



# YEAR IN REVIEW

# 2025



**MPe**  
Myeloma  
Patients  
Europe

Helping patients reclaim  
a life of possibility

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Welcome

2025  
accomplishments

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Member spotlight

Supporters and  
partners

Who we are

# A MESSAGE FROM MPE'S BOARD PRESIDENT AND CO-CHIEF EXECUTIVE OFFICERS

Dear friends,

When thinking about this past year, what stood out most to us was the strength of our community, the motivation to collaborate in new ways to benefit patients and families, the generosity of sharing knowledge and experiences and the power of what we can achieve when working together. While we have always been a strong network, 2025 brought in new members, clinicians and stakeholders who enriched our community and helped us increase our network and impact even further. We also found new ways of working with long-standing partners on generating evidence, enhancing MPE programmes and cooperating on national advocacy and access initiatives.

We will enter the new year with a strong sense of accomplishment and purpose, ready to tackle the challenges before us as one community.

This year marked the launch of MPE's new Vision, Mission, and Values, as well as four new strategic goals, which will guide our work through to 2030. These goals were shaped by many voices – members, patients, carers, hematologists, industry representatives and researchers – reflecting the diversity, insight and needs of our community and defining where we believe MPE can have the greatest impact.

Through our focused efforts, we can help patients move beyond survival and reclaim a life of possibility.

In our Year in Review, you will read about how MPE is already making progress towards these goals. With your support, we published data on the burden of myeloma treatments on patients and carers, advocated for a stronger patient voice in medicines development, approvals and assessments and worked to make information about myeloma and AL amyloidosis accessible to all patients in Europe. We also joined you in September and October in raising awareness of myeloma and AL amyloidosis, reaching thousands of people across the globe.

We extend our sincerest thanks for your continued involvement, trust and partnership. Each achievement is a shared one and none of it would be possible without your commitment. We look forward to seeing what we can accomplish together in the year to come.

Best wishes,



**BARBARA LEONARDI**

President



**KATE MORGAN**

Co-Chief Executive Officer



**KATIE JOYNER**

Co-Chief Executive Officer

# 2025 ACCOMPLISHMENTS

This year MPE launched our new **Strategic Goals**, which will drive our work and activities **until 2030**. These goals reflect the needs of our patient community and identify where we can have the biggest impact.

We have already had several notable achievements within each goal, reflecting our continued commitment to improving the lives of patients and their families and tackling the challenges faced by our members.



Click below to see how we are helping patients reclaim a life of possibility.

DRIVE



LEAD



STRENGTHEN



AMPLIFY





## DRIVE improvements in access to timely diagnosis, optimal treatment and care.

- Influence industry, regulatory bodies, European policy makers and other stakeholders to understand and tackle the heterogeneous needs of myeloma patients as well as improve access to diagnosis, testing and treatment
- Advocate for the holistic care of patients
- Identify and address the needs of carers

## 2025 ACCOMPLISHMENTS

- Worked with members in Poland to resolve issues with access to generic medicines.
- Provided patients and their families with up-to-date information on 360 clinical trials through the Myeloma and AL Amyloidosis Clinical Trial Navigator, supporting informed conversations with healthcare professionals and improving access to trials.
- Published data on the barriers to shared decision-making in myeloma and launched educational resources to help patients take a more active role in their treatment decisions.
- Leveraged data from the Myeloma Access Atlas, alongside MPE members, to advocate for improved treatment and care in their countries.
- Engaged in high-level discussions with industry via three Community Advisory Board (CAB) meetings to advocate for improved patient support, data on quality of life and access to medicines in Europe.

