HEALTHY LIVING MEETING FOR MPS PATIENTS AND THEIR FAMILIES IN TURKIYE (2026)

Results and Social Impact Report of the Patient Support Project Carried Out by MPSTURK Under the 'SSIEM Patient Group Support Programme'

EXECUTIVE SUMMARY

The Healthy Living Meeting for MPS Patients and Their Families in Türkiye brought together 171 participants through a multidisciplinary educational programme supported by the SSIEM Patient Group Support Programme. The project achieved outstanding outcomes, with 91.5% overall participant satisfaction, 97.9% satisfaction with the organisation of the event, and 95.7% of participants reporting that the knowledge gained would have a direct positive impact on their daily lives. The programme strengthened health literacy, enhanced psychosocial support, and promoted patient empowerment. This report summarises the project's measurable outcomes, social impact, and future vision.

BUILDING A STRONGER FUTURE TOGETHER

Mucopolysaccharidoses (MPS) are rare diseases that affect not only patients but also their families, with physical, psychological, social and economic impacts, and require lifelong multidisciplinary care.

Sustainable and successful outcomes in rare diseases depend not only on innovative treatments but also on access to reliable information, holistic care and the development of strong patient communities. With this understanding, our primary objective at MPSTURK since our inception has been to improve the quality of life for individuals living with MPS and their families, to facilitate their access to healthcare services and to make the patient experience integral to the healthcare system. Individuals with rare diseases and their families require psychosocial support beyond medical treatment, as well as safe community spaces where they can share their experiences. To address these critical needs, which are often overlooked by the healthcare system, our project aims to fill this gap through a multidisciplinary, holistic and patient-centred approach.

In line with this objective, the ‘Healthy Living Meeting for MPS Patients and Their Families in Türkiye’, organised at Ankara University on 10 May 2026 with support from the SSIEM Patient Group Support Programme, was not merely an educational meeting; it served as a model patient support programme that brought together patient empowerment, a multidisciplinary approach and social solidarity under one roof. A total of 171 people, including parents, siblings, other family members and MPS patients, attended the event, and a feedback survey was completed by 83 participants.

AIM OF THE PROJECT

The primary aim of this project was to develop a holistic educational model capable of addressing the challenges faced by MPS patients and their families in their daily lives, not only from a medical perspective but also across their physical, psychological and social dimensions.

The programme brought together paediatric metabolism, physiotherapy and rehabilitation, nutrition, oral and dental health, psychology, breathing and meditation practices, and creative arts activities. In this way, participants not only received up-to-date information from specialists but also had the opportunity to engage in one-to-one communication with professionals from different disciplines and share their own experiences.

This approach aimed to strengthen a patient-centred approach to care whilst supporting families in taking a more active role in their own care.

MEASURABLE RESULTS

The evaluation questionnaire conducted following the event indicates that the project largely achieved its objectives.

Whilst 91.5% of participants were satisfied or very satisfied with the event, 89.4% found the programme content adequate, and 97.9% rated the organisation as successful. More importantly, 95.7% of participants stated that the knowledge they had gained would contribute directly to their daily lives. This result demonstrates that the programme did not merely provide theoretical knowledge; it also equipped families with practical skills they could apply in their caregiving practices.

One of the programme's most notable outcomes is its psychosocial impact. 91.5% of participants reported feeling more supported and less alone following the event. This finding highlights just how critical social support networks are in the field of rare diseases and underscores the direct impact that such initiatives have on families' quality of life (Figure 1).

