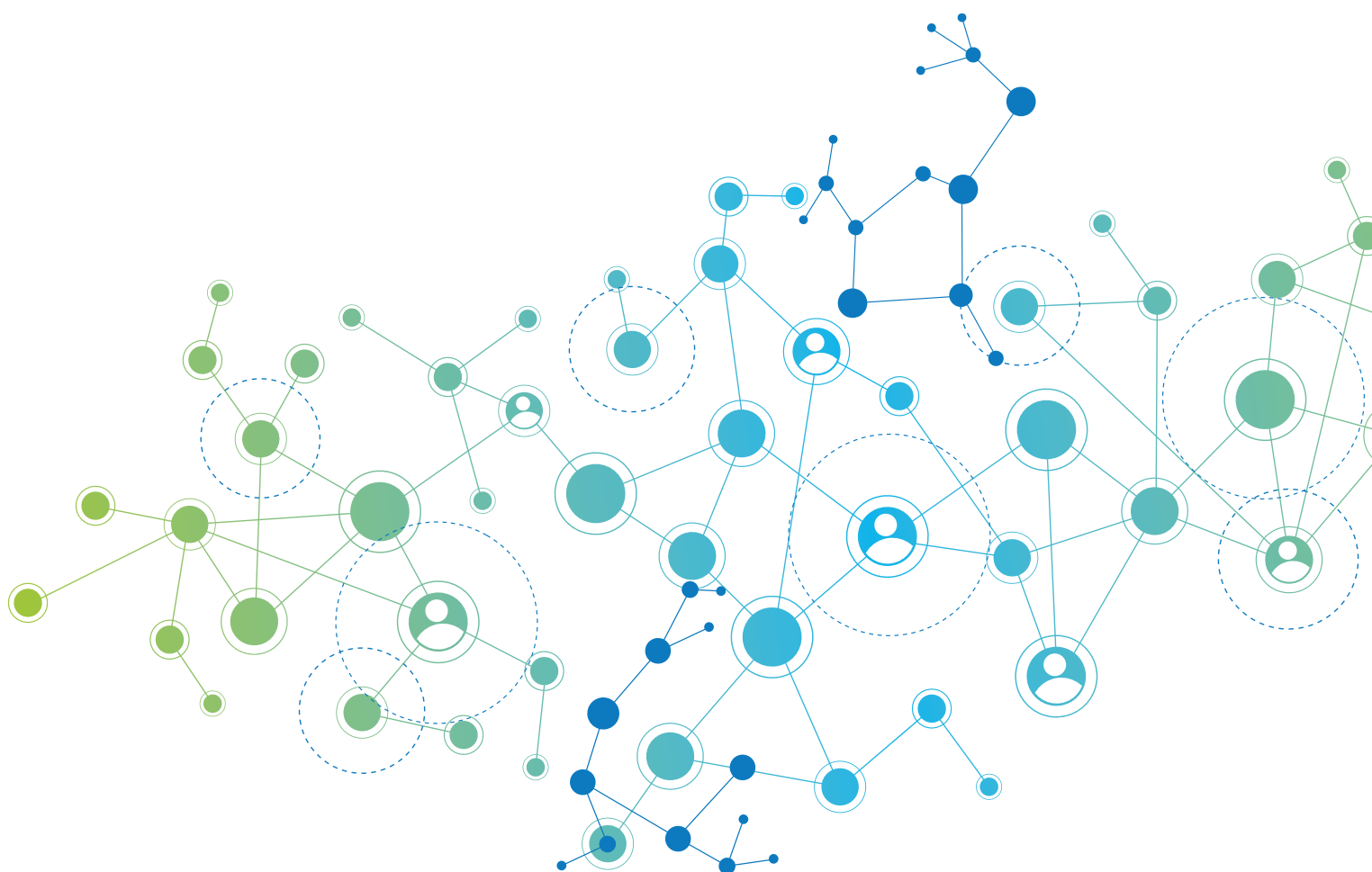


# 2020 Annual Report



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## Message from the President and CEO

*No organisation or individual could have anticipated the outbreak of Covid-19, resulting in a global pandemic and huge changes to daily life and business. Fortunately, MPE started 2020 in a strong position and was able to continue to progress and develop throughout the year, mitigating the challenges of working during these difficult times and ensuring stability on an operational and strategic level.*

*That stability, combined with a commitment to furthering the work of MPE to support member organisations, fellow advocates, and patients, has ensured that MPE continued to deliver against plan on core programmes, meaning that our members and community were supported through capacity building, knowledge exchange, and in addressing the barriers to the best possible treatment and care for patients across Europe. Where this was not possible, we have looked to adapt our programmes to meet the existing and changing needs of our members and the community.*



*Our involvement in two Horizon2020 projects and three Innovative Medicines Initiative (IMI) projects has strengthened our position and partnerships with key stakeholders and institutions across Europe. The objectives of these projects are all closely aligned with the strategic vision of MPE and our involvement represents significant benefits for the myeloma and AL amyloidosis patient community.*

*Additionally, MPE created the COVID-19 Outreach Workstream, specifically designed to support members through this challenging period. Through a tailored communications plan, educational resources, and further assessment of need, MPE is helping members to remain sustainable, robust organisations supporting patients at national level.*

*Whilst there has been significant impact of the Covid-19 pandemic on scientific meetings and congresses, stakeholder meetings, and important internal meetings, MPE has adapted to the challenges of the virtual working environment and has continued to strengthen relationships and partnerships that benefit our work, members, and MPE community agenda. Highlights include hosting our first ever Virtual General Assembly, our continued involvement in the WECAN Academy, and the opportunities we have had to represent and report to the patient advocacy community through congresses such as European Cancer Organisation, American Society of Hematology (ASH) and European Hematology Association (EHA).*

*We are incredibly proud of our Staff and Board members, and the amazing, ever-increasing group of patient advocates active in MPE committees and workgroups; thanks to their commitment and teamwork, MPE was able to continue to function and operate in a way that not only achieved but surpassed our goals for the year. We are also truly grateful for each of our sponsors, collaborators, and partners, without whom it would have been impossible to accomplish all the great things that we have in 2020.*

*And this year especially, we have been amazed by the tremendous efforts, resourcefulness, and capabilities of our members, who have once more shown their extraordinary commitment to supporting patients, carers, and families across Europe through these challenging times.*

*Looking back at 2020, we recognise our successes, and we celebrate those with whom we have stood and worked together with to improve the lives of myeloma and AL Amyloidosis patients across Europe and beyond. We also acknowledge the significant hardships that this year brought, and the impact this had on the community we serve, on our colleagues, on our members, and our friends. MPE will continue its journey to achieving our mission - ensuring access to the best possible treatment and care for every myeloma and AL amyloidosis patient, no matter where they live or who they are. Heading into 2021, the 10-year anniversary of MPE, we hope that we soon get the opportunity to continue this journey in a safer world and celebrate together in person very soon.*

The image shows two handwritten signatures in blue ink. The signature on the left is more stylized and circular, while the one on the right is more linear and cursive.

Hans Scheurer, president of MPE

Ananda Plate, CEO of MPE

## About Myeloma Patients Europe (MPE)

MPE is an umbrella organisation of myeloma and AL amyloidosis patient groups and associations from across Europe. It is registered as an international non-profit organisation under Belgian Law (AISBL) and its headquarters is located in Brussels.

Our Mission 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 the best possible treatment and care. MPE acts as an umbrella organisation for 50 national myeloma patient groups from across 31 European countries.

### **There are three types of members:**

- Full members: non-profit patient organisations that are registered in a European country.
- Associate members: Any individual person who shares Myeloma Patients Europe's goals and all other non-profit organisations that do not fulfil the criteria for full membership.

MPE is run by a Board comprising six to nine members, appointed for a two-year period, of which at least half are patients or carers. Board members may be consecutively re-elected twice. The Board may not include more than two members who are of the same nationality or who represent the same country. It is also agreed that no public or private organisation may be represented by more than one member of the Board.

MPE's Board members are all volunteers who are supported by the MPE staff as well as by an expert Medical Advisory Committee.

