

# YEAR IN REVIEW

# 2023

MYELOMA PATIENTS EUROPE (MPE)

EMPOWERING MYELOMA ADVOCACY ACROSS EUROPE



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

Dear friends,

This past year we continued to see major leaps forward in the landscape of myeloma, with new treatments approved in Europe and a growing pipeline of forthcoming myeloma and AL amyloidosis medicines. Whilst these advances represent significant promise for the patient community in terms of options, outcomes and quality of life, further progress on access to medicines, education and supportive care needs and patient evidence gaps must accompany treatment innovations across Europe.

In this report, you'll read about the key accomplishments of Myeloma Patients Europe (MPE) from 2023, many of which focus on these unmet needs. These included regularly providing members, patients, and carers with accurate and timely information, working with European and national stakeholders to advocate for improved access, understanding and improving the role of patients in treatment and care decision-making, developing tools to help reduce diagnosis delays and much more.

In addition to our programmatic accomplishments, MPE's membership continues to grow as well as our contributions in national and European forums. Now with 49 members, MPE remains a strong and effective network of organisations working tirelessly to support myeloma and AL amyloidosis patients and to advocate for continued improvements in care, treatment, access, research, education, and patient involvement in drug development and HTA. Our collective voice is critical to drive change and each year that voice grows stronger.

We want to thank our members, patients, carers and advocates, we recognize and deeply appreciate 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 dedication to MPE and the patient community.

We look forward to building on these achievements in the year ahead and continuing to work together to make a difference for patients.

Best wishes,



**LISE-LOTT ERIKSSON**  
*President*



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



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

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

# MPE MEMBERSHIP

In 2023, MPE had 49 full and associate members representing 31 different countries. MPE continues to grow and support its members to create a network of highly effective, efficient and sustainable patient organisations across Europe.





## 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

- Perluvinir



### Ireland

- Multiple Myeloma Ireland



### Israel

- AMEN Israel
- Amyloidosis Israel



### Latvia

- Onkologisko pacientu atbalsta biedriba "Dzīvības koks"



### Lithuania

- Asociacija "Kraujas"



### Macedonia

- BORKA
- HEMA



### Netherlands

- Stichting Hematon
- Stichting Amyloïdose Nederland (SAN)



### Norway

- Blodkreft Foreningen



### Poland

- Fundacja Carita – Życ 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 spoločnosť

## Slovenia

- Društvo 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 Förderung der Knochenmarktransplantation Schweiz
- MPS Myelom Patienten Schweiz

## Turkey

- KANKO/BIRKAN

## United Kingdom

- Myeloma UK

## Associate Members

### Czech Republic

- Klub pacientů mnohočetný myelom, z.s.

### Bosnia and Herzegovina

- Bosnian Myeloma Patient Group

### Portugal

- Centro de Histocompatibilidade do Norte (CHN)

### Canada

- Myeloma Canada



This year, MPE welcomed two new member organisations:  
Myeloma Canada and Myelom.Online in Germany!

*MPE extends a special thank you to our members and the myeloma and AL amyloidosis patient community. Your work is invaluable to the patients and families you support, and we remain inspired by your unwavering 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 2023 Board Members



Lise-lott Eriksson, President (Sweden)



Ananda Plate, Vice President (Germany)



Barbara Leonardi, Treasurer (Poland)



Riikka-Leena Manninen, Secretary (Finland)



Reidar Nordby, Board Member (Norway)



Diane Loening-Martens, Board Member (Germany)



Zvika Zilberman, Board Member (Israel)

In 2023 MPE welcomed new Board Member, Reidar Nordby, from the Norwegian Blood Cancer Association



# MPE MEDICAL ADVISORY COMMITTEE

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The MPE Medical Advisory Committee (MAC) 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 is composed of key opinion leaders representing myeloma and AL amyloidosis specialties, as well as MPE's member countries.