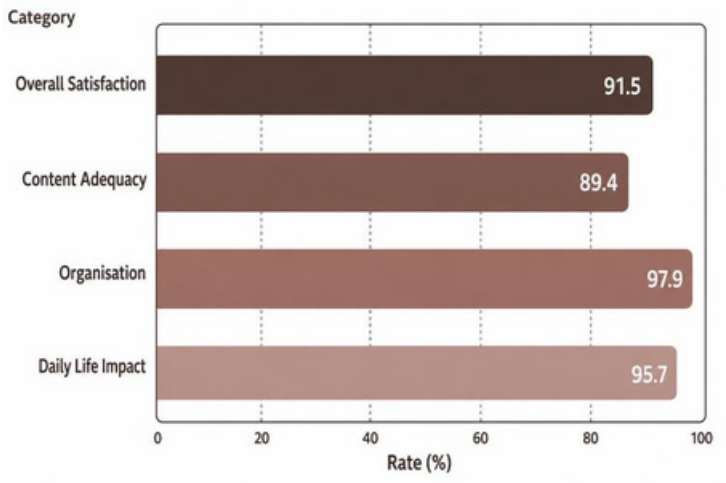

Figure 1. Participant Satisfaction and Perceived Impact of the Programme

Hand-painted tote bags created by our patients during the creative arts workshop.

AN IMPACT BEYOND THE NUMBERS

This project has created a lasting social impact that extends beyond participant numbers and satisfaction rates.

Throughout the event, families had the opportunity to meet others with similar experiences, share information and build long-term networks of solidarity. Direct communication with healthcare professionals has supported families' more active participation in treatment and raised awareness of the importance of a multidisciplinary approach. At the same time, the programme has further strengthened MPSTURK's position as a reliable and sustainable patient support platform at the national level.

ADDED VALUE PROVIDED BY THE PROJECT

This project went beyond educational activities to contribute to patient empowerment, the improvement of health literacy and the development of sustainable social support mechanisms. Feedback at the end of the programme demonstrated that the project delivered significant benefits at both the individual and societal levels.

- **Patient empowerment:** Participants had access to up-to-date, reliable information on disease management directly from specialists and received practical advice they could apply in their daily lives. These gains have enhanced individuals' self-efficacy by supporting more informed and active participation in their treatment processes.

- **Families' access to information:** In rare diseases such as MPS, families are the most important stakeholders in the care process. The event enabled families to receive comprehensive information from various specialist fields, offering scientific and practical solutions to the challenges they face; it also facilitated access to accurate information.

- **Increased health literacy:** The scientific content shared throughout the programme not only raised awareness of the condition but also strengthened participants' health literacy on topics

such as treatment options, rehabilitation, nutrition, oral and dental health, and psychosocial support. The fact that the vast majority of participants stated that the knowledge they gained would contribute to their daily lives is a concrete indication of this impact.

- **Strengthening of interdisciplinary collaboration:** The coming together of specialists from paediatric metabolism, physiotherapy and rehabilitation, dentistry, nutrition, psychology and other fields within the same programme has demonstrated that MPS can only be effectively managed through a multidisciplinary approach. This structure has encouraged the sharing of knowledge amongst healthcare professionals whilst also enabling families to experience a holistic approach to care.

- **Empowering the patient community:** In rare diseases, social isolation and loneliness are among the most significant challenges for families. Through the event, participants met other families with similar experiences, exchanged insights and formed strong social bonds that can endure over the long term. The fact that the majority of participants reported feeling more supported after the event demonstrates that the programme successfully achieved its goal of community building.

- **Improved communication with healthcare professionals:** The programme fostered open, reciprocal communication among patients, their families and healthcare professionals. Through presentations and question-and-answer sessions, families were able to convey their needs directly to specialists, whilst healthcare professionals gained a closer understanding of patients' experiences. This interaction has significantly strengthened the patient-centred care approach and will play a key role in future educational and support programmes.

Consequently, this project was not merely a short-term educational event; by bringing together knowledge sharing, patient empowerment, interdisciplinary collaboration and social solidarity, it has established a comprehensive patient support model that delivers sustainable value for the MPS community. The experience gained and the feedback received provide a strong foundation for developing similar programmes in the future.

THE CONTRIBUTION OF THE MULTIDISCIPLINARY CARE MODEL

Participant evaluations have shown that families have the greatest need for practical information to make their daily lives easier.

