



Kathy Brewer

President & Founder

ECD Global Alliance





Mission

The ECD Global Alliance is dedicated to the awareness, support, education, and research related to Erdheim-Chester Disease.



Patient Support



Over 700 families have received support from the ECDGA since it was formed in 2008. These patients represent 65 different countries.





Statistics



ECDGA REGISTERED PATIENTS

2008 - 2021

780 total patients served

Patient Locations Worldwide

780 Cases Recorded by the ECD Global Alliance



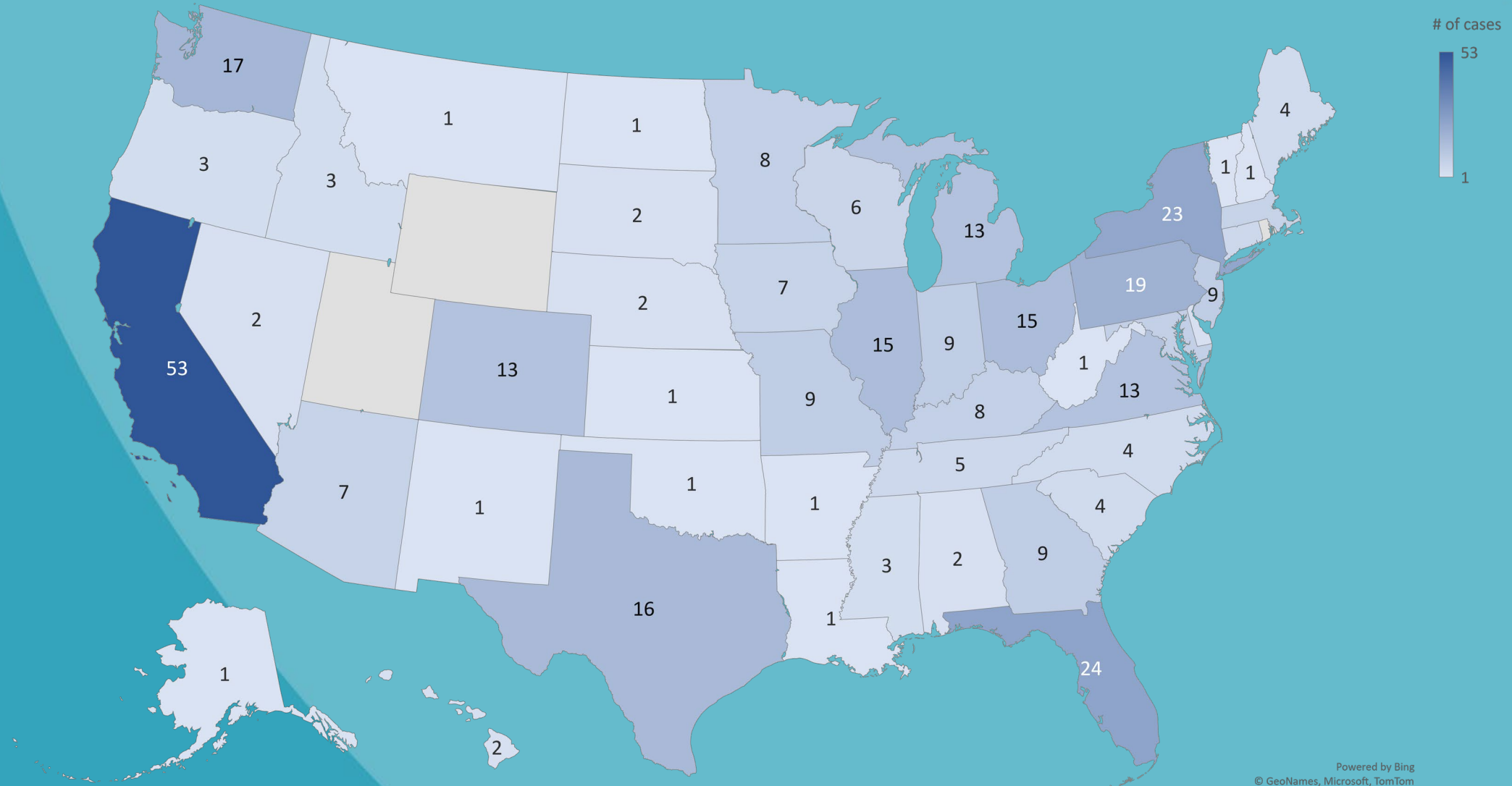
Algeria	1
Antarctica	1
Argentina	4
Aruba	1
Australia	39
Austria	1
Bahrain	1
Belgium	6
Brazil	35
Bulgaria	2
Canada	31
Chile	6
China	12
Colombia	2
Cuba	1
Cyprus	1
Denmark	2
Egypt	2
France	36
Georgia	1
Germany	21
Great Britain	41

