



CEE CELGENE PATIENTS' PARTNERS SUMMIT



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What strategies and advocacy actions are needed to address policy, access and care barriers?

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Myeloma Patients Europe is an umbrella organisation representing myeloma and AL amyloidosis patient groups.

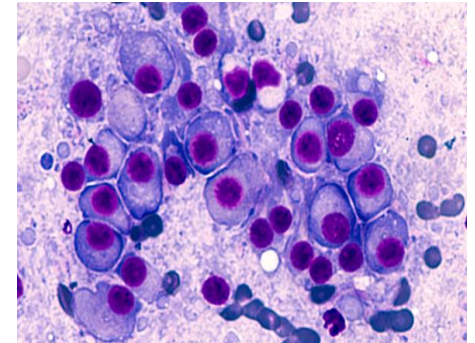


- 46 members in 30 countries
- Provide a range of programmes and resources aimed at building a strong **European advocacy community**

Different challenges
Different GDP
Different level of resources
Different health systems
Different access issues

Myeloma is a complex and incurable cancer of the plasma cells.

- Approximately 40,000 new cases of myeloma each year in Europe
- Relapsing and remitting disease
- Moving towards more chronic forms of treatment
- Statistics show 10-year survival rates are increasing
- Gains can be attributed to availability of novel agents
- Survival increase is not uniform across Europe



European studies have shown that myeloma patients need and value:

- Access to innovative, effective medicines
- Access to medicines with good benefit and risk profile
Considerations around administration, mobility and psychosocial well-being are important
- Patients want access to the **right medicines**, at the **right time** for them
- Access to timely diagnosis, diagnostics and supportive care are also important

Are these expectations being met?



Inequalities in Europe prevent these from being met...

The access challenges in some CEE countries are systemic, complex and multi-faceted. These are preventing patients from receiving optimum standards of treatment, care and support.

Limited GDP and expenditure on healthcare

Systemic government and infrastructure challenges

Off-patent medicines not reaching patients (e.g. Balkan countries)

Complex, expensive myeloma pathway / affordability

Unequal access to procedures and diagnostics

Clinical trials and drugs not launching in some countries

As well as existing challenges, we also have a wave of upcoming challenges for health systems which need to be prepared for....





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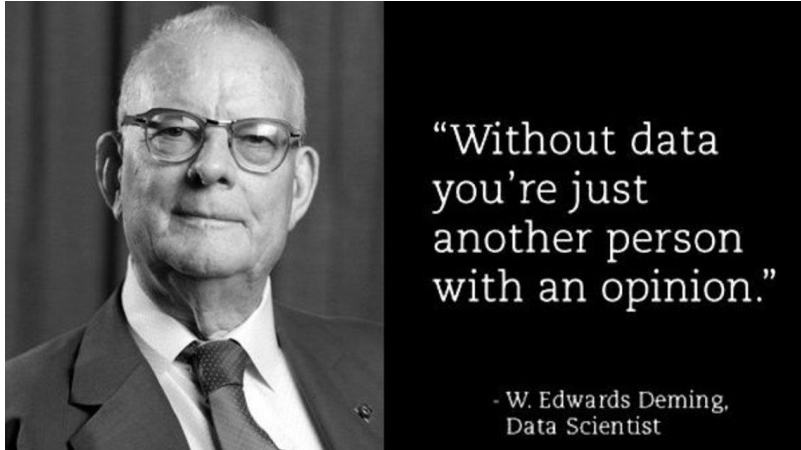
What national strategies and advocacy actions are needed to address these challenges?



National patients advocates and advocacy organisations have a pivotal role to play in addressing access challenges.

- Identify access barriers
- Understand what matters most
- Identify targeted and achievable goals
- Develop a clear strategy
- Map all relevant stakeholders
- Gather evidence
- Build lasting relationships and open dialogue
- Seek advice and collaborate
- Ensure you understand the issue
- Think about solutions to problems
- Diplomacy before escalation

Remember that all advocacy strategies should also be underpinned by evidence...



- Treatment availability
- Evidence of access challenges
- Impact of an access issue
- Patient needs, wants and preferences
- Case studies
- Why an intervention is required

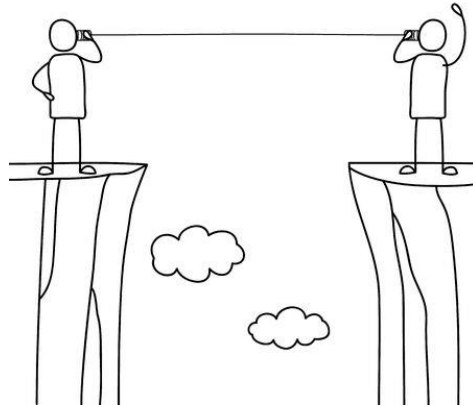
What European strategies and advocacy actions are needed to address these challenges?

Strong advocacy at a European level can underpin and support national advocacy.

- Role **pan-European networks** can play in monitoring, gathering evidence on and escalating cross-cutting access issues
- Work with and hold a range of stakeholders to account at a European level
- Co-design access strategies and initiatives that really help support national organisations achieve their goals
- Escalation and direct intervention where necessary and appropriate



For this to be successful, there needs to be a two-way dialogue and collaboration between national and European advocacy organisations.