**DRIVE**



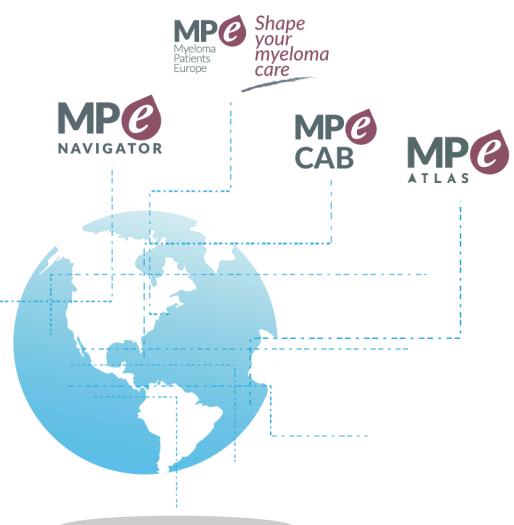
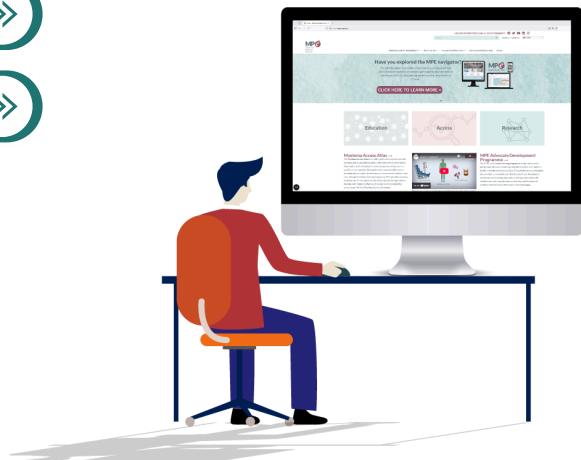
**LEAD**



**STRENGTHEN**



**AMPLIFY**



## 2025 ACCOMPLISHMENTS

- Provided patient insights into eight clinical trial protocols, 18 patient educational resources, and two informed consent forms through the MPE Taskforce, helping to improve clinical trial design, patient experience data collection and patient support.
- Engaged our Medical Advisory Committee (MAC), comprised of leading myeloma and AL amyloidosis specialists in Europe, on an ongoing basis to gather insights on treatment developments and inform MPE's advocacy and education strategies.
- Advocated for a specific section on rare adult cancers in each National Cancer Plan, as part of the Rare Cancers Advocates Network led by EURORDIS.
- Strongly advocated for timely and relevant patient involvement in medicine assessments in the context of the EU HTA Regulation, ensuring the voices of myeloma patients will be heard.
- Revalidated MPE's membership on the European Medicines Agency (EMA) Patient and Consumers Working Party (PCWP) until 2030, enabling us to drive optimum patient involvement and provide patients to support medicines assessments.
- Developed a series of patient educational materials, as part of the Horizon Europe-funded project ASCERTAIN, on pricing, reimbursement and cost-effectiveness and facilitated patient participation in research on medicines pricing.

DRIVE



LEAD



STRENGTHEN



AMPLIFY



8

### CLINICAL TRIAL PROTOCOLS

Provided feedback on protocols to improve clinical trial design and patient experience

18

### EDUCATIONAL RESOURCES

Delivered patient and carer insights to ensure educational resources best meet their needs

2

### INFORMED CONSENT FORMS

Reviewed informed consent forms to confirm information was clear and comprehensive



### TASKFORCE CONTRIBUTIONS DURING 2025



## LEAD the development of robust patient research to improve experiences, outcomes and access for myeloma patients and their families.

- Spearhead novel patient research initiatives to address gaps in evidence and ensure the meaningful inclusion of patient perspectives in research design
- Leverage MPE-led research and data as the guiding force to fuel progress across all initiatives and goals

## 2025 ACCOMPLISHMENTS

- Advocated for better patient support and education with clinicians and industry using MPE-generated data on the perspectives of patients and carers on treatment administration and on shared decision-making.
- Published data on patient reported outcome measures in haematology, providing guidance and recommendations for trialists and industry on how to better capture the impact of CAR-T and bispecific antibodies on patients' lives.
- Led patient engagement in the Horizon Europe-funded project, CERTAINTY, which aims to develop myeloma "virtual twins" or digital representations of patients, which could support treatment decisions by predicting CAR T-cell therapy response and side effects for more personalised medicine.
- Published the final recommendations to enhance patient reported outcomes (PRO) in cancer clinical trials and developed three checklists to support patients in reviewing PRO strategies and results, as a work package leader in the Horizon 2020 and IMI funded project, SISAQOL.

