

MESSAGE FROM MPE'S BOARD PRESIDENT



Dear friends, colleagues, and supporters,

As the new Board President of Myeloma Patients Europe (MPE), I am honoured to continue the legacy of strong and innovative leadership established by my predecessors. A transition allows us to reflect on past achievements and challenges, as well as consider our future goals and direction, and the Board has never been more confident in MPE's ability to fulfill its mission to empower European advocacy and best support myeloma and AL amyloidosis patients.

With the myeloma pathway evolving quickly, I'm optimistic about what the future holds for patients as quality of life improves, treatment options expand, and we progressively work towards a cure. However, patients' unmet needs must be central to this work and, perhaps now more than ever, MPE and our members' role in helping to educate and involve the patient community, shape drug development, fill gaps in patient evidence, and increase access to innovative treatments is indispensable.

In this report, you'll read about MPE's activities and programmes that reflect this role. Key accomplishments in 2022 include the launch of several patient research projects to generate the evidence required to advocate for the complex needs of patients with decision-makers; working closely with members to increase patient involvement in health technology assessment (HTA); and engaging earlier and more often with pharmaceutical partners to ensure that the patient perspective is meaningfully reflected in clinical trial design. I look forward to the continued growth and evolution of these initiatives in the years ahead as we continue our efforts to improve patient treatment, care, and access across Europe.

We extend a heartfelt thank you to our members, sponsors, and stakeholders for your ongoing dedication and inspiration. The milestones MPE has reached this year would not have been possible without your partnership and we share these achievements with each of you.

Best wishes,

LISE-LOTT ERIKSSON

President of Myeloma Patients Europe

MYELOMA PATIENTS EUROPE

Myeloma Patients Europe (MPE) is an umbrella organisation of myeloma and AL amyloidosis patient groups across Europe. The mission of the organisation is to provide education, information, and support to member groups and to advocate at European, national, and local levels for the best possible research and equal access to treatment and care. To achieve its aims, MPE works directly with members, healthcare professionals, reimbursement authorities, regulators, politicians, pharmaceutical companies, and the media to ensure all stakeholders are collaborating to improve patient outcomes and reduce inequalities across Europe.

MPE's Strategic Objectives

In 2019, MPE's board and membership developed and confirmed seven strategic objectives to guide our work programme through 2024. All of the activities of MPE support one or more of the following:

- Provide a strong voice for myeloma and AL amyloidosis patients at a European and international level
- Strengthen members' and individual advocates' ability to advocate effectively
- Secure a larger patient voice in myeloma and AL amyloidosis research
- Accelerate progress in the treatment and care of myeloma and AL amyloidosis patients
- Increase the number of patients who have their myeloma and/or AL amyloidosis diagnosed in a timely manner
- Improve access to optimal treatment and care for all myeloma and AL amyloidosis patients in Europe
- Strengthen MPE's effectiveness, sustainability, and capacity to take collective action









Promotes research in the interests of myeloma patients



Strengthens myeloma patient organisations' advocacy capacity

MPE MEMBERSHIP

In 2022, MPE had 47 full and associate members representing 30 different countries. MPE continues to grow and support its members to create a network of highly efficient, effective, and sustainable patient organisations across Europe.



Full Members

Armenia

• Armenian Hematology Association

Austria

- Multiples Myelom Selbsthilfe Öesterreich (MMSOe)
- Myelom- und Lymphomhilfe Österrecih

Belgium

- Contactgroep Myeloom en Waldenström Patiënten Vlaanderen vzw (CMP vzw)
- MyMu Wallonie-Bruxelles (MyMu)

Croatia

- Udruga za podršku oboljelima od multiplog mijeloma (Mijelom CRO)
- Hrvatska udruga leukemija i limfomi (HULL)

Denmark

• Dansk Myelomatose Forening

+ Finland

Suomen Syöpäpotilaat –
 Cancerpatienterna i Finland ry

France

 Association Française des Malades du Myélome Multiple (AF3M)

Germany

- AMM-Online
- Deutsche Leukämie- & Lymphom-Hilfe e.V. (DLH)
- Myelom-Gruppe RHEIN-MAIN Leukaemiehilfe RHEIN-MAIN e.V. (LHRM)
- Myelom Deutschland e.V.

