

# YEAR IN REVIEW 2024

EMPOWERING MYELOMA ADVOCACY ACROSS EUROPE



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

Dear friends,

As this year comes to a close, we reflect on the key accomplishments of Myeloma Patients Europe (MPE) and our steadfast commitment to improving patient outcomes, access and quality of life. In 2024, MPE delivered new tools, data and educational initiatives to help patients, families and advocates expand access to innovative treatments, advocate for high-quality care and assume more control over their disease.

This past year, MPE launched the **Myeloma and AL Amyloidosis Clinical Trial Navigator**, a patient friendly search tool of ongoing industry and academic trials in Europe, to support informed conversations between patients and their doctors, increase knowledge around clinical trials and improve access to trials. We also published research on **shared decision making in myeloma and patient perspectives on treatment administration** to highlight unmet needs and put forward recommendations on how to improve patient treatment and care. MPE also continued to tackle challenges around patient access through collaboration with members on national reimbursement issues and through expanded policy work, such as joining the **EU Health Technology Assessment (HTA)** stakeholder network and responding to the EU HTA regulation to ensure meaningful patient involvement. Finally, MPE launched the **European Young Myeloma Patients Group** to educate and support younger patients with myeloma.

MPE welcomed new members this year from Hungary, Italy, Poland and Sweden, expanding and strengthening our collective voice across Europe. Several members also launched new initiatives to increase awareness of myeloma and to provide more supportive care for patients and their families, such as rehabilitation services, psychological support and legal counselling on patients' rights. MPE will continue to serve as a unifier and platform to foster best practice exchange among our members and amplify the impressive work they do locally and nationally.

This Year in Review presents major milestones that push forward MPE's vision, as well as the vital, incremental steps we continue to make every day to work towards a better future for patients and their families.

We want to thank our members, patients, carers and advocates—we are very grateful for the work you do every day, as well as your continued support of MPE. We also want to thank our Medical Advisory Committee, industry sponsors and stakeholders for your ongoing partnership. We are pleased to work alongside each of you in our efforts to improve the lives of myeloma and AL amyloidosis patients.

Best wishes,



**LISE-LOTT ERIKSSON**  
*President*



**KATE MORGAN**  
*Co-Chief Executive Officer*



**KATIE JOYNER**  
*Co-Chief Executive Officer*

# MYELOMA PATIENTS EUROPE

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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 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.
- 
- MPE's unique value**
- Brokers knowledge about the needs and realities of myeloma patients
  - Provides a platform for collective action at an EU level
  - Strengthens myeloma patient organisations' advocacy capacity
  - Promotes research in the interests of myeloma patients
  - Facilitates a cohesive voice for myeloma patients

# MPE MEMBERSHIP

In 2024, MPE had 52 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 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 – Leukaemihilfe RHEIN-MAIN e.V. (LHRM)
- Myelom.Online

### Iceland

- Perluginir

### 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

 **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**

- Društvo 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

**Associate Members** **Bosnia and Herzegovina**

- Mijelom u BiH

 **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)

This year, MPE welcomed four new member organisations:

- Blodcancerforum
- Associazione Mieloma Pazienti Italia (AMPI)
- Kierunek Zdrowie (Go for Health!)
- MM Hungary



*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.*

# MPE BOARD

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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 2024 Board Members



Lise-lott Eriksson, President (Sweden)



Diane Loening-Martens, Vice President (Germany)



Barbara Leonardi, Treasurer (Poland)



Zvi Zilberman, Secretary (Israel)



Kristina Modic, Board Member (Slovenia)



Reidar Nordby, Board Member (Norway)



Snežana Doder, Board Member (Serbia)



Vincent Claus, Board Member (Belgium)

In 2024 MPE welcomed new Board Members, **Kristina Modic, Snežana Doder** and **Vincent Claus!**



# MPE MEDICAL ADVISORY COMMITTEE

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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.

