

REPORT

Adult MPS patients meeting

STAND ON YOUR OWN

The second Adult MPS patients meeting was held from 17th to 20th October 2019 in hotel West Point in Verona, Italy.



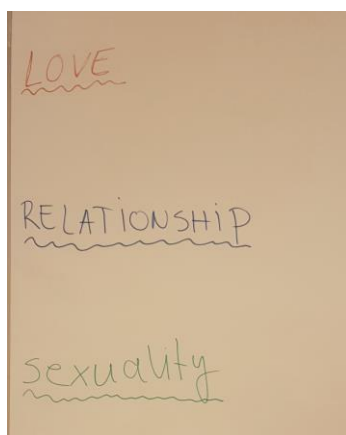
The goal of this meeting was to encourage adult MPS patients to be independent – stand on their own. MPS Europe provided 24 fellowships for adult MPS patients to participate the meeting. The fellowships covered travel costs, accommodation, transfer and meals. Participants age range was between 17 and 55 years from 10 different European countries.



This year we had a very busy agenda, from intensive psychological workshops, communication between patients and physicians, cross-border healthcare, education about clinical trials, drug development and gene therapies, to therapeutic exercises – Pilates. We also exchanged opinions about living in Europe with MPS and spent great time in sightseeing Verona and listening to MPS talents. Sessions were in English and translation to Italian and Spanish was provided by national MPS societies.

First **psychological workshop** *Me, myself and MPS: How to live beyond my symptoms?* was created and facilitated by Milica Ristic, MD, psychiatrist and RE&CB psychotherapist and Andrea Nenadic, social worker and gestalt psychotherapist under supervision. The aim of this workshop was to present self-help cognitive, emotional and behavior techniques as tools to solve problems which people with MPS are dealing with in everyday life.

ABC model has been offered as an approach to recognize irrational beliefs that are blocking them in achieving their social, professional and relationship goals, resulting profound suffering, deprivation, isolation and self-stigmatization. During group interactive discussion they were facilitated to share their own experience which created trusty atmosphere and strengthened the idea that there are not alone. Then the group focused on term “learned helplessness” and how MPS patients can better understand themselves. Through knowledge they got, they were able to realize how environment can be overprotective and make patients to feel like they are without control. MPS patients were asked to write negative messages and believes from environment/society that blocks them. Afterwards patients were asked to write positive messages that present their life path and believes that support them. Workshop was highly useful for them because they got the tools that can be used in the future and allow them to show themselves, be authentic and be accepted.



For the **second psychological workshop** participants were split to male and female group. Milica was working with female, while Andrea was in a male group. The aim was to share their own experiences and ideas about very important fields of our human life: **love, relationships and sexuality**. Roll of the facilitator was to guide through this exchange and to support most effective solutions.

The most precious for participants was opportunity to speak with someone on topics of relationship and sexuality for the first time. They were overwhelmed with possibility to be heard and speak openly so workshop looked more like a support group.

Prof. Maurizio Scarpa, from Udine University Hospital, Italy and Coordinator of European Reference Network for Hereditary Metabolic Diseases (MetabERN) led a discussion with participants about **communication between patients and physicians**. He pointed out positives such as importance of expertise, following medical advice and therapy effect approach but also negatives in how patients feel in this communication such as: missing information, loneliness, lack of interest in transition and difference in prediction vs reality. He introduced **cross-border healthcare services** that are available for patients in EU and how MetabERN and European Commission are working together in the interest of rare metabolic patients on EU level.



In the session **Living in Europe: put needs and expectations together** Sara Burgess first shared with the group personal experiences of living with ML III in UK in her fantastic presentation “Keeping my marbles guide”. Sarah talked about her challenges with getting diagnosis, surgeries, education, employment and living independently.

Steve Cotterell, Advocacy Team Lead from MPS Society UK presented support services they provide for patients and families from telephone helpline, disability benefits, help with housing and equipment, help for independent living and transition to bereavement support. MPS UK recently started with Young adults advisory board and key themes identified are: life skills and independent living, employment, benefits and financial advice, mental health, education, exams and university, practicalities of living with a disability.

Afterwards all attendees had an opportunity to give their inputs on these topics and which support services are available in their countries. Conclusion is that there are huge discrepancies among countries, especially regarding social benefits and provisions, and that social systems don't recognize disabilities caused by rare diseases in a proper way.



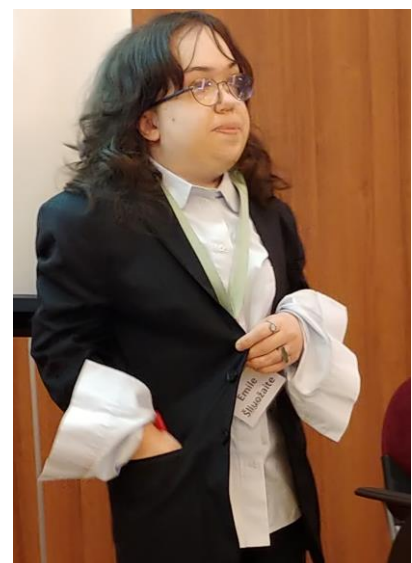


A lot of clinical trials for MPS are currently ongoing and many patients are eligible to participate. This is why we organized a short **education about clinical trials and drug development** to help them understand how the drug is developed and what are the phases of clinical trials. We had an opportunity to hear from Sangamo and Regenexbio, two leading research pharmaceutical companies, about their approaches to gene therapies development for MPS I and II.



Emile Šliuožaitė shared with the group her personal experience with a clinical trial for her condition. Her speech raised questions among participants: Is the result worth going through it? How to deal with family putting pressure? How to fill in a gap between expectations from patient and his/her family?

We had time for a group discussion about clinical trial endpoints and how MPS community can influence. The participants agreed that 6-minute Walk Test (6MWT) has no effect on patients' real life, more important is ie. how tired they get. The group thinks that safety, security and results are important, but also patients want to be treated as humans not as objects, they want to talk to someone with the same condition and not to feel like companies are only doing them a favor.





Born with MPS I Scheie, Barbara Mamatis faced the need from a young age to train her body, listen to its needs while trying out various alternative, therapeutic approaches that experience movement as a medium for healing, expression and personal development ultimately achieving her self-healing, artistic expression and empowerment. She graduated in Therapeutic Refined Pilates addressed to people with or without a disability.

At our meeting Barbara introduced **Pilates** holistic approach, a complete coordination of body–mind–spirit where great emphasis is placed on breathing and on the fine details of how to perform each movement in a slow, precise manner.



In the **Art & MPS** session we found out that MPS has many talents. These amazing people express creativity in various ways such as: singing, playing instruments, photography, directing films, painting, drawing, dancing, stand-up comedy and making jewelry. MPS Europe, together with all national MPS societies, has to find suitable means to support them.

Positive feedback from participants and wishes to be more actively engaged in MPS Europe in an Adult patients' advisory board are highly appreciated and give direction on how to meet their needs in the future.



At the end I want to express great gratitude to all adults who participated at our second Stand on your own meeting and to all National MPS Societies that gave support to this event.



If you are an adult affected with MPS or related disease and are interested in our activities, send an email to adultsupport@mps-europe.org to receive latest news from MPS Europe, follow our Facebook page MPS Europe or join Facebook group MPS Europe Adults.

Looking forward to our next meeting in Spain, 15-18 October 2020!

*Marija Joldic
MPS Europe
October, 2019*