MPe
Myeloma
Patients
Europe

2024

Scholarship and capacity building programme

Myeloma Patients Europe

www.mpeurope.org

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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, six successful applicants received a grant of up to €5,000, 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 have summarised and showcased the projects supported through the MPE Scholarship and Capacity Building Programme in 2024. All the 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.

Associação Portuguesa de Leucemias e Linfomas (APLL)

Portugal

www.apll.org

Empowering myeloma patients, body and mind, a holistic support programme for myeloma patients

The project addressed both the physical and psychological challenges experienced by myeloma patients throughout the course of the disease and treatment.

It offered both group and individual psychological interventions, all conducted online. Additionally, brochures were provided containing exercises that patients could perform at home, such as diaphragmatic breathing or recording and modifying negative thoughts. These brochures also include key information shared during the sessions, as well as practical tips on the topics discussed. Reading these materials at home not only facilitated a deeper understanding of the session content but also allowed patients to explore the topics further and raise any questions for subsequent sessions.

The second part of the project, the physical rehabilitation programme, was conducted online, with a weekly supervised group session lasting six weeks. Patients could access an online platform to view the weekly session videos and continue their training throughout the week. Before and after the programme, patients were evaluated by a physical instructor.

An online platform was also developed for the physical rehabilitation programme to offer weekly training videos to participants. This platform allowed patients to continue their exercises at their own pace, with the option to ask the physical instructor any questions.

Psychologically, patients have shown improvements in their perception of quality of life and cognitive abilities. Emotionally, their levels of anxiety, depression and stress have remained stable at low levels.

Patients participating in the physical rehabilitation programme have reported improvements in their physical abilities, including better control of pain and fatigue, both during and afterwards.

The project will remain open to new participants until the end of June 2025, and there is hope to continue at least the physical rehabilitation programme if APLL receives the necessary funding to hire a physical instructor. The impact of this project has been very positive within the patient community, with patients from across Portugal participating, as well as Portuguese patients living abroad, who have also had the opportunity to join.

Mieloma Múltiplo:
Tratar Corpo e Mente

Programa de apoio psicológico e físico
para melhoria da qualidade de vida de doentes

INTERVENÇÃO PSICOLÓGICA

SESSÕES ONLINE DURANTE 6 SEMANAS, SEGUIDAS DE 3 SESSÕES MENSAIS

Reduzir o sofrimento psicológico
Promover a partilha de sentimentos
Promover a interação social

REABILITAÇÃO FÍSICA

TREINOS ONLINE EM GRUPO DURANTE 6 SEMANAS, COM PLANO DE CONTINUAÇÃO DOS TREINOS

Controlar o cansaço e dor
Melhorar a resistência física
Promover a qualidade de vida

Organização: APLL Associação Portuguesa de Leucemias e Linfomas

Patrocinado por: MPE Myeloma Patients Europe

Apoio:

Speak with your doctors in a friendly manner: patients in focus

UDRUŽENJE OBOLELIH OD
MULTIPLOG MIJELOMA SRBIJE
ASSOCIATION OF
MYELOMA PATIENTS SERBIA

Association of Myeloma Patients Serbia

Serbia

www.mijelom.rs

The availability of specialist doctors (aside from haematologists) for patients suffering from myeloma and/or AL amyloidosis is limited in Serbia. This is primarily due to the difficulties in securing appointments and the short duration of consultations, which often leaves patients without sufficient answers and in a state of uncertainty. The goal of this project was to address these issues by providing patients with answers to their questions through discussions with key specialists in relevant medical fields.

Through the project, the Association of Myeloma Patients Serbia produced a series of podcasts, hosted by a presenter with specialist doctors as guests. The podcasts were edited and uploaded to the Association's YouTube channel, and promotional videos were created for social media to expand the reach and raise awareness about myeloma and AL amyloidosis.

Five podcast episodes, each featuring a different specialist – a haematologist, nutritionist, physiatrist, psycho-oncologist and an oncologist were developed. These episodes were also subtitled in English and shared with other associations to maximise their reach across Europe.

As of the time of this report, the total reach of the podcasts on YouTube was 2,381 views. It is essential that patients are informed not only about the disease itself but also about areas that can improve their quality of life. The podcast recordings were structured based on questions submitted by patients before the recording, ensuring that the content directly addressed their most pressing concerns.

This approach has proven beneficial in enhancing the quality of life for patients, particularly those living in smaller towns in Serbia, where access to medical experts is often limited. Given that the podcasts have gained substantial interest, there are plans to expand the series and feature additional, relevant healthcare professionals.