## 2024 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 Beksac, 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!*





# MPE STAFF

We are a team of 15 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



Katherine Jones, Scientific and Patient Information Manager



Morine Maguri, Project Officer



Thisari Dharmapriya, Medical and Scientific 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 Racovita, Access and Policy Manager

## Communications



Ana Vallejo, Head of Communications



Patricia Matamoros, Communications Officer

## Finance and Operations



Riika Lempiainen, Finance Officer



Valentina Christodoulidou, HR and Operations Officer

WELCOME  
TO THE TEAM

In 2024, MPE strengthened its team with three new staff members - welcome Monica, Jhulia and Katherine!

# MPE'S PROGRAMMES: KEY ACCOMPLISHMENTS IN 2024

MPE has a range of programmes and initiatives designed to address the distinct needs of our members and the patient community, with an aim to:



Ensure all patients have access to the best treatment and care, and to represent their interests at a European level.



Promote scientific progress to address the greatest unmet needs in myeloma.



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



Build and empower a network of effective patient advocates and organisations across Europe.



# ACCESS, POLICY AND REGULATORY

MPE's Access, Policy and Regulatory workstream provides the tools and data needed for MPE and our members to raise awareness around barriers to access and to advocate for improved access to medicines and care. These tools also facilitate engagement with regulators, payers and policymakers to influence decisions that impact access across Europe. MPE's major accomplishments in 2024 included:

Maintained accurate and up-to-date reimbursement data for the **Myeloma Access Atlas** and supported members in their advocacy efforts to overcome variation in access to treatment and care in Europe.



Supported the International Myeloma Society in the development of their **Therapeutic Map (TMAP)** initiative.

Served as a steering committee member of the **European Atlas on Clinical Trials in Cancer and Hematology (EuroAct)**, which guides the understanding of inequalities in the availability of clinical trial sites across European countries and provides evidence on the use of relevant quality of life instruments in clinical trials.

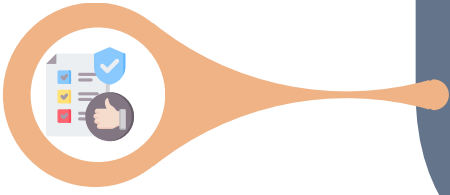


Delivered **training for MPE members** and other hematology patient groups on the drug approval and reimbursement processes.



Provided tailored coaching and support for members to address national access challenges and facilitated data exchange between members to support **patient involvement in the HTA** process.





Raised awareness and knowledge among the patient community around the impacts of the **EU Health Technology Assessment (HTA) Regulation** through in-person and online events that included experts representing the EU Commission, patient organisations, payers, industry and medical societies.

Advocated for meaningful and effective patient involvement in the **EU HTA Regulation** through four open consultation responses and by serving on the EU HTA Stakeholder Network.



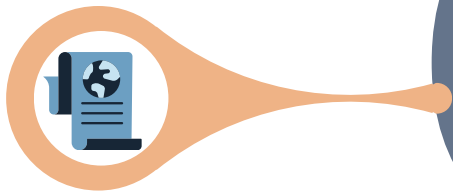
Facilitated **patient representation** for two European Medicines Agency (EMA) assessments.



Advocated for patient representation in regulatory decision-making on medicines through MPE's membership in the **EMA Patients' and Consumers' Working Party (PCWP)** and in our response to the EMA's open consultation on competing interests.



**Monitored policy developments** in the general pharmaceutical legislation, the European Health Data Space, Minimal Residual Disease (MRD) and the Code of Conduct on Fair Access of cancer survivors to financial services, also known as the "right to be forgotten," and engaged with stakeholders to understand and represent patients' needs in health policy.





# MEDICAL EDUCATION AND SCIENTIFIC ENGAGEMENT

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MPE's Medical Education and Scientific Engagement department improves understanding around medicine development, research and the evolving myeloma and AL amyloidosis treatment landscape to strengthen advocacy efforts and to ensure the patient community has comprehensive and up-to-date information. Through this workstream, MPE achieved the following this year:

## MEDICAL EDUCATION

- Published and edited **factsheets** on recently approved myeloma treatments and prepared content for new approvals in 2025.
- Hosted a webinar on investigative **treatments for AL amyloidosis** and participated in **World Amyloidosis Day** to raise awareness around diagnosis delays and challenges.
- Produced 12 video interviews with key opinion leaders and hosted two webinars on the latest myeloma and AL amyloidosis data from the **European Hematology Association (EHA)** and **American Society of Hematology (ASH)** Annual Congresses.
- Supported individual and member patient education needs on myeloma and AL amyloidosis.

