

# ECD CARE CENTER 2023 PATIENT FAMILY GATHERING

PAUL HENDRIE, MD  
FRED HUTCHINSON CANCER CENTER



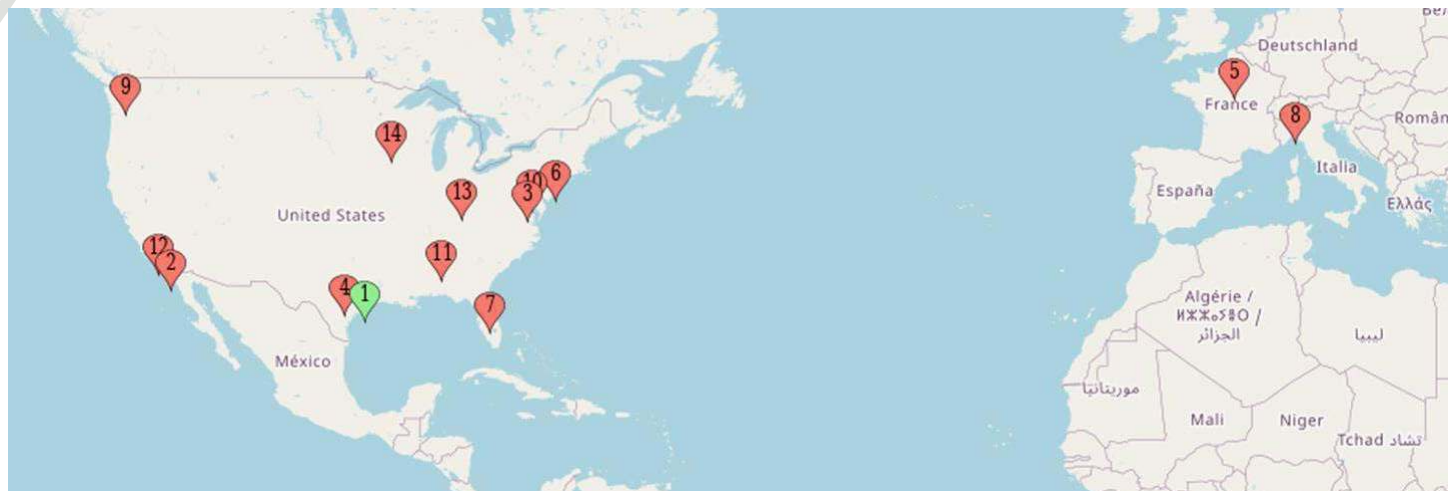
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# Past Annual & Regional ECDGA Event Locations



## Interested in Hosting the 2024 Event?

### Host Agreement

- Support funding
- Onsite support personnel
  - Event coordinator - logistics of the event
  - Patient advocate - provide the patient voice of the local community
  - Medical professional – coordinate the agenda/speakers

## Telehealth Options for All US-Based ECD Patients?



- US Law – Doctor must be licensed in state where patient is located to offer medical services
- Proposal: Query US Care Centers to learn in which the states the lead physician is licensed
- Make this information available to patients
- Likelihood of success?

# Schedule of Meetings



Date	Day of Week	Times	Meeting	Location
April 26	Wed	6-8 pm	Medical Social	Marriott- Ballroom 2
April 27	Thur	8 am – 5 pm	Medical Symposium (MS)	Seibens - Phillips Hall
April 27	Thur	3 – 5 pm	Patient/Family Meet & Greet	Kahler - Elizabethan Room
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 Hall

# Campus Map



# Thank You!



- 1. Our Fantastic Hosts**  
Mayo Clinic



Ronald Go, MD  
Mayo Clinic



Gaurav Goyal, MD  
UAB

- 2. For Your Attendance**

**See you next year!**

Location and date to be announced soon