Coast Guard Auxiliary.

**If you weren't in medicine, what career do you think you'd have pursued?**

I was interested in art and architecture, and I was very close to majoring in architecture.



**Edward Behrens, MD**

**What inspired me to pursue treatment and research of the histiocytic diseases?**

I met my first patient with Macrophage Activation Syndrome as a pediatric rheumatology fellow. I was struck by how little we knew at the time what cause both primary and secondary HLH that I became inspired to pivot my research toward understanding more, and turning that knowledge into better care for those children suffering with these illnesses.

**What's something your patients might be surprised to learn about you?**

When I'm not nerding out about immunology, I'm playing the trombone or playing competitive Magic: The Gathering.

**If you weren't in medicine, what career do you think you'd have pursued?**

I would have been a pure mathematics researcher, likely in number theory/complex analysis.



**Doris  
Dahdouh, MSW, LSW**

**How has working with the Histic Community inspired you?**

I love this question! Working with the Histiocytosis Community has truly been one of the most unexpected and beautiful blessings in my life. The members are incredibly resilient and compassionate - despite everything they've endured or continue to face, they show up for one another with such love and support. Their strength has inspired me to be more mindful in all my interactions and to bring a therapeutic, compassionate presence to every conversation.

**What's something people might be surprised to learn about you?**

People are often surprised to learn that, although I've been engaged twice, I've never been married and don't have biological children. It's a unique part of my journey that has shaped how I relate to others with openness and empathy.

**If you weren't doing this work, what path or passion do you think you'd be pursuing instead?**

If I weren't doing this work, I imagine I'd be pursuing a career in computer science, technology, or programming. I've always been curious about how systems work behind the scenes and love the idea of combining creativity with problem-solving in the tech space.



**Eli Diamond, MD**

**What inspired you to work in the field of histiocytosis?**

When I was starting my training in brain tumors, I saw a patient with an undiagnosed neurologic problem who also had kidney problems and it reminded me of a discussion that I had heard years before about ECD, even though I had never seen an ECD case. We subsequently diagnosed that patient with ECD, and then two others in the next 6 months. And then I was hooked! When I started my faculty position I was already working on the BRAF trial and soon this was my passion.

**What is something your patients might be surprised to learn about you?**

Patients may not be surprised to know that I am a fitness fanatic! In addition, I am very interested in electronic music and nightlife.

**If you weren't in medicine, what career do you think you'd have pursued?**

Before medical school, I studied Comparative Religion as an undergraduate, and before college I did the first portion of school to be a rabbi. After college and before medical school, I did a graduate degree in history and philosophy of science. So, I think I would have pursued a different kind of academic career in the humanities. I am much happier this way!



Olive Eckstein, MD

**What inspired me to pursue treatment and research of the histiocytic diseases?**

I fell in love with histiocytosis because it combines immunology, oncology, and discovery science, and I enjoy the challenge of unraveling complex biology to find solutions. Becoming a parent to two adventurous boys over the years made the work even more personal and deepened my commitment to finding better treatments and real cures. There is nothing more rewarding than seeing children recover, leave the hospital, and go on to live full, happy lives. That is what motivates me every day.

**What's something your patients might be surprised to learn about you?**

Born and raised in the heart of NYC (yes, I had the accent and somehow lost it!). Monkey whisperer 🐒 ...my favorite histio consult was for the Houston zoo. Unapologetic Swiftie 🎵 and secret ear-wiggler 🦻. Halloween costume creator extraordinaire 🎃. I also served in AmeriCorps\*NCCC, where I learned teamwork, the power of service, and how to drive a 15-passenger van like a pro. When I'm not at the hospital, you'll find me cheering loudly at youth sports games (I advocate just as passionately from the stands as I do for my patients), hiking a new trail, designing logos and stickers like it's my side hustle, or teaching a blood-slime science class at school.