## Board members

### **MPE's 202 Board Members:**

- Hans Scheurer, President (Netherlands)
- Ron Dloomy, Vice-President (Israel)
- Johannes Brenner, Treasurer (United Kingdom)
- Riikka-Leena Manninen, Secretary (Finland)
- Biljana Dodeva, Board member (Macedonia)
- Kristina Modic, Secretary (Slovenia)
- Lise-lott Eriksson, Board member (Sweden)
- Nikita Shklovskiy-Kordi, Board member (Russia)
- Roman Slomkowski, Board member (Poland)

## Executive office

With the aim of having a wide structure to build capacity among member organisations and ensure treatment access and early diagnosis across Europe, MPE is strategically growing.

### Ananda Plate, Chief Executive Officer



Ananda joined MPE in March 2013. She holds a law degree from the University of Barcelona and a master's degree in Health Policy, Planning and Financing from the London School of Economics and Political Science and the London School of Hygiene and Tropical Medicine. Her main field of interest is cross border healthcare within the EU and health data protection.

She started getting involved in patient advocacy in 2007. Since then, she has collaborated with a number of patient organisations across Europe. She has worked at the leading Institute of Public Law (IDP Barcelona) and the European Commission (DG Health and Consumers). Currently she is also Vice-chair of the Workgroup of European Cancer Patient Advocacy Networks (WECAN) and a member of the Ethics Committee at the Chamber of Physicians of Bavaria, Germany. Ananda speaks Spanish, German, English, Catalan, and French. She is currently based in Munich, Germany.

### Kate Morgan, Head of Policy and Access



Kate joined the team in September 2017. She holds a bachelor's degree in Government from the London School of Economics and Political Sciences and a Master's degree in International and European Politics from the University of Edinburgh. She also holds a Diploma in Public Relations from the Chartered Institute for Public Relations. Her main area of interest is health policy, with a specific focus on policies affecting drug development and access in European countries.

Kate previously worked for eight years in the Policy Team at Myeloma UK, where she was involved in influencing a range of policy and reimbursement decisions affecting myeloma patient access to good quality care and effective new drugs. She was involved in a number of patient and public advisory panels in the UK healthcare system, including for the Scottish Medicines Consortium, the drug approval body in Scotland.

She been involved in a wide-range of patient organisation networks, both nationally and internationally – most recently chairing the Blood Cancers Alliance, an information-sharing network of haematological cancer charities in the UK. Kate currently lives and works in Edinburgh, Scotland.

### Anne-Pierre Pickaert, Access to medicines Secretariat



Anne-Pierre joined in April 2020 and brings 20 years of experience with a wide range of healthcare stakeholders (charity, patient organisation, governmental agency, consultancy, and pharmaceutical industry). Her skills

and expertise in health communication, cancer prevention and market access, combined with her personal experience as a leukemia survivor, give her a unique perspective on patient engagement, advocacy and equal access to adequate care.

Anne-Pierre holds a MSc in Economic Evaluation for Health Technology Assessment from the University of York, a MSc in European Social Policy from the London School of Economics and a Diploma in Political Sciences from the Institut d'Etudes Politiques of Strasbourg. She worked as general delegate and program manager in cancer prevention through nutrition and lifestyle (World Cancer Research Fund & Institut National du Cancer [INCa]) and market access director (Kantar Health, Lundbeck & Sanofi).



**Ana Vallejo, Communications Manager**

Ana joined the MPE team in September 2016. She holds a bachelor's degree in journalism from the Complutense University of Madrid and a Master's degree in Audiovisual Communication from the University Antonio de Nebrija in Madrid.

Ana worked as a journalist on weekly newspapers specialising in health and on consumer health monthly magazines. She has been involved in different patient advocacy groups, first as a volunteer and later on within the communication department. Since 2014, Ana worked as PR and press consultant in the health department of an international PR agency developing communication strategies for the main pharmaceutical companies. Ana has been involved in producing two books focused on patients with cancer as a co-writer and editorial co-ordinator. She speaks Spanish and English.



**Solène Clavreul, Medical and Scientific Officer**

Solène joined MPE in January 2021. She holds a PhD in Neuroscience and a Master of Biology and Physiology from Sorbonne University (Paris). She studied brain development during her PhD and then worked on brain cellular diversity as a researcher at the Helmholtz Zentrum München. Early involved in education, she has been leading holiday camps for children for many years and worked in a science museum during her studies to promote science,

design exhibitions and lead workshops.

Newly interested in science policy and particularly in the field of health, she trained herself to European policy implementation, clinical data management and industrial pharma management before joining MPE as a medical and scientific officer. She is responsible for the coordination and representation of MPE's involvement in EU projects, the management of MPE's medical advisory board, the development of a European myeloma clinical trial database and developing scientific education and information at MPE. Solène comes from France and currently lives and works in Munich, Germany. She speaks French, English and German.

### **Lili Gundelach, Project Officer**



Lili joined the team in November 2020. Lili holds a bachelor's and a master's degree in Molecular and Cellular Biology from the University of Glasgow, Scotland. During her studies, her main area of interest was Immunotherapy and Antibody Engineering.

Lili has experience as a laboratory-based researcher focusing on novel drug design at pharmaceutical companies and in academia. Since moving to Hannover, Germany in 2019, she has worked as a freelance scientific writer, collaborating with the European Patients' Academy on Therapeutic Innovation (EUPATI) among other organisations. Lili speaks English, Hungarian, conversational German and Japanese.

### **Jayne Galinsky, Head of Patient Evidence**



Jayne joined MPE in October 2020. She holds a BSc in Psychology, an MSc in Child, Adolescent and Family Mental Health, and a PhD in Health Sciences from the University of Stirling. She is interested in the impact of rare and life threatening conditions and generating evidence to support access to health technologies which improve quality of life for individuals and families.

She previously worked as the Health Services Research Manager at Myeloma UK, as a lecturer in Psychology at the University of Stirling, and on clinical trials at the University of Glasgow (Neurology) and University College London (Institute of Child Health). She is an honorary research fellow at the University of Stirling. She has published work in the fields of patient preferences, the economic and societal impacts of disease, perceptions of patient reported outcome measures (PROMs), and patient and carer perceptions of clinical neurology trials in stroke.

Jayne has worked closely with patients as part of her previous clinical roles within the NHS and children's hospices. She has also represented patients on research boards and worked with patient and carer panels on large projects and grants, including the Scottish Government funded Cancer Medicines Outcomes Programme (CMOP) and National Institute of Health Research (NIHR) funded studies. She lives and works in Edinburgh, Scotland.

### **Katie Joyner, Patient Advocacy Programme Manager**



Katie joined MPE in April 2020. She holds a Bachelor of Arts in Journalism and Mass Communication from the University of North Carolina at Chapel Hill and a Master of Arts from Georgetown University in Liberal Studies with a concentration in International Affairs. Katie has a decade of experience with non-profit organizations and higher education institutions. Prior to joining MPE, Katie served as the Director of Development at a large New York City non-profit supporting individuals with developmental disabilities where she oversaw fundraising, grant writing, Board relations, and special events. Her interests include health equity and improving healthcare access for vulnerable populations. Katie is originally from North Carolina, United States and is currently based in Munich, Germany.

### **Ingrid Jenisch, Finance and Reporting Officer**



Ingrid joined the MPE team in August 2018. She holds a degree from the advanced technical college in Ulm, Germany, and has an apprenticeship as an electrical engineering assistant. Ingrid has broad experience in large, medium-sized and start-up companies. She worked as referent and assistant to Executive Boards. In this role she was responsible, for board-, management- and finance-reporting and controlling. She has proficient expertise in project and programme management and implementation of administrative

processes as well as in marketing and public relations.

In the health area she worked for the Innovative Medicines Initiative (IMI) project EUPATI. The European Patients' Academy. This is a pan-European project implemented as a public-private partnership by a collaborative multi-stakeholder consortium from the pharmaceutical industry, academia, not-for-profit, and patient organisations. As Finance and Reporting Officer she supported the EUPATI Director in preparing reports for IMI and the international consortium members. Financial monitoring, control and analysis were part of her responsibility. Ingrid is based in Munich, Germany.

### **Tamika Lang, Head of Clinical Science**



Tamika joined the team in April 2020. She holds a Master's degree in Health Sciences from Duke University along with a certificate and licensure as a Physician Assistant in the United States. She also has a Bachelor's degree in Biology with a minor in Mathematics. Her main interests include medical education, clinical medicine, and patient advocacy.

