

Using Social Media in Advocacy

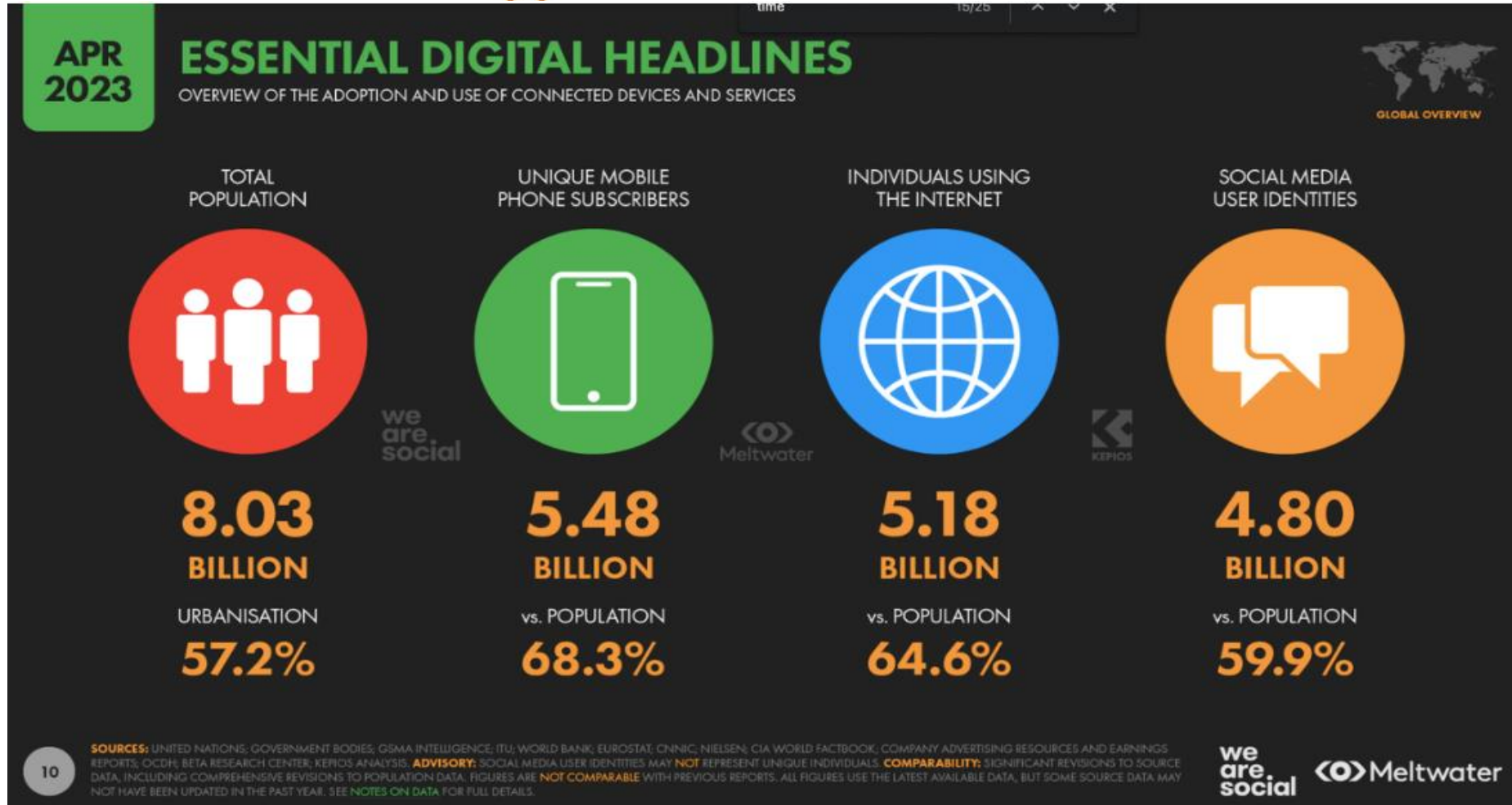


Social Media Advocacy

Social media advocacy involves utilizing social networks to propel your cause forward and foster connections with patients, doctors, caregivers, and other vital healthcare professionals.