## 2023 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 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's Medical Advisory Committee facilitates a critical dialogue between clinicians and the patient community. We're all working to improve patient outcomes, and by sharing what I see in the clinic and what MPE sees through their programmes, haematologists and advocates can better support patients.”*

**Dr. Moshe Gatt, Hadassah Medical Center, Israel**

# MPE STAFF

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MPE is comprised of an international team of professionals dedicated to meeting the 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 and strategic objectives.



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



Morine Maguri, Project Officer



Thisari Dharmapriya, Medical and Scientific Officer

## Patient Evidence



Eilidh Duncan, Head of Patient Research



Silene Ten Seldam, Research Assistant

## Member and Patient Community Programmes



Linda Christopher, Project Manager



Anne-Pierre Pickaert, Access to Medicines Secretariat

## Communications



Ana Vallejo, Head of Communications



Patricia Matamoros, Communications Officer

## Finance and Operations



Riika Lempiainen, Finance Officer



Valentina Christodoulidou, HR and Operations Officer



# 2023 MPE PROGRAMME HIGHLIGHTS

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Through the collective work of our members, staff, and stakeholders, MPE continues to address the challenges in myeloma and AL amyloidosis and deliver tools, evidence and information to help improve patient outcomes, experience and quality of life. Below provides a summary of the major accomplishments from each workstream.

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## ACCESS, POLICY AND REGULATORY

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

MPE's Access, Policy and Regulatory workstream provides tools and data for MPE and our members to navigate the access landscape and advocate for improved access to medicines, as well as work closely with regulators, reimbursement bodies and policymakers to influence decisions and initiatives that impact access across Europe. MPE's major accomplishments in 2023 include:



Completed a comprehensive update of the Myeloma Access Atlas, supporting members in their advocacy efforts to overcome variation in access to treatment and care in Europe.

Delivered tailored coaching and support to members on access challenges.



Presented data on inequalities in access between Western and Central and Eastern Europe at the European Society for Medical Oncology (ESMO), as well as several roundtable discussions and stakeholder events.

Supported colleagues across the cancer community in developing atlases in other disease areas.



Appointed to and served on the EU HTA Stakeholder Network of the European Commission, actively engaging in the implementation of the EU HTA Regulation.





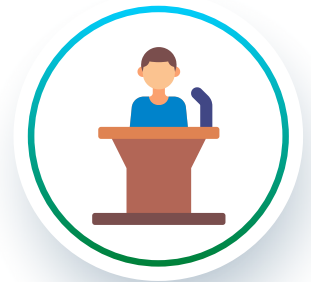
Published and presented research results on the use of quality-of-life (QoL) instruments and patient-reported outcome measures (PROMs) reported in clinical trials and published literature in myeloma.

Provided training on national health technology assessment (HTA) and reimbursement processes and how patient organisations can participate and influence decision-making.



Delivered written submissions to the European Medicines Agency (EMA) in support of two new medicines and facilitated patient representation for three assessment processes.

Continued to advocate for the representation of patients in decision-making on medicines, including through MPE representation on the EMA Patients' and Consumers' Working Party (PCWP) and on the Steering Group for the Patient and Citizen's Interest Group (PCIG) at HTAi.



*“MPE has provided invaluable support for the Association of Cancer Patients in Finland (Suomen Syöpäpotilaat ry) on an access challenge relating to daratumumab. They listened, provided advice, spoke to relevant stakeholders, mentioned it at key congresses and even wrote a supporting letter for us to engage with the Finnish Society of Myeloma Doctors. We have additionally discussed a direction from the Ministry of Social Affairs and Health related to daratumumab. We really enjoyed working with them and a combined voice definitely makes us stronger!”*

**Emma Andersson, Association of Cancer Patients in Finland**

# MEDICAL EDUCATION AND SCIENTIFIC ENGAGEMENT

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

MPE's Medical Education and Scientific Engagement department promotes understanding around medicine, clinical trials, and research to strengthen advocacy efforts and to ensure access to the latest information on myeloma and AL amyloidosis developments. MPE reached the following milestones this year:

