

PRESS RELEASE

Myeloma Patients Europe (MPE) launches first comprehensive overview European myeloma treatment inequalities

Brussels, 19 October 2021 - Myeloma Patients Europe (MPE) has today launched a comprehensive overview of the myeloma treatment inequalities that exist across Europe. The first programme of its kind, the interactive [Myeloma Access Atlas platform](#), has mapped national availability of myeloma drugs and drug combinations in both EU and non-EU European countries. The *Atlas* also provides comparative data on myeloma incidence and mortality across Europe, alongside health systems performance data and strategy tools for patient advocates with a focus on improving access.

To gather the data on drugs identified as central to the myeloma treatment pathway, MPE worked with its members, relevant pharmaceutical companies and haematologists to identify the national access and coverage. Data gathered included information on whether drugs are reimbursed at national level (or not) and whether they are available via compassionate use or named patient programmes.

Ananda Plate, Chief Executive Officer (CEO) of MPE commented:

“The Atlas is designed to allow myeloma patient advocates and advocacy organisations to see a snapshot of how their country “stacks-up” in terms of access and to provide data and tools to inform national advocacy. Of particular interest, the data on national availability of myeloma drugs highlights slower uptake of newer combinations and huge differences between EU and non-EU access to backbone drugs despite the availability of cheaper generics. Now we have successfully mapped this data, MPE will continue to work with members, and other partners, to design effective advocacy initiatives to address identified inequalities.”

The data contained within the *Atlas* will be maintained and routinely updated by MPE. As there is a changing picture of access to myeloma drugs and health system performance, the data contained within it is designed to provide a “snapshot” of access at a specific time-point. A further step is to understand from national advocacy organisations and healthcare professionals whether the national picture of access is reflective of the experience of myeloma patients at a local level – this is work that is ongoing.

A selection of headline advocacy findings from the current access data include:

- There is currently no centrally held information on the reimbursement status of all myeloma drugs in Europe or specific drug or drug combinations. Gathering this data to analyse is a

timely exercise as requires the input of a wide-range of stakeholders to ensure accuracy.

- The myeloma treatment pathway is increasing in complexity. Despite the regulatory approval of a range of drugs and drug combinations, many European countries do not meet recommendations outlined in ESMO myeloma treatment guidelines.
- Triple and quadruple combinations approved in the newly diagnosed setting for patients are facing a slow uptake across Europe.
- Over recent years there have been numerous approvals for triple combinations for patients who have had one to three prior lines of therapy. After a slow start, access to these has recently improved in many European countries, however some countries lag behind (particularly in the Balkans and some CEE countries).
- Access to maintenance therapy in Europe has been very slow in terms of uptake and remains a big issue in most Central and Eastern European countries, despite strong evidence supporting its use in clinical practice.
- Balkan countries, particularly those who are not members of the EU, are facing profound challenges in access to myeloma drugs and potentially rank the lowest in terms of myeloma access. For example, Macedonia and Bosnia face challenges in routine access to generic bortezomib – a backbone for the treatment of myeloma which has been available in most European countries for many years.

Roman Hájek, M.D., Ph.D., University Hospital Ostrava, Czech Republic also commented:

“This is a fantastic resource from Myeloma Patients Europe, and I really commend them on gathering such useful data. From the perspective of a haematologist and researcher it is extremely helpful to see how different countries compare in terms of access and how the best clinical trial data does not necessarily translate into approvals. I was particularly interested in the data on lenalidomide maintenance in Europe and how variable the access is in CEE countries, despite it being approved a long time ago and having strong trial data to support it.”

As well as gathering data on access, a core rationale of the *Atlas* is to use the gathered data to inform MPE advocacy strategies and to provide tailored coaching and support to patient advocates to address identified issues via the *Atlas Coaching Programme*. MPE also promotes regional collaborations on access challenges, such as through its Central and Eastern European Workgroup, where MPE has commissioned a project on access to clinical trials.



Barbara Leonardi, patient representative from The Carita Foundation in Poland commented:

“We really welcome the launch of the Myeloma Access Atlas. Myeloma Patients Europe has supported Fundacja Carita twice via the Atlas Programme by writing to the Polish Health Ministry to support the approval or reinstatement of myeloma drugs for national funding. By highlighting the importance of the drug to patients alongside information on comparative access in Europe, it really supported our case. Through collaborative and strong action, we were able to improve access for Polish myeloma patients.”

You can see case studies and testimonials from the Atlas Coaching Programme [here](#).

About Myeloma Patients Europe

Myeloma Patients Europe (MPE) is an umbrella organisation of myeloma and AL amyloidosis patient groups across Europe. MPE currently has 49 members based in 30 countries. The mission of the organisation 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 treatment and care. To achieve its aims, MPE works directly with members, healthcare professionals, reimbursement authorities, regulators, politicians, pharmaceutical companies and the media to ensure all stakeholders are collaborating to improve patient outcomes and reduce inequalities across Europe.

MPE is registered as a non-profit organisation (AISBL) under Belgian law. You can find the MPE website here: <https://www.mpeurope.org>

About the Myeloma Access Atlas

The *Myeloma Access Atlas* is an online platform designed to provide myeloma and AL amyloidosis patient advocates with information needed to work effectively on access issues. It provides country-specific and comparative information on European health systems, including data on system performance (as well as stakeholder perceptions on this topic) and on access to treatment and care. Through the Coaching Programme, the Atlas also provides advocacy tools, advocacy networks and MPE provides one-to-one support designed to help advocates develop and implement effective strategies to address identified access issues. You can access the *Myeloma Access Atlas* here: www.mpeurope.org/atlas.

For more information

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