The sessions that received the highest benefit scores, in order, were: physiotherapy recommendations (70.2%), medical information (66.0%), oral and dental health (61.7%), breathing and meditation exercises (51.1%), nutrition recommendations (46.8%) and psychological support (44.7%) (Figure 2).

These results demonstrate that a multidisciplinary approach to MPS management is regarded as the most valuable care model not only in theory but also by patients and their families.

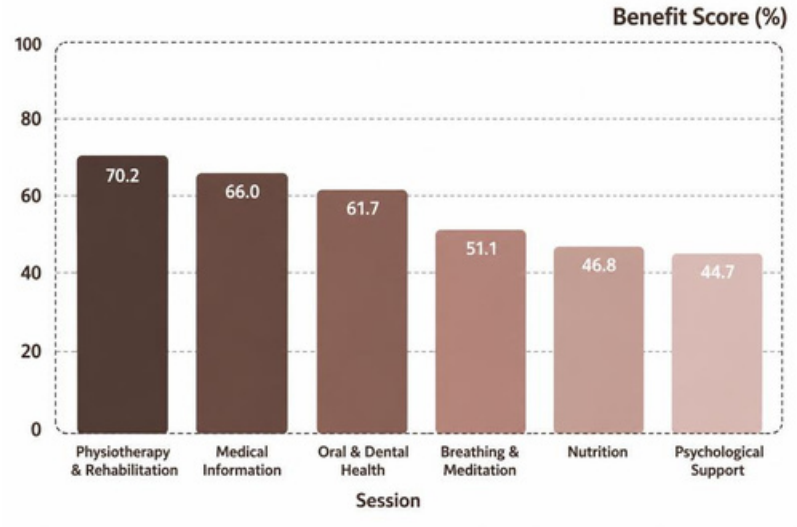

Figure 2. Participant-Reported Benefit of Programme Sessions

LOOKING AHEAD

Feedback from participants has provided an important roadmap for future programmes. The most requested topics included new treatment options, current clinical developments, eye and dental health, disability rights, psychosocial support and educational programmes for children. MPSTURK aims to diversify its educational activities, increase the production of digital content and ensure the sustainability of multidisciplinary patient support programmes, taking this feedback into account.

Public institutions, academic centres, healthcare professionals and sector partnerships committed to ethical principles play a vital role in achieving these objectives. Supporting organisations do not merely contribute to a single event; they also partner to create long-term social impact that enhances the quality of life for individuals living with MPS, strengthens health literacy and brings the patient community together.

IN MEMORIAM

In Memory of Our Beloved Aliye Azra,
Who Courageously Lived with
Mucolipidosis Type II (I-Cell Disease)
and Joined Our Healthy Living Meeting

Her joy, warm smile, and love of life left an unforgettable mark on the hearts of everyone who had the privilege of knowing her. Although she left us far too soon, her memory and the hope she inspired will live on with us.

We dedicate this report, and the hope it embodies, to the cherished memory of Aliye Azra and to all children, young people, and families living with rare diseases. The story of Aliye Azra and her family's courage, love, and resilience continually strengthens our commitment to improving care, raising awareness, and building a more inclusive and supportive future for everyone affected by Mucopolysaccharidoses, Mucolipidoses (ML), and other lysosomal storage disorders.

We remember our dear Aliye Azra with love, gratitude, and deep respect.

ACKNOWLEDGEMENTS

At MPSTURK, we believe that sustainable patient support programmes do more than provide information; they empower families, strengthen patient communities, and contribute to a more inclusive healthcare ecosystem. We remain committed to developing initiatives that bridge scientific knowledge with lived patient experience and ultimately improve the quality of life of people living with MPS.

The SSIEM Patient Group Support Programme was the driving force behind the implementation of this project. Beyond providing financial support, the programme inspired MPSTURK to develop and deliver this initiative and made it possible to prepare educational materials, provide travel support for participants, organise multidisciplinary workshops, and bring together experts from different disciplines to deliver a comprehensive educational programme.

We would like to express our sincere gratitude to the **SSIEM** Board for their invaluable support and trust.