## SCIENTIFIC ENGAGEMENT

- Attended **key scientific meetings**, including the EHA-EBMT 6th European CAR T-cell Meeting, International Society of Amyloidosis conference, European Hematology Association (EHA), International Myeloma Society and American Society of Hematology Annual Congresses.
- Participated in **six advisory boards** for pharmaceutical companies and engaged with companies on research projects, leading to publications and poster presentations at scientific conferences.
- Participated in the **EMA-led Accelerating Clinical Trials in the European Union (ACT-EU)** initiative, which supports smarter clinical trials through regulatory, technological and process innovation.
- Through the MPE Taskforce, facilitated **patient input into the drug development process**, including providing feedback for industry on six clinical trial protocols, six informed consent forms and 16 patient-facing materials.

# MYELOMA AND AL AMYLOIDOSIS CLINICAL TRIAL NAVIGATOR



A major milestone this year was the launch of the **Myeloma and AL Amyloidosis Clinical Trial Navigator**. The Navigator is a patient-friendly search tool to help patients, carers and patient organisations find clinical trials as well as increase their understanding of clinical research, the drug development process, how to enrol in a clinical trial and what to consider before enrolling.



*"The MPE Navigator empowers advocacy groups working for myeloma and AL amyloidosis patients by providing an ultimate tool and information needed to guide patients through the complex clinical trial landscape. It ensures patients have access to information on the latest, most relevant trials and increases patients' chances of finding appropriate and potentially life-saving treatments."*

**Lise-lott Eriksson**

**President, Myeloma Patients Europe**

The Navigator includes trials for myeloma, monoclonal gammopathy of undetermined significance (MGUS), smouldering multiple myeloma (SMM) and AL amyloidosis in Europe, and shows inclusion and exclusion criteria, recruitment status and location. The database currently has **285 trial files**, including **181 recruiting trials** and **896 clinical trial sites in Europe**.

The Navigator went live in April 2024 with **almost 19,000 visits** to the website in the past six months. In August, **Future Rare Disease magazine** showcased the tool and published the interview "Launch of the myeloma and AL amyloidosis European clinical trial navigator by Myeloma Patients Europe: interview with Dr Solène Clavreul."

MPE published the site in its **second language**, Finnish, on European Myeloma Day, 27 September 2024. In the coming year, MPE will launch additional translations to ensure European patients are not hindered by language barriers.



