

**2019** Scholarship and  
capacity building  
programme

# Myeloma Patients Europe



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One of the main strategic objectives of Myeloma Patients Europe (MPE) is to facilitate the development, capacity and sustainability of members. The rationale behind all MPE programmes is that, by equipping members with the right tools and knowledge, they become empowered and capable of delivering essential services to patients. This will over time create strong, professional, independent and sustainable organisations that are able to advocate for the needs and wants of myeloma and AL amyloidosis patients across Europe.

To support this aim, each year MPE offers the Scholarship and Capacity Building Programme, through which we invite 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 2019. All projects and events have been massively successful, with major thanks to the hard work and efforts of our members across Europe and further afield.

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: <https://www.mpeurope.org/what-we-do/programmes/mpe-scholarship-capacity-building-programme> or by emailing [info@mpeurope.org](mailto:info@mpeurope.org).





HEMA



Macedonia



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In 2019, HEMA created and distributed two booklets with the support of the MPE Scholarship and Capacity Building Programme. The first is a patient-friendly myeloma information booklet and the second is about fertility and pregnancy before and after cancer treatment.

The myeloma information booklet is distributed to patients and caregivers in the University Clinic for Hematology in Skopje. The booklet contains information about early symptoms, risk factors and complications, diagnosis and treatment, issues faced by patients and caregivers, among others topics included.

The fertility and pregnancy booklet is the first of its kind published in Macedonia tailored for patients and caregivers. It contains information about the impact of chemotherapy, radiation therapy and bone marrow transplantation on fertility, managing family planning with blood cancer, and fertility preservation techniques. Due to high interest in this issue this booklet will also be published and distributed throughout 2020.

Additionally, a workshop was held in the city of Veles. As a result, a patient who attended the workshop was driven by HEMA's vision and mission and decided to establish a local patient organisation for haematological diseases called HEMA-Veles.

In 2019, **HEMA** created and distributed two booklets with the support of the MPE Scholarship and Capacity Building Programme on **myeloma and fertility and pregnancy**.



One of the booklets developed by HEMA.



The myeloma information booklet was distributed in the University Clinic for Hematology in Skopje.



S.O.S Mielom



Romania



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The Association S.O.S. Mielom received a grant within the MPE Scholarship and Capacity Building Programme in support of producing materials to help myeloma patients and caregivers in Romania to better cope with the disease.

Five Romanian educational guides and information packs were created by translating existing resources developed by Myeloma UK.

Materials translated by S.O.S. Mielom include: Info pack for carers of myeloma patients, info pack for relapsed/refractory myeloma patients, pain info guide, info pack for living well with myeloma, info sheet with exercises for myeloma patients.

The Romanian version of the info pack for carers of myeloma patients covers questions and key topics that carers in Romania noted were of high importance. The guide includes information related to: what is a carer, how can carers take care of themselves when also caring for a myeloma patient, moods and emotions of a carer, how relationships with others can be affected, preparing for hospital visits and understanding medical information, work, finance and benefits, and planning for the future. Approximately 800 copies will be prepared in total for all the guides produced. Distribution will be directly to patients and carers, and through hospitals with hematology departments in Romania.

Five Romanian **educational guides and information packs** were created by translating existing resources developed by Myeloma UK. The Romanian version covers **questions and key topics** that carers in Romania noted were of high importance.



Two of the five educational guides developed by S.O.S Mielom.



Cancer-related fatigue (CRF) is a common problem in cancer patients and affects over 70 percent of all myeloma patients. Since CRF can make even routine tasks feel overwhelming it can profoundly affect quality of life of patients and their families. The Myelom-und Lymphomhilfe Österreich project supported by the MPE Scholarship and Capacity Building Programme in 2019 is called Impulses, which aims to tackle the challenge of CRF by helping myeloma patients to implement small changes in their life to help fight CRF.

