



## ECDGA Information

Diane Schriner, Vice-President



**10<sup>th</sup> Annual ECD Conference**





# ECD Global Alliance Mission



Apoyo

Investigación

Educación

Concienciación



Support

Research

Education

Awareness



Soutien

Recherche

Éducation

Sensibiliser



Unterstützung

Forschung

Ausbildung

Bewusstsein



Supporto

Ricerca

Istruzione

Consapevolezza



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# ECDGA Support Impact



**1,050+** from **75**  
Patients &  
Family Members  
Served  
Countries



**2,739**  
Medical  
Professionals  
Included




**103**  
Countries  
Reached



**1**  
Website




**1**  
Patient  
Navigator




**9**  
Virtual Support Groups

<b>3</b> English-Speaking	<b>2</b> Location-Specific	<b>4</b> Language-Specific
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**41**  
ECD Care  
Centers



**1-on-1**  
Introductions



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# ECDGA Education Impact




**4**  
Grand Round  
Talks  
Sponsored



**19**  
Webinars



**135**  
Videos



**11**  
Brochures



International  
Conferences

**10**  
Meetings

**4**  
Countries

**1,150+** Registrants



**6**  
Regional  
Meetings



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# ECDGA Awareness Impact



**9**

**Medical  
Specialty  
Conference  
Booths**



**8,350+**

**Reached  
through  
emails &  
postal mail**



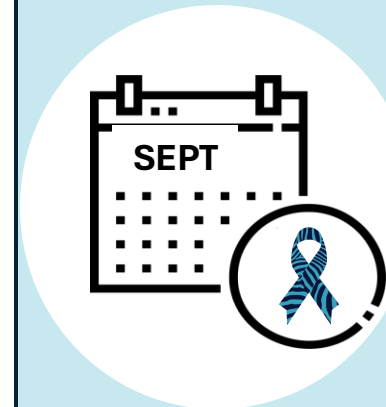
**5**

**Social  
Media  
Channels**



**10**

**Annual  
Awareness  
Weeks**



**16**

**Global  
Histo  
Patient  
Advocacy  
Group  
Member**



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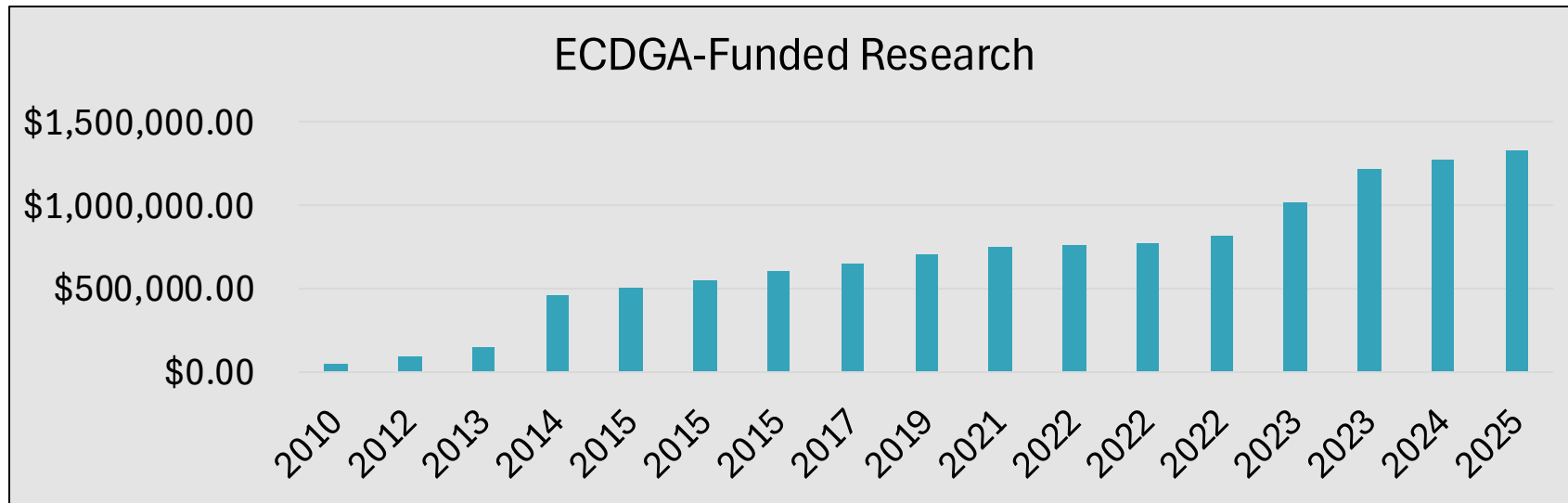
# ECDGA Research Impact



