

2020 Scholarship and
Capacity Building
Programme report

Myeloma Patients Europe



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Through direct support for our members, Myeloma Patients Europe (MPE) aims to ensure that patients have access to the best possible education, treatment, and care. Additionally, we endeavour to help member organisations remain robust, sustainable, and empowered to advocate for myeloma and AL amyloidosis patients across Europe. As part of this commitment, MPE's Scholarship and Capacity Building Programme invites member organisations to apply for an annual scholarship to implement a project that will benefit the patient community in their country, and beyond. After a comprehensive application and review process, each year MPE awards 10 grants of €3,000 to member organisations, as well as one-on-one capacity building and technical support to ensure that activities are carried out effectively.

This publication summarises the projects supported through the MPE Scholarship and Capacity Building Programme in 2020, the impact of these projects on the patient community, and how organisations adapted their activities, when needed, due to the COVID-19 pandemic. 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 2020.

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

www.amen.org.il

info@amen.org.il

AMEN Israel, one of MPE's members in Israel, held 41 informative and interactive webinars on disease, treatment in myeloma, emotional support, nutritional counselling and physical fitness counselling, among other topics.

With support from MPE, AMEN held 41 informative and interactive webinars led by haematologists specialising in myeloma, as well as other clinicians and professionals, to provide patients with the most up to date information about the disease. The bi-weekly webinars ensured that patients living in remote areas of Israel, or who could not attend AMEN's monthly meeting due to COVID-19 or their health, were still able to access this essential information.

While half of the webinars discussed the treatment of myeloma, the other half addressed emotional support, nutritional counselling, physical fitness counselling and related topics, all extremely important due to COVID-19. As many patients were not familiar with online platforms, participants received a computer workshop and were assisted throughout the sessions. To ensure that

the webinars were interactive, patients had the opportunity to prepare questions in advance, as well as to ask questions during the webinars. Several hundred patients attended the live webinars and additional patients watched them on AMEN's website, where they remain accessible. Participants reported an improvement in their mental resilience and their ability to cope with the COVID-19 pandemic due to the webinars.

Finally, AMEN also used some of the scholarship funds to support its yearly convention, which took place online and was attended by approximately 450 patients and caregivers. Several talks took place during the convention, including Israel's response to COVID-19, disease management, breakthroughs in myeloma treatment, sexuality and intimacy, and personalised medicine, among others.



AMEN committee during its yearly convention.



ZDRUŽENIE PACIENTOV S HEMATOLOGICKÝMI MALIGNITAMI



Slovakia

www.hematologickypacient.sk

info@hematologickypacient.sk

The Slovakian Association of Patients with Haematological Malignancies updated and distributed **informational brochures on patients' rights** to respond to an increased interest surrounding this topic as a result of the COVID-19 pandemic.

In 2020, the Slovakian Association of Patients with Haematological Malignancies published updated versions of four brochures addressing the rights of myeloma patients within different areas of the social security system. The decision to renew and disseminate these brochures was in direct response to an increased interest surrounding this topic among patients and caregivers as a result of the COVID-19 pandemic and the extensive amount of questions raised by the patient community regarding social security support. The brochures provided information on disability pensions, state benefits, the rights of patients at work and specific rights regarding transportation. 500 copies of each brochure were printed and distributed among the myeloma patient community.

Further, with the support of MPE's Scholarship and Capacity Building Programme, the association will launch a campaign in 2021 to raise awareness about myeloma that will promote and disseminate an educational video that was prepared by the association in 2019. The video shows how myeloma is diagnosed, what the most common reasons for late diagnosis are and how myeloma should be treated according to current medical standards. The video has been met with positive reactions from patients, physicians and the general public. In addition to online promotion, the video will be shared in person with senior populations when it is safe to do so.



