

2021 Scholarship and
Capacity Building
Programme report

Myeloma Patients Europe



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One of the primary goals of Myeloma Patients Europe (MPE) is to provide education, information and support to member organisations to facilitate their development, capacity, and sustainability. To support this aim, **MPE's Scholarship and Capacity Building Programme** invites member organisations to submit applications for an activity they want to implement to benefit the myeloma and AL amyloidosis 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 2021. All projects and events have been extremely successful, thanks to the hard work and efforts of all our members.

If you are interested in applying to the MPE Scholarship and Capacity Building programme in the future, you can find more information on the MPE website (www.mpeurope.org) or by emailing info@mpeurope.org.





AMEN ISRAEL



Israel



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The rate of research progress in myeloma has accelerated, and sometimes there is a gap between the accumulated scientific information and the availability of new products in the healthcare basket.

The patients experience recurrent remission of the disease at unpredictable times when each return is accompanied by a more advanced treatment line and new drugs that have not been given in a previous treatment line. Currently, there are five approved treatment lines in the Israeli healthcare basket and when a patient finishes with all existing treatment

lines, their path to new treatment is blocked and they need individual treatment from different sources to extend their life.

Therefore, AMEN found it necessary to provide information to patients and family members regarding clinical trials suitable for their medical condition and to make clinical trials accessible to myeloma patients.

To achieve their goal, with the support of the MPE Scholarship, AMEN translated the questionnaire on the site (www.trialjectory.com) into Hebrew and adapted it for myeloma patients. This site analyzes all relevant treatment options and presents only what is a match for the patient's condition in easy-to-understand language.

They also organised a workshop at the annual conference and Dr Yael Cohen gave a lecture in which she explained when and why to participate in clinical research and demonstrated the use of the site to locate personalized clinical research.

On the 23rd of December 2021, AMEN held a demonstration of the system for haematologists and they soon plan to launch the system, which will analyze the relevant treatment options on their website and provide a demonstration for all their patients.



At the end of last year, Amen held a webinar to show hematologist how the system worked



ARMENIAN HAEMATOLOGY ASSOCIATION



Armenia



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In Armenia, there are almost no reports on Monoclonal Gammopathy of Undetermined Significance (MGUS) and smoldering myeloma. It is reasonable to suggest that often primary care physicians, as well as many general practitioners and non-specialists, are dismissing the clinical signs and symptoms suggestive of MGUS/smoldering myeloma. Based on the estimation from the Armenian Hematology Association, on average each patient loses three to six months due to incorrect evaluation and diagnostic workup. Therefore, improving the knowledge, skills and general awareness among non-specialists is essential in tackling this issue.

The Armenian Hematology Association, with the support of MPE's Scholarship,

To improve early diagnosis, the Armenia Hematology Association (AHA) organised a series of webinars with the aim to improve knowledge, skills and general awareness for non-specialist. Also, it developed brochures for general practitioners, patients and caregivers.

organised a series of webinars and seminars, whose aim was to educate non-specialists on the proper assessment, differential diagnostics, and referral of patients susceptible to MGUS/smoldering myeloma. Various educational materials were provided to general practitioners, patients, and caregivers as well.

A professional team of health care providers and educators created specialised webinars and seminars for each target group explaining their role and their perspective about the disease.

The Armenian Haematology Association organised five seminars and two webinars for doctors and translated educational brochures for general practitioners, patients, and caregivers.



AHA organised five webinars and develop brochures for general practitioners, myeloma patients and caregivers.



ASSOCIATION OF CANCER
PATIENTS IN FINLAND

ASSOCIATION OF CANCER PATIENTS IN FINLAND

+ Finland

🏠 <https://www.syopapotilaat.fi>

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The Association of Cancer Patients in Finland, the MPE member in Finland, considers sharing reliable, relevant information to cancer patients as one of their primary tasks, but due to limited resources in Finnish, they are not able to produce videos for Finnish patients very often.

With the aim of keeping Finnish myeloma patients up to date about latest updates in treatment and care in this disease, in 2021 and with the support of MPE's Scholarship and Capacity Building Programme, this organisation was able to translate the webinar on "Personalised medicine in the treatment of Multiple Myeloma and AL amyloidosis" into Finnish. This webinar was originally organised by MPE in English and it was given by Dr Francesca Bonello, hematologist in the Università degli Studi di Torino, in Italy.