As an example, MPE works with a range of stakeholders to monitor and influence national access to myeloma and AL amyloidosis drugs.

- Conduct a biannual survey to identify main access barriers
- Work directly with members and clinicians
- Attending external meetings and congresses
- Information sharing with other European patient advocacy groups, coalitions and professional societies
- Representing interests on a range of steering groups / roundtables
- Targeted work with industry (e.g. regular calls)



We have also developed ways to identify and develop solutions to tackle access challenges.

- Two-pronged approach to access issues
 1. **MPE Access Atlas Programme** provides information and support to members on national access issues
 2. **Monitor and escalate** cross-cutting themes on access at a European level
- **Access Coaching Programme** provides tailored one-to-one support for members to:
 - Request help to implement or develop strategy
 - Provide support on any access issue
 - Direct intervention where appropriate

Examples of MPE support and co-designing strategies on access

- **Romania:** Issues with access to stem cell transplantation
- **Croatia:** Information provision to support work on medicines access and drug shortages
- **North Macedonia:** Work on access to generic medicines
- **Finland:** Support in building a case for two new medicines going through health technology assessment
- **Poland:** Individual patient support (where requested) and upcoming support on access to novel agents



Collaborative approaches, such as the MPE CEE Workgroup, are also crucial for identifying and overcoming access challenges

- Unmet need for coordinated action at a European level on regional access issues in CEE
- An initiative driven by MPE members under the scope of the Access Atlas Programme, with the support of MPE Staff
- Provides a vehicle for information sharing and joint-work on issues affecting members in CEE



Aims and objectives of the MPE CEE Atlas Workgroup

Identify key issues and challenges affecting access in the region

Information-sharing between CEE organisations / MPE

Problem-solving on national and cross-cutting access issues

Ensuring MPE is aware of national challenges

Escalating cross-cutting challenges (e.g. raising them with industry or relevant stakeholders)

Two-way communication between MPE and CEE members

Identify and address of knowledge gaps in advocacy

Publishing reports on key issues

There are clear
benefits to
collaboration...

Potential topics for discussion

Opinions and experiences of national access barriers

Capacity and support needs

Consider different pricing models in CEE region

How we get industry to consider CEE region more of a priority

Prioritisation of drugs – CEE guidelines?

Issues with access to diagnostics and specialist care

Patient preference elicitation

Patent issues

How do we get policy-makers to listen?



Community Advisory Boards (CABs) are an important advocacy action – such as the Myeloma CAB

- **A model** where leading patient advocates set the agenda and invite researchers, academics, authorities, pharma
- **Two-way dialogue** to improve patients' well-being and outcomes
- **Address key challenges** patients face in access
- **Discuss** clinical development pipelines, regulatory issues, collaborative challenges
- **Build capacity and knowledge** in patient community
- Includes representation **from different parts of Europe**



CABs continued...

- Country-specific and regional CAB are also very important for tackling core issues
- In 2020, MPE will be holding our first CEE specific CAB on identified issues
- Important to engage in a formal setting with stakeholders on key issues preventing access to treatment and care in the region
- Again, this a model which can be replicated by different patient communities



Advocacy tips for treatment access

- Understand your disease pathway
- Collect data on access
- Collect data on what patients want
- Understand where **you should be involved**
- Write submissions to assist decision-making
- Develop advice networks and strategic relations with decision-makers
- Have early and regular conversations with industry
- Anticipate the future too...
- Disinvestment and investment
- Ask your umbrella organisation to help you



Where a treatment is not available...

- Think about the multi-faceted reasons why it is not approved
- Think about innovative solutions of getting a medicine approved
- Multi-stakeholder solutions are often required – **can you broker anything?**
- Are any other patient organisations in your country or in Europe having a similar problem?
- Can you collaborate with other stakeholders?
- Campaigns sometimes work (but have to be strategic)
- Influence policy which may be a barrier to access



Overcoming barriers should also be a multi-stakeholder effort...(examples)	Who?
Designing and reaching consensus on optimum treatment pathways	Clinicians, industry, patient organisations
Explore innovative and flexible access solutions (e.g. pricing schemes)	Industry, HTA, regulators, patient orgs, clinicians, payers.
Early preparation, engagement and information-sharing on drug development and market access to new medicines	Industry, patient orgs, HTA, payers and regulators
Developing the value proposition of new medicines in drug development and market access programme	Industry, patient orgs, clinicians, HTA bodies/payers
Developing an understanding and action plan for better prioritisation of CEE countries in clinical trials and market access programmes	Industry, patient organisations, clinicians
Implementing clear cancer plans with national healthcare systems	Patient orgs, policy-makers, industry, clinicians.

Summary and conclusions

- National patient organisations should take the lead in developing and implementing strategies to overcome access challenges
- European patient advocacy organisations, like MPE, have a big role to monitor and escalate key issues that arise at a European level
- European organisations can also help with capacity building and support of national advocacy organisations in identifying and overcoming challenges
- Strategic collaboration and communication is crucial in advocacy to overcome a wide-range of challenges