**If you weren't in medicine, what career do you think you'd have pursued?**

My path would still center on discovery and connection. I'd be a veterinarian, an environmental scientist out in the field, or a science teacher sparking curiosity in kids. When I retire one day, you might find me behind home plate as a Little League umpire 🏏



Mark Fluchel, MD

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I had an amazing teenage patient who became very ill with a histiocytic disorder when I was a fellow. She was even featured on Dateline's Medical Mysteries upon recovery. Her case piqued my interest in the field and led me to my first Histiocyte Society meeting. When I met the amazing and dedicated international group of professionals dedicated to the cause, I was hooked!

**What's something your patients might be surprised to learn about you?**

I write fiction in my free time, although not so much for others to read and certainly not good enough to quit my day job :)

**If you weren't in medicine, what career do you think you'd have pursued?**

I would be a mountain biking guide in Moab, Utah.



Jasmine Francis, MD

**What inspired you to pursue treatment and research of the histiocytic diseases?**

It's the patients themselves that have inspired me to work in the field of histiocytosis. Patients with histiocytosis are very unique, and honestly a joy to work with. They have often traveled a long and arduous medical path to finally land at their diagnosis; and are generally motivated and even passionate to seek out help and engage in treatment. The patients themselves are very important members of the care team and are the biggest motivator to rally against the disease.

**What's something your patients might be surprised to learn about you?**

I am a serial hobbyist and to name a few: fly-tying for fly fishing, finger-picking guitar, no-dig gardening, balayage, wood-burning pizza making, chocolate truffle creation, speaking Nepali etc. Currently my daughter and I are learning to tap-dance.

**If you weren't in medicine, what career do you think you'd have pursued?**

I would have been an inventor by day and a circuit training instructor (OTF, F45 etc) by night.



**Ron Go, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

Serendipity. No ECD patient in 13 years of community practice (2000-2013); 1 new ECD patient on my 3rd month at Mayo Clinic (July 2013); no adult hematologist specializing in histiocytosis. I took the opportunity to specialize in this rare disease. The rest is history.

**What's something your patients might be surprised to learn about you?**

"I am a man of no apparent talents – and as for hidden ones, I am still searching."

**If you weren't in medicine, what career do you think you'd have pursued?**

Astronomer; later found out I am more of a stargazer. Instead of a stethoscope, I now use a microscope. I now look at a different variety of "stars", including histiocytes.



**Fernando Gotz**

**What inspired you to get involved in this line of work?**

I first learned about the Histiocytosis Association 14 years ago, when I began searching for information after my son was diagnosed with multisystem LCH. The HA quickly became a key source of knowledge and support during those early, uncertain days. Years later, during the pandemic, I reached out to then-CEO Deanna Fournier to explore ways for our organization, OR Association, to collaborate with HA — a partnership that has grown stronger ever since.

**What's something people might be surprised to learn about you?**

People might be surprised to learn that everything I do in advocacy started because of my son. When he was diagnosed with histiocytosis, our lives changed completely. What began as a personal crisis became a lifelong mission - and I've since dedicated over a decade to supporting other families on similar journeys.

**If you weren't doing this work, what path or passion do you think you'd be pursuing instead?**

Travel, football, bbq's with family and friends.



**Gaurav Goyal, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I've always been drawn to rare and complex diseases—they challenge me to think deeply and creatively. During my fellowship, I met a patient with Erdheim-Chester disease who had spent nearly a decade searching for answers. She was relieved to finally meet someone familiar with her condition, and being able to help her was incredibly rewarding. That experience sparked my commitment to improving care and advancing research for adults with histiocytic disorders, a group that's often overlooked.

**What's something your patients might be surprised to learn about you?**

Exploring nature helps me recharge and reminds me of the bigger picture — plus, it's a great way to stay active and curious outside of work.

**If you weren't in medicine, what career do you think you'd have pursued?**

I think I'd be hosting a late-night talk show! I enjoy good conversation and making people laugh - so blending humor with storytelling would be a dream job.



**Sara Hastings**

**What inspired you to work in the field of histiocytosis?**

The histiocytosis community is such a resilient community full of passionate people and it's so easy to be inspired by the researchers and the patients and families!

**What's something your patients might be surprised to learn about you?**

I've just started playing tennis and now I spend a few days each week playing tennis with new friends! It's a great way to exercise and meet new people and I was able to attend Wimbledon this year!

