

2018 Scholarship and
capacity building
programme

Myeloma Patients Europe



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Providing our members with the resources they need to effectively advocate and deliver essential services for patients and caregivers is one of the main goals for the team at Myeloma Patients Europe (MPE).

To support this aim, we run the Scholarship and Capacity Building Programme, through which we invite members to submit applications for an activity they want to implement to benefit the myeloma community in their country. MPE offers financial support to successful applicants through a grant of up to 3,000€ and we also provide any additional support required by members to help implement their idea (e.g. logistical help, design advice etc).

In 2018, we issued two funding calls members could apply for:

- **A patient and caregiver day call**, supporting members to hold a patient and/or caregiver information day
- **An open call** for any initiative MPE members required support for

Following a comprehensive application and selection process, MPE received and approved 14 activities through the 2018 Scholarship and Capacity Building Programme – including 5 patient days. Successful applicants were required to report to the MPE team on the progress and implementation of their idea throughout the year.

In this publication, we summarise and showcase the projects we funded in 2018. All the projects have been a massive success, with major thanks to the hard work and efforts of our members across Europe and further afield.

If you are interested in participating in future rounds of the MPE Scholarship and Capacity Building Programme, you can find more information on our website www.mpeurope.org/what-we-do/programmes/mpe-scholarship-capacity-building-programme/ or by emailing info@mpeurope.org.



The organisation Kraujas received two grants within the MPE Scholarship and Capacity Building Programme.

With the aim of educating myeloma and AL amyloidosis patients and discuss topics that can improve patients' quality of life, Kraujas organised a **myeloma day** that was held on 26th October 2018. **62 patients and their relatives** attended this event and rated it as excellent.

Myeloma and AL amyloidosis symptoms and treatments, updates on treatment and guidelines about nutrition or how to cope with these diseases were some of the topics discussed.

The second grant was used to address the lack of information about **sexuality in cancer patients**. Cancer and its treatment can seriously affect sexuality in patients and their partners but this topic is still taboo among some patients and physicians.

Kraujas developed **the first educational publication** about this topic in Lithuania, a 121-page guide with information and tips to cope with these issues developed along with gynaecologists, urologists and physiologists.

3.000 units of the guide **"Sexuality and oncological diseases"** have been printed to be shared for free with patients and their relatives.

The organisation **Kraujas** received two grants that were used to organise a **myeloma infoday** and to develop the book **"Sexuality and oncological diseases"** for people with cancer and their partners.



Guide "Sexuality and oncological diseases"

MYELOMA DAY
26TH OF OCTOBER, 2018









Programme:

- Myeloma: symptoms, causes, complications and treatment (seminar with hematologist).
- Amyloidosis: symptoms, causes, complications and treatment (seminar with hematologist).
- Myeloma and amyloidosis: what is new? (seminar with hematologist).
- Q&A session with hematologists.
- Cancer diagnosis: tips for coping (seminar with psychologist).
- Nutrition guidelines for myeloma and amyloidosis patients (seminar with nutrition specialist).
- Live the life You love: myeloma patient story.
- How association "Kraujas" can support patients and caregivers?

Goals of event:

- To educate myeloma and amyloidosis patients and encourage their interest in the disease and treatment possibilities.
- To bring together people with myeloma and amyloidosis and learn about their concerns.
- To discuss topics that can improve patients' life quality such as psychological support, nutrition that are very important for patients but usually are left behind during the treatment.
- To discuss how patients and association "Kraujas" together can improve the access to treatment.

62
PATIENTS AND THEIR RELATIVES ATTENDED THE EVENT

47 OUT OF 48
PARTICIPANTS WERE VERY SATISFIED WITH THE EVENT

44 OUT OF 48
EVALUATED THE EVENT AS EXCELLENT, 4 OF 48 EVALUATED EVENT AS VERY GOOD

Programme of the myeloma day organised by Kraujas.



AMEN ISRAEL



Israel



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Around 500 people all over the country attended the **myeloma infoday** organised by AMEN in the University of Tel Aviv (Israel) and took place in May 2018.

Patients, doctors and researchers among others participated in this conference that was composed by short lectures on different topics.

The Israeli Health basket, personalised medicines and how to apply in Israel, infectious diseases in myeloma and current treatments were some of the topics discussed at this event.