DRIVE



LEAD



STRENGTHEN



AMPLIFY



## 2025 ACCOMPLISHMENTS

- Collaborated on four EORTC initiatives, including the development of questionnaires assessing the financial impact of cancer care and patient experiences with CAR-T and bispecific antibody therapies, and contributed to the EORTC Quality of Life Group Autumn Meeting in Copenhagen, helping shape future priorities and activities.
- Participated in 10 industry-led research projects on topics including endpoints, treatment sequencing, patient priorities regarding treatment, diagnosis and more to ensure patient perspectives are included and the research results will be meaningful for patients and their families.
- Conducted a robust member needs assessment, using data to drive MPE's programme planning to best support national patient organisations.
- Established a Research Advisory Committee, comprised of 21 members, patients, carers, haematologists and academic researchers to guide our research strategy for the next several years.



21

MEMBERS

in our newly  
established Research  
Advisory Committee



DRIVE



LEAD



STRENGTHEN



AMPLIFY





## STRENGTHEN and empower MPE members to best support patients and enhance the impact of advocacy.

- Provide accessible and evidence-based education to fill gaps in knowledge and ensure patients, advocates and carers are equipped with the latest information.
- Empower organisations with the tools (e.g., data), training and support to strengthen advocacy across Europe.

## 2025 ACCOMPLISHMENTS

- Supported 11 members with scholarships to implement programs focused on myeloma and AL amyloidosis awareness, patient education and supportive care.
- Published 22 educational videos, hosted eight webinars and developed 10 factsheets, Q&As and infographics to ensure myeloma and AL amyloidosis advocates are up to date on treatment and can effectively support patient education.
- Trained 105 members and stakeholders at the MPE Masterclass on topics including early diagnosis, the needs of carers, working with national health ministries, AI in healthcare, and much more.
- Trained 13 new patient advocates through the Advocate Development Programme, who will leverage their skills to improve patient support and national advocacy efforts across Europe.
- Launched an awareness campaign and educational resources on infection prevention and management to help members and patients know the signs, symptoms and risks.

DRIVE



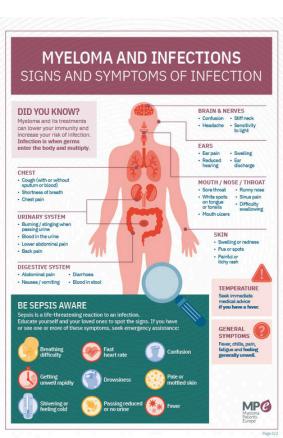
LEAD



STRENGTHEN



AMPLIFY



13

### NEW PATIENT ADVOCATES

completed our Advocate Development Programme

## 2025 ACCOMPLISHMENTS

- Brought together seven members from Central and Eastern European countries to identify common challenges and developed a work plan to help improve access and care in the region.
- Educated the patient community, as part of the Horizon Europe-funded project ASCERTAIN, on the reimbursement process, cost effectiveness and pricing models to support European and national advocacy efforts to improve access to medicines.
- Educated the patient community on conflict of interest and patient involvement in the European Union Health Technology Assessment process and identified new patient experts.
- Provided tailored education for more than 135 patients under the age of 55 through our European Young Myeloma Patients Group.



DRIVE



LEAD



STRENGTHEN



AMPLIFY





## AMPLIFY the influence and impact of MPE and its initiatives.

- Collaborate with members to increase reach and participation
- Launch initiatives to enhance visibility and awareness of our work with external stakeholders

## 2025 ACCOMPLISHMENTS

- Brought together members, patients and stakeholders to raise awareness about shared decision-making during Blood Cancer Awareness Month and on European Myeloma Day.
- Collaborated with members and clinicians to raise awareness of the signs and symptoms of AL amyloidosis and share MPE's diagnosis pathway as part of World Amyloidosis Day.
- Reached 38,000 patients, carers and stakeholders through the MPE website in 2025.
- Presented MPE research at EHA, IMS, ESMO, HNHCP, ISPOR EU and ASH to raise awareness of the issues affecting myeloma patients and their families, gaps in evidence and recommendations to improve patient experiences and access.
- Collaborated with members in Poland, Portugal, Romania, Russia, Spain, the UK and the Czech Republic to bring the European perspective to national advocacy events.
- Worked with members in Poland, Portugal, Serbia, Lithuania, Slovenia and Germany to translate educational materials to ensure patients have access to the latest information on myeloma and AL amyloidosis.
- Achieved an 11% increase in followers across MPE's social media channels.