Prior to joining MPE she worked clinically in New York City as an Internal Medicine Physician Assistant and in South Carolina, USA as a Palliative Medicine Physician Assistant. A Physician Assistant is a professional clinical role specific to the US and UK healthcare systems. The role of a Physician Assistant in these settings is to diagnose, treat, and prescribe medications to patient's with various illnesses in collaboration with a licensed physician. Tamika is originally from Connecticut, United States and has been living in Germany since August of 2019. She is currently based in Munich, Germany.

### **Julia Tolley, Operations Manager**



Julia joined in February 2020. Previously she has worked in a number of roles within the National Health Service (England), most notably as both Project Manager and Commissioning Manager within Community Services, and Urgent Care. She holds a Bachelor's Degree in Business & Psychology from the University of Central Lancashire, England. Since moving to Munich, Germany, she has been employed in Executive-Level Assistance and Project Support for a global financial technology provider.

## MPE members

**MPE is comprised of 50 myeloma patient groups and associations in 31 European countries:**

- Armenia - Armenian Haematology Association (AHA)
- Austria - Multiples Myelom Selbsthilfe Oesterreich (MMSOe)
- Austria - Myelom und Lymphomhilfe österrech
- Belgium - Contactgroep Myeloom en Waldenström Patiënten Vlaanderen vzw (CMPvzw)
- Belgium - Wallonie-Bruxelles (MyMu)
- Bosnia and Herzegovina (Associate, individual)
- Croatia - Mijelom CRO
- Croatia - HULL Croatia - Croatian leukaemia and lymphoma Society
- Czech Republic - Multiple Myeloma Patient Support Group (KPMM) (Associate)
- Denmark - Dansk Myelomatose Forening
- Estonia - Eesti Müeloomiliit
- Finland - Suomen syöpäpotilaat-myelooma potilasverkosto
- France - Association Française des Malades du Myélome Multiple (AF3M)
- Germany - AMM-Online, Multiple Myeloma Online Working Group
- Germany - German Leukemia and Lymphoma Patients' Association (DLH)
- Germany - Myeloma Group Rhine Main - Leukaemia Help Rhine Main - LHRM
- Germany - Myelom Deutschland e.V.
- Hungary - MOHA– Foundation for Hungarian Oncohaematological Patients
- Israel - Amen Israeli Myeloma Patient Foundation (AMEN)
- Israel - Amyloidosis Israel
- Latvia - Latvian Cancer Patient Support Society “Dzīvības koks”
- Lithuania - Kraujas
- Macedonia - BORKA
- Macedonia - Association for help and support of patients and their caregivers with haematological diseases (HEMA)
- Myeloma, Leukemia and Lymphoma Malta
- Netherlands - Stichting Hematon
- Netherlands - Amyloidosis Foundation Netherlands (SAN)
- Norway - Norwegian Blood Cancer Association / Blodkreftforeningenn
- Poland - Carita Fundation
- Poland - Polish Myeloma Patient Help Association
- Portugal - Associação Portuguesa Contra a Leucemia (APCL)
- Portugal - Associação Portuguesa Leucemias e Linfomas (APLL)
- Portugal - Centro de Histocompatibilidade do Norte (CHN) (Associate)

- Romania - Myeloma Euronet Romania (MER)
- Romania - SOS mielom
- Russia - Society for Assistance to Patients with Oncohaematological Diseases
- Serbia - Association of myeloma patients of Serbia (AMPS)
- Slovakia - Association of patients with haematological malignancies
- Slovakia - Slovak Myeloma Society (SMyS)
- Slovenia - Drustvo bolnikov z limfomom (DBL)
- Slovenia - Slovensko Združenje Bolnikov Z Limfomom In Levkemijo L&L
- Spain – AMILO
- Agrupación Española de Entidades de Lucha contra la Leucemia y Enfermedades de la Sangre (AELCLES)
- Sweden - Blodcancerförbundet Sweden
- Switzerland - Foundation for the Advancement of Bone Marrow Transplantation
- Switzerland (SFK)
- Switzerland - Myelom Kontaktgruppe Schweiz (MKgS)
- Turkey - KANKO/BIRKAN
- United Kingdom - Myeloma UK (MUK)

## **MPE's Strategic Objectives**

**MPE has a number of broad aims including:**

- Collaborating on projects to the benefit of the myeloma community
- Exchanging information and best practice
- Helping to developing existing patient groups and encouraging and facilitating the setting up of new groups
- Helping to shape appropriate health-related policies and initiatives on a European and national level
- Ensuring patients across Europe receive timely access to new treatment
- Stimulating and promoting patient-centred research and clinical trials
- Developing a strong evidence base for the needs and wants of patients and their role in research
- Providing information, educational and outreach programmes to member groups

**MPE's strategic objectives 2019-2024 are to:**

- **Provide a strong voice for myeloma patients at a European and international level**
  - MPE's work relies on evidence-based advocacy. In order to represent and be recognised as a legitimate voice for the patient community, MPE must gather evidence about the needs and wants of patients to be able to represent them properly. This is not only the right thing to do but will also positively impact the perception of MPE among all key stakeholders.
- **Strengthen members' and individual advocates' ability to advocate effectively**
  - A skilled and well-prepared member organisation can advocate more effectively and efficiently at a national level, to overcome barriers and challenges. Also, the development of individual advocates at European and national level will help our community in achieving the desired impact.
- **Secure a larger patient voice in myeloma research**
  - In order to make sure myeloma research delivers to patients' unmet needs from a clinical, care and quality of life perspective, MPE needs to empower the community and its individual advocates to become equal partners in research and regulatory affairs and to contribute to discussions and solutions in a meaningful way. To justify a seat at all relevant tables and to be able to provide meaningful, qualified and evidence-based input, MPE needs to continuously educate and prepare individual patient advocates in key knowledge areas. In parallel, MPE strives to collaborate with all key stakeholders as a respected partner, especially the areas of drug development and regulatory affairs.
- **Accelerate progress in the treatment and care of myeloma patients**
  - MPE needs to stay in dialogue with all relevant stakeholders, to ensure the needs and wants of patients across Europe are taken into account during the entire drug development process, but also needs to closely monitor and push for the new treatments to reach the patient without unnecessary delays.
- **Increase the number of patients who have their myeloma diagnosed in a timely manner**
  - Late diagnosis is still a big problem in myeloma, with poor prognosis and important quality of life issues among the main consequences for patients. MPE needs to search for effective ways of addressing this issue at a European level but also help member organisations to address this at national level. It is key for MPE not to raise awareness generally but to strictly target any initiative to ensure a meaningful impact.
- **Improve access to optimal treatment and care for all myeloma patients in Europe**
  - Access to treatment and care is a challenge in most European countries. MPE needs to ensure it supports its members to advocate effectively and efficiently at national level, i.e. by generating and providing evidence to them, by coaching them, by helping them develop strategies to advocate. MPE will at the same time advocate

and engage with stakeholders at European level whenever impact can be achieved at that level and taking into account the limited competencies in access issues that exist at European level.

- **Strengthen MPE's effectiveness, sustainability and capacity to take collective action**
  - MPE needs to continue investing, not only in growth and impact, but in strengthening the organisation from the inside. This needs to be done with proper governance rules and their effective implementation, by gathering feedback from members and staff, by having a well-functioning Board, by diversifying and securing funding sources, among other means. Towards the outside, it is crucial that MPE continues working on a communications strategy (internal and external) and its implementation, to ensure the work done and impact achieved is also well communicated to the outside and understood by both the membership and key stakeholders. This will consolidate the reputation and credibility of MPE to the outside but also increase satisfaction of members, Board and staff.

## **MPE work programme – overview**

MPE's work programme is driven by MPE's mission, shaped around MPE's strategic objectives, and aligned with the needs of members and the European myeloma and AL amyloidosis patient community. This translates into four key activity areas: Access, Policy and Regulatory; Research and Clinical, Capacity Building and Advocacy and Patient Evidence.