To discuss the current situation of **innovative myeloma treatment** such as **antibodies and CAR-T cells**, Amen organised a panel with 6 haematologists from different hospitals in Israel.

This organisation applied for another grant within the Scholarship and Capacity Building Programme that was used to develop a **volunteers' management programme in 2018**.

The programme was divided into three sessions in which **30 volunteers participated**. The first session started with a focus group to understand the issues volunteers have when they are talking to patients. In the second and the third sessions volunteers participated in simulations to learn what is important in a first telephone conversation, how to deal with emotional impact after support calls or how to talk with the patient's family.

AMEN Israel applied for two grants, one of them was used to organise **their annual patient day** that was followed by myeloma awareness month. The other grant was used to develop a **volunteer management programme**.



Around 500 people attended the myeloma infoday organised by AMEN.



Some of the participants during the myeloma infoday.



One of the sessions of the volunteers' management programme.



BLODKREFTFORENINGEN



Norway



www.blodkreftforeningen.no



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Patient involvement in research is increasingly required in Norway. In this country, nominated patients are now required by all major financers of medical research, the Norwegian Research Council, The Regional Health Authorities and the Norwegian Cancer Association.

With the aim of discussing and informing patient about their involvement in clinical research, Blodkreftforeningen organised a **workshop on patient involvement in multiple myeloma research** held in Trondheim in September 2018.

Around **30 participants** attended the workshop which was organised in collaboration with the centre for multiple myeloma research at the **Norwegian University of Science and Technology (NTNU)** and **St. Olavs Hospital**.

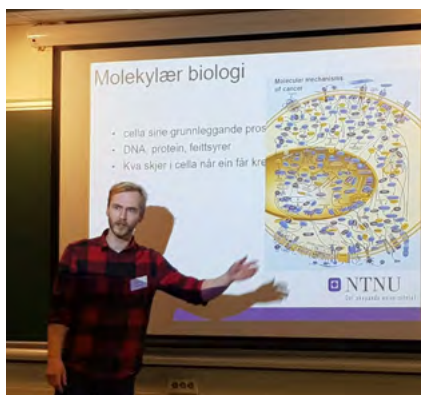
The workshop included presentations given by several scientists. Also, a member of this Norwegian organisation shared her personal experience after being active in myeloma research.

All participants were interested in learning more about their role in clinical research as this is the first step to get more and more patients giving input in future multiple myeloma research projects in Norway.

Blodkreftforeningen, the MPE Norwegian member, got a grant with the Scholarship and Capacity Building Programme to organise a workshop on **patient involvement in myeloma research**.



Around 30 participants attended the workshop on patient involvement in myeloma.



Kristian Starheim (NTNU) during his presentation.

AMYLOIDOSIS ISRAEL



Israel



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Amyloidosis refers to a group of diseases characterised by the accumulation of an abnormal protein called amyloid which builds up in tissues and organs and it is considered a rare disease due to its low incidence.

To address the needs of the amyloidosis patients in Israel, our member Amyloidosis Israel organised a **conference for amyloidosis patients and carers.**

The event covered two different types of amyloidosis, the familiar one and **AL amyloidosis** which is a myeloma-related condition affecting 9 people per 1 million in Europe.

Around **140 patients** attended this conference held in Israel which benefited from the participation of different types of physicians involved in the treatment of amyloidosis patients.

The challenges in the diagnosis and classification of amyloidosis, living with cardiac amyloidosis, personalised medicine, palliative care and even legal advice were some of the topics discussed.

Due to a lack of treatments for this condition and delays in diagnosis, conferences like this one are especially relevant for AL amyloidosis patients

The organisation **Amyloidosis Israel** applied for a grant within the Scholarship and Capacity Building Programme with the aim of organising a conference for patients with **amyloidosis.**



Daniel Drimer (Amyloidosis Israel) during his presentation.

