

# FIN FABRY EXPERT MEETING 2026

*meeting report*

April 24-25, 2026  
Taipei, Taiwan



**FIN**  
Fabry International Network

## Welcome

In April 2026, members of the Fabry International Network (FIN), healthcare professionals, researchers, industry partners and patient advocates gathered in Taipei, Taiwan for the FIN Fabry Expert Meeting 2026.

Under the theme Connecting Science, Experience and Community, the meeting brought together diverse perspectives from across the global Fabry community to share knowledge, strengthen partnerships and explore ways to improve the lives of people living with Fabry disease.

The meeting welcomed participants from more than 20 countries and combined scientific education, patient perspectives, practical workshops and international collaboration. Throughout the programme, one message emerged clearly: progress happens when expertise and lived experience work together.



*FIN members celebrating connections at the Expert Meeting 2026*

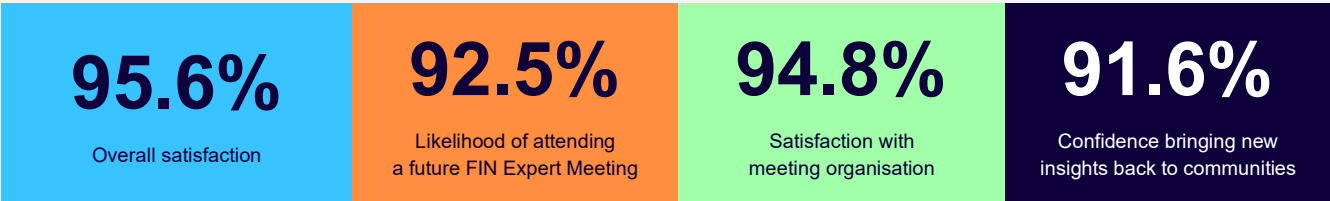
## At a Glance



# Participant Reflections & Meeting Impact

*Bringing the Global Fabry Community Together*

The FIN Fabry Expert Meeting 2026 brought together patient advocates, healthcare professionals, researchers and industry partners from around the world to learn, share experiences and strengthen collaboration. Participant feedback demonstrated the value of combining scientific education, peer exchange and community building in one event.



*Based on post-meeting evaluation responses (n=42)*

*“Meeting people from different countries reminded me that many of the challenges we face are shared, and that we don’t have to solve them alone.”*

*“I’m leaving with ideas that I can take back to my own community and put into practice right away. I left feeling inspired, connected and reassured that we are moving forward together as a global Fabry community.”*

*“I came away feeling more confident to ask questions, have conversations with healthcare professionals and support others in my local community.”*

*“The expert sessions gave me new knowledge, but the conversations with other participants were just as valuable.”*

## What Participants Valued Most

The sessions most frequently highlighted by participants included:



### ENT Symptoms and Their Impact in Fabry Disease

*Dr Yen-Fu Cheng*

Participants particularly appreciated learning about the often-overlooked effects of Fabry disease on hearing and balance and the importance of monitoring these symptoms.



### Strength from Within: Nutrition & Lifestyle

*Dr Seema Kanwal*

Practical advice on nutrition, energy management and lifestyle strategies resonated strongly with attendees and generated lively discussion throughout the meeting.

### Sharing Best Practices Between Patient Organisations

The dedicated exchange sessions provided an opportunity for organisations to learn from one another's successes, challenges and innovative approaches to supporting their communities.



### Understanding Fabry Care Today

*Dr Robert Hopkin*

Participants valued the practical overview of monitoring, treatment and long-term management of Fabry disease.



### Women and Fabry Disease

*Dr Masahisa Kobayashi*

The discussion around the experiences, challenges and unmet needs of women living with Fabry disease was identified as one of the meeting's most impactful topics.

## A Truly International Community

The Expert Meeting welcomed participants from 22 countries across Europe, Asia, North America and Oceania, reflecting the global reach of the Fabry community and the importance of international collaboration.

Participants joined from Australia, Austria, Belgium, Canada, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, India, Italy, Japan, Lithuania, Poland, Russia, Spain, Switzerland, Taiwan, the United Kingdom and the United States.

By sharing knowledge, experiences and practical solutions, participants left the meeting better equipped to support people living with Fabry disease in their own countries and communities.