## **Access, Policy and Regulatory**

### **MPE's Access, Policy and Regulatory workstream has the following objectives:**

- Understand the current access landscape through data collection, analysis, and research, plus relationships with key players, in order to drive forward our mission to achieve best possible access for myeloma and AL amyloidosis patients across Europe. This understanding allows us to advocate more effectively
- Provide tools, data, and support for members to navigate the access landscape and improve access for patients at national level
- Be at the front-line of European discussions around access for myeloma and AL amyloidosis patients with key stakeholders including regulators, policymakers, and reimbursement bodies

## **Myeloma Access Atlas**

### **Description of Project:**

The Atlas programme aims to provide members with the tools and resources to advocate effectively for better access to treatment for myeloma and AL amyloidosis patients in Europe. The following elements allow for this to happen:

- The Atlas website provides an interactive tool containing information and data on healthcare systems and access to treatment across European countries. This data can be extracted, compared, and analysed to understand particular access challenges. Also, the data can be generated on demand whenever MPE members require it for advocating at national or regional level
- A tailored coaching programme with one-on-one support the help members develop their own strategies to overcome national access issues or reimbursement hurdles and provide assistance in implementing these strategies to effectively overcome the addressed access challenges
- A comprehensive analysis on the perceived barriers to access to myeloma treatment in over 30 European countries, based on the results of MPE-conducted surveys with patient organisations and clinicians collected in 2015 and 2018.

#### **Activities and Accomplishments in 2020:**

- Complete rebuilding of the Atlas website to provide members with a fully interactive tool to search, compare, analyse, and extract data as needed. An agency supported MPE with this complex redesign to ensure optimum usability and functions.
- Simultaneously, huge efforts were made to cleanse and refresh the data and data sources feeding into the Atlas dataset, resulting in the updating and addition of country-specific reimbursement profiles and access status of drugs.
- One-on-one support for members continued with the Atlas Coaching Programme, where members were assisted with specific access or reimbursement challenges in their countries and identify solutions to address these.
- On a European level, MPE interacted with the European Medicines Agency via a letter addressed to the Chair of the CHMP, via membership at the PCWP and by sending individual advocates to meetings aimed at assessing the regulatory approval of myeloma medicines.

### **CEE Workgroup**

#### **Description of Project:**

Based on the hypothesis that there is a huge disparity between access to medicines, healthcare, and clinical trials between Central and Eastern Europe, and Western Europe, several MPE members initiated the CEE Workgroup, which aims at gathering evidence on these disparities and specific CEE challenges that patients experience. This will hopefully enable members to take collective and coordinated action, addressing these challenges one by one, through a defined work programme, objectives, and improved dialogue at regional, national, and European level.

The workgroup consists of 13 representatives of MPE and member organisations with representation of over 10 CEE countries within the taskforce, culminating in a dynamic,

motivated, expert group of advocates able to take collaborative actions to address access inequalities.

#### **Activities and Accomplishments 2020:**

- The Workgroup met early 2020 to define and establish priority topics to address in the coming year, considering competing priorities and associated outcome / value for the member and patient community.
- It was decided to focus on access to clinical trials in CEE as a priority work area in 2020, and a plan was developed to conduct extensive academic and scientific research into trials conducted across Europe to understand differences, disparities, and key indicators around the conduct of trials in Europe and particularly compared to Central and Eastern Europe.
- The findings of the study will lead to the publication of a paper on the minimum standards of infrastructure required for clinical trials to take place in Central and Eastern Europe.
- The research also considers the incentives and disincentives around conduct of industry-led and academic-led clinical research in CEE countries, differences between this research, national and local level requirements, and different stakeholder perspectives
- Oversight and steering of this project have been maintained throughout 2020 with expected publication in 2021

#### **Meetings, European Policy and Regulatory**

##### **Description of Project:**

MPE engages with regulators such as the European Medicines Agency (EMA) on their assessment of new medicines and with policymakers to influence ongoing initiatives that impact on myeloma treatment and care access. MPE also works directly with a wide-range of stakeholders to ensure that the right types of clinical and patient-level evidence are being collected for national decision-making on new medicines and overcome identified challenges with access to myeloma drugs when they arise at the regulatory level.

MPE is permanently represented at the EMA via the PCWP, through Ananda Plate (member) and Hans Scheurer (alternate).

##### **Activities and Accomplishments 2020:**

- Continued work on policy proposals in the area of HTA
- Assisting EMA on identification of new patients to help with protocol review and providing patient perspective to assessment of marketing authorisation for new myeloma medicines
- Steering group within HTAi to design template for international HTA bodies and industry to provide information to patient organisations on new medicines participating in decisions

## Research and Clinical

**The Research and Clinical activity area has the following overarching aims and objectives:**

- Understand and demonstrate areas of unmet need in myeloma and AL amyloidosis
- Drive forward and influence scientific progress to address the greatest unmet needs in myeloma and AL amyloidosis
- Ensure that MPE and members have access to the most up-to-date information and research around developments relevant to myeloma and AL amyloidosis patients, including clinical development and research, therapies, treatment, and care
- Promote understanding and education within the patient community around drugs, clinical trials, research, and development in order to strengthen ability to advocate effectively and for patients to make informed choices around their treatment options

### AL Amyloidosis Workstream

#### **Description of Project:**

AL amyloidosis and multiple myeloma are linked in several ways. Firstly, both conditions arise due to abnormal plasma cells in the bone marrow. Secondly, due to the similarity in the pathophysiology of the two conditions, amyloidosis treatment utilises the same procedures and therapeutics as myeloma treatment. Finally, approximately 12–15% of myeloma patients develop clinical amyloidosis during the course of their disease, and up to 30% of myeloma patients have subclinical amyloid deposits. Consequently, there is a clear need for collaboration within the AL amyloidosis and myeloma advocacy field. The AL amyloidosis workstream was created to meet this need, and it aims to:

- Support AL amyloidosis patient community, including advocates, patients, and their families in Europe. This is done in close alignment and collaboration with other European organisations active in AL amyloidosis. The aim is to address needs and fill gaps where there is no current activity and, under no circumstances, to duplicate efforts of other organisations or compete with other organisations
- Raise awareness among patients, clinicians and other stakeholders about the complexity and challenges of the disease (e.g., late diagnosis)
- Understand and overcome therapy access challenges
- Investigate information needs in the context of new therapies coming to market
- Manage information sources and expectations around new treatments and to support members in getting this information to patients at a local level

#### **Activities and Accomplishments 2020:**

In 2020, MPE has defined the AL amyloidosis workstream, including landscape mapping, pathway review and identification of key stakeholders and partnership opportunities. Considering the

importance of collaborating with amyloidosis advocacy groups, MPE has approached the Amyloidosis Alliance, the discussion about projects which the two organisations can develop together is ongoing. Furthermore, conversations with industry partners regarding the AL amyloidosis workstream have been initiated. Finally, a comprehensive work plan has been developed for 2021, which includes:

- working to further define AL amyloidosis workstream including landscape mapping, pathway review and identification of key stakeholders and partnership opportunities
- organising a focus group to better understand the needs and experiences of AL amyloidosis patients, specifically in relation to treatment
- publishing an article in a peer reviewed journal that will include the finding from the focus group, as well as a review of the literature on HRQoL of patients
- developing an extensive AL amyloidosis guideline, similar to MPE's myeloma guideline
- creating a set of educational videos for patients about the mechanism and treatment of the disease

## Educational Resources

### Description of Project:

A core aim of MPE Educational Resources is to underpin the strategic objectives and programmes of the organisation by providing a wide-range of accessible and evidence-based information. MPE wants to ensure that myeloma and AL amyloidosis patients advocates, patients and other stakeholders across Europe are informed about the latest treatment and care developments in their respective diseases. MPE aims to ensure the dissemination of quality patient information throughout the haematology community and will assist members in adapting these to their country and language whenever possible. The core Educational Resources MPE provides are: Factsheets, Q&A, Patient Guides, Educational Clips, Webinars, Videos and Conference Reports

### Activities and Accomplishments 2020:

- All 10 factsheets have been updated and one has been added. These are all publicly available on the website, covering:
  - Thalidomide
  - Pomalidomide
  - Bortezomib
  - Daratumumab
  - Panobinostat
  - Elotuzumab
  - Ixazomib
  - Carfilzomib
  - Amyloidosis
  - Belantamab mafodotin

- The Myeloma Pipeline document has been updated to reflect changes in therapies and treatment options, and the document has been translated into 5 languages by members with assistance of MPE
- 2 Q&A documents have been produced, one specifically around COVID-19 and one around CAR-T
- 12 Educational webinars have taken place throughout the year on various topics of importance to the patient community
- 30 educational clips have been produced and shared through the website and social media
- 2 Conference reports have been produced providing coverage of updates and highlights from EHA, ESCO and ASH

## Scientific meetings

### Description of Project:

MPE attends a range of external scientific congresses and meetings and contributes to important discussions about cancer and myeloma treatment, care, and patient advocacy. This is a major public affairs function of the organisation and enables networking with the key opinion leaders from different fields. Additionally, MPE reports back from major scientific congresses to members and the patient community, providing reports for the largest congresses where access is limited so members, patients and caregivers can understand, and digest key scientific updates related to myeloma and AL amyloidosis treatment and care.