Iceland

Perluvinir

() Ireland

• Multiple Myeloma Ireland

🔻 Israel

- AMEN Israel
- Amyloidosis Israel

Latvia

 Onkologisko pacientu atbalsta biedriba "Dzivibas koks"

Lithuania

• Asociacija "Kraujas"

🏶 Macedonia

- BORKA
- HEMA

Netherlands

- Stichting Hematon
- Stichting Amyloïdose Nederland (SAN)

H Norway

Blodkreft Foreningen

Poland

- Fundacja Carita Żyć ze Szpiczakiem
- Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka

Portugal

- Associação Portuguesa Contra a Leucemia (APCL)
- Associação Portuguesa Leucemias e Linfomas (APLL)

Romania

- Myeloma Euronet Romania (MER)
- SOS Mielom

Russia

 Society for Assistance to Patients with Oncohaematological Diseases "Mercy Bridge"

Serbia

 Udruzenje obolelih od multiplog mijeloma

Slovakia

- Združenie pacientov s hematologickými malignitami
- Slovenská myelómová spolocnost

Slovenia 🖢

- Drustvo bolnikov z limfomom (DBL)
 Slovensko Združenje Bolnikov Z
- Limfomom In Levkemijo L&L
- Društvo bolnikov s krvnimi boleznimi Slovenije

Spain

- Asociación Española de Amiloidosis (AMILO)
- Agrupación Española Contra la Leucemia y Enfermedades de la Sangre (AELCLES)

🐤 Sweden

Blodcancerförbundet Sweden

Switzerland

- Stiftung zur F\u00f6rderung der Knochenmarktransplantation Schweiz
- MPS Myelom Patienten Schweiz

Turkey

KANKO/BIRKAN

United Kingdom

Myeloma UK

Associate Members

Czech Republic

 Klub pacientů mnohočetný myelom, z.s.

National Bosnia and Herzegovina

• Bosnian Myeloma Patient Group

Portugal

 Centro de Histocompatibilidade do Norte (CHN)

MPE extends a special thank you to our members and the myeloma and AL amyloidosis patient community. Your work is invaluable to the patients you support and we remain inspired by your tireless efforts to improve patients' lives.

MPE BOARD

The MPE Board is multidisciplinary and responsible for the strategy, governance, and accountability of the organisation. The Board is comprised of myeloma patients, caregivers, and advocates.

MPE's 2022 Board Members



Lise-lott Eriksson, President (Sweden)



Ron Dloomy, Vice-President (Israel)



Biljana Dodeva, Treasurer (Macedonia)



Riikka-Leena Manninen, Secretary (Finland)



Ananda Plate, Board Member (Spain)



Barbara Leonardi, Board Member (Poland)



Diane Loening-Martens, Board Member (Germany)



Zvika Zilberman, Board Member (Israel)

MPE MEDICAL ADVISORY COMMITTEE

Our Medical Advisory Committee provides evidence-based recommendations to MPE and members in support of advocacy initiatives, as well as updates on myeloma and AL amyloidosis disease, diagnostics, and treatments. It includes key opinion leaders representing myeloma and AL amyloidosis specialties, as well as MPE's member countries.