**17**   
**Research  
Projects  
Funded**



**\$1.3+ Million  
Invested by  
ECDGA**



  
**ECDGA-Funded  
“Seed Grants”  
can grow  
into Major Research  
Programs**



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# ECDGA Community

## Powered by a Passionate Community



- Small Staff (2 Part-time)
- Board of Directors (8)
- Medical Advisory Board (10)
- Volunteers (~30)
- Community (~5,000)
- Donors (~500-600/year)
- 88% of all donations are under \$500 (~500Euros)
- 54% of income is provided by 11 individuals

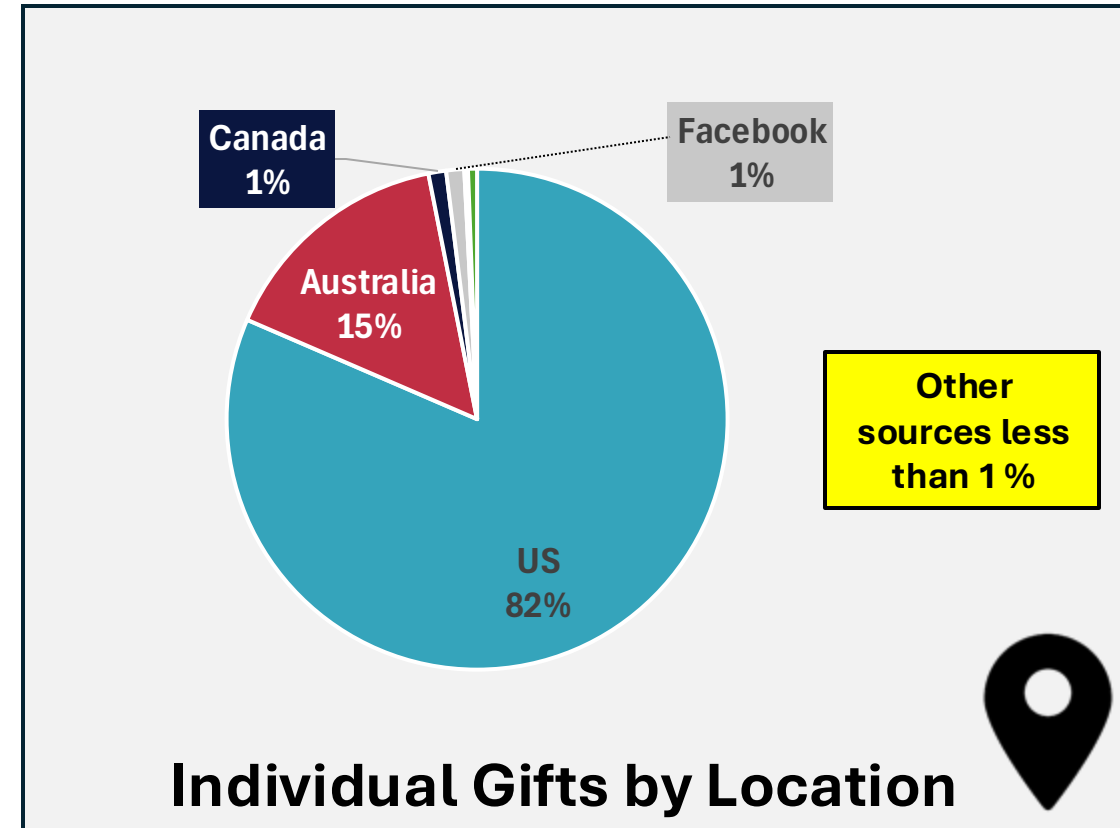
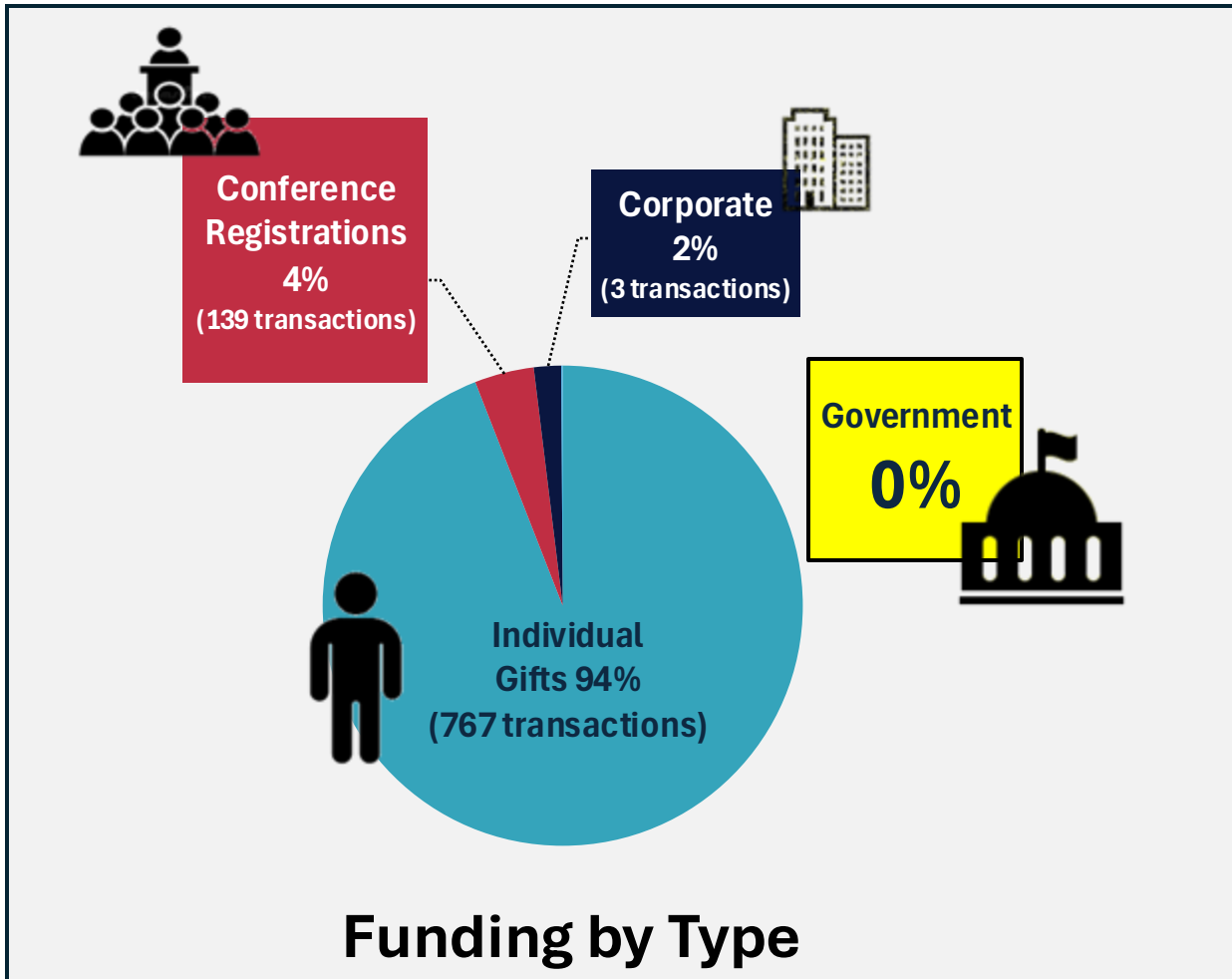
**All Giving Helps! – No matter the magnitude.**



