



## Membership Capacity Building Programme

### Effective campaigning:

What are successful experiences and how to develop effective messaging and influence stakeholders?

# Introduction and Welcome

## Membership Capacity Building

- Allows EMSP to get an in-depth understanding of the activities and challenges MS Societies are facing at the national level aiming to strategize advocacy efforts for a greater impact.
- Allows MS Societies to come together towards a common goal and priorities, **catalyzing the learning process** across societies based on their strengths and needs
- MCB running from 2018

# MCB over the years...



## EMSP team



**Patricia Moghames**  
Programme Coordinator  
EMSP



**Mate Tagaj**  
Senior Communications  
and Membership Coordinator  
EMSP

## Speaker



**Jimmy Smyth**  
Director of JKS Communications

# Objectives

1. Sharing insights and ideas across the network of member organizations
2. Improving and maximizing coordination across member organizations
3. Developing policy messages and campaign objectives
4. Setting the way forward for mapping political targets and setting realistic objectives to influence European social policy and county by country elections

# Agenda

Time	Item	Speakers
10:15 – 10:20	Welcome and introduction	Jana Hlavacova
10:20 – 10:30	Icebreaker	Jimmy Smyth
10:30 – 10:40	General overview of the Barometer outcomes with focus on areas of improvement and ongoing priorities	Patricia Moghames
10:40 – 11:20	<b>Case Study:</b> Learnings and insights from successful pan European campaign(s), with highlight on how to develop successful messaging	Jimmy Smyth
11:15 – 11:25	Virtual Coffee break	
11:25 – 11:55	<b>Model of Care and Patient Pathways:</b> Overview of member states with the best outcomes: How was it achieved?	Representatives from 3 MS Societies
11:55 – 12:35	<b>Break-out sessions:</b> Refining key policy messages for legislative change and impact	All participants
12:35 – 12:40	Virtual Coffee break	
12:40 – 13:05	<b>Way forward</b>	Jimmy Smyth
13:05 – 13:15	Questions and wrap-up	Facilitators





Roundtable



## ADVOCACY

*Persuade and Inspire*



*"When the whole world is silent,  
even one voice becomes powerful."*  
Malala Yousafzai, Pakistani activist and  
Nobel Prize laureate





# Key elements of a successful campaign



*“If you can’t explain it simply, you don’t understand it well enough”*

*Einstein*

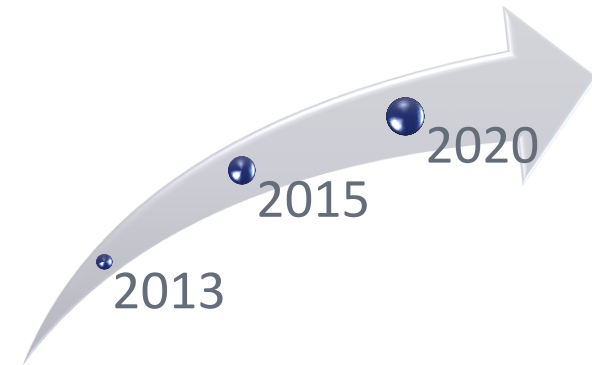
**General overview  
of the Barometer  
outcomes** with  
focus on areas of  
improvement and  
ongoing priorities

**Patricia Moghames, EMSP**



# What is EMSP's MS Barometer?

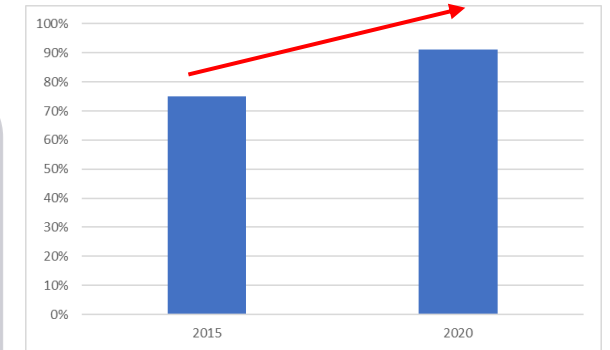
- Analysing MS management and care
- Identifying the most persistent and **challenging gaps in care**, and understanding **how MS management has changed** over time across Europe
- Benchmarking tool
- Not only health care, also social care system
- Periodically since 2008
- 6 editions to date: 2008, 2009, 2011, 2015, 2013, 2020
- Upcoming: 2024



# Use of DMDs

Offer at least one DMD with 100% reimbursement

- 2015: 75% of countries --> 2020: 91%
- 2020: 85% make available at least 6 of the 12 DMDs surveyed.