Five podcast episodes with different specialists were developed and subtitled in English.

Informational film about AL amyloidosis

Blodkreftforeningen

Norway

www.blodkreftforeningen.no

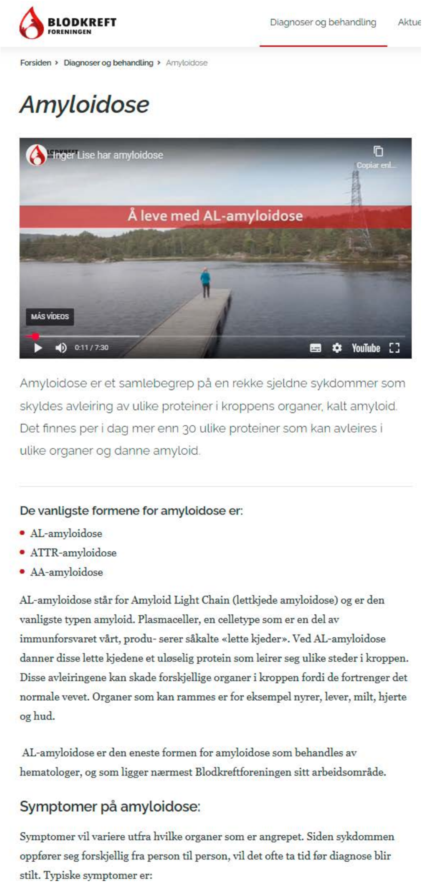
With many members affected by AL amyloidosis, Blodkreftforeningen recognised the need to provide better patient-oriented information about this rare disease. The organisation sought to address the gap in knowledge and improve access to reliable information.

A film was planned, produced and distributed, offering a comprehensive overview of AL amyloidosis. The film includes a patient's personal history and concise information about the diagnosis, treatment and symptoms, explained by one of the leading medical experts, Dr. Ann Kristin Kvam.

Published on the association's website, the film was also shared across its social media platforms and YouTube channels. It can be viewed here: Blodkreftforeningen AL Amyloidosis Film or directly on YouTube: watch on YouTube.

The film has been well received, with positive feedback from both patients and their families. It has also garnered attention on social media, where it has been liked and shared widely.

Additionally, the film will be shown at an upcoming seminar on AL amyloidosis. Since publication, the response from the community indicates that the film is a valuable resource for raising awareness.



Amyloidose

Amyloidose er et samlebegrep på en rekke sjeldne sykdommer som skyldes avleiring av ulike proteiner i kroppens organer, kalt amyloid. Det finnes per i dag mer enn 30 ulike proteiner som kan avleires i ulike organer og danne amyloid.

De vanligste formene for amyloidose er:

- AL-amyloidose
- ATTR-amyloidose
- AA-amyloidose

AL-amyloidose står for Amyloid Light Chain (lettkjede amyloidose) og er den vanligste typen amyloid. Plasmaceller, en celletype som er en del av immunforsvaret vårt, produ- serer såkalte «lette kjeder». Ved AL-amyloidose danner disse lette kjedene et uløselig protein som leirer seg ulike steder i kroppen. Disse avleiringene kan skade forskjellige organer i kroppen fordi de fortrenger det normale vevet. Organer som kan rammes er for eksempel nyrer, lever, milt, hjerte og hud.

AL-amyloidose er den eneste formen for amyloidose som behandles av hematologer, og som ligger nærmest Blodkreftforeningen sitt arbeidsområde.

Symptomer på amyloidose:

Symptomer vil variere utfra hvilke organer som er angrepet. Siden sykdommen oppfører seg forskjellig fra person til person, vil det ofte ta tid før diagnose blir stilt. Typiske symptomer er:

The film is available on Blodkreftforeningen's website, along with additional information about amyloidosis.

HEMA-ONKO

Macedonia

www.hema.org.mk

Enhancing early myeloma diagnosis awareness and support in North Macedonia through GP education, website enhancement, digital campaign and special information event for European Myeloma Day

This project aimed to address two critical challenges faced by individuals diagnosed with myeloma and AL amyloidosis in North Macedonia: delayed diagnosis and the stigma surrounding the disease. Many General Practitioners (GPs) and medical students lacked awareness of the early symptoms of myeloma, leading to late-stage diagnoses and poor outcomes. Furthermore, misconceptions and fear surrounding the disease hindered patients from seeking medical help, disclosing their condition, or maintaining employment.

To combat these issues, the project implemented several key activities:

- Educational workshops for healthcare professionals.
- A public awareness campaign.
- In-Person information event.