2022 Medical Advisory Committee members:

- Prof. Heinz Ludwig (Austria)
- Dr. Vsevolod Potapenko (Russia)
- Prof. Roman Hájek (Czech Republic)
- Dr. Paolo Milani (Italy)
- Dr. Ulf-Henrik Mellqvist (Sweden)
- Dr. Charlotte Pawlyn (United Kingdom)
- Prof. Pieter Sonneveld (The Netherlands)
- Prof. Michel Delforge (Belgium)
- Dr. Anna Sureda (Spain)
- Dr. Laurent Garderet (France)
- Dr. Moshe Gatt (Israel)
- Prof. Oliver Karanfilski (Republic of North Macedonia)
- Dr. Valdas Pečeliūnas (Lithuania)
- Prof. Katja Weisel (Germany)
- Prof. Sonja Zweegman (Netherlands)
- Prof. Meral Beksac (Turkey)
- Prof. Efstathios Kastritis (Greece)
- Prof. Monique Minnema (The Netherlands)
- Dr. Magdalena Olszewska-Szopa (Poland)

MPE STAFF

MPE is comprised of an international team of professionals committed to meeting the evolving needs of our members and the patient community. Through their efforts, MPE successfully develops and implements programmes and projects that fulfil the organisation's mission.

Access and Policy



Kate Morgan, Chief Strategy Officer



Anne-Pierre Pickaert, Access to Medicines Secretariate

Patient Evidence



Silene Ten Seldam, Research Assistant

Medical Education and Scientific Engagement



Solène Clavreul, Head of Medical Education and Scientific Engagement



Morine Maguri, Project Officer

Communications



Ana Vallejo, Head of Communications



Patricia Matamoros, Communications Officer

Member and Patient Community Programmes



Katie Joyner, Chief Operating Officer



Linda Christopher, Project Manager

Finance and Operations



Ingrid Jenisch, Finance and Reporting Officer



Valentina Christodoulidou, Operations Officer

2022 MPE PROGRAMME HIGHLIGHTS

MPE has reached impressive milestones this year through the collaborative efforts of our members, staff, and stakeholders. Below provides a summary of the major accomplishments from each workstream.



ACCESS AND POLICY

To ensure all patients have access to the best treatment and care and to represent their interests at the European level

MPE's Access and Policy workstream provides members with the tools and resources to advocate effectively for better access to treatment and works closely with regulators and policymakers to influence decisions and initiatives that impact access across Europe. MPE's major accomplishments in 2022 include:



Continued to provide country-specific and comparative information on European healthcare systems through MPE's Myeloma Access Atlas to underpin advocacy efforts to overcome variation in access to treatment and care in Europe

Presented the Atlas at several congresses and roundtable discussions to help stakeholders, as well as advocates in other disease areas, understand the utility of the tool in driving evidence-based advocacy





Conducted research on the use of quality-of-life (QoL) instruments and patient-reported outcome measures (PROMs) reported in clinical trials and published literature in myeloma

Delivered tailored coaching and support to members through the Atlas Coaching Programme, helping organisations in Poland, Macedonia, and Portugal address specific national access and/or reimbursement challenges





Provided training on national HTA processes and how patient organisations can participate and influence decision-making

Published research on barriers to access in myeloma clinical trials in Central and Eastern European (CEE) countries and recommendations to reduce access inequalities in the region





Conducted patient interviews and delivered written submissions to the European Medicines Agency (EMA) in support of new medicines and facilitated patient representation for assessment processes



MEDICAL EDUCATION AND SCIENTIFIC ENGAGEMENT

To promote scientific progress to address the greatest unmet needs in myeloma

MPE's Medical Education and Scientific Engagement department aims to promote understanding and education around medicine, clinical trials, and research to strengthen advocacy efforts and support patients to make informed choices around their treatment options. Through this workstream, MPE reached the following milestones this year:



Launched Phase II of MPE's Clinical Trial Navigator, a patient-friendly search tool for myeloma and AL amyloidosis clinical trials in Europe, which included the website design, data input, and user testing ahead of the public launch in 2023



Developed new educational materials including factsheets, animated videos, and an updated edition of our AL amyloidosis guide to help patients and carers better understand the diseases and treatment options



Conducted research to better understand the disease burden on the quality of life for AL amyloidosis patients



