

Medical Symposium



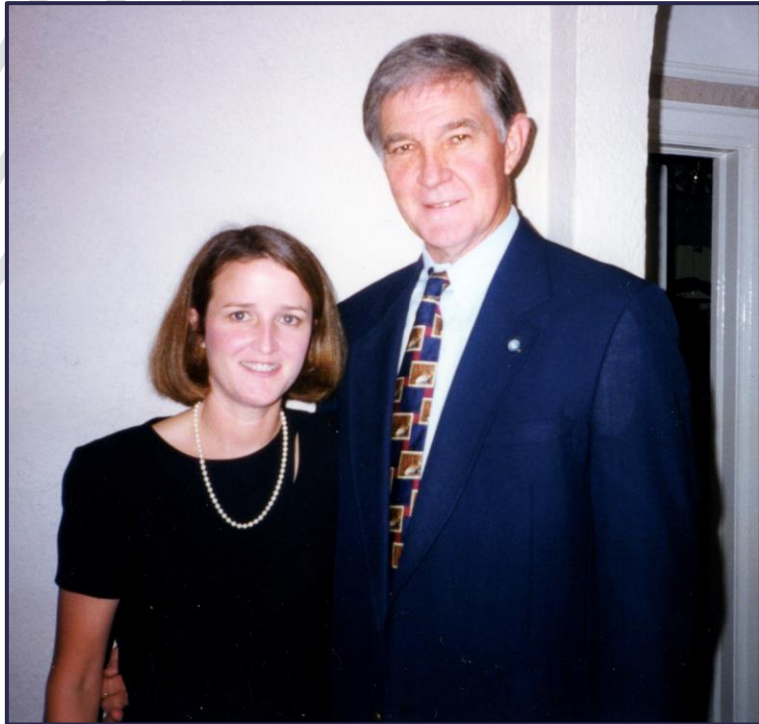
Erdheim-Chester Disease Global Alliance April 2023

Mayo Clinic
Rochester, Minnesota

Kathy Brewer – Founder/President ECDGA

Paul Hendrie, MD, PhD – Fred Hutchinson Cancer Center and ECDGA Board Member

Gary's Diagnostic Odyssey



F. Gary Brewer, EdD
Colonel, US Air Force (Ret.)
Superintendent of Schools



2002 – 2007

Symptoms	Suspected Cause
High blood pressure - 1980's (controlled)	Stressful job
Kidney disease - 1980's	High blood pressure
Knee pain -1990's	Aging
Weight loss / night sweats /extreme fatigue - 2000	Myelofibrosis
Kidney failure - 2003	Decades of high blood pressure
Neurological issues - 2004	Transplant related
Numerous issues in other organs	Unknown!

ECD Diagnosis at Autopsy in 2007

My Journey Alongside Gary



5 Years with Best Medical Care

- Uncertainty
- Fear
- Hopefulness
- Frustration
- Loneliness
- Anger
- Helplessness
- Sadness
- Courage
- Despair

***Even if the hopes you started out with are dashed,
hope has to be maintained.***

- Seamus Heaney

In the Time Before Zoom...

- Message Boards
- Typing Chats & Conference Calls
- Encouraged to Build a Website
- Realized Need for Non-Profit Status



Excerpt from the 1st Chat April 2008

GarysKat: Thank you guys for joining, I am hoping something good can come from us talking.

Robin: Kathy, personally I am thrilled to just get a chance to chat with people who know where were at and such...

mfsehc: Thanks, glad to be here

walter327: If nothing else, we'll have support, Kat.

Yankees Fan: introductions would be good

Beginning Goals



Searching For

- Knowledge / Answers
- Knowledgeable doctors
- Treatments
- Cure



“Big” Ideas

- ✓ A Global Community that Worked Together
- ✓ Funded Research
- ✓ Available Treatments – told FDA approval not possible!
- ✓ Dedicated Doctors
- ✓ Regular meetings of scientists, doctors, patients, families

Focus for the Future



Paul Hendrie, MD, PhD

Hematologist

Fred Hutchinson Cancer Center

Seattle, WA

ECDGA Board Member since 2019

Research Committee Chair



Acknowledge What the Community has Accomplished

Dates	Activity
1930	<ul style="list-style-type: none"> ECD first described in medical literature
1978-2007	<ul style="list-style-type: none"> Prognosis: ~3 years of very difficult life On average, 9 medical papers published per year
2007	<ul style="list-style-type: none"> First treatment discovered Prognosis: ~5 years of poor quality of life
2008	<ul style="list-style-type: none"> ECD Global Alliance founded
2010	<ul style="list-style-type: none"> First ECDGA grant awarded
2011	<ul style="list-style-type: none"> NIH Natural History Study opened
2012	<ul style="list-style-type: none"> Genetic mutation found
2013	<ul style="list-style-type: none"> 1st Medical Symposium & Patient/ Family Gathering
2014	<ul style="list-style-type: none"> ECD Registry at MSKCC funded
2015	<ul style="list-style-type: none"> ECD Care Center Referral Network Established
2016	<ul style="list-style-type: none"> WHO declared ECD a histiocytic neoplasm

