COVID-19 Scholarship and Capacity Building Programme report

Myeloma Patients Europe

www.mpeurope.org
The mission of Myeloma Patients Europe (MPE) 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. To this end, we endeavour to help our member organisations remain robust, sustainable and empowered to advocate for myeloma and AL amyloidosis patients across Europe. As part of MPE’s work to provide members with support during the COVID-19 pandemic, we extended our Scholarship and Capacity Building Programme to offer additional funding during this time. The objectives of this scholarship were to deliver a rapid response to help organisations:

- Develop programmes to address the needs of patients as a result of COVID-19
- Adapt existing programmes to be safely and effectively delivered during the pandemic
- Support organisations’ capacity and sustainability due to the impact of COVID-19

Through this extension, 12 scholarships between 2,500€ and 5,000€ were awarded to member organisations across Europe supporting thousands of patients. This publication summarises the projects supported in 2021, the impact of these projects on the patient community, and how organisations adapted their activities, when needed, due to the pandemic. Overall, these projects were a tremendous success, providing patients and caregivers with much-needed support, disseminating up-to-date information and improving access to services. We extend our heartfelt thanks to our member organisations, their staff and volunteers for their hard work to accomplish so much for the myeloma and AL amyloidosis community in 2021.

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.
During the COVID-19 pandemic, AMEN identified several needs among the patient community. Patients faced uncertainty and fear, and the vast majority of patients who did not have the ability to commute privately were anxious about travelling to the hospital for treatment, to attend support groups and for other services.

After consulting with doctors, and with the support of MPE’s Scholarship, AMEN organised Zoom sessions between doctors and patients for them to receive clear and up-to-date information regarding the treatment plan, the latest updates and information on COVID-19 and myeloma.

The zoom sessions were also helpful in conducting support group programmes, consultation on nutrition, and sharing information about patient rights. Telemedicine through emails and phone calls were also organised.

AMEN was also able to provide private transportation for patients to come to the hospital specifically to get Velcade injections. Through the transportation programme, nearly 1,500 trips were made to hospitals.

The Virtual support was found to be of great help to the patients and their families and AMEN aims to continue to provide these services for myeloma patients.
The Association of Cancer Patients in Finland conducts seminars and other events where it offers expert lectures, peer support and discussions, but due to the COVID-19 outbreak, it was unable to conduct these activities. In order to continue these events, they had to conduct them online so that the patients could continue to benefit from these programmes.

With support from Myeloma Patients Europe (MPE), the Association of Cancer Patients in Finland acquired the Zoom webinar tool, along with other technical equipment, to deliver services to patients and their loved ones online. By doing this, the association was able to produce several webinars, online peer group meetings and podcast episodes.

In Autumn of 2020, a total of seven webinars on haematological malignancies (including one on myeloma), one webinar for patients with gynaecological cancers and two webinars aimed at all cancer patients regardless of cancer type (one on adapting to life with cancer and another about sexuality and cancer) were conducted. The scholarship provided by MPE helped in transforming the way in which the service was provided to patients and their caregivers.

The organisation was able to sustain its main mission of sharing reliable information throughout the pandemic. The online webinars were a huge success and received tremendous positive feedback, therefore the organisation plans to continue conducting such online events regularly.
The COVID-19 situation in Norway affected the planned activities and information projects of Blodkreftforeningen. The organisation has over 2,000 members, with myeloma patients making up a large part of the membership.

Blodkreftforeningen recognised that members needed up-to-date information on how their blood cancer diagnosis was affected by COVID-19 and sought to provide patients with relevant updates on an ongoing basis. The MPE Scholarship aided in creating several short films about myeloma to educate patients and their relatives, including films about myeloma and COVID-19. Also, it was used to organise webinars about COVID-19, myeloma, AL Amyloidosis, blood cancer and COVID-19 and the COVID-19 vaccine for myeloma patients. These webinars were filmed and shared on Blodkreftforeningen’s website and on social media.

The webinars and short films helped in providing relevant and current information to members with myeloma and AL amyloidosis. Blodkreftforeningen has received a lot of appreciation for the efforts taken and they plan to continue using these communication tools to provide the latest information to their members.

Blodkreftforeningen shared webinars and short films on their website, developed with the support of the MPE Scholarship and Capacity Building Programme.
Due to the impact of COVID-19, the Spanish Association of Amyloidosis (AMILO) faced difficulties communicating directly with their patient population. To ensure they were able to continue to provide important information about myeloma and AL amyloidosis during this time, as well as offer ongoing psychosocial support, the organisation implemented the following activities with help from the MPE scholarship.