The new, translated webinar was uploaded onto their YouTube channel and shared with their myeloma patient network.

The Association of Cancer Patients in Finland believes the webinar will offer some new information to those who are not able to watch English webinars and help them gain a better understanding of myeloma, how could be treated, and latest updates and developments in this disease.

The Association of Cancer Patients in Finland is committed with sharing quality information with myeloma patients. To do so, they translated into Finnish a webinar on personalised medicine for those patients who are not able to watch English webinars.

The collage consists of three slides from a webinar. The top slide is titled 'Multiple myeloma' and 'Definition and epidemiology'. It lists three bullet points: 'Multiple myeloma (MM) is a hematological cancer originating from plasma cells, which undergo uncontrolled proliferation and survival in the bone marrow', 'MM represents ~ 2% of all cancers, with an incidence of 5-10/100,000 people per year', and 'Median age at diagnosis is 69 years, and more than 50% of patients are aged 65-85 at diagnosis'. The middle slide is titled 'Ongoing projects about personalised medicine in MM' and 'sMMprofiel'. It lists two bullet points: 'MMprofiel with SKY92 signature reads the expression levels of 92 genes of a myeloma cell' and 'Based on different levels of expression of genes, MMprofiel identifies standard and high-risk patients'. It includes three line graphs showing survival curves. The bottom slide is titled 'Personalised treatment: how far are we?' and 'Risk-adapted approach: prognostic biomarkers'. It lists two bullet points: 'Central molecular profiling of CD138-selected bone marrow MM cells for translocations, copy number aberrations and SKY92 signature status (GEP, MMprofiel)' and 'High-risk MM patients defined by double-hit* and/or SKY92 signature are enrolled'. It includes a flowchart showing the progression from 'Single hit' to 'Double hit' and 'High-risk'.

Images of the webinar on personalised medicine translated into Finnish.



BLODKREFTFORENINGEN



Norway



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The Blodkreftforeningen website has information related to diagnosis, symptoms, treatment and research. The organisation believes it is important to update and improve the information on the diagnosis pages regularly. With the help of MPE's Scholarship, they were able to coordinate haematologists to review and amend the existing information to ensure it was accurate and up to date.

The links to the updated diagnoses pages are:

- <https://www.blodkreftforeningen.no/amyloidose>
- <https://www.blodkreftforeningen.no/myelomatose>

Blodkreftforeningen also arranged a webinar for AL amyloidosis patients and their relatives after discovering that the AL amyloidosis patients in Norway do not receive sufficient information. The webinar on AL amyloidosis was organised in May 2021 and the footage was published on their website: <https://www.blodkreftforeningen.no/webinar>.

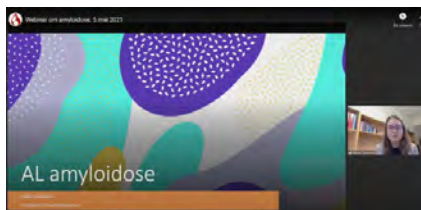
The same information was also published on their Facebook and YouTube channel (<https://youtu.be/mQuAmN3NAuk>).

The organisation received good feedback from their members that the information on the website was useful.

In order to keep informed to their myeloma patients, **Blodkreftforeningen**, review and update the content available in their website. Also they organised a webinar on AL amyloidosis which gather 400 views. The live stream event had an audience of more than 60 people.

They also received feedback from members and health professionals that the webinar on AL amyloidosis was interesting and informative. They hope to have increased the understanding of AL amyloidosis in patients, relatives, and healthcare professionals.

The webinar on their Facebook page was viewed 400 times and over 60 people participated in the webinar live stream event, which, given the rarity of the disease, was an impressive turnout.



More than 60 people join the live stream webinar on AL amyloidosis organised by Blodkreftforeningen.



