MPE helps to ensure that patients’ needs are met and endeavours to create robust and sustainable organisations that are empowered to advocate for myeloma and AL amyloidosis patients across Europe. As part of this commitment, MPE’s Scholarship and Capacity Building Programme provides an annual scholarship for members to implement a project that will benefit the patient community in their country.

Following a comprehensive application and selection process, 10 successful applicants receive a grant of up to €3,000, in addition to any support required by members to help implement their idea (e.g. planning and logistical help, design advice, etc).

In this publication, we summarise and showcase the projects supported through the MPE Scholarship and Capacity Building Programme in 2022. All projects and events have met a specific need for the patient community, and helped improve the lives of those living with myeloma and/or AL amyloidosis thanks to the hard work and efforts of our members.

If you are interested in applying to the MPE Scholarship and Capacity Building programme, you can find more information on the MPE website or by emailing info@mpeurope.org.
Receiving news of a serious illness like myeloma is life changing. During the difficult times of a complex health crisis or serious illness, patients and their families experience feelings of fear, confusion, lack of knowledge and helplessness. In addition, ambiguity regarding medical information, administrative processes and complex bureaucracy, requires running around between insurance and medical bodies, trying to understand a patient's medical and social rights.

To bridge the gap, AMEN, with the support of MPE's scholarship, organised monthly lectures delivered by experts in the relative fields, followed by panel discussions and a Q&A.

This project also created an AI-based system in which patients answered a questionnaire and received a list of relevant rights with a link to fill out forms requesting to exercise those rights.

This information provided by AMEN and the AI system helped patients to feel less powerless and, furthermore, enabled them to access all the information they needed from one place. AMEN believes this has helped improve the quality of life for myeloma patients and they hope to continue developing this project to further benefit patients.
The Norwegian Blood Cancer Association is working on several projects promoting early diagnosis. Early diagnosis has been an area of focus in recent years, and the association creates awareness through information and by increasing knowledge about multiple myeloma, its symptoms and treatment, and the effects of the disease on quality of life.

In 2022, the association enhanced its work on early diagnosis by focusing on healthcare personnel, particularly general practitioners (GPs) and nurses. It produced six films intended for GPs and nurses containing information from patients’ and haematologists' perspectives on symptoms that GPs need to look out for, and the respective clinical examinations that need to be carried out. The association strongly believes that this will be a useful and easily accessible tool for GPs and would contribute to earlier diagnosis of multiple myeloma. The films will be used by the Norwegian Medical Association, and they will also be offered at universities.

In addition to the film projects, the association is working on developing a separate portal on its new website, which will contain tips and advice for healthcare personnel. Much of the information in the portal will be aimed at early diagnosis. The new website is scheduled to launch in the first quarter of 2023.

Blodkreftforeningen, the MPE Norwegian member, enhanced its work on early diagnosis with six films containing information from patients’ and haematologists’ perspectives on symptoms that others can look out for.
In July 2022, Fundacja Carita held a bike event in Poznan, Poland, to raise awareness of myeloma, integrate the community and collect money for physiotherapy for those in need.

More than 200 cyclists joined the event! They had a diverse range of representatives, from patients, carers, doctors and nurses to pharma representatives and policymakers, but with their rally gear, they dropped their daily status and roles and shared one goal standing arm in arm against myeloma. The cyclists wanted to demonstrate that multiple myeloma patients can be physically fit, socially active and can enjoy life, if their disease is well-controlled.

Fundacja Carita organised a few special booths on sites such as the education zone and healthcare zone with free diagnostic tests, entertainment for kids and live music on stage.

The Polish Minister of Health, Mr Adam Niedzielski, sent a special note in appreciation of the event, as did Hans Scheurer, the former President of MPE.

It was a great success for myeloma patients and their carers. The event helped raise awareness about myeloma and its challenges, and it also showed that when treated properly, myeloma doesn't stop patients from enjoying their life, being active and supporting each other.

During the event, a number of video interviews with patients, doctors and policymakers were conducted. These are available (in Polish) on their Facebook page, and more information about the rally can be found on their website (EN).