Use of DMDs varies considerably by countries

- Treatment rates are as high as 90% in Lithuania, Malta and Switzerland, but far lower in Moldova (6%), Bosnia and Herzegovina (10%) and Serbia (12%)

# Symptomatic treatment

- MS symptom management is not systematically structured.
- No formal clinical guidance in Europe for MS symptomatic treatments; dependence on individual neurologist's expertise
  - **Use of national or international guidance for symptomatic treatment of MS**
    - 2015: 15 countries
    - 2020: 20 countries
  - **In 2015, 7 countries mentioned symptomatic treatments are available and reimbursed:**
    - 2015: 7 countries
    - 2020: 14 countries

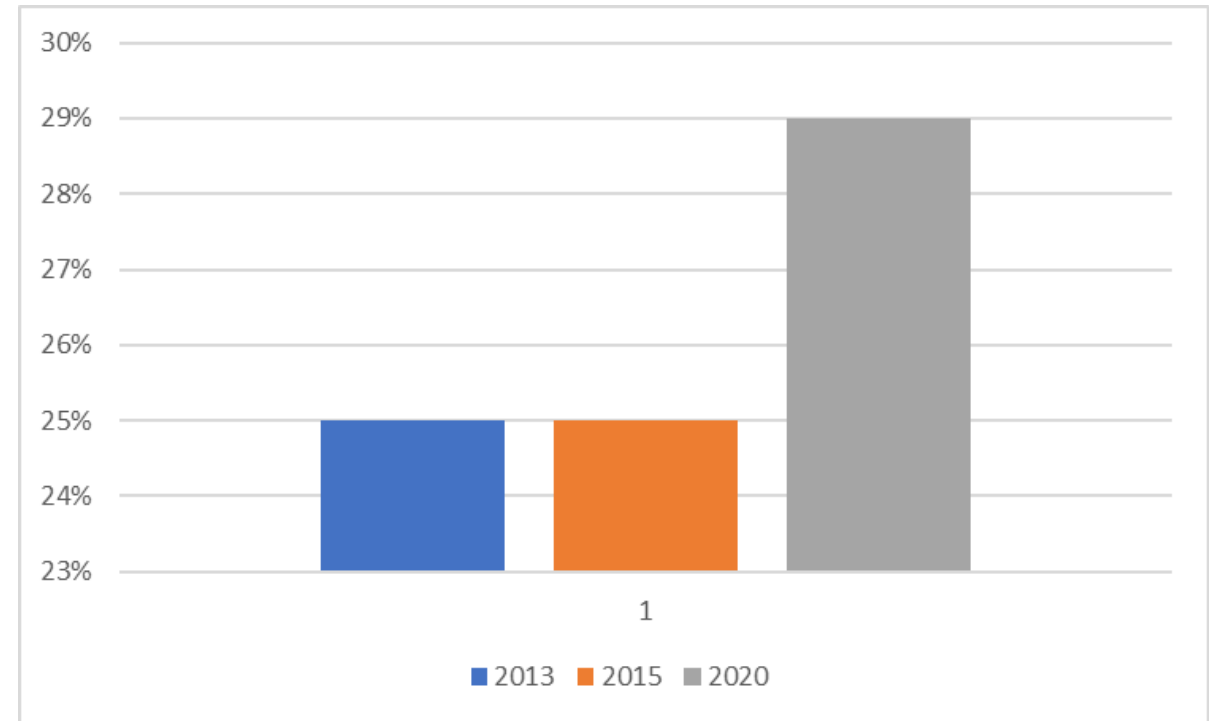


# Pediatric MS

- 2015 to 2020: from 54 to 57%
  - 46% of countries provide any social support specific to pediatric MS carers
  - 52% provide child disability allowances
- More focus on children with MS
  - French foundation for MS research has annual day for PwMS under 21
  - Romania's national MS patient society has annual retreat
  - More research on pediatric MS