Informational brochures on patients' rights and the social security system



BLODKREFTFORENINGEN



Norway



www.blodkreftforeningen.no



post@blodkreftforeningen.no

Blodkreftforeningen, the MPE Norwegian member, originally planned to organise two seminars on myeloma and AL amyloidosis, but due to COVID-19 was not able to safely host in-person events. However, the organisation quickly adapted the activities so the information could be delivered effectively through other channels. In place of the seminars, Blodkreftforeningen produced a film on myeloma and one on AL amyloidosis, as well as two accompanying brochures. Both contain a brief summary of symptoms, treatment and follow-up, as well as information about ongoing research in Norway and worldwide.

Further, the experiences of patients living with myeloma and AL amyloidosis are highlighted as well. The films have been shared on social media platforms and are also available on the organisation's website. The videos will be screened during future webinars on myeloma and AL amyloidosis in 2021.

The supplementary brochures, created in collaboration with one of the leading myeloma experts in Norway, were provided to approximately 500 myeloma and AL amyloidosis patients who are members of Blodkreftforeningen. They will also be sent out to new members as they join. In addition, 200 brochures were distributed to several haematology departments in hospitals, as well as a large number of haematologists in Norway.

Blodkreftforeningen, the MPE Norwegian member, developed educational films and brochures on myeloma and AL amyloidosis with the aim of summarising the main symptoms, treatment and follow-up appointments required for these diseases.

Blodkreftforeningen received positive feedback on the brochures and films. Their members stated that these materials were informative and aided in their understanding of myeloma and AL amyloidosis diagnosis, treatment, symptoms and examinations. The resources also provided a helpful overview of relevant research in the field.



Images of the videos filmed by Blodkreftforeningen.



AMILO



Spain



www.amilo.es



info@amilo.es

The Spanish Amyloidosis Association, AMILO, organised a myeloma and amyloidosis Infoday, the second in a series of annual informational summits. Approximately 100 amyloidosis patients and caregivers attended.

AMILO received a grant as part of the MPE Scholarship and Capacity Building Programme to host a myeloma and amyloidosis Infoday, the second in a series of informational summits they deliver annually. Originally scheduled as an in-person meeting in November 2020, due to the COVID-19 pandemic, the meeting was moved to a virtual format and postponed to February 2021. The goal of this meeting was to discuss advances in the diagnosis and treatment of amyloidosis, early detection, living with the disease, working towards a national patient registry, and strategies for improving care.

Approximately 100 amyloidosis patients and caregivers attended the Infoday. The talks were split into two different round tables followed by a

panel discussion. The first round table focused on clinical topics including new therapeutic options in amyloidosis, clinical trials in AL amyloidosis and the role of primary care in the diagnosis of the disease.

The second round table focused on the genetic implications of certain types of amyloidosis and how to access genetic counselling, as well as different examples of how to work towards a national patient registry.

The two round tables were recorded and are available for amyloidosis patients in the form of short videos. These are available on AMILO's website and were shared through AMILO's social media channels: Facebook, Twitter and YouTube.



Invitation and agenda of the Infoday organised by AMILO.



CARITA FOUNDATION

POLAND

www.fundacjacarita.pl

kontakt@fundacjacarita.pl

At the height of the 2020 COVID-19 outbreak, the Carita Foundation recognised that the situation was evolving rapidly and patients were overwhelmed with the amount of information being disseminated, some of which was conflicting. To protect their patient community, the Carita Foundation organised a series of webinars with healthcare experts to provide accurate, concise information about the ongoing pandemic, its effects on the health and daily lives of myeloma patients, and how to access support.

The webinars were created in collaboration with haematologists, dietitians, psychologists, and other healthcare professionals and were interactive, allowing patients to ask questions and speak directly to the experts. Carita produced five webinars, addressing the following topics:

- The impact of medicines used in myeloma treatment on the possibility of a COVID-19 infection
- Procedures/protocols for myeloma patients with a COVID-19 infection
- The treatment of COVID-19 for a haematological patient
- Supporting myeloma treatment during the COVID-19 outbreak
- Psychological support

The Carita Foundation organised a series of webinars with healthcare experts to provide information about the ongoing COVID-19 pandemic, its effects on the health and daily lives of myeloma patients, and how to access support, among other topics.