Greece	2
Hungary	1
India	6
Iran	3
Iraq	1
Ireland	2
Israel	13
Italy	23
Japan	1
Kazakhstan	2
Korea	1
Kyrgyzstan	1
Lebanon	1
Libyan Arab Jamahiriya	1
Mexico	8
Moldova	1
Morocco	1
Namibia	1
Nepal	3
Netherlands	9
New Zealand	6
Norway	6

Pakistan	3
Panama	1
Peru	2
Philippines	2
Poland	2
Portugal	2
Romania	4
Russian Federation	2
Saudi Arabia	2
Slovenia	1
South Africa	2
Spain	20
Sweden	4
Switzerland	3
Thailand	1
Trinidad and Tobago	1
Tunisia	1
Turkey	6
Turkmenistan	1
Ukraine	1
United Arab Emirates	2
United States	375
Uruguay	2

U.S. Patient Locations

375 Cases Recorded by the ECD Global Alliance







Physician Support

The ECDGA currently reaches over 1,300 medical professionals from around the world.

- ▶ **ECD Care Center Referral Network**
Consults offered at 35 medical institutions in 13 countries
- ▶ **Histiocytosis Research Funding**
Over \$750,000 awarded to research projects
- ▶ **Education & Awareness**
Annual scientific meetings, Grand Rounds, exhibits, resources



Care & Referral Network



U.S. CENTERS OF CARE

Institution	Location
Baylor College - Texas Children's Cancer Center	Houston, TX
Columbia University Medical Center	NYC, NY
Dana-Farber Cancer Institute	Boston, MA
Duke Cancer Institute	Durham, NC
Johns Hopkins Hospital	Baltimore, MD
Mayo Clinic	Rochester, MN
Memorial Sloan-Kettering Cancer Center	NYC, NY
Seattle Cancer Care Alliance (E)	Seattle, WA
Stanford University (E)	Stanford, CA
UC San Diego Moores Cancer Center	San Diego, CA
UF Health Cancer Center - Orlando Health	Orlando, FL
University of Alabama at Birmingham (E)	Birmingham, AL
University of Cincinnati (E)	Cincinnati, OH
University of Colorado School of Medicine	Denver, CO
University of Michigan	Ann Arbor, MI
University of Texas MD Anderson Cancer Center	Houston, TX
Vanderbilt University Medical Center	Nashville, TN
Washington University in St. Louis	St. Louis, MO



Care & Referral Network



INTERNATIONAL CENTERS OF CARE

Institution	Location
Assuta Medical Center	Tel Aviv-Yafo, Israel
American University of Beirut	Beirut, Lebanon
AOU Meyer	Florence, ITALY
Chu Caen – Universite Basse-Normandie	Caen, France
Elisabethinen Hospital	Linz, Austria
Erasmus University Medical Center (E)	Rotterdam, The Netherlands
Hôpital Pitié-Salpêtrière	Paris, France
Instituto do Cancer do Estado de Sao Paulo (E)	São Paulo, Brazil
IRCCS San Raffaele Scientific Institute	Milan, Italy
Mount Sinai Hospital (E)	Toronto, Canada
Newcastle University	Newcastle upon Tyne, UK
Peking Union Medical College Hospital	Beijing, China
Peter MacCallum Cancer Center	Melbourne, England
Shaare-Zedek Medical Center	Jerusalem, Israel
Université Libre de Bruxelles, Hopital Erasme (E)	Anderlecht, Belgium
University of Alberta (E)	Alberta, Canada
St. James's University Hospital, University of Leeds	Leeds, England





Ask the Experts



Moderator
Mark Heaney, M.D., Ph.D.

Panel

- Pr. Matthew Collin
- Dr. Eli L. Diamond
- Dr. Benjamin Durham
- Dr. Gaurav Goyal
- Pr. Julien Haroche
- Dr. Augusto Vaglio



THANK YOU!



coming to your email...

Webinar recording

Post-meeting survey, please help us improve

Information about clinical trials, studies, and the registry

New Pathology Guide to Erdheim-Chester
Diagnosis

Registration information for the 2022 meeting

**If you have more questions
following the meeting,
please reach out!**

Support@Erdheim-Chester.org

Erdheim-Chester.org