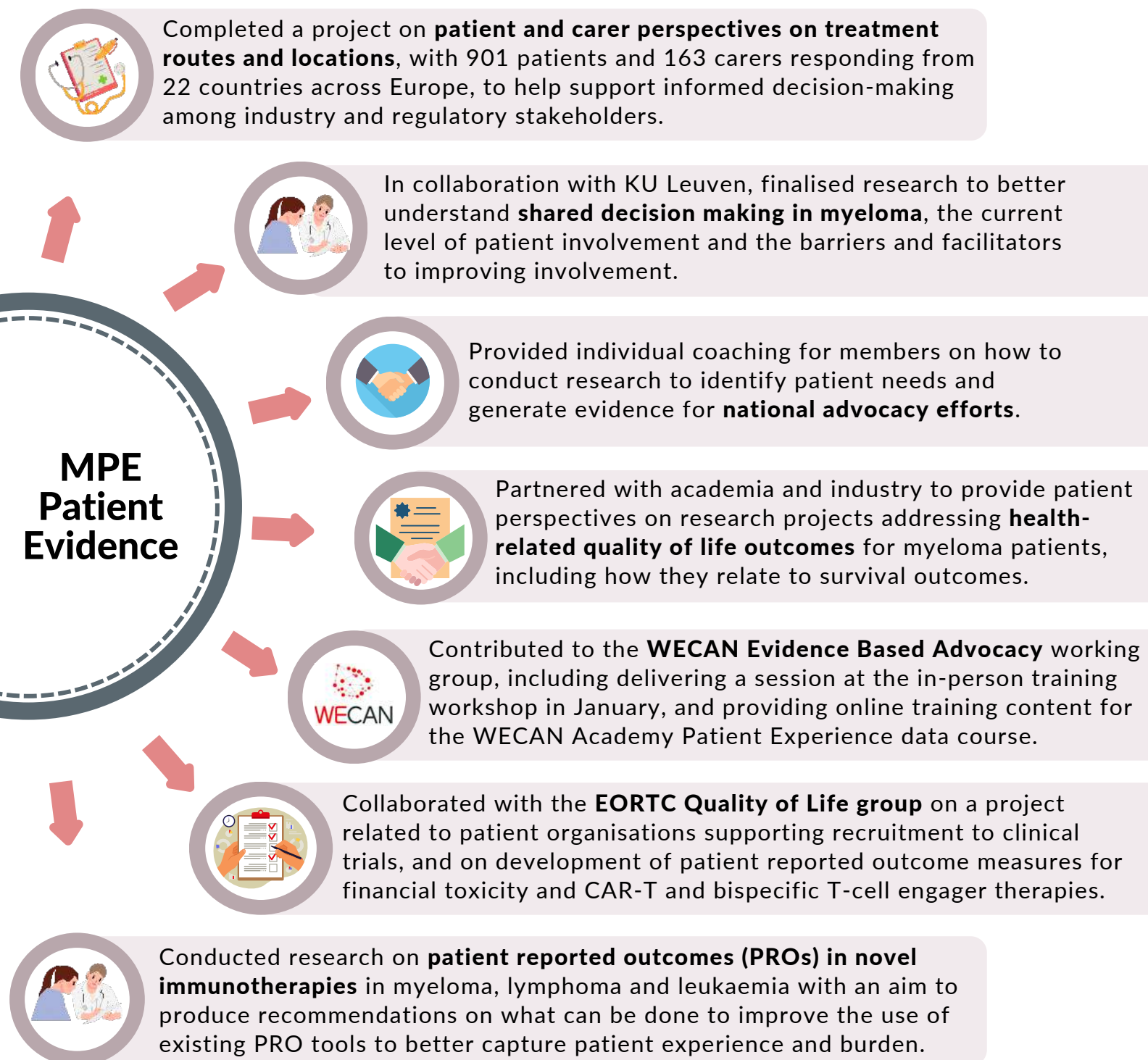
*"In 2024, we see the cure of myeloma becoming real. All our patients having participated and participating in clinical trials have made this possible. However, myeloma remains a complex disease. The MPE Clinical Trail Navigator helps to find the right trial for the right treatment situation."*

**Prof. Dr. Katja Weisel**

**University Medical Center Hamburg-Eppendorf, Hamburg, Germany**

# PATIENT EVIDENCE

MPE's Patient Evidence department carries out research projects with patients and their families at the centre. It generates robust data on patient needs and experiences to support decision-making in myeloma and AL amyloidosis and advocacy efforts for improved care, treatment and policies. Key achievements from 2024 included:



# MEMBER AND PATIENT COMMUNITY PROGRAMMES

MPE's Member and Patient Community Programmes are designed to strengthen members' and patients' ability to advocate effectively, and to develop a network of strong and sustainable patient organisations across Europe. This year, we accomplished the following:

Hosted 100 members, industry partners and other stakeholders at the **MPE Masterclass** in Madrid, Spain, with education and advocacy sessions addressing treatment updates, the EU HTA regulation, cross border healthcare, supportive care, shared decision making, real world evidence and more.



Provided **scholarships** for six member organisations to implement projects to meet the needs of their local patient communities. These included initiatives on holistic health, patient education, rehabilitation, AL amyloidosis diagnosis and care, patients' rights and more.



Held **European Myeloma Day on 27 September 2024**, bringing together patients, carers, advocates, clinicians, medical societies, industry and other stakeholders to raise awareness of the role of clinical trials in advancing myeloma treatments and the persistent inequalities in access to trials for many patients in Europe.



Trained 15 participants through the **MPE Advocate Development Programme**, our largest cohort to date, empowering a new group of dedicated patient advocates who will help shape the future of national and European advocacy efforts.