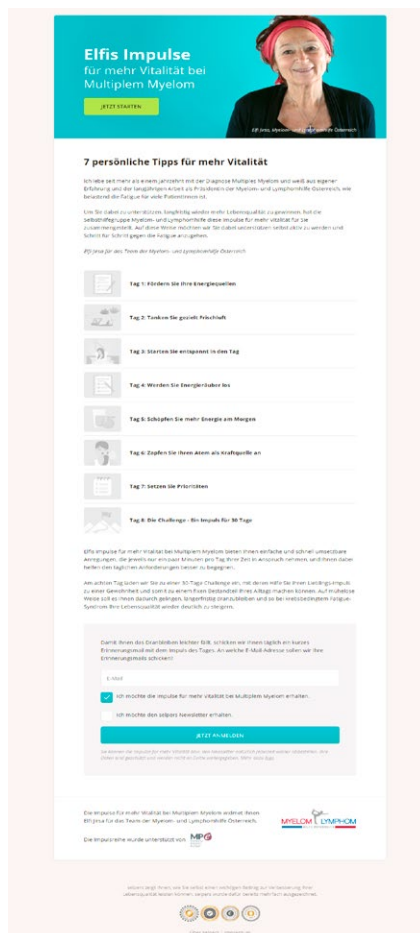
For seven days, subscribers receive one impulse per day by email in the form of a prompt. It can be a suggestion for a micro adjustment of the daily routine or a short instruction for a specific exercise. Each prompt is easy to implement and requires only a few minutes.

On the eighth day, the subscriber is invited to pick one impulse and put it into practice for a full month. Committing to one of the impulses helps the patients to slowly form a new supportive habit.

Our impulses are available via the following link: [www.selpers.com/elfis-impulse-fuer-mehr-vitalitaet-bei-multiplemyelom](http://www.selpers.com/elfis-impulse-fuer-mehr-vitalitaet-bei-multiplemyelom)

At present the impulses are only available in German, but they could easily be replicated for other countries and languages at low cost.

One of our Austrian members, **Myelom- und Lymphomhilfe Österreich**, developed the project '**Impulses**' to help patients to cope with **cancer-related fatigue (CRF)**. This successful project could easily be replicated by other countries and in other languages at low cost.



Screenshot of one of the "impulses" included in this programme.



One of the biggest challenges of this disease is shortening the length of time until the disease is diagnosed. Early diagnosis is critical and may allow patients to receive treatment before it is too late.

Despite this, it is known that most patients suffer for a long time, at an average of two years, until diagnosis. This is largely due to lack of awareness about the disease, both among physicians and the general public.

Amyloidosis Israel received a grant within the MPE Scholarship and Capacity Building Programme in 2019 towards the development of an informational video. This video adds to the various activities that the organisation performs for raising awareness (e.g. meetings with doctors, webinars, conferences, etc.). The main goals of the video are:

- Increasing awareness among patients and physicians about amyloidosis.
- Increasing knowledge about symptoms.
- Explaining the importance of early diagnosis.
- Increasing awareness and encouraging patients and caregivers to get in contact with the organisation.

The video is being shared through several platforms and is available on Vimeo. It includes English subtitles.

Late diagnosis is one of the most important problems for amyloidosis patients. **Amyloidosis Israel** has filmed a video to increase **awareness about symptoms** of this disease and encourage patients and caregivers to get in contact with the organisation.



Daniel Drimer and Sara Scherwood, from Amyloidosis Israel, and Dr Moshe Gatt, Hadassah Hebrew University Medical Center, participated in this video.





## BLODCANCERFÖRBUNDET SWEDEN



Sweden



[www.blodcancerforbundet.se](http://www.blodcancerforbundet.se)



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On the 18th of October 2019 the Swedish Blood Cancer Association (TSBCA) arranged a very successful internal workshop for local/regional representatives in Stockholm. The event had several aims, including spreading knowledge about the latest treatments in myeloma, understanding challenges in access to treatments, and taking steps towards forming a Myeloma Expert Patient Body in Sweden. The workshop also led to the development of a plan of action to collectively pursue these vital issues in the future. Knowledge of these complex issues is vital to have if one is to contribute to a positive change.

