

GCOM 2024

5th Global Conference
on Myositis

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

Patient Advocacy Organizations at GCOM 2024

Let's get acquainted



Patient Advocacy Organizations (PAOs) Across the Globe



PAO Core Mission Activities

- **Educating and empowering** patients
 - IIM specific information (types, diagnosis, treatment etc.)
 - Programs on mental wellbeing, diet, coping, work, treatment options
 - Annual patient conferences
- **Raising awareness** in the general population
- Offering local **support groups**, meet & greets
- **Fund-raising** events
- **Education materials for HCPs**
- Assistance in **recruitment for clinical trials**

Impacting research throughout project lifecycle:

- Advising on **research design**
 - Direct involvement in design
 - Consumer panel Membership
- Funding and **Reviewing Grant Applications**
- Preparing and **disseminating results**
 - Data collection and analysis
 - Co-authoring publications
- **Enrolling** in research studies (subjects/patients)
- Educating **Patient Research Partners (PRPs)**

Expanding the scope of myositis research

- Creation of **research agendas**
- Help in **building new consortia** (e.g. on QoL, bone health)
- Directly **funding** myositis research projects
- Adding the **patient voice to the regulatory process** (
 - Patient- focused drug development (PFDD) with US FDA)
- Advising on and/or funding **Centers of Excellence**

Our 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 interested parties

Let's get acquainted and build relationships for the benefit of the Myositis Community



Please find and visit us!



Meeting point:
Patient group posters in the Ballroom Foyer