### Activities and Accomplishments 2020:

- MPE attended several scientific congresses this year including EHA, ASCO, ASH, IMW, COMY, and ECCO. Social media coverage of all congresses was provided through MPE's social media channels, and selected coverage was available through the MPE website
- A conference report was published detailing the latest updates from ASCO, EHA and ASH respectively. These are publicly available through the MPE website.

## Patient Evidence

**The overarching objectives in the area of Patient Evidence are:**

- To generate evidence on the needs and wants of patients, for the purpose of providing a strong voice which is backed up by real data for myeloma and AL amyloidosis patients at a European and national level
- Secure a large patient voice in myeloma and AL amyloidosis research, including around access, which is incorporated and considered in the drug development process, trials, and assessment / regulatory processes

- Influence research across Europe
- Generate evidence on the barriers to early diagnosis
- Increase impact of MPE on the work of key stakeholders at scientific, regulatory and policy level

## Evidence Generation Unit

### Description of Project:

Patients' needs and wants are complex and heterogeneous. In addition, healthcare providers, policy makers, authorities and researchers need to base their decisions on evidence. However, decisions about care and treatment are often based on anecdotal reports of patients' real attitudes and preferences to risks, benefits, priorities, and concerns, rather than appropriately collected patient data.

The MPE Evidence Generation Unit systematically generates data to support robust decision-making in the best interest of people affected by myeloma and AL- amyloidosis. It builds on years of experience in the areas of data generation and collaborations with key stakeholders, such as academic institutions, regulatory authorities, and pharmaceutical companies.

MPE will use the findings from the EGU as evidence in policy discussions and briefings to advocate for better and fairer myeloma care and treatment for patients. Emerging research findings will additionally help MPE better understand the needs and wants of patients and their families, which will guide our strategy and enable us to provide the most appropriate support and guidance to our members.

### Activities and Accomplishments 2020:

- The EGU strategy was developed throughout 2020, including scope, aims, objectives, and a clear operational model.
- Recruitment for the Unit Lead took place mid-2020 and the Head of Patient Evidence was employed in October 2020, when further work was undertaken to refine the strategy and identify key priorities and areas of focus for remainder of 2020 and 2021
- Opportunities for initial research projects have been identified and potential collaborators mapped including industry sponsors, academic partners, and support within the advocacy community.

## Capacity Building and Advocacy

Our Capacity Building and Advocacy workstream is designed specifically with our members in mind, and provides several key functions and programmes aligned with the workstream objectives, which are:

- Strengthening members' and individual advocates' ability to advocate effectively

- Providing support to member organisations to build capability, capacity, sustainability, and resilience in order to continue to advocate and support patients at national or regional level
- Provide a strong platform at European level for the voice of myeloma and AL amyloidosis patients to be heard.
- Use MPE's position to capitalise on opportunities for networking, dialogue and communication with other members, key stakeholders, and patient advocates to be more effective and take coordinated or collective action

## Advocate Development Programme

### **Description of Project:**

The pioneering Advocate Development Programme (ADP) was launched in 2015. This is a training programme directed to patient advocates with the aim of providing them with the necessary skills and knowledge in key areas required to advocate for the needs and wants of myeloma and AL amyloidosis patients. Main areas covered include the drug development process, drug licensing and reimbursement, evidence-based advocacy and engaging with key stakeholders effectively and efficiently.

The programme does not target MPE member organisations as such, but individual advocates. Applications will focus solely on the profile of the person applying, and not on whether he or she belongs to a member organisation, which makes this programme especially interesting for advocates who live in countries where there still is not a myeloma or AL amyloidosis patient organisation.

The programme combines a series of theoretical sessions delivered by experts in a relevant field with practical sessions that take place during important scientific meetings in Europe relevant to myeloma advocates: the European Haematology Association (EHA) Annual Meeting and the European Cancer Organisation (ECCO) European Cancer Summit. Additionally, the ADP trainees have the opportunity to attend other conferences and learning opportunities such as the European Conference of the Professional Society on Health Economics and Outcomes Research (ISPOR Europe), the WECAN Academy and the MPE Annual Masterclass.

### **Activities and Accomplishments 2020:**

- Six students from five countries (Spain, Sweden, Turkey, Italy and Germany) completed the programme in 2020
- MPE has successfully converted the Advocate Development Programme to a fully virtual learning environment, with full programme delivery, coaching and supported virtual Congress attendance for students
- To support delivery, a virtual classroom environment was developed, offering a centralised resource for all learning materials, and supporting educational resources, plus a communication platform for students to support learning

- A complete refresh of the programme took place in preparation for the 2021 cohort to ensure that the programme discusses cutting-edge developments in clinical, scientific and advocacy aspects of the programme
- Recruitment for ADP 2021 was completed, interviews took place and the candidates for the 2021 programme have been selected, with the programme kicking off in January 2021 and attended by 8 students from eight countries (Greece, Ireland, Lebanon, Israel, Denmark, UK, Austria and Poland).

### Myeloma Community Advisory Board (MM-CAB)

#### **Description of Project:**

Community Advisory Boards are community-run advisory boards where the patient community invites stakeholders to discuss topics of the highest relevance and impact for patients. The MPE Myeloma-CAB is a working group of MPE, comprised of leading patient advocates from across Europe, many of whom live with myeloma, working together to improve outcomes of myeloma patients.

The main aim of the MM-CAB is to influence the drug development process from as early as possible (i.e., setting research priorities) throughout until patients access treatment and care. In this sense, it covers areas such as patient information, patient engagement strategies, research and development and access strategies.

CAB meetings are highly strategic meetings that currently take place between the patient community and industry, but that in the future might take place with other stakeholders. In order to prepare CAB members to participate in MM-CAB meetings, there is an important training and capacity building element, which impacts any interaction with any stakeholder holding decision power that affect myeloma patients across Europe. Therefore, CAB meetings are planned with a holistic approach, leveraging the opportunity for comprehensive training on data, concepts, and content as it relates to the CAB sessions at hand. This ensures adequate preparation for the sessions, as well as continued learning and development of CAB members.

The MM-CAB carries out groundwork by influencing industry-led research at European and global level, with the aim to support the important work of MPE members in advocating for the best possible treatment and care for any patient, no matter where they live. Some examples of topics that need to be addressed at European and global level, but which have the potential of addressing challenges at country level are trial design, informed consent, early diagnosis, treatment of high-risk patients, access to treatment, availability of trial sites across all European countries, market exclusivity and patent law.

#### **Activities and Accomplishments 2020:**

- Comprehensive review of CAB pilot phase, adapting 2020 strategy to key learnings of that first year
- Improved CAB training curriculum to include general trainings related to myeloma, access, and patient engagement, as well as more robust company-specific medical training

- Launched regular meetings between CABs to discuss community priorities and broader strategies
- Implemented structured follow-up processes to track activities between CABs to ensure progress and tangible outcomes of value to the community
- Improvement of CAB processes, including CAB preparation, training and development programme, regular meetings between CABs and meeting follow-up, to ensure tangible outcomes of value to the myeloma patient community
- Recruitment of 2 new CAB members with diverse experiences, backgrounds and skills adding to collective CAB representation, knowledge, and expertise
- Number of CABs held with number of companies
- Over the course of 2020 the MM-CAB met with Pfizer, Roche, Janssen, BMS and twice with GSK
- Finalised MM-CAB strategy 2021, which includes
- important increase in contact with relevant stakeholders (other than industry) with power to influence industry decisions
- important reduction in the number of meetings held, limited to those with realistic opportunity of impact by the patient community
- Developed CAB strategic planning matrix to inform 2021 CAB meetings based on the best opportunities for impact for the patient community

### Scholarship and Capacity Building Programme

#### **Description of Project:**

The rationale behind all MPE programmes is that by equipping members with the right tools and knowledge, they become empowered and capable of delivering essential services to patients. This will over time create strong, professional, independent, and sustainable organisations that are able to advocate for the needs and wants of myeloma and AL amyloidosis patients across Europe. To achieve this, MPE has developed the Scholarship and Capacity Building Programme. Members are invited to submit applications to the Programme, and if requirements are met and their initiative is selected by the review committee, they are awarded a grant of 3.000 € to implement to implement their project. They are also invited to participate in one-to-one tutorials aimed at improving knowledge and skills on several topics they have identified as important and relevant to the project at hand. Recipients report to MPE on their project for inclusion in an annual publication to showcase their work and share best-practices. There are 10 scholarships available per year.