This approach harnesses a wealth of specialized knowledge and diverse perspectives, uniting efforts for maximum impact and outreach within the healthcare community





**APR
2023**

OVERVIEW OF SOCIAL MEDIA USE

HEADLINES FOR SOCIAL MEDIA ADOPTION AND USE (NOTE: USER IDENTITIES MAY NOT REPRESENT UNIQUE INDIVIDUALS)



NUMBER OF SOCIAL
MEDIA USER IDENTITIES



4.80
BILLION



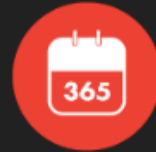
QUARTER-ON-QUARTER CHANGE
IN SOCIAL MEDIA USER IDENTITIES



+0.9%
+45 MILLION

we
are
social

YEAR-ON-YEAR CHANGE IN
SOCIAL MEDIA USER IDENTITIES



+3.2%
+150 MILLION



AVERAGE DAILY TIME SPENT
USING SOCIAL MEDIA



2H 24M

GWl.

AVERAGE NUMBER OF SOCIAL
PLATFORMS USED EACH MONTH



6.6

SOCIAL MEDIA
USER IDENTITIES vs.
TOTAL POPULATION



59.9%



SOCIAL MEDIA USER
IDENTITIES AGED 18+ vs.
POPULATION AGED 18+



78.0%



SOCIAL MEDIA USER
IDENTITIES vs. INDIVIDUALS
USING THE INTERNET



92.7%



FEMALE SOCIAL MEDIA USER
IDENTITIES vs. TOTAL SOCIAL
MEDIA USER IDENTITIES



46.5%

we
are
social

MALE SOCIAL MEDIA USER
IDENTITIES vs. TOTAL SOCIAL
MEDIA USER IDENTITIES



53.5%



Benefits of Social Media in Advocacy



Purpose,
accelerated



Wider
Reach



Building
Network



Fostering
Communities



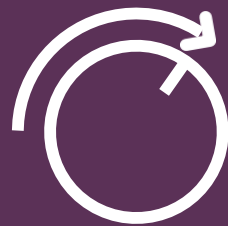


Purpose accelerated



- **Raise Awareness:** Promote understanding of health topics, treatments, and available services
- **Connect Patients with Experts:** Enable direct communication between patients and healthcare professionals for advice and opinions
- **Timely Updates:** Keep the community informed of changes in policies, treatment advancements, and condition-related updates.
- **Advocate for Patient Rights:** Raise awareness about patient rights, healthcare policies, and access to quality care.
- **Collaborate with Advocacy Groups:** Partner with patient advocacy organizations to strengthen support networks and outreach efforts.





Wider and Faster Reach





Factors to identify a suitable platform to ensure wider & faster reach

- **Target Audience:** Choose based on the age and preferences of your intended audience.
- **Content Type:** Match the platform with the content you primarily produce (e.g., visuals, articles, discussions).
- **Engagement Goals:** Decide if you want to foster discussions, provide updates, or create a sense of community.
- **Analytics and Insights:** Use platform analytics to track engagement and refine your strategy.
- **Multi-Platform Approach:** Consider using a combination of platforms for broader outreach and engagement.



- Social media advocacy is an incredibly powerful tool for connecting with key influencers and building relationships with potential stakeholders.
- It gives you the opportunity to create valuable content that resonates with your target audiences, establish yourself as an industry expert, and ultimately generate awareness among the stakeholders and decision makers.
- With the power of strong social media, you can build a strong presence and boost the organizational objective and create awareness with minimal effort.





Building a Strong Network



Compelling content and engagement strategies lay the groundwork for a robust social media presence, ultimately culminating in a strong network of dedicated supporters and advocates

- **Creating Compelling Content:** Blog posts, Videos, Visual Media, Story Telling

Compelling content forms the foundation of a robust social media presence. It's the magnet that draws in and captivates your audience, ultimately strengthening your network.

- **Engaging your audience:** Responding to customer feedback, Interacting with followers, Answering questions

Engagement is the bridge that connects you with your audience. It's the dialogue that builds relationships, turning followers into active participants and advocates. Prompt responses demonstrate that you value your audience's input, cultivating trust and loyalty. Interactive content invites participation, turning passive observers into engaged contributors..