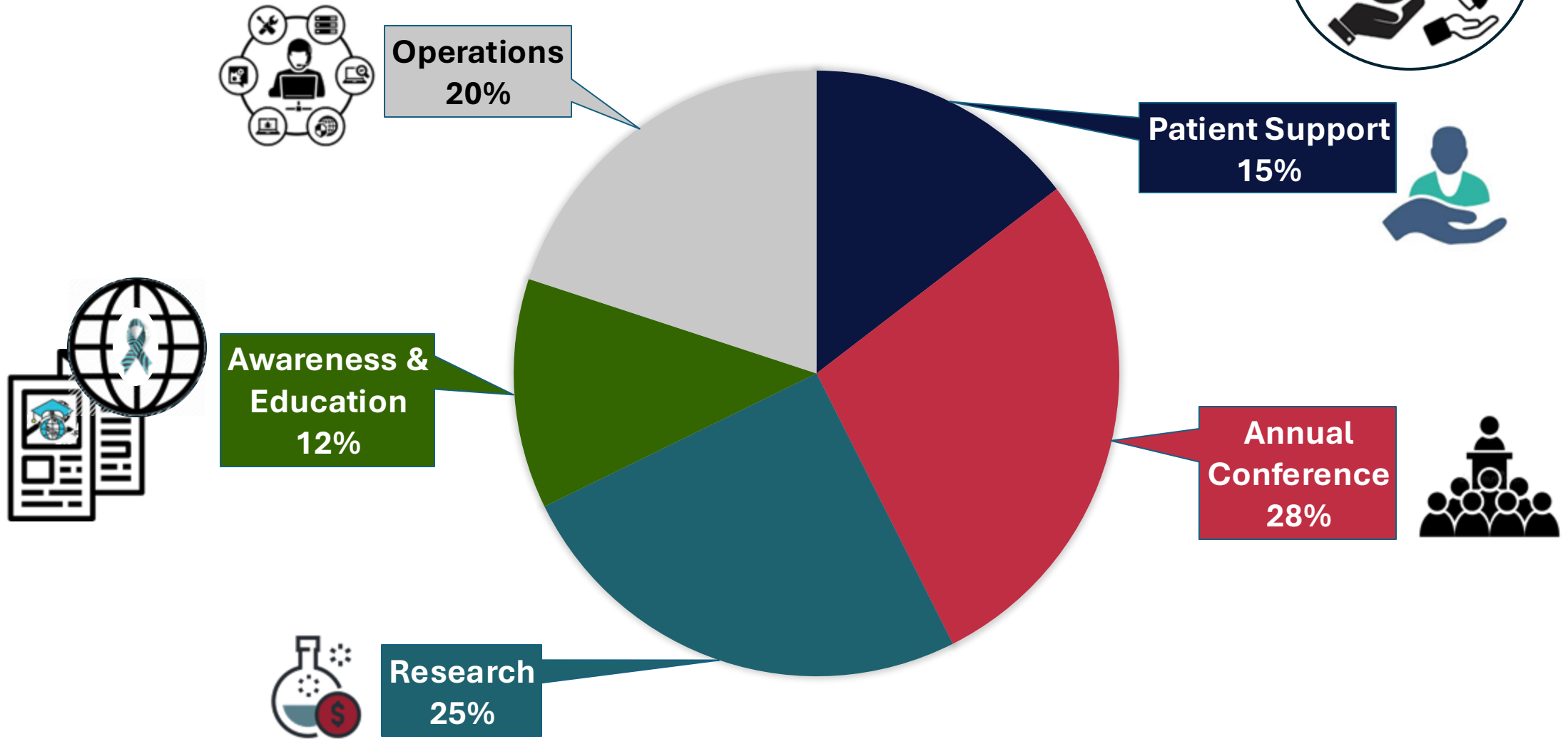
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# 2024 ECDGA Funding Sources



# 2024 ECDGA Expenditures





# ECD Community Medical Needs



Earlier/Easier  
Diagnosis



Access to Care



Access to  
Treatment



Medication  
Cessation



Medication  
Side Effects  
Managed



Pain Managed



Fatigue Managed



Neuro Issues  
Managed



Psychological  
Issues Managed



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# ECD Community Survivorship Needs



Carer Psychological  
Support



Financial Burdens  
Resolved



Nutrition Advice



Sleep Hygiene



Integrated  
Medicine Access



Physical Therapy



Recreational  
Therapy



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# Volunteers Needed

## Please Join Us



**Volunteer**



**Donate**



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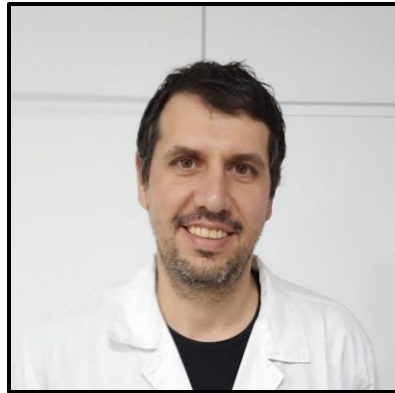