- Beta launch of Myeloma and AL Amyloidosis Clinical Trial Navigator, a patient-friendly search tool of recruiting clinical trials in Europe, which will undergo exhaustive testing before the official launch in 2024.
- Published new AL amyloidosis Q&As on diagnosis and monitoring, living with AL amyloidosis, and the differences between AL amyloidosis and myeloma, as well as a new AL amyloidosis patient guide.
- Published new myeloma educational materials including factsheets on approved treatments, resources on minimal residual disease (MRD), Q&As and a webinar on CAR-T therapy, and an updated myeloma patient guide.
- Produced video interviews and webinars with key opinion leaders on the latest myeloma and AL amyloidosis data from the European Hematology Association (EHA) and American Society of Hematology (ASH) Annual Congresses.
- Published research on the disease burden on the quality of life for AL amyloidosis patients and on the challenges and impacts of delayed diagnosis in AL amyloidosis.



*“European patients with myeloma can have easier access to clinical trials. The website can serve as a trusted source of accurate and up-to-date information on myeloma clinical trials in Europe. Patients and their families can rely on it to find information that is verified by a reputable organisation.”*



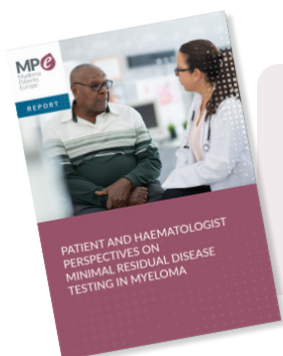
**Ariunsanaa Baatar, Sanna Foundation,  
Hungary**

# 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 robust data to support decision-making in myeloma and AL amyloidosis and to advocate with scientific, industry, regulatory and policy decision-makers for improved care and treatment for patients across Europe. Key achievements from 2023 include:

Launched pan-European survey on patients' and carers' perspectives on how and where treatments are administered to inform decision-making among industry and regulatory stakeholders as they consider how drugs should be developed and administered.



Published research on patient and haematologist perspectives on Minimal Residual Disease (MRD) and hosted an online workshop to discuss the results.

Published research findings on the needs of working age myeloma patients, in collaboration with the University of Stirling and MPE members in Poland, Germany and Czech Republic.

Provided input into EORTC quality of life working group projects exploring financial toxicity, interpretation guidelines, and reference values, and began contributing to a new project investigating different modes of patient recruitment.



Commenced a patient and haematologist survey on shared decision-making, in partnership with KU Leuven, to understand how to improve the processes for patient involvement in treatment and care decisions.

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*"I have participated in a few research projects run by the MPE Patient Evidence Team. The results shed new light on the myeloma community and their lives. By collaborating with European universities, and patient organisations, the Patient Evidence team demonstrates MPE's academic and border-breaking capabilities."*

**Barbara Leonardi, Carita Foundation, Poland**

# MEMBER AND PATIENT COMMUNITY PROGRAMMES

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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 strengthen members' and patients' ability to advocate effectively and to build a network of impactful patient organisations across Europe. 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 psychological support for newly diagnosed patients, generating data to use in HTA assessments, general practitioner awareness programmes and much more.

Launched quarterly MPE Member meetings to highlight the ongoing achievements of national organisations and provide a forum to exchange ideas among members.

Trained seven new participants through the MPE Advocate Development Programme, continuing our efforts to build a network of active and empowered patient advocates.



*"The Advocate Development Programme (ADP) exceeded all my expectations. The program is very well-structured, with an incredible panel of speakers who were always willing to help us. I am deeply thankful to the entire MPE team for the knowledge, expertise, support and genuine care they provided me. Being part of the programme was pivotal because, since I joined the ADP, I have had and continue to have the chance to participate in different projects, with the aim of helping and empowering multiple myeloma patients."*

**Ana Filipa Lopes, Portuguese Association Against Leukemia (APCL)**

# MEMBER AND PATIENT COMMUNITY PROGRAMMES



Hosted 80 members, industry partners, and other stakeholders at the MPE Masterclass with educational sessions addressing treatment updates, patient involvement in HTA, clinical trial access and the most pressing needs of the patient community.