Conference plan for Amyloidosis patients and care givers

Proposal for the annual conference program:

Possible dates:

26/10/18 ; 12/10/18 ; 5/10/18 ; 14/9/18

- 8:30-9:00 Gathering
- 9:00-9:20 Welcome speeches (professor Mitelman or Ben-Yehuda Or doctor Gat + AMY organization delegate)
- 9:20- 9:40 Amyloidosis and Myeloma and what's in between (doctor Yael Cohen?)
- 9:40-10:00 What is new in treatment options (hematologist)
- 10:00-10:20 Lecture on day care procedures - lecture given by a nurse
- 10:20-10:40 Mouth hygiene and treatments in Amyloidosis
- 10:40-11:10 Coffee break
- 11:10-11:45 Round Table (cardiologist + nephrologist)
- 11:45-12:20 Round Table (neurology and dietician)
- 12:20-12:50 Lecture for the soul (mental health)
- 12:50-13:00 Closing words
- 13:00-13:30 Lunch

Number of Participants about 140.

Programme of conference organised by Amyloidosis Israel.



BLODCANCERFÖRBUNDET SWEDEN



Sweden



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Access to new and innovative treatments in myeloma is a challenge in Europe, especially with **combinations of new drugs** that make the myeloma treatment more expensive.

New myeloma drugs in monotherapy may be effective in treating the disease, but they are not enough to reach the **Minimal Residual Disease (MRD)** which is a concept difficult to understand for those able to include these combinations in the Swedish system.

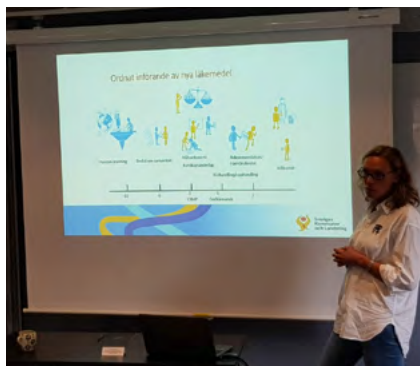
With the aim to largely enhance the policy work on the challenge about myeloma combination therapies in this country, our Swedish member organised a workshop to make authorities understand the magnitude of this challenge for myeloma patients in Sweden as well as discuss solutions that can be implemented at a national level.

Around 20 people participated in this workshop. Current challenges of combination therapy in myeloma, possible solutions to these current challenges, how to take action at regional and national level or actions plans were some of the topics discussed in this event.

Blodcancerförbundet Sweden, the Swedish blood cancer association, got a grant dedicated to organise a **combination therapy workshop** aimed to discuss the current challenges of these treatments in Sweden.



Some participants after the workshop.



Lise-Lott Eriksson (Blodcancerförbundet Sweden) during her presentation

MOHA



Hungary



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Around 180 people attended the **Myeloma Information Day** organised by the MPE Hungarian member (MOHA). The event was held in Budapest and was rated as excellent by the patients and carers who participated in this infoday.

An update of myeloma treatments options in Hungary, the impact of cancer treatments in the nervous system ("chemo-brain"), how to cope with this disease within the family and new options in myeloma treatments were some of the topics discussed.

Along with their Annual Information Day, MOHA applied for another grant to develop a **myeloma educational booklet** for patients.

Hungarian myeloma patients highlighted the need to this kind of information in a survey done by MOHA in 2017. In 2018, MOHA started to develop this myeloma booklet which will be ready in 2019. Their main goal is developing quality patient information in a patient-friendly way that can be understandable for all myeloma patients and carers.



Around 180 people attended this myeloma information day.



Programme of the Annual Myeloma Infoday
organised by MOHA.



MYELOMA UK



UK



www.myeloma.org.uk



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With the aim of supporting patients with myeloma and their family members in better understanding, engaging with, and benefiting from research into myeloma, **Myeloma UK** held **two Research Capacity Building workshops** in Glasgow and London.

Feedback from Myeloma UK's work with patients, and the literature more widely, suggests that the language of research can feel inaccessible to some patients and their family members. These workshops aimed to address these gaps in knowledge and support patients and family members in engaging with myeloma research.

Through these two workshops, delegates worked as a group to generate **recommendations for clearer patient information on trials**. Patient feedback will be presented to Myeloma UK's research partners to further improve patient information on future myeloma studies.

These collaborative pilot workshops highlighted that patients with myeloma and their family members are eager to know more about research processes and have many questions about research outcomes. In particular, it is clear that **patients want to be actively involved** to ensure research leads to tangible improvements in health services and access to treatments.

Myeloma UK received a grant to support the **Research Capacity Building Workshops** that MUK organised in Glasgow and London with aim to clarify the language of research and engage patients this area.