## Taiwan: A Valued Partner in the Global Fabry Community

The 2026 Expert Meeting was made possible through the close collaboration between FIN and the Taiwan Association of Fabry Disease (TAFD).

For more than a decade, TAFD has been an active member of FIN and an important bridge between patients, families, healthcare professionals and policymakers in Taiwan. Founded in 2011 by patients and families, TAFD has grown into a respected patient organisation representing approximately 100 members and supporting people across both classical and late-onset Fabry disease.

TAFD's work spans four key areas:

- Patient rights and advocacy
- Health education
- Patient support and care
- International collaboration

The Expert Meeting reflected this longstanding partnership and highlighted the importance of strengthening relationships throughout Asia. Beyond hosting the meeting, TAFD played a key role in shaping the program. TAFD facilitated local engagement and strengthened connections between the Taiwanese and international Fabry communities.



*The TAFD team and Mary Pavlou, FIN president — Taiwan Association of Fabry Disease*

## A partnership built on Community and Collaboration

The Expert Meeting in Taipei also created a wonderful opportunity to celebrate a significant milestone: the Taiwan Association of Fabry Disease (TAFD) marked its 15th anniversary. Since its founding in 2011, TAFD has grown from a small patient support group into a nationally recognised organisation — and this anniversary was a moment to recognise the dedication, resilience and advocacy of its members, families and supporters over more than a decade.

Alongside the Expert Meeting, TAFD also held its annual general meeting, bringing together members from across Taiwan to reflect on the past year, share experiences and plan for the future. The presence of the international FIN community added a special dimension to these celebrations, reinforcing the deep ties between Taiwan's Fabry community and the global network.

The anniversary was a powerful reminder of what patient organisations can achieve over time: improved awareness, stronger advocacy, better access to care and a community where no one faces Fabry disease alone. FIN congratulates TAFD on 15 years of impactful work and looks forward to many more years of collaboration.



*TAFD 15th anniversary celebration — the entire Fabry community gathers*

## Sharing What Works: Learning from One Another

The meeting began with a dedicated member exchange programme where FIN member organisations shared successful initiatives, challenges and lessons learned from their national communities.

Discussions covered case studies around advocacy initiatives, awareness campaigns, patient support programmes, fundraising approaches and community engagement strategies.

These exchanges demonstrated one of FIN's greatest strengths: the ability to connect organisations facing similar challenges and create opportunities for mutual learning.



*Member exchange sessions — participants sharing experiences and initiatives*

## Scientific Programme Highlights

### Fabry Disease in Taiwan

*Dr Dau-Ming Niu*

Dr Niu provided an overview of Taiwan's unique experience with Fabry disease, including one of the world's most extensive newborn screening programmes.

Participants learned how large-scale screening has expanded understanding of Fabry disease and led to the identification of many individuals carrying disease-causing variants. Particular attention was given to the IVS4 cardiac variant, which is especially prevalent in Taiwan and has contributed significantly to international understanding of later-onset Fabry disease.

#### Key Messages

- Early diagnosis creates opportunities for earlier intervention.
- Disease progression can begin long before symptoms become apparent.
- Long-term monitoring remains essential throughout life.
- Screening programmes continue to generate important clinical insights.



*Dr Dau-Ming Niu presenting on Taiwan's Fabry screening programme*

## The Voice and Impact of the Taiwan Fabry Community

### *Taiwan Association of Fabry Disease (TAFD)*

TAFD shared its journey from a small patient support group to a nationally recognised patient organisation. The presentation highlighted how patient-led initiatives can improve communication, strengthen care and influence policy. Importantly, TAFD emphasised that patient voice becomes meaningful when it leads to practical action.

#### **Four Messages from the Taiwan Fabry Community**

1. See the person, not only the biomarker.
2. Communicate uncertainty clearly and honestly.
3. Treat families as long-term partners.
4. Build systems that are practical and fair.



*TAFD presentation — patient perspectives and community impact*

## Heart Health in Fabry Disease

*Dr Chih-Hung Lai*

Dr Lai explored the relationship between genetics and cardiac manifestations in Fabry disease, highlighting the importance of personalised monitoring and management. Participants gained insight into the complexity of Fabry cardiomyopathy and the role of precision medicine in understanding individual disease risk.