DRIVE



LEAD



STRENGTHEN



AMPLIFY

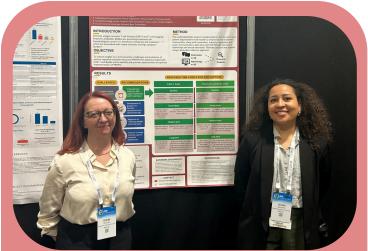


**38k**

Visits to our  
website so far  
this year

Shared decision-making video  
for European Myeloma Day

# 2025 BY THE NUMBERS



**16**

Research posters and presentations across 7 congresses



**11%** increase in followers across all MPE social media channels



**21**

members recruited for MPE's new Research Advisory Committee



**594**

patients and

**109**

healthcare professionals surveyed for our shared decision-making research

**5**  
number of peer-reviewed publications MPE co-authored

**14**  
patient advisory committees with policy, medical and industry partners

**5**  
patient experts recruited for EUHTA



**2**

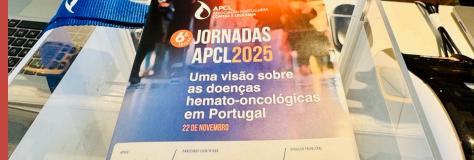
new members joined MPE's network

**3** checklists   **14** glossary definition videos   **12** interviews with stakeholders

**SISAQOL | IMI**  
Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints



MEMBER  
ORGANISATIONS



# SUPPORTERS AND PARTNERS

## Pharmaceutical industry supporters:

- AbbVie
- Alexion
- Amgen
- AstraZeneca
- BeOne Medicines
- Binding Site
- Bristol Myers Squibb
- GlaxoSmithKline
- Johnson & Johnson
- Kite, a Gilead Company
- Menarini Stemline
- Octapharma
- Oncopeptides
- Pfizer
- Prothena Biosciences
- Regeneron
- Roche
- Sandoz
- Sanofi
- Takeda

## Public and other supporters:

- Horizon ASCERTAIN
- Horizon CERTAINITY
- IMI2 SISAQOL
- Medscape



Funded by  
the European Union



## COMMUNITY COLLABORATION

MPE works collectively with patient organisations, medical societies, academia and other stakeholders to represent the needs of the myeloma and AL amyloidosis community and advocate for improved access and care for all European patients. Thank you for your continued partnership:

- ECO
- EHA
- EMA
- EMN
- EORTC
- EPF
- ESMO
- EAA
- EURORDIS
- EU HTA Stakeholder Network
- HTAi
- IMS
- IPOPI
- University Hospital of Würzburg
- WECAN

# MPE'S VISION AND MISSION

## OUR VISION

is a world where every person affected by myeloma has access to the knowledge, diagnostics, treatment and care they need to have the best possible outcome and quality of life.

## OUR MISSION

is to drive advocacy by empowering the myeloma community through research, education and collaboration.



# OUR VALUES



## Patient focused

Patients are the reason we're here. Everything we do aims to improve their lives, outcomes and survival. Patients help lead our work, driving us to deliver meaningful change for people living with myeloma and those closest to them.



## Leadership

We innovate and pioneer bolder, better solutions to challenges in myeloma, leading the conversation around barriers and inequalities to transform care for myeloma patients.



## Connection

Improving the lives of patients and families cannot be done alone. We collaborate with our members and other stakeholders to deliver better patient outcomes and provide a trusted platform to take collective action.



## Excellence

We are committed to excellence in everything we do. We strive to deliver the highest quality information and resources to improve the lives of myeloma patients and their loved ones.



## Transparency

We believe our work is strengthened by sharing what we do, how we do it and the knowledge we generate, empowering the myeloma community.