A total of 15 people attended the workshop, including representatives from the six Patient Councils in Sweden, as well as six patients affected by myeloma. They were joined by Chairwoman Lise-lott Eriksson, Head of Secretariat Christian Pedersen, board member Michael Blomqvist and several other members.

The TBSCA Chairwoman spoke about new treatments in myeloma and challenges in gaining access to these. Invited speakers from the pharmaceutical industry also spoke about the process of gaining access to new treatments in Sweden and how governmental bodies in Sweden calculate the so called "cost effectiveness" of a new drug.



Patient expert workshop organised by  
blodcancerforbundet



Anna Lampa and Lise-lott Eriksson during the event

15 people attended a very successful **internal workshop** organised by the MPE Swedish member in Stockholm. The exciting work has been initiated to continue working towards cultivating **Expert Patient Advocates** in Sweden.



## Armenian Haematology Association (AHA)



Armenia



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The Armenian Hematology Association (AHA) received an MPE scholarship in 2019 to support capacity building in Armenia in myeloma. AHA organised a series of Myeloma Schools which had several aims. Firstly, to raise awareness among patients and caregivers about myeloma and the specificities of the disease. AHA aimed to involve as many patients and caregivers as possible from the distant regions of Armenia.

The Myeloma School also targeted medical professionals. General Practitioners from the non-central region of Armenia were invited to the events and improved their skills in recognising early signs of myeloma and referring patients to the Haematology Center for the further investigation.

AHA organised seven Myeloma School events during May, June, September, October, November, December 2019 for general practitioners and six Myeloma School events for patients and caregivers.

The MPE grant also helped AHA to organise a Myeloma Awareness Day, which included teleconferences with interdisciplinary discussions. Around 75-80 patients and 58 doctors participated in the events mentioned above. One of the greatest achievements of these activities is the establishment of the first Armenian patient organisation for haemato-oncology.

The **Armenian Haematology Association (AHA)** organised a series of **Myeloma Schools** to raise awareness among patients and caregivers. The MPE grant also helped AHA to organise a **Myeloma Awareness Day**, which included teleconferences with interdisciplinary discussions.



AHA organised seven Myeloma Schools between May and December with patients and doctors.



## Spanish Amyloidosis Association (AMILO)



Spain



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The MPE Scholarship and Capacity Building Programme supported two workstreams with the Spanish Amyloidosis Association, AMILO, in 2019.

The first workstream was the preparation of an AMILO Information Day. The meeting was held in Madrid in February 2020 and included presentations from haematology and amyloidosis specialists. All types of amyloidosis were included in this information day. The main goal of AMILO is to give information to patients and raise awareness about the symptoms amyloidosis can have.

Around 100 amyloidosis patients and doctors coming from different parts of Spain attended this meeting accompanied by media communications and social media activities.

The meeting included two round tables and was moderated by Ana Vallejo from MPE.

The second workstream involved fieldwork in inpatient and outpatient clinics throughout Spain. This largely involves building connections with doctors and other healthcare providers, patients and families to drive awareness of amyloidosis and the support offered from AMILO.

AMILO organised an **Information Day** attended by 100 people coming from different parts of Spain. This is the first big event organised by AMILO and it will be followed by a number of activities designed for amyloidosis patients.



Around 100 patients, carers and doctors attended the Information Day organised by AMILO.



## SLOVENIAN LYMPHOMA AND LEUKAEMIA PATIENT ASSOCIATION, L&L



Slovenia



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Since 2017, the Slovenian Lymphoma and Leukaemia Patient Association, L&L, in partnership with the Slovenian Haematological Society, has been implementing a comprehensive rehabilitation programme for blood cancer patients, "Together on the Path to Health". In 2019, the programme included 80 patients diagnosed with various types of blood cancer, the majority with the diagnosis of myeloma.