MPE launched the **European Young Myeloma Patients Group**, designed to address the needs of patients under 55, and held online educational sessions on treatment specificities and the importance of nutrition for younger patients. A private Facebook group was also created for members to connect and share experiences.





Drustvo BKB, Slovenia, releases myeloma patient guide

WECAN Academy



Association of Myeloma Patients Serbia on national TV



Mercy Bridge hosts myeloma conference

## SPOTLIGHT ON MEMBERS

Throughout 2024, MPE members have developed remarkable projects and initiatives aimed at offering information, resources and support to myeloma and AL amyloidosis patients across Europe.



Fundacja Carita's Rally for Health



Multiple Myeloma Ireland "miles for myeloma" cycling event



Kierunek Zdrowie, Poland, rehabilitation camp for blood cancer patients

L&L Slovenia, online platform for consultation with experts



Mijelom CRO myeloma awareness booth

HEMA-ONKO awareness booth



MPE online member support meeting



AELCLÉS Masterclass



# MPE PUBLICATIONS AND PRESENTATIONS

Through presentations at congresses, meetings and events, MPE contributes to important discussions about myeloma and AL amyloidosis treatment, access and care. Some highlights from this past year were:

- Solène Clavreul co-authored “Safety and feasibility of SLAMF7-directed, transposon-engineered CAR-T cells in the phase I CARAMBA-01 study,” an oral presentation given at the **EBMT-EHA 6th European CAR T-cell Meeting**.
- MPE co-authored the poster “The multiple myeloma patient perspective on the use of patient-reported outcomes in CAR-T clinical trials” as part of our work with CARAMBA, which was presented at the **EBMT-EHA 6th European CAR T-cell Meeting** in February.
- As part of CARAMBA, MPE published **two reports on CAR-T**: “The myeloma patient perspective on the use of patient-reported outcomes (PROs) in CAR-T clinical trials” and “Patient-based evidence requirements in the regulatory and reimbursement assessment of CAR-T cell therapies in Europe.”
- Ana Vallejo moderated two events for MPE member **AMILO**, their annual Info Day in February and their event for **World Amyloidosis Day** in October.
- Solène Clavreul presented the poster “**Health-Related Quality of Life, Diagnosis and Treatment Experiences of AL Amyloidosis Patients**” at the International Society of Amyloidosis symposium in May.
- As part of SISAQOL-IMI, Silene ten Seldam presented on data challenges and the importance of patient reported outcomes for an **EMA-FDA workshop** in June.
- As part of T2Evolve, Solène Clavreul co-authored the poster “Patient reported outcomes of CAR T-cell therapy: an international European study evaluating patients’ experiences, quality of life and unmet care needs,” **presented at the EHA annual congress in June**.
- **MPE published our Working Age report**, highlighting the needs of younger than average myeloma patients and making policy, research and practice recommendations.
- Katie Joyner presented on the “Financial Sustainability of Patient Organisations” **at the WECAN Academy 2024**.



- MPE authored the article “Addressing multiple myeloma and AL amyloidosis patient information gaps on clinical trials in Europe,” which was **published in International Clinical Trials** in August.
- Monica Racovita, Access and Policy Manager, gave a presentation on “How are drugs approved and become available?” for **the MPN Horizons 2024 meeting**.
- Katie Joyner presented the poster “How do patients feel about how, when and where they get their treatments,” MPE’s project looking at patients’ perspectives on treatment routes and locations at the **International Myeloma Society annual conference** in September.
- Kate Morgan and Silene ten Seldam were co-authors on a **peer reviewed publication**, “Description of Feelings, Perception, and Experience Before and After Switching from IV Daratumumab to the SC Form: A Mixed-Method, Cross-Sectional Survey in Multiple Myeloma Patients in Europe,” published in Patient Preference and Adherence (2024).
- Silene ten Seldam presented **MPE’s research on myeloma diagnosis across Europe** at the European Cancer Organisation’s (ECO) “Uniting Forces: Addressing Needs in Blood Cancer Care” Stakeholder Forum.
- Ana Vallejo gave a talk about shared decision making for MPE member **AELCLÉS** at their **first-ever Masterclass**, held in Madrid, Spain.
- A poster at ISPOR Europe 2024 on “Price Determinants and Pricing Policies Concerning Potentially Innovative Health Technologies: A Scoping Review” as **part of the ASCERTAIN project**.
- **MPE’s shared decision-making project** was presented with a poster and oral presentation at the International Society for Decision Making conference in July and at a poster at ISPOR Europe.
- Eilidh Duncan gave an oral presentation at **the ISPOR Europe conference in November**, presenting findings from MPE’s project examining what can be done to improve the use of existing patient reported outcome (PRO) tools to better capture patient experience and burden of novel immunotherapies in haematology.
- Solène Clavreul co-authored the poster “Examining Discrepancies in Perspectives of Healthcare Providers and Patients with Relapsed/Refractory Multiple Myeloma on Novel Therapies Across Diverse Clinical Landscapes: An International Prospective Study” presented at the **ASH annual congress** in December.