#### **Activities and Accomplishments 2020:**

- 14 applications were received for the MPE Scholarship in 2020, all of which were scrutinised through an independent committee to assess project alignment with needs of the community, impact, feasibility and project plan, and other factors. 10 scholarships were awarded to members in 10 countries. Please note that additional

- 54.350€ were provided in grants to members affected by Covid-19 (see section 2.6.5 for more information)
- Ongoing support was provided to those members to whom scholarships were awarded in line with project objectives and requirements with the aim of building capabilities within the patient community
  - A report was published on the projects, outcomes, and learnings from the scholarship programme (early 2021) which is available publicly and sent to members

## MPE Annual General Meeting

### Description of Project:

Once a year MPE holds its Annual General Meeting (AGM). All MPE members, sponsors, and special guests (prospective members, potential sponsors, etc.) are invited to this event which includes a one-and-a-half-day Masterclass to provide training to MPE members with scientific sessions, given by the most important specialists in Europe, and advocacy sessions. In previous years, the AGM also included the MPE General Assembly and a sponsor meeting with the MPE Board and staff members and the MPE's current and prospective sponsors in order to explain the present and future MPE projects.

### Activities and Accomplishments 2020:

- In 2020, the AGM was scheduled to take place in March, however the outbreak of COVID-19 meant the cancellation of the face-to-face event. The General Assembly took place virtually, and the rest of the AGM programme was rescheduled to take place later in the year through a series of webinars.
- MPE has supported members to host virtual events through the year, notably support with developing and hosting webinars, and providing tech/comms support.
- Work commenced in 2020 to plan the AGM 2021, MPE's 10<sup>th</sup> Anniversary Celebration, which was planned as a face-to-face event taking place in July 2021. Members will note however that the event has been replanned as a virtual event and MPE continue to work on hosting an interactive and valuable event for members. Again in 2021 the virtual General Assembly will take place separately on 22 March.

## COVID Outreach Workstream

### Description of Project:

The COVID-19 outbreak has affected myeloma patients and members in different ways, from the access to treatment and the follow-up of patients to the job MPE members are developing in their organisations. This situation is very different from country to country and MPE is trying to find out how COVID is affecting myeloma and AL amyloidosis patients and member at a national level to shape and adapt the way MPE can support them.

### Activities and Accomplishments 2020:

- Development of educational materials on the impact of the virus for myeloma and AL amyloidosis patients, including potential physical, emotional, and treatment-related affects Translation of educational materials into the languages of our national members, to ensure dissemination at a national level in a timely way
- Series of mini-videos (COVID-19 video series)
- Changes in Myeloma Treatment during COVID-19
- Impact of COVID-19 on clinical trials including advice for patients
- COVID-19 and CAR T myeloma clinical trials
- Dexamethasone and COVID-19
- Long term impact of myeloma treatment changes during COVID-19
- Second outbreak: are health systems ready?
- Modification of treatment during COVID-19
- COVID-19 and the new normal for myeloma patients
- Stem cell transplantation and COVID-19
- Ongoing calls and webinars – industry sponsors, community / policy/regulatory webinars to understand wider landscape / identify opportunities and best practice
- Support to members through one-on-one coaching, mentoring, other practical support as required
- Extended the MPE Scholarship and Capacity Building Programme to offer additional funding to member organizations to develop or adapt programmes to response to the needs of their patient community during the pandemic.
- Development of a Telegram channel on COVID-19 and myeloma
- Conducted needs assessment survey among member organizations to understand the impact of the pandemic on organisational operations and sustainability, how patients in members countries have been affected, and the types of support that MPE can offer to help in these circumstances.
- Extended the MPE Scholarship and Capacity Building Programme to offer additional funding to member organizations to develop or adapt programmes to response to the needs of their patient community during the pandemic.
- Planning for Phase 2 of COVID Outreach Workstream which includes the development of materials regarding the COVID-19 vaccine, conducting a follow up needs assessment of member organizations, and hosting patient and carer focus groups to gather evidence of the impact of the pandemic on patients' quality of life.

### Public Funded Projects

MPE is involved in several European projects. MPE's involvement focusses on ensuring that the voice of the myeloma and AL amyloidosis patient community is adequately reflected within the programme of work, and that educational resources linked to the programmes are designed with this in mind.

## IMI HARMONY

### Description of Project:

IMI HARMONY is a project consortium, involving over 50 partners from across the haematological community, looking at the collection and utilisation of “big data” in haematological cancers. Specifically, the project gathers together, integrates, and analyses anonymous patient data from high quality sources including European clinical trials. The project consortia will also define core outcome sets for haematological diseases.

Whilst not an official project partner, MPE is involved in IMI HARMONY through Work Package 6: Stakeholder Forum. The patient involvement element of the work package is led by Leukanet and their role is to ensure that patient stakeholders from each haematological cancer are involved in the development of the dataset, in the definition of the core outcomes set and in any additional outputs from this wide-ranging project. MPE therefore provides the myeloma patient voice into the HARMONY project, and its myeloma subgroup, ensuring that relevant patient outcomes sets are defined, and that the data is utilised in a way that benefits patients.

### Activities and Accomplishments 2020:

- MPE has been involved in several HARMONY General Meetings in 2020, providing opportunity to further understand important scientific elements of the project and translate this to the patient community
- Disseminated information about Harmony through MPE communications channels (website, newsletters and social media channels) to keep members up to date about the latest developments achieved by Harmony.
- As part of the HARMONY Patient Cluster, MPE supported Harmony in their work to define a set of treatment outcomes in myeloma. MPE has been involved in the creation of the “long-list” of outcomes and provided final feedback on the outcomes list which has been defined for myeloma. The final list of outcomes was sent out to the community in a three-round “Delphi survey” to reach consensus on the outcomes that should make the agreed upon final list. This was disseminated to the myeloma patient community with the help of MPE members.
- MPE has been involved in the development of the Harmony Added Value Framework (HAVF), supporting the Harmony consortium with the project scope, and providing feedback on the information developed around myeloma and myeloma treatments.

## HORIZON 2020

Horizon 2020 is the **biggest EU Research and Innovation programme** ever, with nearly €80 billion of funding available over 7 years (2014 to 2020). The goal is to ensure Europe produces world-class science, removes barriers to innovation and makes it easier for the public and private sectors to work together in delivering innovation.

Myeloma Patients Europe is part of **two projects** within the European Commission's Horizon 2020 programme:

## CARAMBA

### Description of Project:

Horizon2020 CARAMBA was approved and preparation started at the end of 2017 and will run until 2022. Ten partners from six EU-countries are collaborating through CARAMBA. The project consortium is researching an innovative immunotherapy for the treatment of multiple myeloma, known as Chimeric Antigen Receptor T-cell therapy (CAR-T). Through strategic collaboration with a wide-range of stakeholders, including MPE, the consortium aims to ensure the streamlined transition of a CAR-T product from the laboratory through to myeloma patients in the clinic. As well as the clinical aspects, the project consortium will also collaborate on regulatory and access issues and on ensuring that patient preferences are utilised in the project.

### Activities and Accomplishments 2020:

- MPE has continued to provide input on behalf of the myeloma patient community into work packages 1, 3, 6, and 7 which concern regulatory approval of the clinical trial protocol and clinical trial, the socioeconomic burden and going to market of CAR-T, and dissemination activities.
- In 2020, MPE attending the ASCO, EHA, and ASH meetings and published various interviews and videos with CAR-T leaders.
- MPE published a pipeline document on the CARAMBA clinical trial.
- MPE created a general Q&A publication on CAR-T

## MMpredict

### Description of Project:

Horizon2020 Mmpredict, a 42-month project, was approved by the European Commission and started in November 2016 and will run until 2020. The European Commission has supported the whole project with €3.755,802 worth of funding distributed proportionately across project consortium members. SkylineDx, a member of the project consortium, has already developed and validated a diagnostic device called the MMprofiler™ which can determine the level of risk of a myeloma patient by classifying them into “high” or “standard” risk groups. Patients with “high” risk myeloma do not normally respond as well to treatment and are likely to relapse more quickly than patients who have “standard” risk myeloma.