The programme is comprised of three key modules focused on physical, nutritional, and psychosocial aspects. When joining the programme, patients conducted an interview with a haematologist, who assessed their medical condition, and took measurements related to all three programme modules. After the initial assessment and measurements, patients attended the rehabilitation programme for six months. The programme was comprised of monthly workshops with a psychologist, monthly dietary consulting, regular weekly exercise with a physical therapist or kinesiologist, and various forms of consulting services.

The Institute for Biostatistics and Medical Informatics has analysed and compared the initial and final measurements. The results show improvements and benefits of the programme for patients.

L&L, in partnership with the Slovenian Haematological Society, implemented the rehabilitation programme: **"Together on the Path to Health"**. According to a survey, 100% of users would recommend this programme to other patients.



The CEO of L&L, Kristina Modic, along with some of the patients and experts involved in the campaign.



Poster of the campaign developed by L&L.





## ZDRUŽENIE PACIENTOV HEMATOLOGICKÝMI MALIGNITAMI



Slovakia



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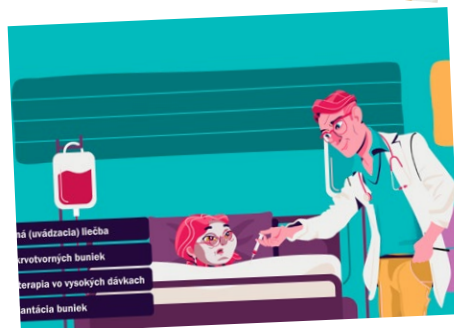
The Association of Patients with Haematological Malignancies received a grant within the MPE Scholarship and Capacity Building Programme in 2019 in support of the development and promotion of an animated video about multiple myeloma. The main objective of the project was to raise awareness of myeloma and to contribute to its early diagnostics. The user-friendly format of an animated video is a great way to transmit complex information in an interesting and engaging manner.

The story is about Zuzana, a shop assistant in her late fifties. In recent months, Zuzana's back, leg, and head ached, and she was exhausted. She thought these were signs of aging and ignored the pain. When she could no longer stand it, she visited her doctor, who sent her to a haematologist. The haematologist suspected myeloma and ordered a biopsy and lab tests and, finally, myeloma was confirmed and treated with a stem cell transplant (ASCT). After the transplantation, Zuzana continued with maintenance therapy and is able to return to work.

The video was created in October 2019 and is posted on the organisation's website and Facebook page.

The video is used to explain myeloma to patients and their relatives and to warn the general public about its symptoms.

The **Association of Patients with Hematological Malignancies in Slovakia** developed an **animated video** to explain what myeloma is and to warn the general public about symptoms of this disease.



Images of the animated video created by the MPE Slovakian member.



## Multiples Myelom Selbsthilfe Österreich (MMSOe)



Austria



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Multiples Myelom Selbsthilfe Österreich used an MPE Scholarship and Capacity Building grant in 2019 to develop a Young Myeloma Patients Austria workstream and to host an Austrian Myeloma Information Day.

The Information Day was held in October 2019 in Lower Austria with the theme "Knowledge is Encouragement". Healthcare professionals provided presentations and Q&A sessions that were recorded and made available on YouTube on various topics including treatment of patients who receive bone marrow transplantation, therapy options for pre-treated patients or new developments in myeloma and new substances, among others.

Work towards the development of Young Myeloma Patients Austria was impacted by the unfortunate passing of several volunteers within the organisation and the head of the sub-group having to step down for health reasons. Yet, a logo and printed informational posters were developed, and a webinar for young patients and their families is planned for April 2020.

After recovering from a very difficult year, Multiples Myelom Selbsthilfe Österreich will continue to develop this work stream by developing a microsite, Facebook group and publications for young myeloma patients.

"Knowledge is Encouragement". This is the theme chosen by **Multiples Myelom Selbsthilfe Österreich** to celebrate a Myeloma Information Day. In addition, this organisation is working actively in several activities focused on **young myeloma patients**.



Some of the attendees at the Myeloma Information Day held in October 2019.



A full house in the Information Day organised by Multiples Myelom Selbsthilfe Österreich.





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