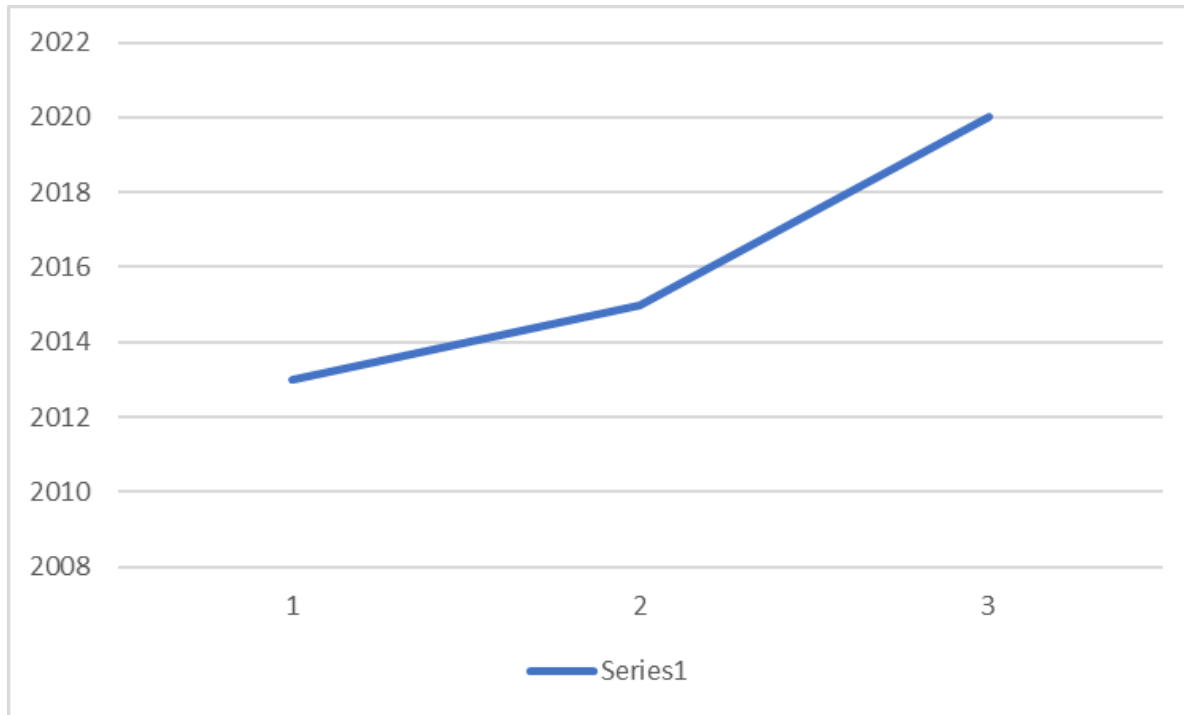
# Palliative care

- Europe does not prioritize early palliative care for people with MS
  - 10 countries in 2020 reported providing this for PwMS
- 2013 and 2015, similar rates but increased to 29% in 2020
  - Slow progress but forward