**If you weren't in medicine, what career do you think you'd have pursued?**

I would have loved to be a florist! I love to arrange flowers and grow flowers to decorate my house.



**PAUL HENDRIE, MD, PHD**

*Fred Hutchinson Cancer Center  
Seattle, WA*

Dr. Hendrie is a board-certified hematologist at Fred Hutch and an associate professor of hematology and medicine at the University of Washington. His clinical and research focus spans both malignant and nonmalignant blood disorders, including leukemia, lymphoma, multiple myeloma, and myelodysplastic syndromes. He is particularly passionate about integrating cutting-edge research with compassionate, individualized patient care.

With a background in white blood cell development research, Dr. Hendrie brings a scientific, detective-like approach to his consultations - thoroughly investigating symptoms to arrive at a clear diagnosis and care plan. He works with a broad spectrum of patients, including those participating in clinical trials, and is dedicated to ensuring they feel informed, supported, and empowered throughout their treatment journey.

His areas of expertise include acute and chronic leukemias, myeloproliferative neoplasms, bone marrow failure syndromes, and rare hematologic conditions such as mastocytosis and Langerhans cell histiocytosis.



**Michael Jordan, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I remember when the first paper came out describing a genetic cause of HLH - I heard about it because one of my favorite professors in medical school was the senior author. This was very intriguing for me because I had seen a patient with familial HLH early in my training and was shocked about how poor the prognosis was and how no one understood how such a strange process could ever develop in a child. I immediately imagined how HLH could develop and have spent the last 3 decades exploring this idea, learning from and treating patients.

**What's something your patients might be surprised to learn about you?**

I took up bee keeping about 5 years ago and it is one of my favorite past times (along with gardening and related culinary hobbies).

**If you weren't in medicine, what career do you think you'd have pursued?**

Hard to say - I knew since elementary school that I would either be a scientist or a physician - if not one then the other. I feel fortunate to have both vocations. I think plan B in second grade (I actually had one) was to join the army, though I never pursued that one.



**Stephan Ladisch, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

During my fellowship at NCI in 1975-78, caring for a child with a tragic outcome and similarly tragic extended family with multiple early infant mortality, that led us to study and define what is now called primary HLH as an immunodeficiency disease. That led to my curiosity about histiocytosis in general.

**What do you enjoy doing when you're not working?**

Mountain climbing and longer distance biking



**Blake Langley, ND**

**What inspired you to get involved in this line of work?**

I was drawn to naturopathic medicine and acupuncture after living in an area of the country with very limited access to integrative and alternative approaches to wellness. I first worked in integrative oncology as a student acupuncturist at the Providence Medical Center and Immune Enhancement Project (IEP) in Portland, OR. While acupuncture was given during infusion-based therapies at Providence, IEP is a nonprofit that used a concierge model of care to provide acupuncture and massage services in addition to naturopathic medical consultations. After going into clinical research after graduation, the initial postdoc opportunity at Fred Hutch was the perfect harmony of each experience!

**What's something people might be surprised to learn about you?**

Surprising fact: the place that I really thrive most is in some kind of desert. My escapes from the Pacific Northwest tend to be the eastern sides of Oregon and Washington, California, and Nevada.

**If you weren't doing this work, what path or passion do you think you'd be pursuing instead?**

If I weren't in healthcare (broadly), I would likely return to some of the work I was doing in college. I previously was a professional organizer and worked to design and install shelving units through the Container Store. I'm a self-proclaimed maximalist (get the most out of the space you have without it seeming cluttered and disorganized) 😊



**Kenneth McClain, MD, PhD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

In my fellowship at the University of Minnesota I was learning how to read bone marrow aspirate and biopsy slides as part of a hematopathology rotation. I did a bone marrow test on a kidney transplant patient who had a virus infection that caused fevers, low blood counts, and liver problems. These were the initial signs of the hemophagocytic syndrome (HLH). When I looked at the bone marrow slides I was amazed by the large number of histiocytes (macrophages) eating other blood cells-hemophagocytosis. It was so dramatic that it really caught my attention. My professors were just starting to understand the connection between viruses and HLH so it was exciting to be at a hospital where some of the early work on HLH was taking place.