*"Nothing is more powerful than learning from each other, and that is exemplified in the MPE Masterclass. For the past two years, I have had the pleasure of presenting at the Masterclass and working together with the MPE members on patient and advocate involvement in HTA. I have been struck by the level of knowledge, commitment and sheer power of the MPE community to make change happen. Through training sessions addressing the key needs of patient advocates, the Masterclass empowers the community to work together to address some of the most challenging healthcare issues."*

**Neil Bertelsen, Steering Committee Member and past Chair of HTAi PCIG**



Held European Myeloma Day on September 27, 2023, uniting patients, carers, advocates, clinicians, medical societies, industry and other stakeholders to raise awareness of myeloma and the need for a timely diagnosis for every patient.





# TOWARDS A TIMELY DIAGNOSIS FOR ALL PATIENTS

Increase the number of patients who have their myeloma and/or AL amyloidosis diagnosed in a timely manner.

To raise awareness about myeloma and AL amyloidosis, and help reduce delays in diagnosis for each disease, MPE developed the European Myeloma Diagnosis Pathway and the European Amyloidosis Diagnosis Pathway. These tools are designed to help general practitioners (GPs) recognize the signs and symptoms earlier and which tests to undertake if myeloma or amyloidosis is suspected.

## Myeloma Diagnosis Pathway

**MYELOMA DIAGNOSIS PATHWAY**  
Myeloma, also known as multiple myeloma, is a rare bone marrow cancer arising from the plasma cells. In Europe, there are around 50,000 new cases diagnosed each year.

**SUSPECT MYELOMA?**  
Myeloma signs and symptoms  
If a patient presents with one or more of the following symptoms, consider testing for myeloma:  
• Bone pain: back, chest, ribs, joints, arms and wrists  
• Anemia: fatigue, weakness, shortness of breath, dizziness  
• Weight loss: unintentional weight loss  
• Infection: frequent infections  
• Kidney problems: changes in urination, swelling, fatigue  
• Nerve damage: tingling, numbness, weakness  
• Blood clots: bruising, bleeding, nosebleeds  
• High calcium: thirst, constipation, weakness, confusion  
• Hyperviscosity: blurred vision, dizziness, fatigue

**THINK MYELOMA!**  
Myeloma tests and investigations  
If you suspect a patient has myeloma, you should consider the following tests and investigations:  
1. Full blood count and blood chemistry  
• Hemoglobin  
• Urea and electrolytes (U&E)  
• Creatinine  
• Serum calcium  
2. Serum protein measurement  
• Serum protein electrophoresis (SPEP)  
• Immunofixation (IFE)  
• Serum free light chain assay (SFCA)  
• Urinary light chain assay (UPEP)  
• Serum immunoglobulin (IgG, IgA and IgM)  
3. Additional tests to consider  
• Serum albumin  
• Serum immunoglobulin  
• C-reactive protein  
• Ferritin  
• Lactate dehydrogenase (LDH)  
• Erythrocyte sedimentation rate (ESR)  
• Fibrinogen  
• Prothrombin time (PT)  
• Fibrinogen (FIB)

**RELATED DIAGNOSIS**  
Monoclonal gammopathy of undetermined significance (MGUS)  
No treatment  
• Progression to AL amyloidosis, multiple myeloma or solitary plasmacytoma: 1% per year  
Smoldering myeloma  
No treatment  
• Progression to multiple myeloma: 10% per year

**REFERRAL AND FURTHER INVESTIGATIONS**  
In order tests and investigations needed myeloma, or a patient has symptoms suggestive of myeloma, the following tests and investigations are needed to confirm diagnosis:  
• Bone marrow aspirate + biopsy  
• X-ray skeletal survey  
• Low dose whole body CT  
• Whole body MRI  
• PET-CT

**ADDITIONAL RESOURCES**  
1. European Myeloma Network recommendations on tests for the diagnosis and monitoring of multiple myeloma, what to test and when.  
Hematologica 2018; 103(12): 1772-1784  
2. Multiple myeloma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology 2015; 26(10): 2089-2122