Welcomed new members of MPE's Medical Advisory Committee and continued to provide guidance on research priorities and educational materials, as well as treatment updates



Published educational resources for the patient community, including an updated myeloma patient guide, treatment factsheets, videos on CAR-T, myeloma, and minimal residual disease, interviews with clinicians, conference reports, and infographics

PATIENT EVIDENCE



To support informed, data-driven decision making through the generation of evidence on patient needs and preferences

MPE's Patient Evidence department generates data to support decision–making in myeloma and AL amyloidosis. Through collaborations with academic institutions, regulatory authorities, and pharmaceutical companies, MPE conducts research to inform clinical development, regulatory, reimbursement, and policy decisions with the aim of advocating for better and fairer care and treatment for patients across Europe. Achievements from 2022 include:

Launched research projects on shared decision-making and on the needs of working age myeloma patients in collaboration with industry, academia, and patient organisations





Conducted research on patient and haematologist perspectives on minimal residual diseases (MRD) and its use in treatment decision making

Developed research protocols for upcoming projects exploring patient preferences in drug administration and adaption of existing PRO tools to capture newer side effects in myeloma treatment





Continued to provide input into EORTC quality of life working group projects exploring financial toxicity, interpretation guidelines, and reference values

Published research on myeloma and AL amyloidosis diagnosis challenges and recommendations to reduce delays and impacts on quality of life



MEMBER AND PATIENT COMMUNITY PROGRAMMES

To build and empower a network of effective patient advocates and organisations across Europe and to provide a strong platform for the voice of myeloma and AL amyloidosis patients to be heard

MPE's Member and Patient Community workstream is comprised of several distinct programmes designed to educate, train, and galvanize patient advocates and patient organisations, as well as ensure meaningful patient involvement with stakeholders at the local, national, and European levels. This year, we accomplished several key objectives:

Provided scholarships for 10 member organisations to implement projects to meet the needs of their local patient communities, which included initiatives on patients' rights, personalised medicine, establishing patient support groups, and much more

Trained our largest cohort of the MPE Advocate Development Programme, a 12-month training programme for patient advocates, with 9 participants ranging from individual patients launching their advocacy careers to leaders of established organisations aiming to expand their activities

Hosted the first in-person Masterclass since the onset of COVID-19, bringing together 70 MPE members, industry partners, and other stakeholders for a two-day training event to exchange ideas, discuss challenges, and identify opportunities to work together to support patients

Engaged with key industry partners through MPE's Community Advisory Board (CAB) to discuss patient involvement in the drug development process, access challenges, unmet needs, and gaps in evidence, and identified specific action items to carry forward in the year ahead to improve outcomes for patients

Expanded the Myeloma Community Taskforce, a standing group of expert patients, to include additional members and take on new activities to ensure strong patient involvement in the drug development, research, and regulatory processes

EUROPEAN MYELOMA DAY



To raise awareness about myeloma, highlight the most important issues for European patients, and generate data to identify solutions

MPE launched the first-ever European Myeloma Day on 27 September 2022. The focus for 2022 was on diagnosis and the consequences of delays in detecting myeloma on time. To explore this issue, and support the patient community and member organisations in tackling the challenges, we carried out the following activities leading up to European Myeloma Day:



Conducted a pan-European study to capture patient diagnostic experiences, the impact of a later diagnosis, and solutions to improve diagnosis



Published infographics in 26 languages highlighting the diagnosis challenges



Developed the European Myeloma Diagnosis Pathway outlining the main signs and symptoms of myeloma and the tests that should be undertaken if myeloma is suspected

On September 27th, MPE launched an awareness campaign on social media and hosted an online event, bringing together more than 100 patients, carers, advocates, clinicians, industry representatives, and stakeholders to hear patients' diagnosis experiences, examine the results of MPE's research, and discuss actions to reduce delays in diagnosis across Europe.