**What's something your patients might be surprised to learn about you?**

"In 2006 5 other guys and I rode fixed gear bikes from Davis, CA to Boston, MA in an event sponsored by the Histiocytosis Association known as the Big Fix to raise money for histiocytosis research. We covered 3,500 miles in 27 days (one rest day), climbing 130,000 feet of elevation over 7 mountain ranges. We raised \$300,000 and had a fabulous time!

Other fun facts, I am an amateur trumpet player, enjoy exercising, gardening, and cooking with my wife of 50 years, Sandy."

**If you weren't in medicine, what career do you think you'd have pursued?**

Probably archeology. I really love learning about ancient cultures.



**Milen Minkov,  
MD, PhD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

It was love at first glance:-). During my early residency, I heard the word "histiocytosis" during a professor's rounds and became intrigued by what it was all about. I began searching the literature, reviewed the cases treated at the institution over several decades, and was appointed to care for the LCH patients... This incident, which occurred in Moscow in the early 1990s, led me to decide to pursue a Ph.D. Thesis on diagnostics and treatment of pediatric LCH. To compare our results with those of the best treatment protocols at the time, I visited the LCH Study Reference Center in Vienna. I am still working there and have had the privilege to take its lead in 2008.

**What's something your patients might be surprised to learn about you?**

Perhaps the fact that I am not only a physician-scientist specializing in pediatric hematology/oncology, but also have a practice in general pediatrics, performing well-baby visits and administering immunizations. I am a passionate dancer of Bulgarian folk dances and an avid downhill skier as well.

**If you weren't in medicine, what career do you think you'd have pursued?**

I cannot imagine that a different profession would have fulfilled my dreams of helping kids. Still, I had considered becoming a musician (played violin, accordion, clarinet, and saxophone) before entering medical school.



**Vasanta Nanduri, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I trained in Paediatric Oncology and Endocrinology and in both my specialities I managed children with LCH.

I met Dr John Pritchard when I was working at Great Ormond Street Hospital, and he was a wonderful paediatrician with a special understanding of histiocytosis and one of the founders of the Histiocyte Society. He was a great inspiration and got me really involved in the care of these patients and working with their families.

**What's something your patients might be surprised to learn about you?**

I love cooking and entertaining and enjoy having big groups of friends around. I also enjoy dancing and parties!

**If you weren't in medicine, what career do you think you'd have pursued?**

I would have liked to be a vet, but my mother dissuaded me as I am quite small and she was worried I would get trampled by a horse or cow! I would love to work with "big cats" or other wild animal rescue when I retire.



**Kim Nichols, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I became interested in the field of histiocytosis for several reasons. The first was because I saw how challenging the histiocytic disorders were to diagnose and treat. I am personally very interested in immunology so this group of diseases naturally “lit my fire”. Back when I was a medical trainee, I wanted to see what I could do to better understand these diseases – especially HLH – so that we could come up with new and more effective treatments. My overall goal is to push the boundaries of cure so that, one day, we will be able to cure every patient with histiocytosis. This still serves as my major motivation.

The second reason goes back to my mentor, Dr. Robert Arceci. Dr. Arceci was my supervisor when I was a resident at The Children’s Hospital of Boston. He was a true “tour de force” in the field with an infectious energy and love of these diseases that made it impossible not to want to work in histiocytosis. I will never forget Dr. Arceci and the lasting impression that he made on me, his colleagues, and his patients and their families.

**What's something your patients might be surprised to learn about you?**

I grew up in a small rural town in upstate New York and rode horses. Like most girls of my era, I wanted to grow up and become a veterinarian. Oddly, after 21 years with this dream, I woke up one day with the sudden realization that this was not exactly the right future for me. So, I took a year off and then decided to become a pediatrician. I have never looked back and love every minute.

**If you weren't in medicine, what career do you think you'd have pursued?**

If not in medicine, I would like to have become a party planner. Even though I am rather shy, I loved planning my children’s celebrations! If not a party planner, I would probably run an organization that helps with animal rescue and adoption – an outshoot of my love for animals 😊.