*Cardiology session with Dr Lai*

## The Fabry Ear: What Patients and Clinicians Should Know

*Dr Yen-Fu Cheng*

Dr Cheng highlighted an often-overlooked aspect of Fabry disease: hearing and balance. Research presented during the session demonstrated that hearing loss, tinnitus and vestibular dysfunction are common among people living with Fabry disease and may occur even before symptoms are recognised. Auditory abnormalities were shown to be associated with greater cardiac disease burden, suggesting that hearing assessments may provide additional insight into overall disease progression.

### Key Messages

- Hearing and balance problems are common in Fabry disease.
- Many abnormalities are present before symptoms are noticed.
- Auditory findings may reflect broader disease burden.
- Routine hearing surveillance should be part of Fabry care.



*Dr Yen-Fu Cheng presenting on hearing and vestibular symptoms in Fabry disease*

## Women and Fabry Disease

*Dr Masahisa Kobayashi*

Dr Kobayashi challenged outdated perceptions that women experience only mild manifestations of Fabry disease. Through clinical examples and scientific evidence, he demonstrated the wide range of symptoms experienced by women and highlighted the impact of random X-chromosome inactivation in determining disease severity.

The session also explored the psychological burden experienced by women living with Fabry disease and the importance of appropriate recognition, monitoring and support.



*Dr Masahisa Kobayashi presenting on women and Fabry disease*

## Strength from Within: Nutrition, Lifestyle and Building Resilience

*Dr Seema Kanwal*

Dr Kanwal focused on practical strategies that can support health and wellbeing alongside medical treatment. Topics included cardiovascular health, kidney protection, gastrointestinal symptoms, hydration, fatigue management, sleep, movement and stress reduction.

Participants were encouraged to focus on sustainable changes and realistic goals rather than perfection. Nutrition and lifestyle were presented as tools that complement treatment and support long-term resilience.



*Dr Seema Kanwal presenting on nutrition, lifestyle and resilience*

## Understanding Fabry Care Today: What every patient should know

*Dr Robert Hopkin*

Dr Hopkin provided a comprehensive overview of current Fabry disease management and monitoring. The session highlighted the importance of multidisciplinary care and helped participants better understand how monitoring supports treatment decisions throughout life.

A central message was that informed patients become stronger partners in their own care.



*Dr Robert Hopkin presenting on Fabry disease diagnosis and care*

## Workshop Highlights

### Fabry Care in Real Life

*Facilitated by Dr Robert Hopkin*

Participants explored practical challenges associated with treatment decisions, symptom monitoring and communication with healthcare teams. Key themes included self-advocacy, preparing for appointments and understanding the purpose of ongoing monitoring.



*Workshop: Fabry Care in Real Life — facilitated by Dr Robert Hopkin*

## Strength From Within

*Facilitated by Dr Seema Kanwal*

Participants discussed practical approaches to nutrition, energy management, stress reduction and healthy routines. The workshop encouraged attendees to identify realistic actions they could implement in their daily lives.



*Workshop: Strength From Within — facilitated by Dr Seema Kanwal*

## Key Themes Emerging from Taipei

Across all sessions and discussions, several themes consistently emerged:

### Key Themes

- Earlier diagnosis creates opportunities for better outcomes.
- Patients and families are essential partners in care.
- Holistic wellbeing matters alongside medical treatment.
- Women living with Fabry disease require greater recognition and support.
- International collaboration accelerates learning and progress.
- Strong patient communities improve resilience and quality of life.

## Looking Ahead

The 2026 Expert Meeting demonstrated the power of bringing together science, experience and community. The connections formed in Taipei, the knowledge shared by experts and the perspectives offered by patient leaders will continue to inform FIN's work throughout the coming year.

FIN extends its sincere thanks to all speakers, participants, industry partners, volunteers and member organisations who contributed to the success of the meeting.

Special thanks to the Taiwan Association of Fabry Disease for their partnership, hospitality and dedication to strengthening the global Fabry community.

We look forward to continuing these conversations and building on these relationships as we prepare for the next FIN Fabry Expert Meeting in Warsaw, Poland, in 2027.



*FIN Fabry Expert Meeting 2026 — FIN Board*