



2023 Scholarship and
capacity building
programme

Myeloma Patients Europe



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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 2023. 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.





AMYLOIDOSIS ISRAEL



Israel



www.amyloidosis.org.il

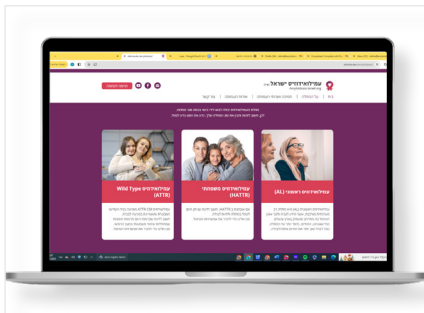


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Amyloidosis is a rare disease with minimal literature. The resources on the Amyloidosis Israel Association's website were outdated and the Association felt the need to update the website with the latest information.

With the help of the MPE Scholarship, the Association was able to work on the website, making it user-friendly and easily accessible for patients. The upgraded website will be launched in the first quarter of 2024. The new website has all the relevant information on different types of amyloidosis, diagnosis, latest drugs, treatment options, Q&As, recorded lectures, management of the disease and much more.

This serves as a one-stop option for patients, carers and doctors who are seeking to learn about amyloidosis.

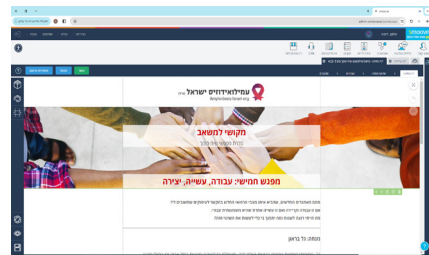


The updated front website page of Amyloidosis Israel.

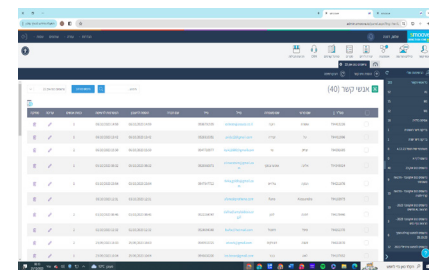
The Amyloidosis Israel Association, supported by the MPE Scholarship, revamped its website to provide updated and comprehensive resources on amyloidosis, serving as a one-stop hub for patients, caregivers and healthcare professionals.



The new website provides relevant information about different types of amyloidosis.



The website has updated information on diagnosis, the latest drugs, treatment options, Q&As and more.



An example of one of the sections on the Amyloidosis Israel website.

ASSOCIATION OF MYELOMA PATIENTS SERBIA



Serbia



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Patients diagnosed with myeloma and/ or AL amyloidosis face tremendous psychological and emotional obstacles. Often, their psychological well-being is not taken into consideration, because the focus is on providing the right treatment for the patients. Psychological support is found to improve patient well-being and so the Association, with the support of the MPE Scholarship, launched an online workshop and counselling programme, “Mentally stronger in the fight against myeloma.”

Through this project, the Association was able to conduct 74 hours of psychological group workshops and 36 hours of individual counselling, supporting 30 myeloma patients. In the sessions, the patients were able to share their diagnosis stories and their treatment experiences, and it helped them know that they were not alone. These sessions helped elicit a positive outlook and provided patients with useful information and the latest updates on treatments.

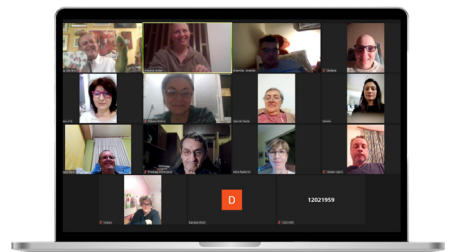
The main impact of the psychological workshops was empowering and educating patients, which contributed to their easier inclusion into daily life and overcoming the challenges that the disease brings. About 91% of patients who attended the sessions said they could sense an improvement in their psychological health and below are a few statements from the patients themselves:

The Association of Myeloma

Patients Serbia, with the help of the MPE scholarship was able to launch “Mentally stronger in the fight against myeloma,” an online workshop and counselling programme that supported 30 myeloma patients.