CARITA FOUNDATION

 **POLAND**

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In 2021, the Carita Foundation with the support of MPE's Scholarship conducted the MM Patient European Forum - Patient Academy which consisted of educational meetings for patients, led by healthcare experts, as well as forums to facilitate knowledge exchange between leaders of patient organisations. The highlight of this year's Patient Academy series was a panel in which experts discussed the most important challenges and the situation of multiple myeloma patients in Poland as compared to Europe.

The following live webinars were held during the Forum:

- New standards of therapies
- How to support patients during the COVID-19 pandemic
- Therapies for newly diagnosed patients
- Immune disorders
- Fracture treatment
- Rehabilitation of MM patients

The forum was followed by an expert panel on treatment standards and new challenges in multiple myeloma during the COVID-19 pandemic consisting of guests from Poland and abroad. Simultaneous translation

The Carita Foundation conducted the MM Patient European Forum which included six live webinars and an expert panel on treatment standards and new challenges in myeloma during the COVID-19 pandemic. The Forum was following for over 150 people.

was also provided. The recordings of these webinars were posted on the Foundation's website in the CARITA TV section and on their YouTube channel to provide an accessible compilation of information for myeloma patients. The webinars can be accessed here: <http://fundacjacarita.pl/whatwedo/tv/1>

Through this initiative over 150 people attended the live Forum, with hundreds more later viewing the recordings. A summary of the Forum, including the experiences of Polish multiple myeloma patients and recommendations on treatment, was shared as well and can be found here: [MedExpress.pl](https://www.medicalexpress.pl).





HEMA



Macedonia



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Cancer patients who eat well and maintain a healthy body weight often tolerate treatment side effects better. Good nutrition helps the body replace blood cells and tissues broken down by treatment. A healthy lifestyle plays a key role in keeping the body strong, supporting the immune system and reducing the risk for heart disease and certain types of cancers. Despite this, there are very limited resources and research on nutrition and cancer. Patients find it difficult to get science-based advice, which can lead to them following misinformation and myth.

HEMA, with the support of the MPE Scholarship and Capacity Building Programme, created and distributed booklets titled "Nutrition and blood cancers". Developed by a specialist nutritionist, the booklet contained information on the following:

- Foods to be avoided by blood cancer patients
- Foods to be consumed by blood cancer patients
- Best foods to be consumed during and after chemotherapy
- Impact of nutrition on overall wellbeing

The booklet was distributed at the University Clinic for Haematology in

With the aim of providing information about nutrition and its effects in people with blood cancer, Hema developed a booklet to explain what kind of food is recommended during chemotherapy and other recommendations for blood cancer patients.

Skopje to patients, carers and other interested community members. The publication was also made available online on HEMA's website and social media channels. In addition, with the help of the scholarship provided by MPE, HEMA translated the booklet into Albanian. The translation was a great success, as the Albanian minorities living in North Macedonia can now access the booklet in their native language.

Overall, the booklet had a significant impact on myeloma and AL amyloidosis patients, providing an excellent guide for the community and answering common questions that blood cancer patients have about nutrition.



Booklet developed by HEMA about nutrition and blood cancers, available in Macedonian and Albanian.



KANKOBIRKAN



Turkey



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The organisation **KANKOBIRKAN** conducted a survey to assess the risk of patients with haematological disorders of getting COVID-19. This organisation also worked in an app to calculate the risk of each participant in the survey.

Cancer patients with haematological disorders or hematopoietic stem cell transplants are at high risk of COVID-19 infections due to multiple comorbidities and immunosuppression. Thus, there was an emerging need to create awareness in cancer patients to protect themselves from COVID-19.

In early 2021, it was generally acknowledged that cancer patients and patients with haematological malignancies and transplant patients were at increased risk, but there was no scientific questionnaire or survey to assess personalised risk.

KANKOBIRKAN (BİRKANKO), along with the support of MPE's scholarship, launched a survey to assess the risk of getting COVID-19. The survey was extended to myeloma patients and their caregivers and consisted of 20 questions designed to reveal the real, personalized risk. Each question was based on published scientific data and the responses were evaluated by a scientific team. The survey assessed the following: the risk of myeloma patients

getting infected; risk levels in different regions of Turkey, and risk categories in remission and relapsed patients. The survey was published online, and it went live on covid19riskim.org. More than 400 patients and 200 caregivers took part in the survey.