First, AMILO worked to improve their digital communication channels, including their website and social media pages, to share up-to-date information more effectively with patients. They also organised two webinars to respond to the main concerns amyloidosis patients had regarding COVID-19: “COVID-19 and vaccinations for amyloidosis patients” and “The psychological impact of COVID-19 on amyloidosis patients.” In addition, the organisation translated relevant videos into Spanish to reach a larger number of patients and carers.

Regarding psychosocial support, AMILO coordinated counselling sessions between patients and specialists to help patients manage the mental and emotional impacts of COVID-19. Through the MPE Scholarship and Capacity Building Programme, AMILO was able to provide essential and timely information about myeloma and amyloidosis, as well as offer individual support to patients during the pandemic.
Carita aims to provide cancer patients and communities with comprehensive support in the field of health care, social assistance, education and awareness. The organisation also advocates for the newest treatment methods to be available in Poland to improve access for every patient.

During the outbreak of COVID-19, the organisation identified the growing need among patients for information about the newly developed scenario, the effects it would have on them and their treatment and the need for constant psychological and emotional support.

To tackle the issue, Carita introduced the 360° care programme by collaborating with MPE and hospitals. With the support and scholarship provided by MPE, Carita was able to achieve the following:

- Provide personal protective equipment for hospitals.

- Provide “Onkoprotection” safety kits for patients, which included 50 single-use masks, a protective helmet and 20 single-use gloves.

- Through Carita TV, the organisation was able to organise online webinars, which telecasted information on the newest treatment standards, precautions to be taken by myeloma patients during the pandemic and procedures to be followed in case of being infected by COVID-19.

- “Onkoline”, a 24-hour remote support service for patients, was introduced. The Onkoline has dedicated telephone numbers for patients to speak with a haematologist, psycho-oncologist and dietician.

- Since many patients had difficulty travelling to the hospitals for treatment, Carita arranged taxis for them.

These programmes were of great benefit to the patient community and Carita plans on developing them further so it can continue to best support myeloma patients and their families.
In the first three months of COVID-19, BORKA identified the need for a new approach designed to assist patients, to help them during the pandemic, to protect their condition from additional complications and to understand the global impact of COVID-19 on cancer. BORKA first focused on providing patients timely and relevant information about their illness, availability of therapy, and delays in treatment due to lockdown. The challenge to effectively resolve patients' needs and issues with the new situation in the oncology and haematology clinics was urgent since it affected a large group of citizens from all over the country who were in a state of panic.

The scholarship from MPE was critical to ensuring the continuation of BORKA's activities, helping more cancer patients successfully overcome the situation. With help provided by MPE, they were able to achieve the following:

Patients were provided with ongoing support in terms of information and education about COVID-19. A dedicated page on the BORKA website containing necessary information on COVID-19 was created.

Patients and their families were provided with psychological assistance and support, including coping methods on managing the crisis and adjusting to the new situation with COVID-19. They were also provided with guidance on how to continue therapy, treatment, and follow-up examinations with the clinics.

Delivery of tablet therapy was organised for patients living outside Skopje, the nation's capital. In co-operation with an oncology clinic, Red Cross, and BORKA, therapy was delivered directly to their city in order to avoid exposure to the COVID-19 virus. During the project from June 2020 to the end of July 2021, over 280 patients were provided with tablet therapy.

An online survey was conducted on the impact of COVID-19 on patients with malignancies. Results showed high levels of fear and anxiety among patients, treatment delays, and screening delays. BORKA made efforts to regularly communicate with the Minister of Health about the problems identified by their survey and tried to jointly bring the best solutions for patients with malignant diseases.

A social media campaign was conducted with daily announcements. The campaign had 400,000 views.

BORKA organised a literary challenge on the topic “I HAVE THE STRENGTH TO CROSS EVERY OBSTACLE.” Several patients took part in this programme and wrote poems which were published on BORKA's website and social media page on World Cancer Day, February 4, 2021.
The COVID-19 pandemic left myeloma patients feeling isolated, and as a result the need for fact-based information, contact with other myeloma patients and the urge to take part in activities became greater. At the same time most activities arranged by local associations under The Swedish Blood Cancer Association (TSBCA) were cancelled or postponed due to the pandemic. The organisation identified a great need to develop the digital skills of local associations and their representatives to continue with their activities online.