This classification is done using gene expression profiling (GEP), a technology in which the activity (or “expression”) of specific genes is measured in tissue samples – creating a patient specific picture. The GEP of an individual patient, represents their biology and can give important clues on response to drugs.

The aim of the project consortium is to build upon this approach by developing a tool which can help myeloma doctors predict the most effective treatment for patients. This will be done through using predictive biomarkers, which are measurable indicators of response to treatment and disease progression. Assessing this within patient tissue samples should give researchers information on the treatment or treatment combinations which are most effective in each individual patient based on their own myeloma subtype. Correlations between predictive biomarkers and the effect of treatment or treatment combinations, will then be processed into a treatment decision matrix, which should enable myeloma doctors to determine personalised medicine strategies

#### **Activities and Accomplishments 2020:**

- MPE has continued to be very involved in the project throughout 2020. This has included a key role in the development and review process of the final patient survey including design and content to ensure that this was fit-for-purpose and maximised the data collection potential whilst also presenting a positive user experience for patients completing the survey.
- MPE has also developed a suite of communication activities for the project, related to the final outcomes of the project and intended to inform, educate and update the patient community on the aims and progress of the project
- Recruitment was supported by MPE and importantly through MPE members. MPE also coordinated the recruitment of patients for the testing of the survey prior to its launch.
- Final reporting of the project remains in progress at the end of 2020, however MPE continue to be involved in the review and development of the final report and presentations.

## **IMI SISAQOL**

#### **Description of Project:**

An international multidisciplinary consortium, co-led by the European Organisation for Research and Treatment of Cancer (EORTC) and Boehringer Ingelheim (BI), has been convened to generate recommendations to standardize the use, analysis, and interpretation of PRO data in cancer clinical trials. SISAQOL-IMI (Setting International Standards of Patient-Reported Outcomes and Quality of Life Endpoints in Cancer Clinical Trials – IMI) will develop a set of standards for the design, analysis, interpretation, and presentation of Patient Reported Outcome (PRO) data for cancer clinical trials.

SISAQOL-IMI is a public-private collaborative research project under the Innovative Medicines Initiative (IMI). Forty-one stakeholder groups are involved in the partnership, including researchers from the pharmaceutical industry, academia, cancer institutes, regulators, and patient advocacy organisations.

MPE are a work package leader in SISAQOL on behalf of WECAN, leading jointly with AbbVie on work package 8, Communications and Dissemination. This means MPE has a pivotal role to play in communicating progress, news, and updates in the consortium with the cancer patient and

myeloma patient community, and ensuring meaningful dialogue takes place between the patient community and consortium stakeholders for the purpose of ensuring that the results are of true value for cancer patients in Europe.


#### Activities and Accomplishments 2020:

- Project kick-off was in January 2021. Work took place in 2020 to align WECAN partners on understanding the consortium in terms of aims and objectives, assign resource and identify key WECAN partners, work together to understand key opportunities for the patient community and prepare a high-level work plan in line with work package aims
- MPE oversaw and managed the contracting process on behalf of WECAN, submitting a detailed activity assessment in line with the work above, and aligned with community objectives with regards to this project.

## Driving advocacy through collaboration

### Collaborations with the cancer community (WECAN)

MPE recognise that sharing information, knowledge and resources across the cancer community only helps to serve our communities better. For this reason, MPE are involved in a number of projects and initiatives as part of the Workgroup of European Cancer Networks (WECAN).

Professional Organisation	MPE Involvement - Aims & Objectives
 <p>Workgroup of European Cancer Networks (WECAN)</p>	<p>MPE has had a very active role in WECAN, leading on a project entitled ‘Reasonable agreements between patient advocacy and the pharmaceutical industry’ and the WECAN Academy, but also through Ananda Plate, Vice-Chair of WECAN since 2019 (Chair 2017-2019)</p>

### Legal Agreements Project

#### Description of Project:

Collaboration between pharmaceutical companies and patient advocates often requires both parties to sign agreements covering various types of activities such as consultancy, collaborations, speaking engagements and advisory boards. These agreements define the terms

and conditions of the engagements, covering such matters as confidentiality, intellectual property, copyright, data protection, compensation, and other responsibilities of both parties. The multi-stakeholder project “Reasonable agreements between patient advocates and pharmaceutical companies (RAPP)” is a Workgroup of European Cancer Patient Advocacy Networks (WECAN) project coordinated by Myeloma Patients Europe (MPE) in collaboration with Patient Focused Medicines Development (PFMD) and independent participation of 12 pharmaceutical companies respectively.

This project developed Guiding Principles on legal agreements and analysed legal contracts between patient organisations/patient advocates and pharmaceutical companies to develop Reference Agreements for different types of engagements (Advisory Boards, Collaborations, Speaking Engagements and Consultancy) to be aligned with the Guiding Principles.


#### **Activities and Accomplishments 2020:**

- In early 2020 the Guiding Principles were published in the form of a physical and electronic booklet which is widely available to support patient advocates in their contract development and negotiation with the pharmaceutical industry
- In 2020, MPE has continued to be involved in the project through the multi-stakeholder “Reasonable Agreements between Patient Organisations and Pharmaceutical Companies” (RAPP) which developed a set of templates which can be adapted and used by patient advocates and pharmaceutical companies in different contracting situations
- The templates and supporting guidance are available online and MPE has been involved in the development of an interactive toolkit to support ease of use and access
- Implementation of the guiding principles and adoption of the associated templates continues to be monitored and in 2021 there is an intention to formalise this monitoring in the form of an assessment of implementation and recommendations around progressing this with industry partners. This work will be developed within the WECAN collaboration and the multi-stakeholder environment.

### **Driving advocacy in hematology (HEM CAB and EuroBloodNet)**



MPE drives advocacy alone and in collaboration where appropriate. In some areas that have cross disease challenges and priority areas, there is a need and benefit to the hematology community working together, mainly where resources and information can be shared, and the community shares the same objectives. This has proven to be very effective, and helps drive advocacy forward in a united way, with maximum benefits for the wider community.

	<b>Professional</b>	<b>MPE Involvement - Aims &amp; Objectives</b>

	Organisation	
	<p>EuroBloodNet</p> <p>European Reference Network (ERN) for rare haematological diseases</p>	<p>Ananda Plate is part of the European Patient Advocacy Group (ePAG) which brings together elected patient representatives and patient organisations who will ensure that the patient voice is heard in the development, programming and evaluation of ERN initiatives and activities.</p>

## Driving advocacy and initiatives in rare disease

MPE continue to represent myeloma and AL amyloidosis patients within the rare disease community, recognising that a collaborative approach to advocacy builds awareness and creates opportunity for working together to achieve common goals.

	Professional Organisation	MPE Involvement - Aims & Objectives
	Rare Cancers Europe (RCE)	This is a multi-stakeholder initiative dedicated to raising awareness of rare cancers in the European policy agenda. Currently Riikka-Leena Manninen is representing MPE at this forum.
	Rare Diseases Europe	Kate Morgan has been appointed to the EURORDIS health technology assessment (HTA) advisory group. This is a taskforce designed to advise EURORDIS on their work programme on the topic of medicines access.

## Collaborations with industry partners

In order to influence research and advocate for access to the best possible care of patients across Europe, MPE reaches out to a number of stakeholders in the field, including pharmaceutical companies.

Putting in place the most effective and efficient advocacy strategies, requires us to also understand the strategies of these companies. For that purpose, regular calls and meetings in the areas of research, patient engagement and access are of utmost importance and ensure highest possible impact by our patient community.

MPE also can sometimes play a mediation role, whenever there is little or no contact between the MPE member organisation and the company affiliate in the respective country/region. A collaboration therefore yields significant benefit for members and the community.

These touchpoints, strategic meetings and collaborations between MPE and the pharmaceutical industry, only take place in areas of mutual interest, ensuring our focus always stays on the needs and wants of the patient community.