KANKOBIRKAN (BİRKANKO) also worked with students at the University of Montreal Polytechnic, Canada to design an app that would gather data to calculate the risk of each participant. The answers provided by each participant were reviewed by a specialist team assigned by KANKOBIRKAN (BİRKANKO) and each responder received their calculated risk assessment report in 3 days.

They also prepared a report to the governor's office and the health authorities.

The results enabled the organisation to understand the risks of myeloma patients in Turkey contracting COVID-19 and helped individuals take necessary measures to reduce their risk.





APCL



Portugal



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The Portuguese Association Against Leukaemia and Other Blood Cancers (APCL)

has helped 463 families through the programme APCL cares. With the MPE scholarship, APCL provided 115 grants to haematological patients.

In 2021, MPE supported the Portuguese Association Against Leukaemia and Other Blood Cancers (APCL) to provide financial support for haematological patients. The programme, APCL Cares, directly assists patients facing economic hardships caused or aggravated by their haematological disease. Over the past year, due to the COVID-19 pandemic, APCL received an increasing number of requests from patients for social support grants.

When patients receive a diagnosis, there are social, emotional and economic implications for the patient and their family. Patients and caregivers must travel frequently, and sometimes for long distances, which can create an undue financial burden for families. In addition, as treatment can often be

a long process, economically fragile families can face rising debt or struggle to obtain essential goods. APCL Cares seeks to ease the financial stress families face so that patients and carers can focus exclusively on treatment and recovery.

APCL partners with social workers in hospital haematology units across the country. A patient's request for a social support grant is administered by the social worker and approved through a comprehensive review process by the APCL Board. Since the organisation was founded, more than 463 families have been supported through APCL Cares with a total of €170.000 in grants awarded. In 2021 alone, with the support of MPE's Scholarship, APCL provided 115 grants, helping 36 patients and families with financial difficulties.



Since the organisation was founded, more than 463 families have been supported through APCL Cares.



SLOVENIAN LYMPHOMA AND LEUKAEMIA PATIENT ASSOCIATION, L&L



Slovenia



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Blood cancer patients in Slovenia have very good access to novel therapies and novel diagnostics, but they don't 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 consists of three key modules: a physical, a nutritional, and a psychosocial module. It is comprised of 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 who were interested in participating in "Together on the Path to Health" had to complete an interview with a haematologist, who assessed their medical condition before enrolling them in the programme. Each patient participated in the programme for six months. During this time, the patient attended all activities, and the participating experts and programme coordinator were available for any questions. The programme also has an "info phone", where patients can call any day of the week at any time and receive support from an employee of the L&L Association.

L&L organised the rehabilitation programme for patients with blood cancers "Together on the Path to Health". Due to the COVID-19 pandemic the programme was run online which made possible to open it to many more patients across the country.

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 (www.nazajvziviljenje.si) and Facebook page.

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

Due to the COVID-19 pandemic, the programme was run online and thus accessible to many patients from all regions of Slovenia.





SOS Mielom



Romania



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The myeloma and AL amyloidosis patients in Romania struggle to find accurate information about their diagnosis. To fill this knowledge gap, SOS Mielom, with the support of MPE's scholarship, developed seven different brochures containing information about myeloma and AL amyloidosis, which were distributed in 14 hospitals across the country. The brochures were titled:

- Little things that make a difference for myeloma and AL amyloidosis patients
- Suggestions and written advice by people with myeloma for people with myeloma
- Myeloma and pain: Guide on symptoms and complications
- Exercise for patients with myeloma
- Guidelines for Caregivers of patients with myeloma
- Guidelines for patients with refractory or relapsed myeloma
- Guidelines for the wellness of patients with myeloma

SOS Mielom also translated MPE's myeloma guide from English to Romanian so that patients could get more information about their diagnosis.

Seven brochures containing different information about myeloma and AL amyloidosis were developed by SOS Mielom, one of the Romanian MPE members. These materials were distributed in 14 hospitals across the country.

The organisation reported that the brochures and myeloma guide were informative and helpful for the patient community.



Cover of the Romanian version of the MPE myeloma guide developed by SOS Mielom.





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