MPE  
Myeloma  
EUROPE

## Amyloidosis Diagnosis Pathway

**TIPOS DE AMILOIDOSIS**  
Asignar el tipo de amiloidosis requiere pruebas de diagnóstico. Los tres tipos principales son:  
1. Amiloidosis AL (Cadenas ligeras de cadena pesada)  
2. Amiloidosis ATTR (Transtilamida asociada al transtirretina)  
3. Amiloidosis AA (Asociada a la enfermedad inflamatoria crónica)

**SIGNOS Y SINTOMAS DE LA AMILOIDOSIS**  
Si un paciente presenta uno o más de los siguientes síntomas de especificación oportuna, se debe considerar la posibilidad de realizar pruebas para detectar amiloidosis:  
• Pérdida de peso  
• Debilidad  
• Anemia  
• Fiebre  
• Pérdida de apetito  
• Fatiga  
• Dificultad para respirar  
• Hinchazón  
• Problemas renales  
• Problemas cardíacos  
• Problemas hepáticos  
• Problemas nerviosos  
• Problemas digestivos  
• Problemas de la piel  
• Problemas de los ojos  
• Problemas de los dientes  
• Problemas de los huesos  
• Problemas de los vasos sanguíneos  
• Problemas de los riñones  
• Problemas de los pulmones  
• Problemas de los nervios  
• Problemas de los músculos  
• Problemas de los tendones  
• Problemas de los ligamentos  
• Problemas de los cartílagos  
• Problemas de los discos intervertebrales  
• Problemas de los tejidos conectivos  
• Problemas de los tejidos epiteliales  
• Problemas de los tejidos endoteliales  
• Problemas de los tejidos mesenquimales  
• Problemas de los tejidos hematopoyéticos  
• Problemas de los tejidos linfoides  
• Problemas de los tejidos glándulas  
• Problemas de los tejidos glandulares  
• Problemas de los tejidos epiteliales  
• Problemas de los tejidos endoteliales  
• Problemas de los tejidos mesenquimales  
• Problemas de los tejidos hematopoyéticos  
• Problemas de los tejidos linfoides  
• Problemas de los tejidos glándulas  
• Problemas de los tejidos glandulares

**PRUEBAS Y ESTUDIOS SOBRE LA AMILOIDOSIS**  
1. Examen del paciente  
• Anamnesis y examen físico  
• Anamnesis de síntomas y signos  
• Anamnesis de antecedentes médicos  
• Anamnesis de antecedentes familiares  
• Anamnesis de antecedentes de enfermedades crónicas  
• Anamnesis de antecedentes de enfermedades autoinmunes  
• Anamnesis de antecedentes de enfermedades infecciosas  
• Anamnesis de antecedentes de enfermedades oncológicas  
• Anamnesis de antecedentes de enfermedades reumáticas  
• Anamnesis de antecedentes de enfermedades neurológicas  
• Anamnesis de antecedentes de enfermedades gastrointestinales  
• Anamnesis de antecedentes de enfermedades respiratorias  
• Anamnesis de antecedentes de enfermedades cardiovasculares  
• Anamnesis de antecedentes de enfermedades renales  
• Anamnesis de antecedentes de enfermedades hepáticas  
• Anamnesis de antecedentes de enfermedades endocrinas  
• Anamnesis de antecedentes de enfermedades metabólicas  
• Anamnesis de antecedentes de enfermedades de los huesos  
• Anamnesis de antecedentes de enfermedades de los vasos sanguíneos  
• Anamnesis de antecedentes de enfermedades de los nervios  
• Anamnesis de antecedentes de enfermedades de los músculos  
• Anamnesis de antecedentes de enfermedades de los tendones  
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• Anamnesis de antecedentes de enfermedades de los tejidos glándulas  
• Anamnesis de antecedentes de enfermedades de los tejidos glandulares

**DIAGNÓSTICOS RELACIONADOS**  
Gammopatía monoclonal de significado renal  
Mieloma múltiple  
Microalbuminuria de Waldenström

**DERIVACION Y DIAGNOSTICO**  
Ante la sospecha de un paciente con amiloidosis, se debe derivar a un especialista en el diagnóstico y tratamiento de la amiloidosis AL, en primer lugar, y a un especialista en amiloidosis, en caso de que el paciente no responda a un tratamiento especializado en amiloidosis, o en caso de que el paciente no responda a un tratamiento especializado en amiloidosis, o en caso de que el paciente no responda a un tratamiento especializado en amiloidosis.