# MPE BOARD

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

## MPE's 2025 Board Members



Barbara Leonard, President (Poland)



Diane Loening-Martens, Vice President (Germany)



Snežana Doder, Treasure (Serbia)



Zvi Zilberman, Secretary (Israel)



Kristina Modic, Board Member (Slovenia)



Lidija Pecova, Board Member (North Macedonia)



Vincent Claus, Board Member (Belgium)



# MPE STAFF

We are a team of 14 dedicated professionals with the expertise to develop and implement programmes that fulfil MPE's mission and meet the needs of our members and the European patient community.



Kate Morgan, Co-Chief Executive Officer



Katie Joyner, Co-Chief Executive Officer

## Medical Education and Scientific Engagement



Solène Clavreul, Head of Medical Education and Scientific Engagement



Dominik Candea, Medical and Scientific Officer



Morine Maguri, Project Officer

## Patient Evidence



Eilidh Duncan, Head of Patient Research



Jhulia Salviano, Research Assistant



Silene ten Seldam, Research Assistant

## Member and Patient Community Programmes



Linda Christopher, Head of Member and Patient Community Programmes

## Access and Policy



Monica Racoviță, Access and Policy Manager

## Communications



Ana Vallejo, Head of Communications



Adam Davenport, Communications Manager

## Finance and Operations



Riika Lempainen, Finance Officer

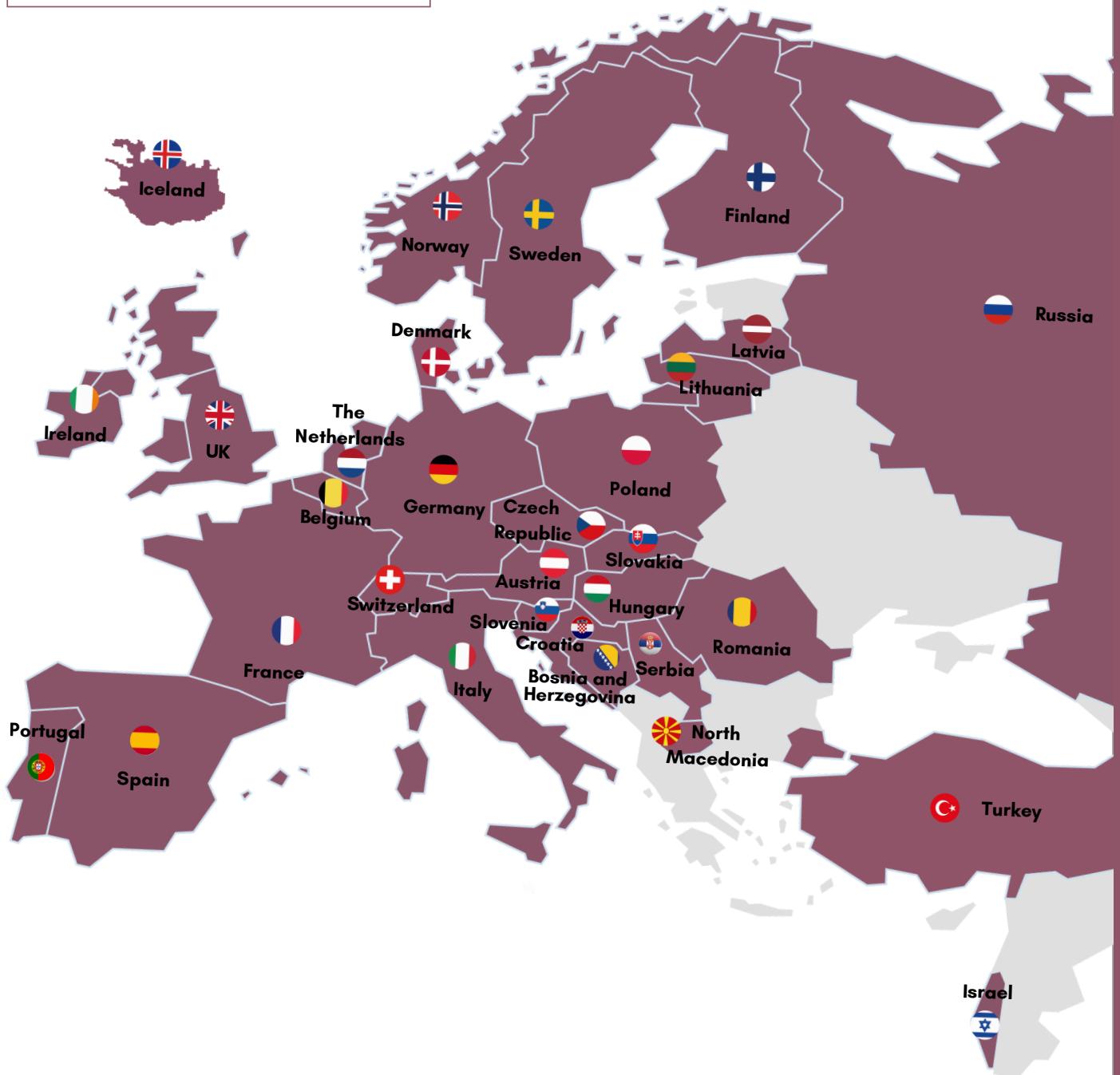


Valentina Christodoulidou, HR and Operations Officer



# MPE MEMBERSHIP

In 2025, MPE had 53 full and associate members representing 33 different countries. Together, we represent a network of highly effective and impactful patient organisations working to advance standards of care in myeloma and AL amyloidosis, reduce health inequalities and improve patient outcomes.



**Full Members****Armenia**

- Armenian Hematology Association

**Austria**

- Multiples Myelom Selbsthilfe Österreich (MMSOe)
- Myelom- und Lymphomhilfe Österreich

**Belgium**

- Contactgroep Myeloom en Waldenström Patiënten Vlaanderen vzw (CMP Vlaanderen vzw)
- MyMu Wallonie-Bruxelles (MyMu)
- AmyBel Amyloidosis Patients Association

**Bosnia and Herzegovina**

- Mijelom u BiH

**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.Online

**Iceland**

- Perluvinir

**Ireland**

- Multiple Myeloma Ireland