# PROJECTS FUNDED BY THE EUROPEAN UNION

MPE is involved in several research projects financed by the European Union where we help facilitate a strong patient voice at European and international levels and collaborate with key stakeholders to take collective action on behalf of the patient community. Notable accomplishments for each project in 2024 included:



**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 standardise patient reported outcome (PRO) data in cancer clinical trials:

- Attended the **4th consensus meeting** where MPE (on behalf of WECAN) voted on the final set of recommendations and presented on the challenges and learnings of patient involvement in SISAQOL-IMI.
- Delivered **presentations on challenges with PRO** data and case studies for the WECAN Patient Experience data course.
- Developed **plain language checklists** for patient advocates to support them in reviewing the patient reported outcome analysis and design sections in cancer clinical trial protocols.



**Horizon Europe ASCERTAIN** (Affordability and Sustainability improvements through new pricing, Cost-Effectiveness and Reimbursement models to Appraise Innovative health technologies) is a four-year project consortium, led by the University of Erasmus MC in Rotterdam, exploring alternative models of pricing, cost-effectiveness and reimbursement to improve access to innovative therapies for patients:

- Delivered a webinar and training on **“The Basics of Pricing”** designed for a patient advocate audience.
- Helped develop the **EHA-Patient Joint Symposia on fair pricing** at the 2024 European Hematology Association annual congress.
- Developed a **patient engagement plan** and coordinated with all work package leaders to ensure patient perspectives are meaningfully embedded throughout deliverables.







**Horizon Europe CERTAINTY** (cellular immunotherapy virtual twin for personalised cancer treatment) is a five-year research collaboration between 16 partners from seven EU countries and the USA, which aims to develop a “virtual twin” that could potentially improve treatment with personalised cancer immunotherapies such as CAR T-cell therapy in myeloma:

- Recruited **patient experts** to provide feedback on key deliverables throughout the project.
- Developed **educational materials** on CERTAINTY and virtual twins.
- Facilitated **patient engagement** across work packages.

A virtual twin is a digital representation of a human health or disease state. It is built using software models and data, and is designed to mimic and predict behaviour of real patients. It aims to support doctors and patients by offering insights that may guide decisions during treatment, contributing to a more informed approach to cancer care. This project aims to predict treatment outcomes of CAR T-cell therapy and the risks of developing severe side effects in patients considered for CAR T-cell therapy.

Find more information about this project [here](#).



Funded by  
the European Union

# MPE 2024 FUNDERS

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## Pharmaceutical industry supporters:

- Amgen
- Alexion, AstraZeneca
- AstraZeneca
- BeiGene
- Binding Site
- Bristol Myers Squibb
- GlaxoSmithKline
- Janssen
- Kite, a Gilead Company
- Oncopeptides
- Pfizer
- Prothena Biosciences
- Regeneron
- Roche
- Sanofi
- Menarini Stemline
- Takeda

## Public supporters:

- Horizon ASCERTAIN
- IMI2 SISAQOL
- Horizon CERTAINTY

# Thank you!

MPE is grateful for the continued commitment of our sponsors and would like to thank them for their support this year.

## COMMUNITY COLLABORATION

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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
- EURORDIS

- EU HTA Stakeholder Network
- IMS
- HTAi
- PFMD
- University of KU Leuven
- University of Stirling
- WECAN

# 2024



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