- *“It is much easier for me, because I have someone to openly talk to about the myeloma. People who go through the same journey and have the same diagnosis understand each other best.”*
- *“For me, it was a step forward in the way of communicating about the disease. That’s where I felt and gave myself more freedom in talking about how I feel and what I’m going through.”*

This programme also helped strengthen the relationship with the patient community and the Association hopes to continue this project in the coming years.



Attendees at the patient online workshop hosted by Association of Myeloma Patients Serbia.



BLODCANCERFÖRBUNDET



Sweden



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Advancements in myeloma research have led to the exploration of new and innovative treatments, including potential one-time therapies, offering significant improvements in patients' quality of life. However, high costs and the need for advanced hospital infrastructure pose barriers to widespread access to these treatments, limiting availability to only a few patients in Sweden. Blodcancerförbundet prioritizes access to innovative treatments and patient participation in clinical trials, aiming to address key challenges faced by members living with myeloma.

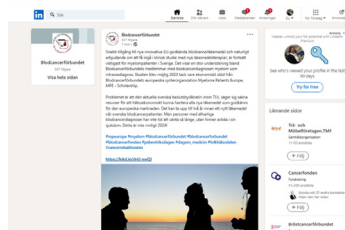
With the support of the MPE Scholarship, the organisation was able to conduct an in-depth survey to find out how patients navigate their day-to-day living with myeloma. They also wanted to investigate how myeloma patients perceived the opportunity to be involved in decisions regarding their care and treatments, and their interests in immunotherapies such as CAR-T and bispecific antibodies. The survey also shed light on the potential side effects and complications of certain treatments, and whether these treatments affected patients' quality of life.

Blodcancerförbundet [published an article on the results of the survey in Mynewsdesk](#) (a Swedish digital press company). The findings were also published on the [organisation's website](#) and [social media platforms](#).

Blodcancerförbundet Sweden, conducted a comprehensive survey to understand how myeloma patients navigate daily life, perceive treatment decisions, and their interest in new therapies like CAR-T and bispecific antibodies.

With the findings of the survey, the organisation approached the regulatory Health Technology Assessment (HTA) bodies and highlighted the need for more rapid action to help patients have access to new drugs and immunotherapies and for patient involvement when evaluating new treatments. A written submission of the findings was sent to the Swedish Dental and Pharmaceutical Benefits Agency (TLV). The organisation strongly believes that this kind of project helps strengthen evidence-based advocacy, which in turn helps to provide valuable input from the patient's perspective. This project also helped gain recognition from the TLV.

Blodcancerförbundet planned a roundtable in March 2024 to enhance collaboration among patients, clinicians, regulators and industry to boost patient involvement in drug development and access to treatments. Additionally, an educational webinar was also planned for March 2024 to raise awareness about myeloma.



Blodcancerförbundet's LinkedIn post explaining the survey



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DRUŠTVO BKB SLOVENIJA



Slovenia



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Newly diagnosed patients find it challenging to navigate through the complexities of the diagnosis, which can cause not only severe physical complications, but also psychological and emotional problems. The treating doctor does not always have the time to help patients through their emotional experiences and needs. To support patients, Društvo BKB launched the 'Patient to Patient' programme in collaboration with the Hematology Department, University Clinical Centre Ljubljana. Through this programme, patients provide individual support for newly-diagnosed patients. Although patients receive good medical help from doctors, someone who has been through a similar experience can understand and empathise with patients.

Patient volunteers from Društvo BKB visit the hospital to meet with patients once a week, and with the support of the MPE Scholarship, the Association was able to complete 151 visits to seven hospitals in Slovenia. Through this project, they were able to publish a training manual, a book and a leaflet for patients. These materials provide information on signs and symptoms of myeloma and other blood diseases, available treatment, treatment side effects and management of side effects.

Many patients have benefitted from this programme and Društvo BKB Slovenija plans on continuing this programme for their patient community.

Društvo BKB launched the 'Patient to Patient' programme, offering individual support from patients who can empathise with and understand the experiences of newly diagnosed patients.



Patient volunteers meet up with patients during their hospital visits.



Volunteers completed 151 visits to seven different hospitals in Slovenia.