The project resulted in several deliverables:

- Training materials for healthcare professionals: educational resources, including presentations and reference materials, were created and used during workshops.
- Digital awareness content: An online campaign was launched, featuring educational posts, videos and interactive content for both healthcare professionals and the public.
- Patient and HCP exchange: The event featured insightful discussions with experts, strengthening the connection between patients and healthcare providers.

This project had a profound impact on both the healthcare system and the myeloma community in North Macedonia. By addressing gaps in early detection, challenging stigma and advocating for policy change, the project led to significant improvements in patient care and medical education.

However, continued efforts are required to sustain these improvements and ensure lasting changes in healthcare policy.

As a result of this activities, the government of North Macedonia committed to implementing the HEMA-ONKO 2025 Cancer Plan.

мост милосердия
межрегиональная общественная организация

Information and legal support for patients with myeloma and AL amyloidosis

Mercy Bridge

Russia

www.mmpatient.ru

This project addressed the challenges posed by limited knowledge of the disease and the legal rights of patients. Information was provided via the website mmpatient.ru, which was regularly updated with expert-level materials.

Key activities included:

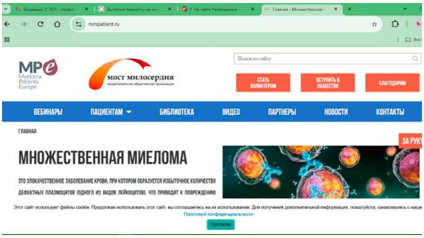
1. Website development and information dissemination: the website was regularly updated with new materials and information. A brochure titled “Amyloidosis from Light Chains of Immunoglobulins” was made available online for AL amyloidosis patients.

2. Legal rights section: A new section, “The Patient is in His Right,” was created on the website, providing answers to frequently asked questions, legal advice and resources on how to navigate the legal aspects of treatment.

3. Legal consultations: online group legal consultations were held for a group of 95 patients over a six-month period. These consultations provided patients and caregivers with essential legal knowledge regarding drug provision, their rights to therapy, employer relationships, and filing complaints and lawsuits.

The project significantly improved legal literacy among patients, empowering them to better advocate for their rights and navigate the legal challenges they face. This support has been highly appreciated by patients and their caregivers, improving their quality of life and providing them with the tools to better manage their treatment and legal matters.

Information brochure “Amyloidosis from light chains of immunoglobulins”



МНОЖЕСТВЕННАЯ МИЕЛОМА

ЭТО ЗЛОКАЧЕСТВЕННОЕ ЗАБОЛЕВАНИЕ КРОВИ, ПРИ КОТОРОМ ОБРАЗУЕТСЯ ИЗБЫТОЧНОЕ КОЛИЧЕСТВО ДЕФЕКТНЫХ ПЛАЗМОЦИТОВ (ОДНОГО ИЗ ВИДОВ ЛЕЙКОЦИТОВ), ЧТО ПРИВОДИТ К ПОВРЕЖДЕНИЮ

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Mercy Bridge’s website with some information developed through this project.

Together on the path to health

Slovensko združenje bolnikov z limfomom in levkemijo (L&L)

Slovenia

www.limfom-levkemija.org

Patients with blood cancers in Slovenia have excellent access to innovative therapies and diagnostics ; however, they face significant gaps in rehabilitation services during and after treatment. Rehabilitation is an essential aspect of comprehensive care, helping patients reintegrate into their social lives and return to work.

The L&L Association organised the rehabilitation programme “Together on the Path to Health” for blood cancer patients, which included three core modules: physical, nutritional and psychosocial support. In addition to these, the Association produced several videos, including one on the “Psychosocial aspects of returning to work after a long-term medical leave,” available on YouTube. In collaboration with a specialist in cardiology and vascular medicine, the Association also created a video entitled “Exercise for heart health.” This video emphasises the importance of physical activity for cardiovascular health after intensive haematologic-oncologic treatments and addresses the potential long-term effects of treatment on the heart. The video is also available on YouTube.

In total, 24 group workshops were held with experts in psychology, clinical nutrition and oncology. Additionally, in 2024, 76 extended individual consultations (45 minutes each) were conducted with specialists in clinical nutrition, psychology and oncology.

Through the “Together on the path to health” programme, patients with myeloma, AL amyloidosis and other types of blood cancer were able to participate in a professionally managed programme that provided nutritional, psychosocial and physical support both during and after their treatment. By promoting it and producing video content, the Association was able to reach and support a wide range of blood cancer patients and their caregivers.

L&L shared the information of the programme on its website.

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