UKRAINE RAPID RESPONSE WORKSTREAM

At the onset of the crisis in Ukraine, MPE worked quickly to understand the immediate impact of the war on cancer patients, including myeloma and AL amyloidosis patients in Ukraine or fleeing from Ukraine. We spoke with haematologists in Ukraine and neighboring countries, our members in border countries, and our colleagues across haematology and cancer to understand how we can work effectively together to support cancer patients and ensure their continued care.

We identified several specific concerns and needs for myeloma patients including differing standards of care across Europe and ensuring patients had continued access to their treatment regimen; language and translation issues for medical notes and in medical consultations; the average age of myeloma patients, which can lead to additional complications, co-morbidities, and medical needs; and the additional burden on the capacity of haematology units in health systems that are already struggling post COVID-19 or due to lack of resources.

To help address these challenges, MPE conducted the following activities:

- Developed and translated materials/information specifically for Ukrainian myeloma patients seeking treatment and care in other European countries
- Created an MPE help centre to coordinate care and support for patients who have fled Ukraine and need myeloma, AL amyloidosis, haematology, or other cancer support in new countries, including where to access treatment and psychosocial support
- Coordinated the translation of medical records to help expedite treatment and care
- Worked closely with member organisations to assist them in providing direct support for Ukrainian patients locally, including safe transportation to hospitals/clinics, navigating local healthcare systems, psycho-social support, and more



MPE would like to extend a special thank you to our industry partners who responded quickly to our requests for support and made this work possible. MPE remains committed to ensuring that member organisations, patients, and carers are as well informed as possible and to helping patients in making decisions about their health and care during this crisis. We will continue to provide support and services for as long as necessary.

EUROPEAN COMMISSION PROJECTS

To provide a strong voice for myeloma and AL amyloidosis patients at European and international levels and collaborate with key stakeholders to take collective action on behalf of the patient community

MPE remains involved in several European projects, ensuring that the perspectives of the myeloma and AL amyloidosis patient community are represented and that resources and deliverables are designed with patients' needs in mind. Significant accomplishments for each project in 2022 include:

SISAQOL-IMI

(Setting International Standards of Patient-Reported Outcomes and Quality of Life Endpoints in Cancer Clinical Trials - Innovative Medicines Initiative), an international consortium convened to generate recommendations to standardize patient reported outcome (PRO) data in cancer clinical trials



- Organised workshops between the patient community and consortium stakeholders to ensure that the results of this project are of true value for cancer patients in Europe
- Finalized and launched educational work plans, including animated videos, plain language summaries, interviews with work package leaders, and a webinar series

HORIZON2020 CARAMBA

a five-year research collaboration between ten partners from six EUcountries exploring Chimeric Antigen Receptor T-cell therapy (CAR-T) for the treatment of multiple myeloma



- Conducted research on patient evidence requirements in the regulatory and reimbursement assessment of CAR-T cell therapies and on the patient experience and PRO collection in CAR-T clinical trials
- Developed educational materials on CAR-T focusing on the patient experience, clinician perspective, and manufacturing

IMI HARMONY

a consortium of 50 haematological partners, aims to facilitate personalized medicine, identify the most effective treatments, and improve diagnosis by collecting and disseminating valuable clinical data on hematologic malignancies through a big data platform



- Provided ongoing input into research proposals and analysis to ensure the patient voice is represented in all studies
- Worked with new and established contributors to facilitate the addition of PRO and QoL data to the HARMONY platform



MPE 2022 FUNDERS

Pharmaceutical industry supporters:

- AbbVie
- Amgen
- Binding Site
- Bristol Myers Squibb
- GlaxoSmithKline
- Janssen
- Novartis
- Oncopeptides
- Pfizer
- Prothena
- Roche
- Sanofi
- Sebia
- SkylineDx
- Sandoz
- Takeda

Public supporters:

- Horizon 2020 CARAMBA
- IMI HARMONY
- SISAQOL IMI

Thank you!

MPE is very grateful for the continued support of our partners and would like to thank them for their generosity this year



2022



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