FUNDACJA CARITA

 POLAND

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Fundacja Carita always aims to bring the latest international research to the Polish myeloma community, export their expertise for the benefit of the European myeloma community and promote the importance of international cooperation and patient advocacy. The organisation's goal was to allow knowledge and expertise exchange across national borders, and through the MPE Scholarship, Fundacja Carita was able to accomplish the following:

- **Translate and disseminate the MPE report** on “Addressing access barriers to myeloma clinical trials in Central and Eastern Europe.”
- **Present a poster at the MPE Annual Masterclass 2023** on “Nothing Is Impossible - Bicycle Event for MM Fighters and Friends!”
- **A booth at the Third Bike Rally** where the rally participants could test for osteoporosis and melanoma and learn more about other health issues, various diagnostic tests, the Polish health system and patient organisations supporting patients.

These projects had a great impact on the patient community:

- The Polish version of the MPE report informs the community about the importance of clinical trials and the issues patients face when it comes

Fundacja Carita used the MPE scholarship to **translate and distribute an MPE report, present a poster at the MPE Annual Masterclass, and organise an education zone at the Third Bike Rally**, all contributing to greater awareness of myeloma.

to accessing myeloma trials. Also, it helped the patient community, and other partners of Fundacja Carita, in cross-border initiatives, raising the profile of the organisation and showing the expanding scope of their expertise.

- The poster presented at the MPE Masterclass was designed to encourage fellow organisations to hold a large-scale event to grow their communities, bring them closer together and attract partners and sponsors.
- The Education Zone set up at the Bike Rally helped the participating patients and carers learn about haematology organisations, patient organisations, the functioning of the Polish health system, available diagnostic tests and health issues faced by myeloma patients.



Carita members presenting their poster at the MPE Masterclass 2023 in Dubrovnik, Croatia.



HEMA- ONKO



Macedonia



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Addressing the imperative issue of “information for patients,” HEMA-ONKO’s project aims to cater to the unmet needs of individuals grappling with blood cancers, particularly myeloma. Therefore, the organisation developed a patient-friendly brochure titled “Patient Information Handbook.” This resource comprehensively addresses patients’ needs, clarifies their rights to be integral contributors to decision-making, and encourages them to pose pertinent questions about their disease and treatment options. The handbook also provides a guide to patients on choosing the right haematologist-oncologist, instilling confidence in their ability to articulate their concerns and facilitate an informed decision-making process.

With the support of the MPE Scholarship, HEMA-ONKO was able to provide the following for their patient community:

- **Brochure -What Should I Ask the Doctor?** The brochure offers crucial insights on myeloma, such as the disease overview, causes, symptoms, diagnosis, treatment options and much more.
- **Printed leaflet - Myeloma Diagnosis Pathway:** The MPE myeloma diagnosis pathway was translated into Macedonian and disseminated into Skopje and other cities across Macedonia.

HEMA-ONKO with the support of the MPE Scholarship, **provided resources such as brochures, printed leaflets and an educational video**, empowering Macedonian myeloma patients to make informed decisions.

- **Educational video - “[Finding Strength: Ljubinka’s Myeloma Tale - Battling the System for Diagnosis, Navigating Challenges and Overcoming Delays](#)”:** A compelling video featuring the real-life experiences of Ljubinka Stoilova, an active member and volunteer of HEMA-ONKO.

The leaflet and brochure have become a source of empowerment and support regarding patients’ rights and opportunities. Additionally, the community’s response reflects an increased understanding of myeloma, coupled with a heightened determination to navigate their healthcare journey with confidence. Individuals within the community, including patients, caregivers, and general practitioners, express profound gratitude for this valuable resource.



HEMA-ONKO members distributing the brochure and printed leaflet.



KRAUJAS



Lithuania



www.kraujas.lt



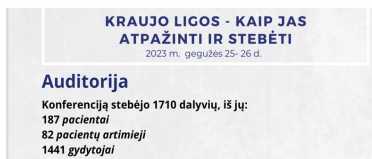
info@kraujas.lt

With the support of the MPE Scholarship, Kraujas was able to organise a conference on “Blood Diseases: How to Identify and Monitor?” The purpose of the conference was to educate patients, caregivers and General Practitioners. On day one, the focus was to provide patients and their carers with information on the latest methods of blood cancer treatment. Day two was dedicated to educating General Practitioners on ways to identify blood cancers, including myeloma, available testing and the importance of early diagnosis.

The MPE Myeloma Diagnosis Pathway was translated into Lithuanian and distributed to all the participants who attended the conference.