The MPE Scholarship was used to conduct online webinars, trainings and counselling sessions and to print brochures. The purpose of the training series was:

- To develop the digital competence of the target group with a focus on the technology used for web-based meetings, seminars and conferences
- To raise awareness about myeloma
- To increase knowledge of patient influence in HTA processes
- To create virtual support groups for myeloma patients and related parties

The project was a massive success and had several important outcomes. First, it improved participant knowledge about the process of introducing new drugs and treatments in Sweden, an issue that the Swedish Blood Cancer Association has been advocating for and is of the utmost importance to myeloma patients. Second, local associations developed a digital competence that empowers them to better share information with members and participate in international events, including MPE’s activities. Finally, by using digital expertise, the local associations have created virtual support groups for myeloma patients, which has provided significant support during the pandemic and ensured continued care.

Blodcancerförbundet conducted online webinars, trainings, counselling sessions, and made print brochures to improve participant knowledge about different processes and treatments.
Since the start of the COVID-19 pandemic, blood cancer patients were (and still are) fearful of contracting the disease and experiencing its potential side-effects. Patients’ regular check-ups were delayed, and they had a lot of questions about their health, nutrition and psychosocial support. Face-to-face meetings for consultations were cancelled and the easiest way to get their questions answered without leaving their home was by using digital health solutions.

Therefore, upon discussions with patients and caregivers, and with support of the MPE Scholarship and Capacity Building Programme, HEMA launched Virtual Counselling, which is a digital platform built within their website for patients with blood cancers and their caregivers, to facilitate free online consultation with nutritionists and psychologists, as well as participate in online yoga classes. This platform was promoted on HEMA’s social media channels and on television.

The impact of the project on the myeloma and AL Amyloidosis community was significant. To date, 104 patients and caregivers have used this platform for free consultations and classes. Online solutions are a great way to support patients and caregivers especially during the pandemic and are the easiest way to get their questions answered from the safety of home. This platform will continue to exist and be available for patients and caregivers. HEMA also plans to upgrade the platform to involve other cancer diagnoses besides blood cancers.
The goal of Mercy Bridge’s project was to provide informational resources and support services for multiple myeloma patients to improve their quality of life during the COVID-19 pandemic.

The major objective was to inform patients and caregivers about treatment issues, treatment lines, innovative medicines, ways to overcome complications, and clinical trials through the organisation’s website, mmpatient.ru, and social media networks.

The MPE scholarship enabled the organisation to improve and upgrade its website for patients with multiple myeloma. The upgrade provided a convenient mobile-responsive version easily accessible by patients and their caregivers.

Mercy Bridge also developed four social media networks for multiple myeloma patients (Facebook, Twitter, Zen and Telegram). The social media sites were used to provide consultations between patients and a haematologist, a nutritionist and a lawyer. The haematologist provided information about the disease, drugs used, new methods of treatment, adverse effects and complications. The nutritionist spoke about the guidelines of nutrition during chemotherapy and the effects of nutrition during complications. The lawyer provided consultation on patient rights and ways to procure expensive drugs.

Through the website and social media networks, patients were provided with up-to-date information in the form of brochures, webinars and videos consisting of tips from the haematologist, nutritionist and lawyer. Virtual consultations were also organised for myeloma patients and caregivers. This allowed the patients to be in touch with their haematologist at any time and get answers to their questions. To date, 32 virtual consultations have been conducted and nearly 47,331 viewers have accessed the social media pages.
Romania was critically affected by the COVID-19 pandemic. The health care system wasn’t prepared for a pandemic of this intensity, which resulted in a scarcity of medical equipment including ventilators, masks, gowns and protective gear, and this caused panic among blood cancer patients.

By consulting with doctors from Colentina Hospital, and with the support of the MPE Scholarship, Myeloma Euronet Romania (MER) was able to acquire basic medical gear for medical staff, patients and their caregivers.

They also set up a Telemedicine Platform, which was acknowledged as the first-of-its-kind to be established by a patient organisation in Romania. This platform enabled myeloma patients and caregivers to receive medical advice at home and, most importantly, removed the need to travel long distances which might have subjected them to contracting COVID-19. Eighteen haematologists from prominent haematological centres in Romania consulted with patients through the Telemedicine Platform.

To authorise the platform, and to enable the haematologists to officially work outside their standard working hours, MER got the State Secretary at the Ministry of Health to endorse this initiative.