Dates	Activity
2017	<ul style="list-style-type: none"> 1st FDA approved treatment (50% of patients)
2020	<ul style="list-style-type: none"> Over 100 medical papers published per year
2021	<ul style="list-style-type: none"> NCCN Guidelines published
2022	<ul style="list-style-type: none"> 2nd FDA approved treatment (44% of patients) Prognosis: More of a chronic disease!
Future Needs?	<ul style="list-style-type: none"> Earlier diagnosis Access to treatment for all Lessened financial burden of ECD Cessation of treatment Effective treatments for all patients Quality of life – neurological issues, pain, fatigue, psychological burdens, medication side-effects issues solved, all survivorship issues Easier access to knowledgeable health providers and information

ECDGA Programs & Accomplishments



Program	Achievement
Annual Meetings	<ul style="list-style-type: none"> • 8 Medical Symposiums & Patient/Family Gatherings
Regional Meetings	<ul style="list-style-type: none"> • 5 Regional Meetings
Awareness	<ul style="list-style-type: none"> • Medical specialty conference booths • Grand Round presentations scheduled
Education	<ul style="list-style-type: none"> • Website (www.erdheim-chester.org) • Medical and patient brochures
Webinars	<ul style="list-style-type: none"> • Educational topics presented in multiple languages
Research	<ul style="list-style-type: none"> • Over \$1.2M funded since 2010
ECD Care Centers	<ul style="list-style-type: none"> • 34 Care Centers in 14 Countries
One-on-One Support	<ul style="list-style-type: none"> • Patient Navigator (Belinda.Cobb@erdheim-chester.org) • 873 patients registered from 71 countries
Chat Sessions	<ul style="list-style-type: none"> • Monthly Patient sessions • Every other month for Caregivers and those Grieving
International Support	<ul style="list-style-type: none"> • 11 languages supported
Social Media	<ul style="list-style-type: none"> • Facebook: closed group & organization page • LinkedIn • Twitter • YouTube • Instagram • RareConnect

Summary of the Current ECDGA 2-Year Goals



Goal 1:

Dramatically increase the number of persons with ECD to receive an early diagnosis



Goal 2:

Support relevant research to improve the quality of life for people with ECD and their loved ones.

Goal 3:

Build an even stronger global community of informed and connected patients, caregivers and physicians

Goal 4:

Develop long-term sustainability plans for the ECD Global Alliance

Focus for the Future



Focus for the Future

What should be ECD Global Alliance's top priorities? These are ECDGA's current strategic priorities. Please rank 1-4 of what you think is most important for the next few years.

___ Build awareness of ECD symptoms among physicians to increase earlier diagnosis.

___ Support research to improve quality of life for people with ECD and caregivers.

___ Build an even stronger global community of informed and connected patients, caregivers, and physicians.

___ Deepen and accelerate ECDGA's impact by partnering with the various rare disease organizations.

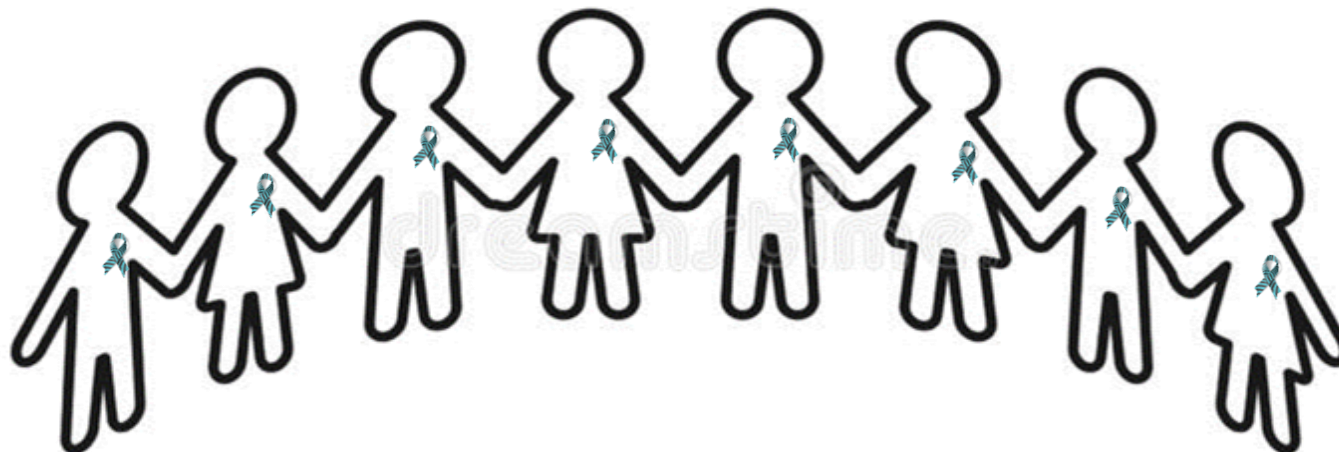
What other priority should ECDGA consider?