The webinars were advertised through social media channels and approximately 200 patients attended each broadcast. Recordings of the webinars are available on Carita's website as an ongoing resource for patients.

WEBINAR

• CYKL WYKŁADÓW •

AKADEMIA PACJENTA

Standardy terapeutyczne oraz terapie na które czekamy w leczeniu szpiczaka mnogiego

TERMIN	HARMONOGRAM
11.09.2020 piątek	16:00 - 16:55: Wykład - prezentacja 16:55 - 17:30: Pytania

Prelegent:
prof. dr hab. Krzysztof Giannopoulos
Kierownik Zakładu Hematoonkologii, Doświadczalnej
Uniwersytetu Medycznego w Lublinie i lekarz konsultant
Oddziałem Hematologicznym Centrum Onkologii Ziemi
Lubelskiej im. św. Jana z Dąbki jest ekspertem z dziedziny
hematologii klinicznej i doświadczalnej. W badaniach
nowotworów zajmuje się biologią molekularną oraz
charakterystyką procesów immunologicznych w przebiegu
rozrostowych chorób hematologicznych. Członek prezydium
Polskiej Grupy Szpiczakowej (PGSz) i przewodniczący prac
PGSz w 2020, współautorzytel i członek zarządu PMK,
prezes Stowarzyszenia Hematologia Nowej Generacji.

Prowadzący:

Krzysztof Rokicki
Prezes Fundacji Carita
im. Wiesławy Adamiec

Emilia Demczur
Wiceprezes Fundacji Carita
im. Wiesławy Adamiec

Logos: MPE, FUNDACJA CARITA, janssen, AMGEN

Approximately 200 patients attended each broadcast included in the series of webinars.



HEMA



Macedonia



www.hema.org.mk



contact@hema.org

Medications used in the treatment of myeloma may produce unpleasant, potentially dangerous side effects. In order to educate patients, HEMA created and distributed a booklet discussing the management of side effects caused by the therapeutics most commonly prescribed to treat multiple myeloma. This booklet is the first of its kind in Macedonia. It is designed for patients and their caregivers and aims to aid in the management of side effects during radiotherapy and chemotherapy, as well as other treatments, such as corticosteroids, thalidomide, bortezomib and lenalidomide.

Side effects are outlined in the booklet with an emphasis on how patients can manage them without interrupting their treatment schedule and advising them to report to a physician if they notice any of the toxicities. Part of the booklet is dedicated to the risks of a COVID-19 infection for myeloma patients and methods to prevent infection are also discussed.

The booklet was distributed by HEMA's volunteers to patients and caregivers in the University Clinic of Haematology in Skopje, North Macedonia, the country's only healthcare institution where multiple myeloma patients are treated. Booklets were also sent by mail to HEMA's members. The publication can also be accessed via HEMA's website and it will be reprinted in 2021 due to

Supported by the MPE Scholarship and Capacity Building Programme, HEMA created and distributed a booklet discussing the management of side effects caused by the therapeutics most commonly prescribed to treat multiple myeloma.



Booklet developed by HEMA around the management of side effects caused by myeloma treatment.

Association Kraujas, the MPE member in Lithuania, recognised a need among their patients for better information regarding bone marrow and stem cell transplants. Based on feedback from their community, patients receiving a transplant for the first time often felt overwhelmed and had a number of questions regarding the treatment. To address this, Association Kraujas published "Bone Marrow and Stem Cell Transplants: A Handbook for Patients" for myeloma and AL-amyloidosis patients, as well as their relatives and carers.

The booklet was prepared in collaboration with haematologists, a psychologist, a nutritionist, and other specialists and provides clear, comprehensive information about transplants, while addressing the common concerns of patients. Specifically, the handbook covers transplant treatment in Lithuania, transplant preparation, emotional challenges, managing pain, nutrition, side effects, sexual health and family planning, and advice for carers, among other topics.