We also extend our heartfelt thanks to our project partners and stakeholders: the Ankara University Faculty of Medicine, Department of Paediatrics, Division of Paediatric Metabolic Diseases; the Ankara University Rare Diseases Application and Research Centre (NADIR Centre); and the Ankara University Faculty of Medicine Rare Diseases Student Society (NADIRAN) for their outstanding collaboration and commitment.

Our deepest appreciation also goes to all patients and their families whose participation gave true meaning to this project, as well as to every speaker, volunteer and team member whose dedication made this meeting possible.

We hope this successful partnership will continue to grow, enabling us to reach more families, strengthen the MPS community, and have an even greater impact in the years ahead.

Together, we are building a stronger future for everyone living with MPS — one family, one partnership and one step at a time.

MPSTURK Board of Directors

EVENT PHOTO ARCHIVE;

https://drive.google.com/drive/folders/1aMT_wgXu0Y7sVpmNp_liUSWUEks6GSGX?usp=sharing

OUR SOCIAL MEDIA POSTS ABOUT THE EVENT;

https://www.instagram.com/p/DYE4-9Ajcrv/?igsh=dDRjd2FmYW11eDl6

https://www.instagram.com/p/DZDJOqvjRrh/?img_index=1&igsh=MXN4bDR6YzdrZHlxeQ==

https://www.instagram.com/reel/DY9o4k-Nyf4/?igsh=MWxmclTk4Znd0cDZqaA==

CONTACT US;

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- **Instagram:** instagram.com/mpslhdernegi
- **Facebook:** facebook.com/mpslhdernegi
- **YouTube:** youtube.com/mpslhdernegi
- **X:** x.com/MPSLH

Official event poster and programme leaflet prepared for the Healthy Living Meeting for MPS Patients and Their Families, held on 10 May 2026.

May 10, 2026 – Sunday	
09:00 – 09:20	Registration
09:20-10:10	**Opening Session** Program Introduction and Opening Remarks Ayfer Ergüzel President, MPS-LH Association Prof. Dr. Fatma Tuba Eminoğlu Ankara University Faculty of Medicine Department of Pediatric Metabolism & The Rare Diseases Application and Research Center of Ankara University
10:10-10:30	**Patient and Family Guidance in MPS: Informational and Supportive Approaches** Dr. Merve Koç Yekedüz Ankara University Faculty of Medicine Department of Pediatric Metabolism & The Rare Diseases Application and Research Center of Ankara University
10:30-10:40	*Coffee Break*
10:40-12:00	**Workshop: Breathing and Meditation Practices** Dr. Burcu Cirit Atatürk Sanatorium Training and Research Hospital Department of Chest Diseases
12:00-12:10	**Group Photograph**
12:10-13:00	*Lunch Break*
13:00-13:20	**Oral and Dental Health Management in Patients with MPS** Dr. Merve Berika Kadıoğlu Ankara University Faculty of Dentistry Department of Orthodontics

13:20-13:40	**Physiotherapy Applications in MPS** Dr. Süleyman Korkusuz Atılım University Faculty of Health Sciences Department of Physiotherapy and Rehabilitation
13:40-14:00	**Nutritional Management in MPS: Practical Recommendations for Daily Life** Dr. Furkan Yolcu, MD, Dietitian Ankara University Faculty of Medicine Cebeci Children's Hospital Nutrition and Diet Unit
14:00-14:20	**Living with a Chronic Disease: Psychological Resilience and Empowerment** Fürüzan Eroğlu, Clinical Psychologist *MPS-LH Association*
14:20-14:30	*Coffee Break*
14:30-15:30	**Workshop: Percussion (Rhythm Instruments)** Sevgi Kaplan
15:30-16:30	**Workshop: Creative Arts** Alev Şaylan
16:30-17:00	**Closing Session** **General Evaluation** **Patient and Family Experience Sharing Discussion and Q&A**
	Satisfaction Survey **Certificate of Appreciation Ceremony** **Closing Remarks**