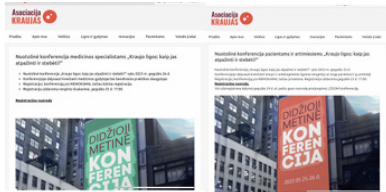
A total of 1,710 participants took part in the conference; 187 patients, 82 patients’ relatives and 1,441 doctors.

Kraujas was able to gather a large number of participants through social media advertisements. The Association received positive feedback with a high demand for making the sessions available online, so patients, doctors and advocates could access it later.



Banner used on social media to announce the conference.

Kraujas organised a conference to educate patients, caregivers and general practitioners on blood diseases. The event attracted 1,710 participants, with positive feedback and a demand for online session availability.



Final conference programme.



Screenshot of the registration page for the Kraujas conference.



SLOVENSKO ZDRUŽENJE BOLNIKOV Z LIMFOMOM IN LEVKEMIJO L&L



Slovenia



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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. In addition to these three aspects, the Association also released a video on "[Vocational Rehabilitation](#)" and published a book on "[Sex during and after treatment of blood cancers.](#)"

As part of this project, in 2023, the Association organised 10 group consultations with a clinical dietician, two group consultations with a haematologist and 12 group workshops with a psychologist. In addition, regular physiotherapy and kinesiology sessions were conducted for patients twice a week.

Through "Together on the Path to Health", patients with myeloma, AL amyloidosis and other types of blood cancers were able to join a professionally managed programme where they received nutritional, psychosocial

L&L Association initiated the "Together on the Path to Health" programme, offering physical, nutritional and psychosocial support, along with vocational rehabilitation resources, enhancing patient well-being during and after treatment.

and physical support during and after treatment. Through the promotion of the programme, the published booklet and the production of video content, the Association was able to help a wide range of blood cancer patients and their caregivers.



Attendees watching a video about the programme.



Screenshot of the video about vocational rehabilitation.



MYELOMA EURONET ROMANIA



Romania



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Myeloma Euronet Romania launched the Telemedicine Platform with the support of the MPE Scholarship to enable myeloma patients to get in touch with their treating haematologists in time and with fewer costs. This was particularly beneficial for patients living in remote places and for whom transportation represented a real financial burden.

For patients who were in urgent need and could not wait until their appointment,

Myeloma Euronet Romania **launched a Telemedicine Platform**, offering myeloma patients timely consultations with their haematologists, particularly benefiting those in remote areas facing transportation challenges in Romania.

the Telemedicine Platform also enabled speedy access to their hematologists.

Patients were made aware of this programme through advertisements on the organisations' website and flyers posted at hospitals.

Through this programme, patients received timely consultations from their haematologists



This programme helped patients who were in urgent need and could not wait until their doctor's appointment.



SOS MIELOM



Romania



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SOS Mielom organised an International Myeloma Action Day with the support of the MPE Scholarship. The goal of the event was three-fold:

- **Raising awareness:** Bringing attention to myeloma as a relatively uncommon yet significant type of blood cancer. Educating the public about its signs, symptoms and impact on individuals and their families.
- **Empowering patients:** Empowering individuals diagnosed with myeloma by providing them with resources, information and support networks to navigate their disease, make informed decisions and improve their quality of life.
- **Community engagement:** Bringing together patients, caregivers, healthcare professionals, researchers and advocates to foster a sense of community, exchange knowledge and collaborate in advancing myeloma-related initiatives.

The goal was achieved through an awareness campaign where educational materials, such as brochures, infographics and online resources, were published and distributed.

SOS Mielom was able to create increased awareness about myeloma and AL amyloidosis among the general public, in the hopes of leading to earlier detection, diagnosis and access to appropriate care for patients.

SOS Mielom organised an International Myeloma Action Day with three main goals: **raising awareness about myeloma, empowering patients with resources and support and fostering community engagement among stakeholders.**

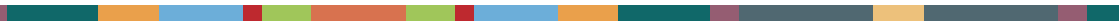
Through this advocacy effort, the campaign influenced policy changes, leading to improved access to treatments, better healthcare policies and increased research funding.

Overall, International Myeloma Action Day has made strides in improving the lives of patients, caregivers and community members affected by myeloma and AL amyloidosis. It has brought about positive changes in awareness, support, advocacy and collaboration, contributing to a better quality of life and improved outcomes for those facing the disease.



SOS Mielom members and stakeholders at the International Myeloma Action Day.







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