**Jennifer Picarsic, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I had the world’s pathology guru (Dr Ron Jaffe) get me excited about this fascinating disease which blended cancer and inflammation together...he mentored me by helping to reveal the intricacies of this disease under the microscope and also introduced me to the best clinicians, researchers, and other pathologists in this field.

**What's something your patients might be surprised to learn about you?**

I ran a marathon in medschool.  
I am a crazy Pittsburgh Steeler football fan.  
I am a Mumford and Son's groupie (I've traveled around the country to watch them play).

**If you weren't in medicine, what career do you think you'd have pursued?**

I couldn't think of not being in medicine -I have also wanted to be a doctor since 8th grade. But I was going to be a geriatric medicine doctor before going into pathology.

When I retire, I plan to work at a garden nursery or botanical garden, volunteer holding babies in the hospital, and be a hospice volunteer.



**Aishwarya  
Ravindran, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

My first meaningful exposure to histiocytosis came during my research fellowship years in hematology following medical school in 2015. I met a patient with Rosai-Dorfman Disease (RDD) who presented for evaluation of multiple subcutaneous nodules at the Hematology diagnostic clinic. I was deeply intrigued by the diagnostic process itself, particularly the critical role of histopathology in identifying this rare entity. That experience sparked a lasting interest, and as I tried to understand the evolving classification and biology of histiocytic disorders, I became increasingly drawn to the field. The rarity of these diseases and the diagnostic challenges they present ultimately influenced my decision to specialize in hematopathology. Since then, I have been actively engaged in the study and diagnosis of Histiocytic disorders, continuously expanding my expertise over the past decade.

My motivating factor everyday is that although we consider histiocytosis a rare disease, to the patient diagnosed with a histiocytic disorder, it means a great deal to have their medical team be knowledgeable about this rare entity. I hope to continue contributing as part of the histiocytosis care team, working to improve patients' lives while making every attempt to lead the path toward a potential cure."

**What's something your patients might be surprised to learn about you?**

I love adventures: my favorite ones thus far has been skydiving in Virginia, ice climbing in Alaska, and SCUBA diving in Hawaii. One day, I hope I can do SCUBA dive at the Great Barrier Reef.

**If you weren't in medicine, what career do you think you'd have pursued?**

I have always loved sports (favorite ones being cricket and tennis). I have played a couple of tennis matches at the national level in India. If I weren't a nerd, I would have pursued a career in sports preferably a professional tennis player ;)



**Joseph Rocco, MD  
Immunologist  
National Institutes of Health (NIH)  
Bethesda, Maryland USA**

Joe Rocco, M.D., an assistant clinical investigator at NIAID (National Institute of Allergy and Infectious Diseases) works in the Laboratory of Immunoregulation, where he studies cytokine storm syndromes such as hemophagocytic lymphohistiocytosis (HLH), which is a severe hyperinflammatory syndrome. Joe's role involves patient care, laboratory work, data analysis, writing papers, and teaching students, residents, and fellows. He is currently working on starting a natural history clinical trial to investigate secondary HLH and identify new targeted immune therapies to improve survival.

Dr. Rocco won the Nesbit Award of Excellence last year for his work in clinical science. This is a prestigious award given to investigators of the Histiocyte Society of physicians.



**Astrid  
van Halteren, PhD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

I accidentally entered the histiocytosis field because of a vacant research staff position at the Dept of Pediatrics in the academic hospital in 2008. The position was offered by the pediatric research leading professor at that time who is a now retired expert in pediatric LCH (Professor Maarten Egeler). He wanted me on his team under the sole condition that I had to spend 50% of my time on LCH research. During the remaining hours I could continue my research on graft-versus-host disease, a potentially lethal complication of hematopoietic stem cell transplantation. I liked the histiocytosis research so much that since then I have guided numerous undergraduate and graduate students who all worked on histiocytosis-related internships or PhD theses. As of 2022, my research focus is solely on histiocytic disorders.