**OTRAS PRUEBAS O ESTUDIOS**  
• Biopsia de médula ósea  
• Biopsia de tejido conectivo  
• Biopsia de piel  
• Biopsia de riñón  
• Biopsia de hígado  
• Biopsia de pulmón  
• Biopsia de nervio  
• Biopsia de músculo  
• Biopsia de tendón  
• Biopsia de ligamento  
• Biopsia de cartílago  
• Biopsia de disco intervertebral  
• Biopsia de tejido conectivo  
• Biopsia de tejido epitelial  
• Biopsia de tejido endotelial  
• Biopsia de tejido mesenquimal  
• Biopsia de tejido hematopoyético  
• Biopsia de tejido linfoide  
• Biopsia de tejido glandular  
• Biopsia de tejido glandular

**CENTROS ESPECIALIZADOS EN AMILOIDOSIS**  
En algunos países europeos existen centros especializados en el diagnóstico y tratamiento de la amiloidosis AL, así como de otros tipos de amiloidosis. Se encuentran a continuación:  
• Centro de Amiloidosis, Hospital de la Universidad de Valencia  
• Centro de Amiloidosis, Hospital de la Universidad de Zaragoza  
• Centro de Amiloidosis, Hospital de la Universidad de Sevilla  
• Centro de Amiloidosis, Hospital de la Universidad de Granada  
• Centro de Amiloidosis, Hospital de la Universidad de Murcia  
• Centro de Amiloidosis, Hospital de la Universidad de Alicante  
• Centro de Amiloidosis, Hospital de la Universidad de Córdoba  
• Centro de Amiloidosis, Hospital de la Universidad de Huelva  
• Centro de Amiloidosis, Hospital de la Universidad de Cádiz  
• Centro de Amiloidosis, Hospital de la Universidad de Málaga  
• Centro de Amiloidosis, Hospital de la Universidad de Jaén  
• Centro de Amiloidosis, Hospital de la Universidad de Almería  
• Centro de Amiloidosis, Hospital de la Universidad de La Rioja  
• Centro de Amiloidosis, Hospital de la Universidad de Cantabria  
• Centro de Amiloidosis, Hospital de la Universidad de Castilla-La Mancha  
• Centro de Amiloidosis, Hospital de la Universidad de Castilla y León  
• Centro de Amiloidosis, Hospital de la Universidad de Aragón  
• Centro de Amiloidosis, Hospital de la Universidad de Navarra  
• Centro de Amiloidosis, Hospital de la Universidad del País Vasco  
• Centro de Amiloidosis, Hospital de la Universidad de Burgos  
• Centro de Amiloidosis, Hospital de la Universidad de Valladolid  
• Centro de Amiloidosis, Hospital de la Universidad de León  
• Centro de Amiloidosis, Hospital de la Universidad de Salamanca  
• Centro de Amiloidosis, Hospital de la Universidad de Extremadura  
• Centro de Amiloidosis, Hospital de la Universidad de Castilla-La Mancha  
• Centro de Amiloidosis, Hospital de la Universidad de Castilla y León  
• Centro de Amiloidosis, Hospital de la Universidad de Aragón  
• Centro de Amiloidosis, Hospital de la Universidad de Navarra  
• Centro de Amiloidosis, Hospital de la Universidad del País Vasco  
• Centro de Amiloidosis, Hospital de la Universidad de Burgos  
• Centro de Amiloidosis, Hospital de la Universidad de Valladolid  
• Centro de Amiloidosis, Hospital de la Universidad de León  
• Centro de Amiloidosis, Hospital de la Universidad de Salamanca  
• Centro de Amiloidosis, Hospital de la Universidad de Extremadura

To ensure wide-spread dissemination, MPE and our members translated the myeloma pathway into 7 languages and member organisations led national efforts to disseminate the tool to GPs through congress attendance, info booths at GP events and direct outreach.