By addressing both the medical information regarding the transplants, as well as the health and psychosocial needs following the transplant, the publication provides information and support for patients and carers throughout the entire process.

Association **Kraujas** developed a patient handbook on bone marrow and stem cell transplants, where patients can find information about a range of topics related to the most common concerns around this procedure.



The handbook on Bone Marrow and Stem Cell Transplants was distributed to 300 patients.

The Slovenian Lymphoma and Leukaemia Patient Association (L&L) received support from MPE for their annual rehabilitation programme for blood cancer patients. This comprehensive rehabilitation programme, entitled "Together on the Path to Health," is organised in partnership with the Slovenian Haematological Society. Starting in 2017, the programme provides professionally organised, comprehensive rehabilitation for patients with myeloma, lymphoma, leukaemia, and other types of blood cancers.

It serves to prevent or mitigate problems caused by aggressive treatment and to increase the patients' quality of life during and after treatment. Further, the programme aids in the successful return of patients to their social and working environments.

The programme 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. Patients interested in participating in "Together on the Path to Health" take part in an interview with a haematologist, who assesses their medical condition prior to enrolling them in the programme.

In 2017, **L&L** launched a new rehabilitation programme for patients with blood cancers called "**Together on the Path to Health**". This programme continued in 2020 with the support of the MPE Scholarship and Capacity Building Programme.

In 2020, the programme was modified due to the COVID-19 pandemic. When programme activities could not take place in person, they were conducted online using Zoom. Monthly workshops, group consultations, and regular exercise activities were also hosted online. In addition, L&L held a technology workshop to ensure that patients understood how to use the online platform and resources. Fifty patients attended the rehabilitation programme for 6 months. Overall, 18 workshops and group consultations were conducted in person and a further 14 were held online. Additionally, numerous individual consultations took place and 20 educational videos, featuring experts from all three modules, were created and can be accessed on L&L's website: www.nazajvziviljenje.si



Due to the COVID-19 pandemic, the programme was conducted online.



MOHA



Hungary



www.onkohemat.hu



moha@onkohemat.hu

In 2020, with the help of the MPE Scholarship and Capacity Building Programme, MOHA created a concise, informative booklet about disability pensions for haematological cancer patients in the Hungarian language. Despite the availability of several kinds of social benefit schemes for cancer patients in Hungary, no up-to-date, easy-to-understand resource existed to aid patients in choosing the appropriate service.

In addition to the fear and anxiety patients experience during the diagnosis process, they also face confusion and uncertainty regarding their rights and entitlements. To meet this important need, MOHA created a booklet that summarises disability benefit options in a transparent way. The publication

The booklet on disability pensions for haematological cancer patients, developed by MOHA, is now available on their website. This publication will be delivered to blood cancer centres once the COVID-19 lockdown in Hungary ends.

provides details on the types of benefits, rules for receiving them, qualification requirements, benefit amounts, and how to apply for benefits.

The booklet is now available on the MOHA website. Hard copies will be delivered to blood cancer centres once the COVID-19 lockdown in Hungary ends. Patients can also request the booklet directly from MOHA, and it will be delivered to them free of charge.



Informational booklet regarding disability pensions for haematological cancer patients.



APCL



Portugal



www.apcl.pt



geral@apcl.pt

In 2020, MPE supported the Portuguese Association Against Leukaemia and Other Blood Cancers (APCL) to provide financial support for haemato-oncological patients. Entitled APCL Cares, the programme directly assists patients facing economic hardships caused or aggravated by their haemato-oncological disease. Over the past year, due to 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

The Portuguese Association Against Leukaemia and Other Blood Cancers (APCL) developed the programme APCL Cares with the aim of assisting patients facing economic hardships caused or aggravated by their haemato-oncological disease.

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 hematology 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 430 families have been supported through the programme APCL Cares with a total of €145.000 in grants awarded. In 2020 alone, APCL provided more than 100 grants, helping 33 patients and families with financial difficulties.



The programme APCL Cares has helped more than 400 families.





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