**Israel**

- AMEN Israel
- Amyloidosis Israel

**Latvia**

- Onkoloģisko pacientu atbalsta biedrība "Dzīvības koks"

**Lithuania**

- Asociacija "Kraujas"

**North Macedonia**

- HEMA-ONKO

**Netherlands**

- Stichting Hematon
- Stichting Amyloïdose Nederland (SAN)

**Norway**

- Blodkreft Foreningen

**Poland**

- Fundacja Carita – Życ ze Szpiczakiem
- Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka
- Kierunek Zdrowie (Go for Health!)

**Portugal**

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

**Romania**

- Myeloma Euronet Romania (MER)
- SOS Mielom

**Associate Members** **Canada**

- Myeloma Canada

 **Czech Republic**

- Klub pacientů mnohočetný myelom, z.s.

 **Hungary**

- MM Hungary

 **Italy**

- Associazione Mieloma Pazienti Italia (AMPI)

 **Portugal**

- Centro de Histocompatibilidade do Norte (CHN)

**MPE extends a heartfelt thank you to our members. Your dedication and drive make a difference in the lives of patients and their families every day and we remain grateful and inspired by your work and partnership.**

 **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 spoločnosť

 **Slovenia**

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

 **Spain**

- Asociación Española de Amiloidosis (AMILO)
- Agrupación Española de Entidades de Lucha contra la Leucemia y Enfermedades de la Sangre. ( AELCLÉS)

 **Sweden**

- Blodcancerförbundet Sweden
- Blodcancerforum

 **Switzerland**

- Stiftung zur Förderung der Knochenmarktransplantation Schweiz
- MPS Myelom Patienten Schweiz

 **Turkey**

- KANKO/BIRKAN

 **United Kingdom**

- Myeloma UK

# MPE MEDICAL ADVISORY COMMITTEE

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

Thank you to our MAC members for your continued guidance and support of MPE's initiatives.

## 2025 Medical Advisory Committee members:

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



MPE is grateful for the time  
and expertise the MAC  
provides to our organisation.  
On behalf of the patient  
community, thank you for  
your support!

# 2025



## CONTACT US



Myeloma Patients Europe AISBL  
Avenue Louise 143/4  
1050 Brussels - Belgium



[info@mpeurope.org](mailto:info@mpeurope.org)



[www.mpeurope.org](http://www.mpeurope.org)

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