# Thank You!



Sponsor  
Fr. Charles Balnaves



Host  
Xavier Solanich, MD, PhD

## Planning committee

- Paul Hendrie, MD, PhD
- Juvianee Estrada-Veras, MD
- Adria Badoch Zambrano
- Belinda Cobb
- Renita Page
- Diane Schriener
- Kathy Brewer
- ECDGA MAB Members
- Patient & Family members who participated in the planning survey
- All speakers who generously donate their time

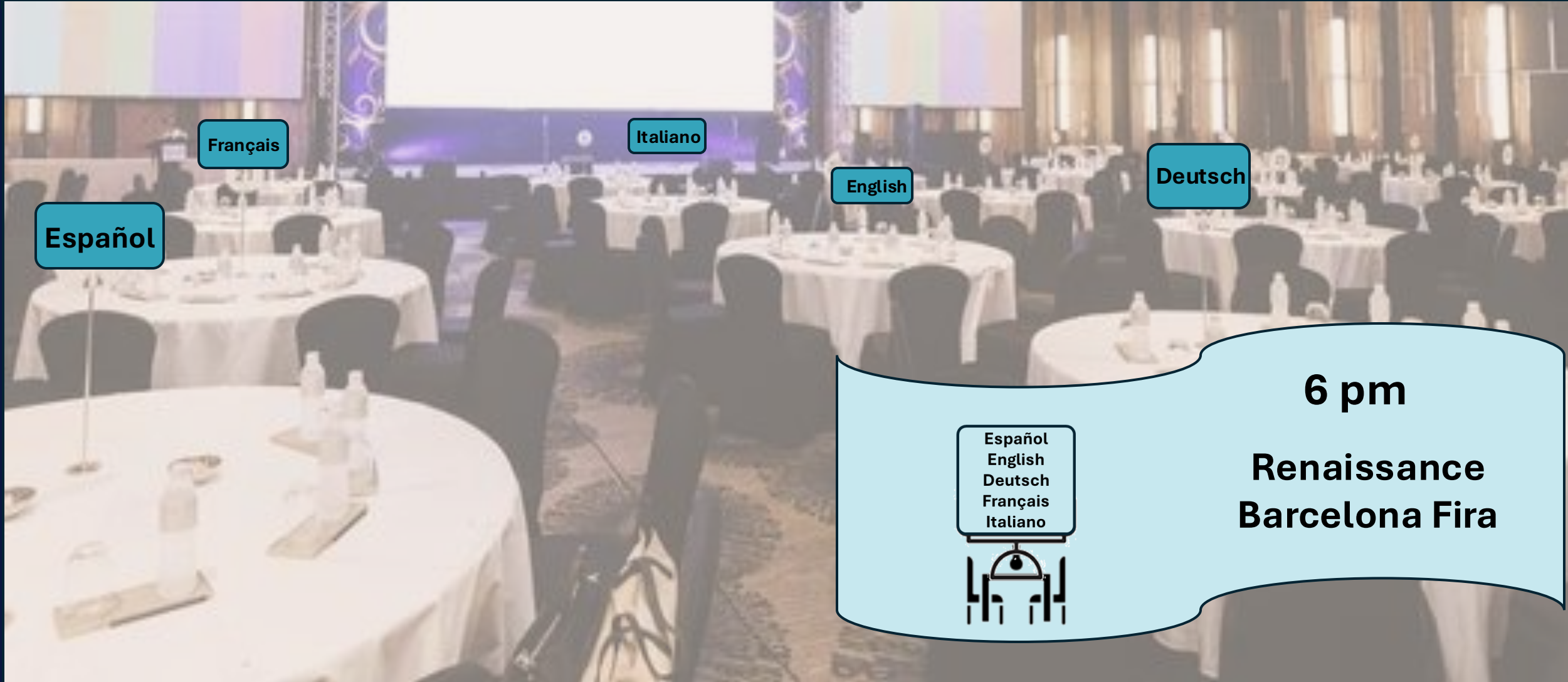


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# Celebration Dinner



Español

Français

Italiano

English

Deutsch

Español  
English  
Deutsch  
Français  
Italiano



6 pm

Renaissance  
Barcelona Fira



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# Feedback



Sus comentarios solicitados



Your feedback requested



Vos commentaires demandés



Ihr Feedback erbeten



Il tuo feedback richiesto



Add in information about the fun run???



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