

**MPN Horizons**  
Understanding the  
New Complexity of MPNs

13-15 October  
Zagreb, Croatia

**2023.**  
 mpn an

# MPN Advocates Network ANNUAL UPDATE

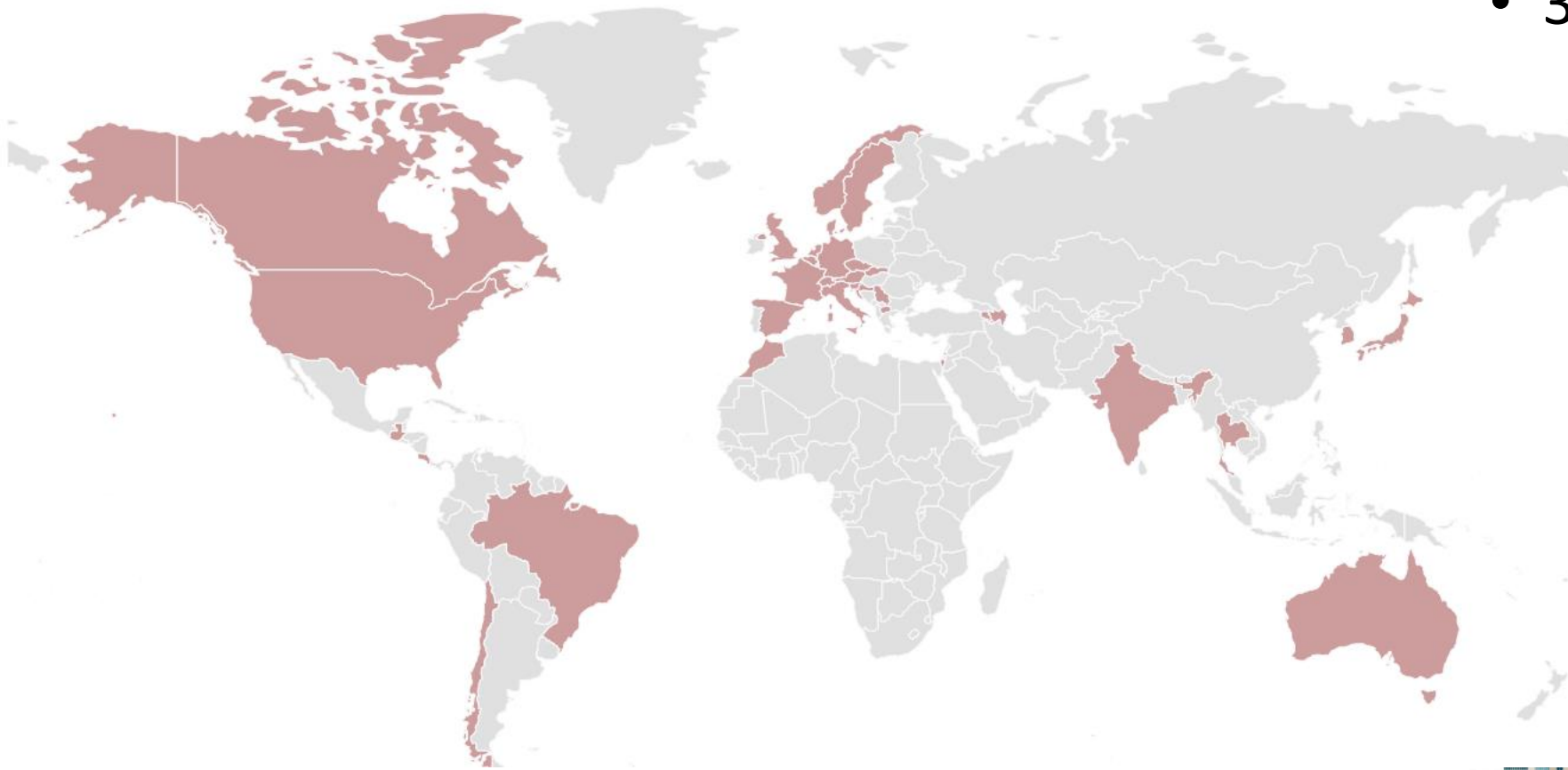


- MPN Advocates Network initially established in 2013
- Founding leadership from UK, Spain, and Netherlands, all linked together by Claire Harrison
- Formalized under the Leukemia Patient Advocates Foundation (LePaF)
- First MPN Horizons was held in Belgrade in 2016



# Reach

- 44 Members
- 35 Countries



Dedicated Management  
**Marija Stefkova**  
Macedonia





**Werner Zinkand**  
MPN-Netzwerk Germany



**Param Puthen**  
Friends of Max, India



**Felice Bombaci**  
Gruppo ALL Pazienti LMC, Italy



**Lyat Granati Espinosa**  
Max Foundation, Chile



**Giora Sharf**  
LePaf Representative  
Israeli Flute of Light  
Patients Organization, Israel



**Jon Mathias**  
MPN Voice, UK



**Ken Young**  
MPN Alliance, Australia



**Kapila Vigés**  
MPN Research Foundation, USA



**Dražen Vincek**  
Croatian Leukemia and Lymphoma  
Society (HULL), Croatia



*MPN Advocates Network was founded by representatives from several MPN patient support groups as a way of creating and maintaining collaboration between these organisations and providing a platform for joint activity*





To enhance MPN patient care by collaboratively:

- Acting as an **international collective** representative of MPN patient groups, interacting with healthcare funding, treatment approval, and treatment research organisations
- Sharing **best practices** of support and advocacy activities between all patient groups
- Sharing available information on all **current treatments, technologies and research results**
- Encouraging **cooperation** between advocates, researchers, clinicians, and health care organizations



*MPN Advocates Network operates purely for the benefit of MPN patients and acts independently of any other organisation or company.*

*MPN Advocates Network continues to be supported by a broad base of sponsorship & funding*



# Activities

## Global Survey

- 50 questions from treatment access to financial impact
- Phase 1 completed in 2019 with 1700 responses
- Phase 2, with additional language translations, is on hold due to capacity constraints

## Advocates Development Program

- Webinars for current members and new advocates to learn and connect
- Topics vary from understanding and recruiting for clinical trials to using 'story telling'
- On hold for demand and capacity

## MPN Awareness Day

- New 2023 campaign and branding
- Knowledge Makes a Difference
- #MakeSenseofMPN
- Facts about ET, PV, MF

## MPN Horizons

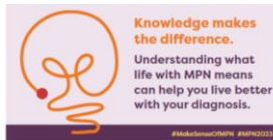
- Premier global program for MPN patient advocates
- Started in 2016 now the 8
- ***Understanding the New Complexities of MPNs***





## MPN Awareness Day

- New 2023 campaign and branding
- Knowledge Makes a Difference
- #MakeSenseofMPN
- Facts about ET, PV, MF



## MPN Horizons

- Premier global program for MPN patient advocates
- Growing global footprint
- Staying connected in complex times



- 2016 Belgrade
- 2017 Frankfurt
- 2018 Prague
- 2019 Lisbon
- 2020/21 virtual
- 2022 - Netanya



# Thank you to our Sponsors

## Initiating Platinum Sponsor



## Gold Sponsor



## Silver Sponsor



## Bronze Sponsor