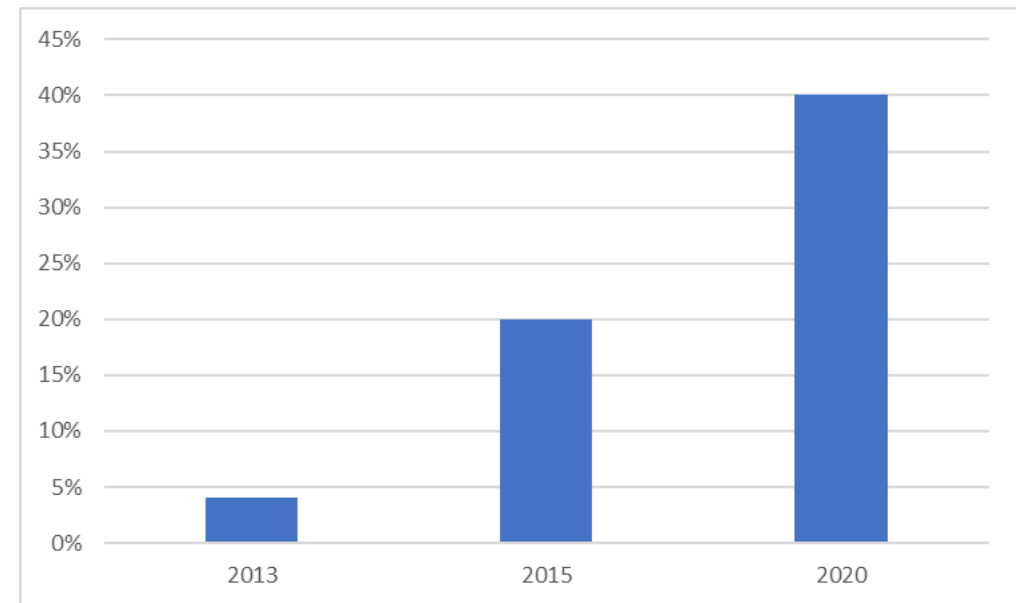
# Financial support for early retirement due to disability

- 32% to 36% to 80%!



# Decision making

- National MS societies are involved in decisions on reimbursing new MS therapies: 4 to 20 to 40%
- People with MS, their carers and patient groups: personal understanding of gaps in care and support means that they need to be consulted on the development of all new MS-related policies and programmes, in addition to care and reimbursement decisions.



# Case Studies

Learnings and insights  
from successful European  
campaigns, with highlight on how to  
develop successful messaging

**Jimmy Smyth, Director of JKS Communications**





# EUROPEAN YEAR OF PEOPLE WITH DISABILITIES - EYPD



# EFNA – UNDER THE UMBRELLA



**ARE YOU OR PEOPLE YOU CARE ABOUT AFFECTED BY A BRAIN DISORDER?**

**THEN SHOW YOUR SUPPORT BY GETTING TOGETHER #UNDERTHEUMBRELLA**



grab an umbrella  
& gather your group



grab your  
phone or camera



take a photo or  
video of your group  
under the umbrella



share your story &  
image with the hashtag  
#UnderTheUmbrella

[WWW.UNDERTHEUMBRELLA.EU](http://WWW.UNDERTHEUMBRELLA.EU) [@UNDERUMBRELLAEU](https://twitter.com/UnderUmbrellaEU)

**WE'RE GETTING TOGETHER  
#UNDERTHEUMBRELLA  
FOR BRAIN DISORDERS,  
ARE YOU?**



Find out more at:  
[www.undertheumbrella.eu](http://www.undertheumbrella.eu)  
and follow [@UnderUmbrellaEU](https://twitter.com/UnderUmbrellaEU)

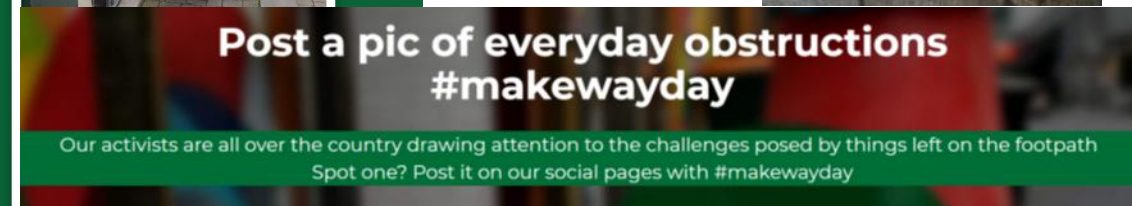


# MEGA LUNGS





# IRISH WHEELCHAIR ASSOCIATION ENABLE IRELAND FIGHTING BLINDNESS



# CF – Orkambi Reimbursement

Cystic Fibrosis – 65 Roses





# Key elements of successful campaigns

- Increased public awareness – EU Barometer and post campaign research
- Increase in statutory funding + fundraising
- Political “asks” delivered through policy/legislation – e.g.: National Disability Strategy
- Investment in specialist nurses, referrals, early detection, clinical pathways
- Involving people with MS in decision making and campaign designing
- Voice at Cabinet table + senior departmental level
- Transformational + funded policy change with review mechanisms
- Reimbursement for treatment