Please complete and return to staff member or registration desk.

We Need YOU!



- Return to Registration Desk – Completed Focus for the Future Card and Evaluation Forms
- Volunteer your skills & talents
- Donate to help the cause



Schedule of Meetings



Date	Day of Week	Times	Meeting	Location
April 27	Thur	6 – 8 pm	Banquet	Marriott - Ballroom 1 and 2
April 28	Fri	7:30 am	Catholic Mass	Kahler - Regency Room
April 28	Fri	8 am – 5 pm	Patient/Family Gathering (PFG)	Seibens - Phillips

Campus Map



*** Phillips Hall is within Siebens Building shown above.**

Thank you to the ECD Staff & Volunteers!



ECDGA Staff



Jean Pudlo
Interim Executive Director



Belinda Cobb
Patient Navigator



Renita Page
Donor Relations & DB Manager

ECDGA Volunteers

Barry Atnip

Melinda Atnip

Father Charles Balnaves

Shannon Bennich

Susie Cooper

Josef Lacy

Sonia Maskas

Chad Michael

JC Quintero

Diane Schriener, Vice-President

David Smythe, Board Member

Michael Stanley

Kathy Wisniewski



Thank You!

To the ECD Community Leaders and to You for Your Attendance

Our Fantastic Hosts

Mayo Clinic

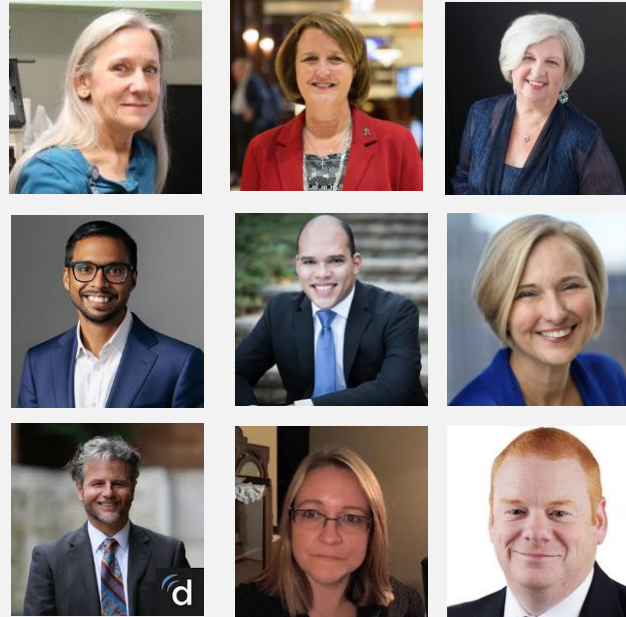


Ronald Go, MD
Mayo Clinic



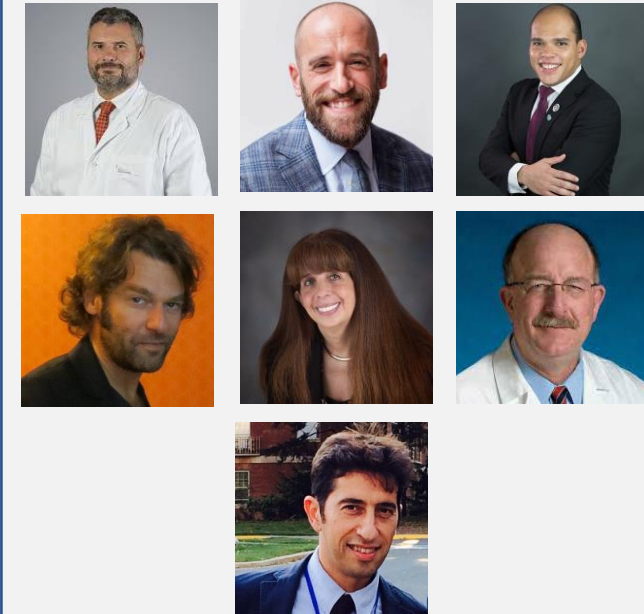
Gaurav Goyal, MD
UAB

ECDGA Board



Top left to bottom right: Linda Adams; Kathy Brewer (Founder/President); Jean Campbell; Mohammad Chowdhury (Treasurer); Juvi Estrada-Veras; Janet Froetscher (Secretary); Paul Hendrie, MD, PhD; Diane Schriener (Vice-President); David Smythe

ECDGA Medical Advisory Board



Top left to bottom right: Lorenzo Dagna, MD; Eli Diamond, MD; Juvianee Estrada-Veras, MD; Julien Haroche, MD, PhD; Razelle Kurzrock, MD; Paul Scheel, MD; Augusto Vaglio, MD

Hope to see you next year!

Location and date will be announced soon