Fundacja Carita received extremely positive feedback from the participants, which has led the foundation to plan another event in 2023. This year, Fundacja Carita aims to break its record and welcome even more participants! Check out the website and prepare your bike for Fundacja Carita’s 3rd Rally for Health in 2023!
Personalised healthcare, also called personalised medicine or precision medicine, is an evolving field in which physicians use diagnostic tests to determine which medical treatments will work best for each patient. By combining the data from those tests with an individual's medical history, circumstances and values, healthcare providers can develop targeted treatment and prevention plans. Personalised healthcare is not only about treating and preventing disease for individual patients - it is also about rethinking the healthcare system in the future. Cancer patients and blood cancer patients (among them myeloma and AL amyloidosis), and their caregivers, as well as the general public in North Macedonia, are not very familiar with personalised healthcare and its benefits.

Therefore, HEMA, with the support of the MPE Scholarship, designed and printed booklets containing the following information:

- Research and definition of the Concept of Personalised Medicine
- Explaining Personalised Medicine (PM)
- Advantages of Personalised Medicine
- How to personalise the treatment, biomarkers, and therapeutic options for patient's treatment
- Monitoring, side effects and resistance
- Obstacles of Personalised Medicine
- Importance of data and useful advice for patients

HEMA has continued to see the impact of this project among the blood cancer community. Patients and caregivers who received the brochure reported that they were grateful to learn about personalised medicine and discover the benefits of this approach, and that the information was very valuable. Personalised medicine is a fantastic opportunity to individualise diagnostics, drug therapy and prevention.

To learn more about personalised medicine, check out HEMA's website.

One of the booklets that were designed and printed for patients, caregivers and the general public.
In 2022, MPE supported the Portuguese Association Against Leukaemia and Other Blood Cancers (APCL) by starting the first-ever myeloma support group for patients in Portugal. APCL identified that myeloma patients struggle to find a supportive place to share their challenges in accessing information about their diagnosis.

To provide assistance to patients, APCL started the first myeloma support group in April 2022. The aim of the support group is to offer individual support to patients, provide disease information and emotional support, address psychosocial and financial issues, provide context when patients return from doctor’s appointments and facilitate the sharing of experiences.

Since April 2022, APCL has been organising two support group sessions per month and patients from all over Portugal take part. Patients have greatly benefitted from these support group sessions and there was an increased demand to join the group, therefore a second support group was started in October 2022.

The myeloma patients that are part of the support group have provided positive feedback and feel this is life-changing and very impactful. APCL will continue providing support group services for all of their myeloma patients.
AL amyloidosis is a rare disorder with too little information in the Lithuanian language, and to this day, there is no disease-related content on the association’s website. Kraujas also noticed the lack of AL amyloidosis awareness among GPs.

To raise awareness, Association Kraujas, with the support of the MPE Scholarship, implemented an educational project that seeks to inform patients, family members and GPs about AL amyloidosis, its symptoms, treatment and other related issues.

In October 2022, Kraujas organised an educational webinar, “What should you know about amyloidosis?” to provide essential information about the rare disorder, including its symptoms, treatment, prognosis and practical matters. The online event was delivered by a haematologist and intended for patients, their relatives and GPs. Around 270 people joined the webinar.

To educate amyloidosis patients and their relatives, and help them understand and encourage their interest in the disease, specific fact-based content about AL amyloidosis was designed for the website. Association Kraujas has a special section, “Types of diseases” on the website where people can find information about different blood diseases. The information was prepared in collaboration with a haematologist and published in December 2022.

The information was also sent via email to around 260 GPs in Lithuania. The details can be found on the association’s website.

The project improved the knowledge of AL amyloidosis patients and their relatives by providing relevant information, and encouraging interest in the disease. It was also beneficial for GPs as it expanded their knowledge about a rare conditions.

The specific content about AL amyloidosis on the website has lasting value, as it could be a reference for future patients that are searching for more information, as well as for GPs.
Blood cancer patients in Slovenia have very good access to novel therapies and novel diagnostics, but they do not have suitable access to rehabilitation during and after treatment. A rehabilitation programme is an essential aspect of comprehensive care, helping patients get back to their social life and work.

L&L Association, along with the support of MPE’s Scholarship, organised the rehabilitation programme for patients with blood cancers “Together on the Path to Health,” which consisted of three key modules: physical, nutritional and psychosocial. It included monthly workshops led by a psychologist, monthly dietary group consultations with a nutritionist, regular weekly exercise with a physical therapist or kinesiologist and various forms of consulting services. The patients that were interested in participating in “Together on the Path to Health” first completed an interview with a haematologist, who assessed their medical condition before enrolling them on the programme. Each patient participated in the programme for six months and, during this time, they attended all activities, and had access to the participating experts and programme coordinator, who were available for any questions. The programme also had an “info phone”, support from an employee of the L&L Association.