**What's something your patients might be surprised to learn about you?**

Apart from work and taking care of my family - which includes 2 lovely rabbits and 1 sometimes bit naughty horse - I love to walk into my garden to cut flowers and to make a lovely bouquet either for myself or to give away.

**If you weren't in medicine, what career do you think you'd have pursued?**

I also have a keen interest in the financial world, in particular the New York and Amsterdam stock exchange. Unfortunately, my biggest loss in the last few years was on Bluebird Bio, a US-based biotech company trying to commercialize gene therapy for red blood cell disorders.



**David Werny, MD**

**What inspired you to pursue treatment and research of the histiocytic diseases?**

During my endocrine fellowship I became interested in diabetes insipidus and it has been a focus for me since then.

**What's something your patients might be surprised to learn about you?**

I enjoy playing guitar and singing.

**If you weren't in medicine, what career do you think you'd have pursued?**

I likely would have had a career in public health, probably with more time to start a band on the side.

## KEYNOTE SPEAKERS

We're honored to welcome our keynote speakers - extraordinary individuals from our own histio community. Their powerful stories, insights, and experiences remind us why we come together and inspire us to keep pushing forward in our shared journey.

### Friday, September 26

#### Meet Ana Valdez, Warrior/Histio Ambassador



##### **How did you first learn about the Histiocytosis Association, and what inspired you to get involved with the Histio Community?**

I first learned about the Association when my team of doctors decided to explore the possibility of histiocytosis. I took a deep dive into learning about the illness and came across the Association. At that time the association didn't have any support groups and I was eager to connect with more adults. I was inspired to get involved in the ambassador program to help facilitate support groups and help those newly diagnosed.

##### **What's something others in the community might be surprised to learn about you?**

I am ALWAYS looking for resources. Not only do I love having resources in my toolbox for when needed, but when I come across someone in need I am thrilled to provide support in this way. I also have a serious case of the travel bug and always researching deals on flights and travel packages.

##### **Outside of Histio, what's a passion or interest that's especially meaningful to you?**

I have a passion to help and serve people. I enjoy and find meaning in providing resources, help in advocating, and uplifting others in my community and those affected by a cancer and/or rare disease journey.

### Saturday, September 27

#### Meet Molly Zangrilli, Parent/Caregiver/Histio Ambassador



##### **How did you first learn about the Histiocytosis Association, and what inspired you to get involved with the Histio Community?**

I first heard of the Histiocyte Society from one of my daughter's providers and after things calmed down a few months after her bone marrow transplant, I started searching on ways to get involved and started with the Histiocyte Society which led me to the Association.

##### **What's something others in the community might be surprised to learn about you?**

I've run 9 marathons, including the Boston Marathon 3 times. I'm working to get back into shape after taking time off to care for my daughter and the process has been humbling but I use my daughter's fight to get back to normal life as motivation :).

##### **Outside of Histio, what's a passion or interest that's especially meaningful to you?**

I am fairly politically engaged and I spend a lot of time around elections working on voter assistance and protection and helping the disabled get access to voting.

# COMMUNITY Lounge

Capitol Hill - OPEN 9:00AM - 4:00PM

The Summit is family-friendly, and we know that everyone - kids, teens, and adults - may need a break from the busy schedule. That's why we've created the Community Lounge: a welcoming space for all attendees to relax, recharge, and connect. Youth are absolutely welcome, and there will be activities available and comfortable spaces for all ages.



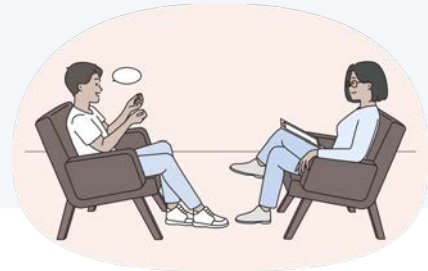
## 🤝 Peer Support

Office Hours with Doris Dahdouh, MSW, LSW



Need someone to talk to or looking for support? Schedule a one-on-one session with Doris Dahdouh, MSW during designated office hours. These private, supportive conversations are open to anyone seeking connection, guidance, or simply a listening ear.