A photograph of a coffee break. In the foreground, a black cup filled with a frothy coffee sits on a matching black saucer. The cup is positioned on the right side of the frame. To the left and slightly behind the cup, a white plate holds a golden-brown croissant. The entire scene is set on a wooden table, with warm, golden light from a window in the background creating a soft, inviting atmosphere. The text "Coffee break" is overlaid in white on the left side of the image.

Coffee break

# Model of Care and Patient Pathways

Overview of member states with the best  
outcomes: How was it achieved?

# Who is sharing their experience with us?

**Despina Zelianaiou**, Office Manager of the Hellenic Federation of persons with MS - Greece

**Jan van Amstel**, President of the Dutch MS Association - The Netherlands

**Jonathan Blades**, Head of Campaigns and External Relations of the UK MS Society – United Kingdom

# Break-out sessions:

## Refining key policy messages for legislative change and impact



# What Next?

Advocacy Toolkit Checklist		
MANIFESTO		<input type="checkbox"/>
PLEDGE CARD/INFOGRAPH WITH KEY AIMS		<input type="checkbox"/>
STAKEHOLDER MAP TIER 1 AUDIENCES		<input type="checkbox"/>
DETAILS OF LOCAL TDS/COUNCILLORS		<input type="checkbox"/>
CONTACT DETAILS FOR LOCAL MEDIA PRINT AND BROADCAST		<input type="checkbox"/>
SPEAKING POINTS FOR RADIO/PRESS INTERVIEWS		<input type="checkbox"/>
DRAFT BOILER PLATE		<input type="checkbox"/>
SOCIAL MEDIA - MESSAGES FOR DIFFERENT PLATFORMS FACEBOOK/TWITTER/INSTAGRAM		<input type="checkbox"/>

# PLEDGE

## CALL FOR THE DEVELOPMENT OF A NATIONAL STRATEGY FOR COLITIS AND CROHN'S DISEASE

The ISCC is calling on politicians and policymakers to develop a national strategy for Colitis and Crohn's disease

This strategy should progress the following core aims:

1. Equitable access to an IBD Nurse and multidisciplinary care team.
2. Self-care and patient empowerment.
3. Sustainable funding model.



Crohn's disease and ulcerative colitis affects nearly **20,000** people in Ireland and the numbers are rising.



**iHHub**

International Heart Hub

The Global Alliance for Heart Patients Organizations

# BREAK-OUT SESSIONS

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**With Patricia and Mate!**

A photograph of a coffee break. In the foreground, a black cup filled with a frothy coffee drink sits on a matching black saucer. The cup is positioned on the right side of the frame. To the left and slightly behind the cup, a white plate holds a golden-brown croissant. The entire scene is set on a wooden table. Warm, golden light from the upper right corner casts long, soft shadows across the table, creating a cozy atmosphere. The text "Coffee break" is written in a white, sans-serif font on the left side of the image.

Coffee break

# Way Forward

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**Jimmy Smyth**

**Director of JKS Communications**

# Collaborative Campaigning

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What is realistic?

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What support is required?

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Agreement on key issues + supporting messages

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Identifying key political “asks” – 3-5 National MS Strategy, funded with political and policy oversight

# Way Forward *(continued)*

- Identify key national and EU audiences – stakeholder mapping session
- Upcoming elections – national + EP 2024
- Next Barometer 2024 – launch pan EU campaign
- MS Manifesto – 8 to 10 pillars e.g.: reimbursement, effective clinical pathways, political oversight, public awareness, patient focused policy, financial support



# This activity was supported by:



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VIATRIS™

An aerial photograph of a multi-lane highway bridge spanning a body of water. The bridge has several lanes in each direction, with white lane markings. Several vehicles, including cars and trucks, are visible on the bridge. The water is a deep teal color with visible ripples. The text "Thank you" is overlaid in the center of the image in a white, sans-serif font.

Thank you