The amyloidosis pathway was presented at the Spanish Hematology Congress and will be translated into additional languages in the year ahead.

Over the next year MPE will build on this momentum and reach hundreds, if not thousands, of GPs across Europe with the pathways.

# TOWARDS A TIMELY DIAGNOSIS FOR ALL PATIENTS

“

*Sharing the myeloma diagnosis pathway had a great impact in local communities in raising awareness about myeloma. We distributed 4,000 copies of the pathway and educational materials about multiple myeloma to health centres throughout Serbia. Every day we receive pictures of our members from all around Serbia from local clinics, where we can see how posters and flyers are distributed in smaller communities and villages throughout the country. Due to poor knowledge about the symptoms of myeloma among most GPs, we have received invitations from some local clinicians to organize lectures on the topic of myeloma together with leading haematologists.”*

**Snezana Doder, Association of Myeloma Patients Serbia**



Multiple Myeloma Ireland



AMM Online, Germany



Društvo BKB Slovenija, Slovenia



Association of Myeloma Patients Serbia



# UKRAINE RAPID RESPONSE WORKSTREAM

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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. As the war continues, MPE remains committed to ensuring that patients and carers receive the help they need in accessing treatment and care during this crisis.

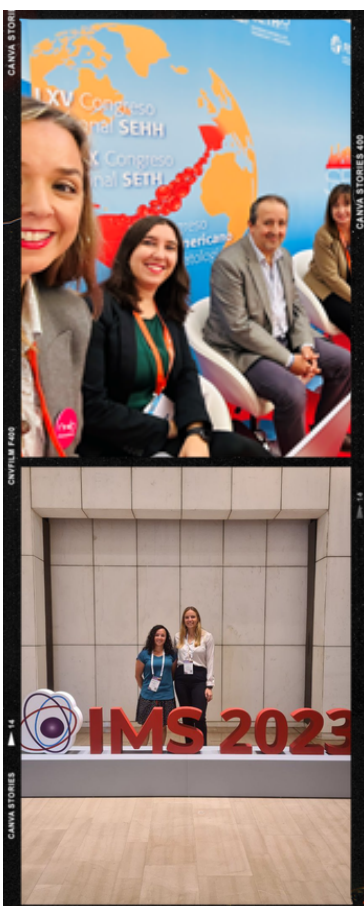
Throughout 2023, MPE assisted in **the translation of medical records** to help expedite treatment and linked patients who have fled Ukraine and need myeloma, AL amyloidosis, haematology, or other **cancer support** in new countries. We will continue to provide support and services for as long as necessary.



# MPE PUBLICATIONS AND PRESENTATIONS

Through presentations at congresses and meetings, MPE contributes to important discussions about myeloma treatment and care, patient advocacy and patient evidence. Some key highlights from 2023 are:

- A presentation at the EHA annual congress by Kate Morgan, MPE Co-Chief Executive Officer, on the importance of measuring quality of life in myeloma clinical trials during an EHA Guidelines Session.
- A poster presentation at the International Myeloma Society (IMS) annual meeting by Silene ten Seldam, MPE Research Assistant, on patient and clinician perspectives on minimal residual disease.
- A presentation at the European Society for Medical Oncology (ESMO) 2023 given by Kate Morgan on “A gap analysis on access to modern medicines and treatments: A comparison between West and Eastern Europe.”
- An ISPOR 2023 poster presentation, in collaboration with KU Leuven, of work supported by MPE titled “Needs and Experiences of Patients and Healthcare Professionals Towards Shared Decision Making in Multiple Myeloma Clinical Practice: A Qualitative Study in Europe.”



