



GCOM 2024

5th Global Conference
on Myositis

March 13-16, 2024
Pittsburgh, PA - United States

Patient Advocacy Organizations Closing Session



**World
Myositis
PAOs**

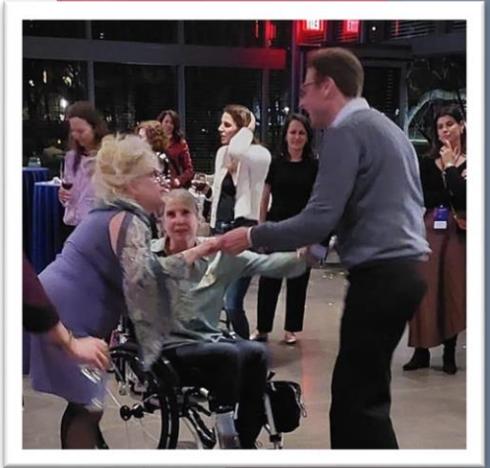
Patient Advocacy Organizations (PAOs) Across the Globe



Thank You



- **GCOM Steering Committee**
 - Dana Ascherman, Rohit Aggarwal, Chester Oddis
 - Karen Cheng, patient representative
- **iMyos**
 - Jens Schmidt
 - Silke Schlüter, patient representative
- **PAO planning coalition**
 - Linda Kobert, organizer
- **PAO speakers and facilitators**
- **Patient and PAO delegates, in Pittsburgh and virtually**
- **GCOM delegates**



PAO Goals for GCOM 2024

-  Network amongst PAOs to share best practices, empower each other, and facilitate international collaborative efforts
-  Expand collaborations with research groups, companies and networks
-  Meet, network, and facilitate communications between patients / PAOs, clinicians, researchers and other parties



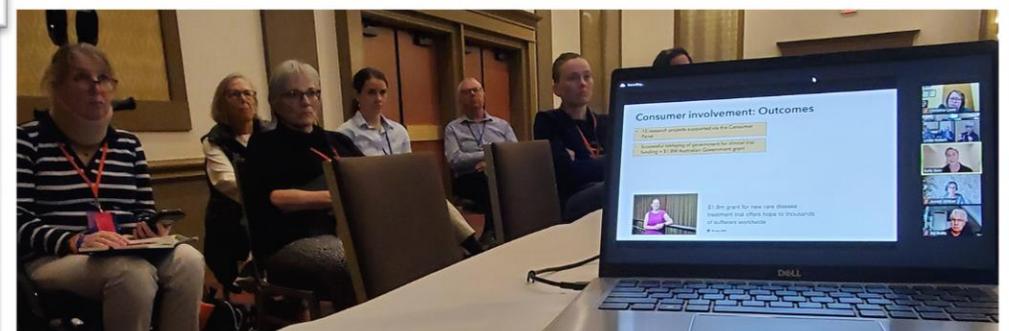
**World
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PAOs at GCOM 2024: By the Numbers

- **~40 attendees** in Patient/Patient Advocate category
- 270 minutes of **Parallel Program** for PAOs
- 230 minutes contributed to **Scientific Program** for all
- **9 PAO posters**
- **3 scientific posters**
- **10 countries**

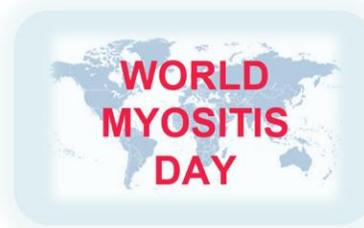






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Patient Session
Friday, 15 March 2024



Take-Home Messages

- Global myositis PAOs are progressive, resourceful, eager to collaborate
 - Effective collaborations include us prior to initiation!
- Patients are partners in discovery
 - Clinical trial protocols
 - Endpoints
 - Symptoms
- Language matters
 - Anti-synthetase syndrome nomenclature
 - 'Patient' can be limiting label

Looking to the Future

World Myositis Day

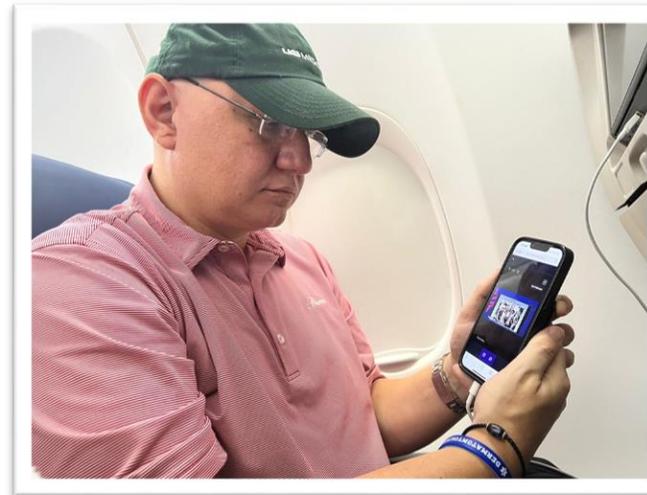
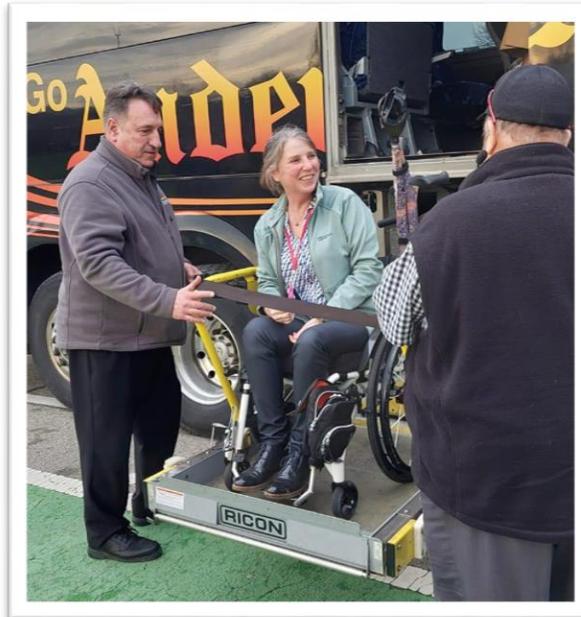
- 21 September 2024

GCOM 2026

- Hybrid
- Accessibility and inclusivity
- Patient and PAO planning



**World
Myositis
Day** 21 Sept





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Patient Advocacy Organizations Thank You



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Myositis
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