Visit the registration desk for availability and to sign up.



## Histio Happy Hour (In-Person Only)

Friday | 5:00 – 7:00 PM | Seattle Foyer

Unwind and mingle after a full day at the Summit!

Join us for complimentary food and drinks, hosted by the Histiocytosis Association's Histiocytosis Ambassadors. Enjoy light fare, cocktails and soft drinks, and great conversation with others in the histio community.

📸 Don't forget to snap photos and tag us on social media!

📷 @histiocytosis\_association

📘 @histio



#HistioSummit25

## ACTIVITIES

### **Blue Ribbon Run: Saturday @ 7:00 AM**

**Start Your Day with Purpose – Join the Fun!**

Whether you're in Seattle or cheering us on from afar, kick off your Summit day with energy, connection, and a shared mission by participating in the Blue Ribbon Run!

#### **In Person at the Summit?**

Lace up your sneakers and join fellow attendees for a scenic walk/run through Seattle! Enjoy fresh air, great conversation, and help raise awareness for histiocytic disorders. It's a fun and meaningful way to start the day together!

#### **Participating from Home?**

Take a walk or run in your own neighborhood and share your photos on the Summit platform - we'd love to see where you're raising awareness!

#### **Can't Join the Walk/Run?**

You can still support the cause by donating to the runners and walkers, including the Histiocytosis Association team. Every step and every dollar brings us closer to increased awareness and better outcomes for our community.



Scan the QR code or stop by the registration table to sign up, donate, or learn more.

**SCAN ME**




### **#SEAofBLUE Baseball Game Excursion** **Saturday Evening at the Mariners Game**


#### **Group Transportation:**

If you signed up for the bus, please meet in the Hilton Motif lobby by 5:00 PM. Buses will depart promptly at 5:15 PM, getting us to the stadium by gate opening at 5:40 PM. After the game, buses will return to the Motif - driver will share meeting instructions.

#### **Traveling on your own?**

Stadium gates open at 5:00 PM.

 **Tickets were emailed - your phone is your ticket, so be sure to download it in advance. If you haven't received yours, stop by the registration table for help.**

 **First pitch is at 6:40 PM. See you there!**

#### **Not joining us at the game?**

We'll miss you - but we hope you'll tune in and catch a glimpse of us in the crowd! We'll be rocking our blue Histio t-shirts, raising histio awareness and creating our very own **#SEAofBlue** in the stands.

 **You can watch on Root Sports in the Seattle area, or the MLB app if you're anywhere else.**

**A very limited number of tickets are available for purchase!**  
**If interested, stop by the registration table.**  
**First come, first served.**

**We'll be rootin' for BLUE!**



## Access the Summit Anytime, Anywhere!

All attendees - including those joining us in person - have full access to the Summit's virtual platform for an entire year.

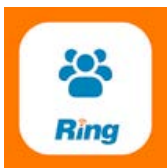
Connect with participants from around the world, watch session recordings on your schedule, and revisit important content anytime. Be sure to check out the Expo tab to explore resources from the Histiocytosis Association and our generous sponsors.

Need help downloading or logging into the app? Stop by the registration table - we're happy to help!

Please follow the instructions below to get started.



Downloading the RingCentral Events mobile app will insure that you get the most out of your Summit experience.



- To download the app, simply go to your app store (*available on iOS and Android*) and search for **RingCentral Events**.
- Once downloaded you can log in and have access to everything that will be happening during the meeting. Alternatively, you can also access the online platform in your browser by using the following link: <https://app.events.ringcentral.com/events/histiocytosis-association/reception>

### Tech Support:

If you have questions while using the online platform or the mobile app, we will have tech support available. To access, simply navigate to the schedule and look for the Tech Support room. Once you enter, there will be someone there on screen to assist you.

Note: You may see the platform also listed as Hopin or StreamYard throughout the system. These are all the same interconnected platforms that are part of our mobile app.

**We want to share our  
gratitude for YOU - for all the  
support, commitment, and  
passion you have poured into  
the histiocytosis community  
and the Histiocytosis  
Association. YOU make events  
like this possible!!**