The patients were informed of the programme and the possibilities of enrolment through printed posters and leaflets placed in hospitals. They were also informed about the programme via the patient community on social media.

The workshops were recorded and made available on their YouTube channel, website and Facebook page. In 2022, the association was able to conduct 24 successful workshops.

The rehabilitation programme made an important contribution to the quality of life of patients with multiple myeloma and AL amyloidosis, and it resulted in better treatment outcomes. Patients recovered faster and more easily during and after treatment, and it was easier for them to return to social and work environments.

Patients can visit the website to access the rehabilitation modules.
Mercy Bridge was able to publish two brochures to help myeloma patients. They also collaborated with haematologists to publish regular information on its social media platforms to raise awareness of the disease.

Mercy Bridge, with the support of the MPE Scholarship in 2022, was able to publish two brochures to help multiple myeloma patients:

1. 'Thrombosis and Bleeding'

Thrombosis and bleeding are complications that occur with multiple myeloma and can be life-threatening. Therefore, Mercy Bridge published brochures to increase awareness of these complications and educate patients and carers to identify these symptoms before they become life-threatening.

2. 'Oral care during radiation and chemotherapy'

This brochure explains how the use of bisphosphonates in multiple myeloma patients can cause oral health problems. The brochure also includes information about proper nutrition to support good oral health and proper oral care during different periods of chemotherapy.

Along with the brochures, Mercy Bridge collaborated with haematologists to publish regular information on its social media platforms to raise awareness about the disease and answered questions from patients.

This information has helped patients be more aware and up-to-date about their diagnosis, and make the right decisions for their treatments. More information can be found on Mercy Bridge's Youtube Channel and official Telegram channel.
In March 2022, as part of Myeloma Awareness Month, SOS Mielom, with the support of the MPE Scholarship, organised a one-day conference to address the need for “Early Diagnosis of Myeloma and Access to Treatments in Romania”.

The main aim of the conference was to raise awareness among general practitioners and national health authorities.

Most Romanian multiple myeloma patients are referred to a haematologist during the later stage of the disease, which is too late. Therefore, during the conference, there were sessions to raise awareness of multiple myeloma's specific symptoms and how general practitioners can recognise the symptoms, and provide the right referrals.

Currently, in Romania, patients must be on the waiting list for several months to a year before their investigation is conducted and not all of these patients have the financial capacity to seek a private investigation. Through this conference, health authorities were requested to facilitate free and timely access to specific multiple myeloma investigations such as electrophoresis, MRI and CT scans etc. Opening regional centres for the diagnosis and treatment of multiple myeloma was also recommended to the national health authorities.

SOS Mielom was able to collaborate with another MPE member, AMEN Israel, and Varda Shoham, the CEO of AMEN, shared the best practices on early diagnosis and equal access to investigation and treatment of multiple myeloma followed in Israel.

The outcome was tremendous, and SOS Mielom received 30 in-person participants and 1,400 online participants. The representative of the Romanian Presidency, the representative of the National Agency of Medicines (NAM) and the representative of the Association of Family Doctors expressed their support and willingness to collaborate with Romanian haematologists and multiple myeloma patients’ associations to accomplish the discussed objectives.
"In 2022, with the support of the MPE Scholarship, the MPE Spanish member, AMILO joined the second World Amyloidosis Day by organising an event in Clinical Universitaria de Navarra (CUN), one of the reference centres in the diagnosis and treatment of amyloidosis in Spain.

With the goal of creating awareness among the wider population and among healthcare professionals, AMILO organised this event in CUN so that haematologists, nephrologists, cardiologists and other specialists could join and learn about the signs and symptoms of all types of amyloidosis. Furthermore, the event was broadcast live via YouTube, so that all patients and carers in Spain could participate.

Renowned names in haematology such as Jesús San Miguel, Head of Clinical and Translational Medicine at the University of Navarra, and Dr Ramón Lecumberri, haematologist at CUN, also took part in this event.

Aside from the World Amyloidosis Day event, AMILO has been organising campaigns with the support of the national media to get the approval of daratumumab for AL amyloidosis patients, and AMILO wishes to continue campaigning until the drug is approved."