MPE is committed to a proactive, community needs-driven approach to evidence generation which is evidenced in the development and establishment of the Evidence Generation Unit.

### Amgen Patient Preference Study

#### **Description of Project:**

One example of such a collaboration was the work conducted with Amgen between 2019 – 2020, a survey to understand the information needs of European myeloma patients. The survey asked patients a range of questions designed to better understand myeloma patient information needs and preferences, particularly focusing on the types of information that are valued by patients to make informed treatment decisions.

The study also aims to understand:

- Patient involvement in their last treatment decision and the factors that influenced this
- How information is associated with confidence in treatment decision-making
- Communication between healthcare professionals and patients on treatment decisions

The results of the survey will provide valuable insight into the needs of patients and will be used to inform the information provision strategies of a wide range of stakeholders, including pharmaceutical companies and patient groups. MPE, and its members, will also utilise the results of the survey to inform their advocacy and campaigning strategies which aim to improve the experience of patients across Europe.

#### **Activities and Accomplishments 2020:**

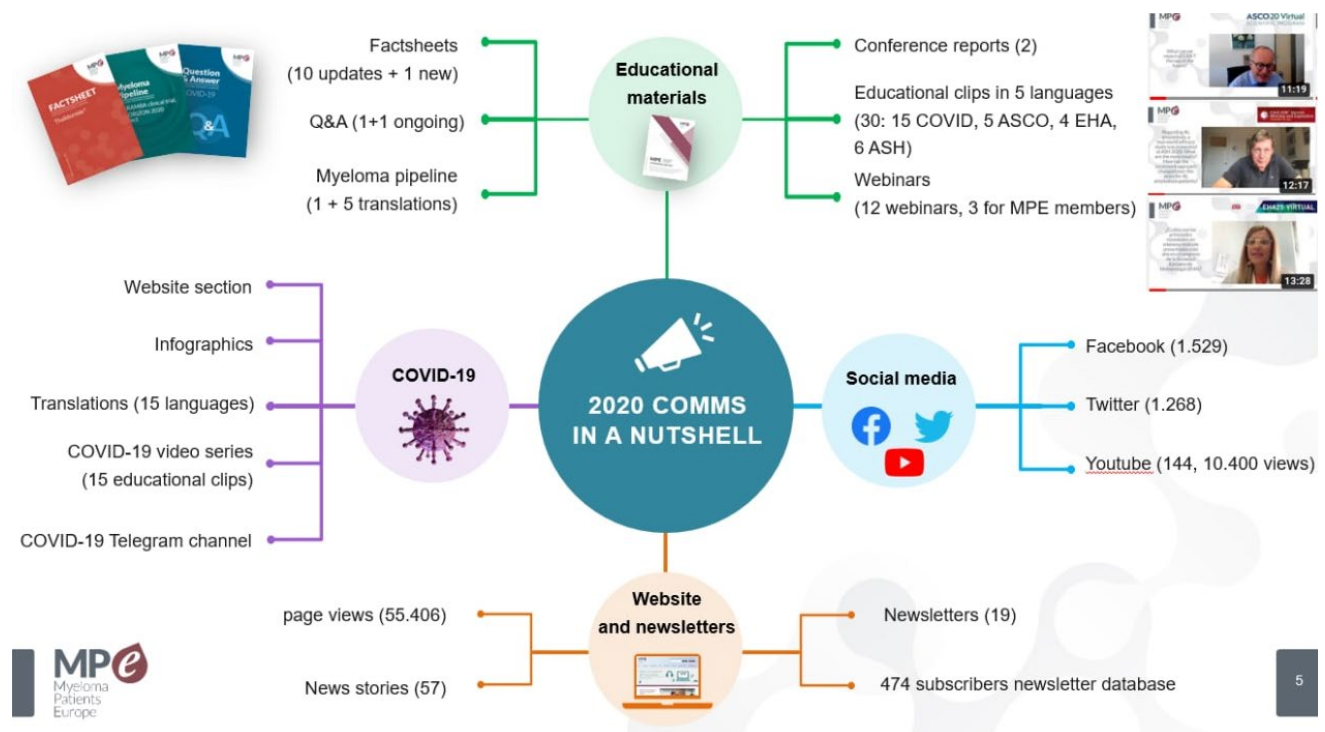
- The study completed as expected at the end of 2020, having been conducted in 12 different countries and having received approximately 1000 responses
- MPE managed the recruitment, communication and dissemination aspects of the final phases of the study in 2020
- The study abstract was accepted for ASH 2020, MPE were included as co-authors of the publication.

- There is an intention to share a report on the results of the survey, including country-specific data and a general summary, with members to inform national advocacy efforts.

## Communications, engagement, and public relations

### MPE Communications

As part of the MPE communications activities, MPE developed several communication and educational materials in 2020: 11 factsheets 2 Q&A, a myeloma pipeline publication, two conference reports, 30 educational clips, and 12 webinars. Additionally, the MPE website received more than 55.000 visits in 2020 plus 10.400 views in the MPE YouTube channel.



### Public relations

Developing relationships with key stakeholders for the purpose of furthering MPE's mission and objectives is an important part of our communication and public relations programme. The MPE team work together to ensure that key information is disseminated to our members, and the patient community, in an appropriate, tailored and effective way.

## Stakeholder meetings

### Description of Project:

The purpose of MPE stakeholder meetings is to build our relationships with our existing industry partners and to develop new ones. This is done through regular meetings in person and via teleconference. MPE also attends a wide range of advisory boards with industry partners, often presenting or inputting into their work programmes.

Throughout the reporting period, MPE has participated in several activities in order to further develop relationships with external stakeholders.

These include:


- Meetings with pharmaceutical industry, clinicians, regulators, and other relevant stakeholders
- Attendance at Advisory Boards, investigator meetings, and other relevant committees
- Participation in masterclasses and webinars
- Involvement in steering committees

### Activities and Accomplishments 2020:

- Opportunity / horizon scanning has taken place regularly through 2020 to identify potential new companies / organisations / people of interest who could be valuable to furthering MPE's mission or realising a strategic objective
- This has included identifying opportunities around large (virtual) events such as scientific congresses for meetings to take place with key speakers and other companies / people of interest in attendance
- In 2020 MPE established a relationship management system to support with managing, monitoring and growing important relationships

## Working with professional organisations

MPE continue to build on strong relationships established with professional organisations whose agenda, objectives or impact has critical important for the myeloma and AL amyloidosis patient community. A summary of these is presented below.

Professional Organisation	MPE Involvement - Aims & Objectives
 European Society of Medical Oncology Patient Advocates Working Group (ESMO PAWG)	Collaborating with ESMO, patient advocates and other stakeholders to optimise cancer patient care, the continuous improvement of cancer-specific information and education, the strengthening of patient autonomy and the support of patient rights.

	The European Cancer Organisation Patient Advisory Committee (ECCO PAC)	MPE collaborates with European professional cancer organisations and provides ECCO with direct insight into the issues and challenges faced by myeloma patients across Europe. The ECCO-PAC is the patient advisory body in ECCO.
	European Haematology Association (EHA)	EHA invite patient organizations to meet and discuss current issues in haematology, to exchange information, and to develop joint projects. MPE is one of the organisations collaborating with EHA and representing myeloma patients in these discussions.
	International Society for Pharmacoeconomics and Outcomes Research, Inc (ISPOR)	The leading professional society for health economics and outcomes research (HEOR) globally. The Society's mission is to promote HEOR excellence to improve decision making for health globally. Ananda Plate sits on the patient roundtable of ISPOR.
	Health Technology Assessment international (HTAi)	Health Technology Assessment international (HTAi) is the global, non-profit, scientific and professional society for all those who produce, use or encounter health technology assessment (HTA). Kate Morgan sits on a steering group focussed on the design of patient information.

## Acknowledgements

The activities and accomplishments of 2020 are the result of the collaboration and commitment between several individuals, organisations, and stakeholders. Together, we have developed and implemented programmes and initiatives that aim to improve diagnosis, treatment and the quality of life of myeloma patients.

We would like to extend a special thanks to all MPE members, as they are central to our mission and drive the work of MPE. Without your support we could not have achieved so much this year.

MPE is very grateful to the ongoing dedication of our stakeholders and sponsors, your partnership helps make it possible for MPE to continue working for myeloma patients across Europe.



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