Rebecca Dawson, Jayne Galinsky and Rosie Ashworth during the workshop.



Jayne Galinsky (MUK) during her presentation.



SLOVENIAN LYMPHOMA AND LEUKAEMIA PATIENT ASSOCIATION, L&L



Slovenia



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The rehabilitation programme for patients with blood cancers called **“Together on the Path to Health”** started in 2017 to support blood cancer patients to go back to their lives and empower them to have a healthy and an active life even after their treatment has been completed.

The programme is being carried out in collaboration with the **Slovenian Haematological Society** and with extensive financial support from the Ministry of Health and other sponsors as well as donations from the general public in the #BackToLife campaign.

This programme comprises three key modules (physical, the psychosocial and the nutrition module) over six months to obtain important knowledge, experience and support from professionals and learn how to lead an easier and better-quality life during and after the treatment.

Analysis of the first 18 users involved in the first year of the programme shows that the programme represents great added value for patients and helps patients to preserve or even to improve their physical, psychosocial and nutritional status after the treatment. By January 2019 around 70 patients had joined 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 2018 with the support of the Scholarship and Capacity Building Programme.



Načelnik programa: Partner v programu: Program sofinancira: Ministrstvo za zdravje Republike Slovenije

This programme comprises three modules: the physical, the psychosocial and the nutrition module.



Some of the patients and experts involved in this programme.



ZDRUŽENIE PACIENTOV HEMATOLOGICKÝMI MALIGNITAMI



Slovakia



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Združenie Pacientov S Hematologickými Malignitami, the Slovakian Association of Patients with Haematological Malignancies attended the Košice Peace Marathon on 7th October 2018 where they had stand. During this event, the Slovakian organisation distributed two booklets supported by the MPE Scholarship and Capacity Building Programme: **a guide for general practitioners (GPs) about blood cancers and a brochure on social security rights for patients.**

It is well known that haematological malignancies (especially multiple myeloma, chronic leukemia and lymphomas) are often diagnosed late and symptoms are underestimated by patients and, sometimes also by GPs. The aim of the project is to raise awareness among patients, GPs and geriatricians about warning signs of blood cancers.

In 2017, A GPs' guide to blood cancers (Sprievodca všeobecného lekára hematologickými malignitami) was prepared in cooperation with the Clinic of General Medicine of Comenius University in Bratislava and Slovak Society of General Practitioners and was distributed to all GPs in the Slovak Republic. In 2018, the goal was to reprint and distribute this guide also among geriatricians, in collaboration with **Slovak Society of Geriatricists**, and also among GPs starting practice in 2018.

The Slovakian Association of Patients with Haematological Malignancies created and distributed **a guide for GPs about blood cancers and a brochure on social security rights** supported by the MPE Scholarship and Capacity Building Programme.



Stand of the Slovakian Association of Patients with Haematological Malignancies during the Marathon.



Guides and brochures developed by the Slovakian Association of Patients with Haematological Malignancies.



BORKA



Macedonia



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In past years, Borka has advocated better access to myeloma treatments, and more treatment options.

Each myeloma patient needs to receive tailored information about his disease and treatment. In 2018 Borka organised a campaign to raise awareness of myeloma, to inform the patients about the symptoms this disease can have, treatments and side effects. Another important goal of this campaign was to collaborate and involve stakeholders and policy makers with the aim to improve diagnosis, to have real data about treatment efficacy, to reduce inequalities and to improve access to new treatments.

A **patient day** and the **awareness campaign "Let's make changes"** was organised in Macedonia which involved myeloma patients from all over the country, haematologists, healthcare professionals, representatives from Ministry of health and other relevant institutions. Additionally, the president of MPE, Hans Scheurer, gave a talk about education, support and advocacy for myeloma patients in Europe.

Borka also translated into Macedonian the MPE myeloma guide and created a new myeloma platform to provide specific information about this disease to myeloma patients in Macedonia. It can be found at: borka.org.mk/mielom.

Supported by the MPE Scholarship and Capacity Building Programme, **Borka** organised a patient day and an **awareness campaign**, translated into Macedonian the MPE myeloma guide and created a **myeloma platform**.



Presentation of the campaign organised by Borka.



Borka translated into Macedonian the MPE myeloma guide.



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