- A presentation on “AL amyloidosis diagnosis: challenges and recommendations” given by Ana Vallejo, MPE Head of Communications, during a World Amyloidosis Day event organised by the Spanish Amyloidosis Association (AMILO), in collaboration with the Spanish Society of Hematology.
- Solene Clavreul, MPE Head of Medical Education and Scientific Engagement, co-authored a poster at the ASH annual meeting entitled "Cytokine Release Syndrome: The Patient, Caregiver and Healthcare Professional Experience."
- Presentation at the European Myeloma Network (EMN) annual meeting of MPE’s Myeloma Access Atlas, given by Kate Morgan.
- Hans Scheurer, former President of MPE, presented the patient perspective during a round table on “Ethical issues in CAR T-cell treatment” hosted by the European School of Hematology.

# 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 is involved in several European projects, ensuring that the perspectives of the myeloma, AL amyloidosis, and the broader haematology and oncology patient communities are represented, and that deliverables are designed with patients' needs in mind. Key accomplishments for each project in 2023 include:

## SISAQOL-IMI

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



- Held in-person workshop at the WECAN Academy in Frankfurt, Germany educating patient advocates on the challenges in designing, analysing and reporting PRO data and the importance of SISAQOL-IMI to standardise the way this is done.
- Facilitated input of patient advocates across oncology into the plain language glossary, which aims to allow all stakeholders, including patients and patient organisations, to have a better understanding of the context and terminology used in PRO data collection, analysis and reporting.
- Developed plain language executive summaries to ensure transparency for the patient community of the project's process.



*MPE, representing WECAN, is an invaluable contributor to SISAQOL-IMI. From involving patients in each work package to organising patient meetings with work package leaders, MPE is ensuring the patient voice is heard and incorporated throughout the project and its deliverables. SISAQOL-IMI is a technical project involving setting standards on the design, analysis and interpretation of quality of life and patient reported outcome data. MPE exemplifies a way of working that bridges the communication gap between the experts and the patient community. The commitment and openness of MPE to make sure that the results are truly relevant for the patients has made SISAQOL-IMI even more meaningful to all project partners and different stakeholders."*

**Madeline Pe, PhD, Head of Quality of Life Department, EORTC**

# EUROPEAN COMMISSION PROJECTS



## HORIZON EUROPE ASCERTAIN

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.



- Developed an iterative patient engagement plan to ensure the patient perspective is included across all work packages and deliverables.
- Provided patient input in all work package meetings and across deliverables to-date.
- Planned educational resources and focus groups on drug pricing for patient advocates.

## HORIZON2020 CARAMBA

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



- Completed 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 and published educational materials (webinars, Q&As, interviews etc.) on CAR-T, focusing on the patient experience, clinician perspective, side effects and manufacturing.
- Provided patient perspectives on the CARAMBA trial results and next steps.

## IMI HARMONY

is a consortium of 50 haematological partners, aiming to facilitate personalised medicine, identify the most effective treatments and improve diagnosis by collecting and disseminating valuable clinical data on haematologic malignancies through a big data platform.



- Provided input into research proposals and analyses to ensure the patient voice is represented in all studies.
- Advocated for the addition of PRO and QoL data to the HARMONY platform, and for better quality data.
- Provided feedback on HARMONY sustainability plans from a patient perspective.

# MPE 2023 FUNDERS

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## Pharmaceutical industry supporters:

- AbbVie
- Amgen
- Alexion AstraZeneca
- BeiGene
- Binding Site
- Bristol Myers Squibb
- GlaxoSmithKline
- Janssen
- Menarini Stemline
- Novartis
- Oncopeptides
- Pfizer
- Prothena Biosciences
- Regeneron
- Sandoz
- Sanofi
- Sebia
- SkylineDx
- Roche
- Takeda

## Public supporters:

- Horizon 2020 ASCERTAIN
- Horizon 2020 CARAMBA
- IMI HARMONY
- SISAQOL IMI

# Thank you!

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

## COMMUNITY COLLABORATION

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MPE works with key stakeholders to strengthen the voice of myeloma and AL amyloidosis patients, advocate for the patient community's needs and interests and work collectively to improve patient outcomes and experiences across Europe. Thank you for your continued partnership:

- ECO
- EHA
- EMA
- EMN
- EORTC
- ESMO
- EU HTA Stakeholder Network
- EURORDIS
- HTAI
- PFMD
- WECAN

# 2023



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