- **Leveraging Influencers:** Building relationships with key influencers, Promoting messages to their followers





Fostering Communities



Advocacy groups on social media serve as platforms for mobilizing support, sharing resources, and building a sense of belonging among members

- **Accessible Platform:** Social media offers global accessibility for community building.
- **Shared Interests and Values:** Communities form around common interests, creating a sense of belonging.
- **Content Sharing and Creation:** Members exchange relevant content, enriching the community.
- **Events and Activities:** Organize and promote gatherings, webinars, and meet-ups.
- **Networking Opportunities:** Connects like-minded individuals for potential professional relationships.





Risks Involved in using Social Media



Reputational Damage

- **Misinformation or Miscommunication:** Sharing inaccurate or misleading information can erode trust in the advocacy group and potentially harm patients' well-being.
- **Controversial Stances:** Taking polarizing positions on healthcare issues may alienate certain segments of the patient population, leading to reputational damage.

Cybersecurity Threats

- **Privacy Breaches:** Mishandling of patient information or sharing sensitive medical data on social media platforms can lead to privacy breaches and legal consequences.
- **Target for Hacking:** Patient advocacy groups may be targeted by cybercriminals seeking to gain unauthorized access to social media accounts or patient databases.



Patient Safety Concerns

- **Misguided Medical Advice:** Well-intentioned but incorrect medical advice shared on social media can potentially harm patients, especially if it contradicts professional medical guidance.
- **Delay in Seeking Professional Help:** Patients might rely solely on social media advice, potentially delaying seeking appropriate medical attention in urgent situations.

Loss of Control over Advocacy Message

- **User-Generated Content:** Content shared by supporters, while well-intentioned, may not always align perfectly with the advocacy message, potentially leading to confusion or dilution of the cause



Overreliance on Social Media Algorithms

- **Algorithm Changes:** Sudden changes in social media algorithms can significantly impact the visibility and reach of advocacy content, potentially hindering the effectiveness of advocacy efforts.

Lack of Crisis Preparedness

- **Unpreparedness for Medical Emergencies:** Advocacy groups may not have a well-defined crisis communication plan in place, leading to delayed or ineffective responses during medical crises or controversies.

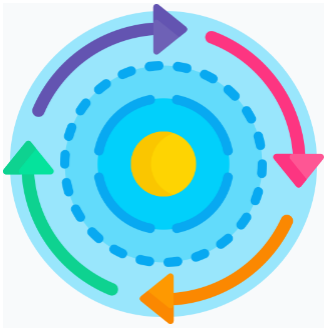




Strategy To Maximise Social Media Advocacy



Strategy to Maximise Social Media Advocacy



Consistency in posting



Engagement



Platform Update



Platform Trends



Community Involvement



- **Consistency is Key**

Consistent posting keeps your advocacy efforts visible and engaged.

- **Engage with Your Audience**

Interact with your audience actively, fostering a supportive community.

- **Collaborate and Network**

Collaborate with patient organizations, healthcare professionals, and influencers.

- **Encourage User-Generated Content (UGC)**

Encourage patients to share their own stories, adding authenticity to your advocacy.

- **Monitor Analytics and Adjust**

Analyze metrics to refine your content and strategy for better impact.



- **Define Clear Objectives**

Set specific, measurable goals for your patient advocacy efforts

- **Know Your Audience**

Understand the unique needs and concerns of your target patient community.

- **Content Planning and Calendar**

Plan diverse content and schedule regular posts to maintain engagement

- **Leverage Various Content Types**

Share personal stories, informative videos, and resources tailored to each platform.

- **Optimize for Each Platform**

Customize content for different platforms to maximize its impact.





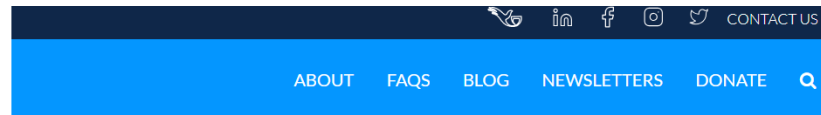
Friends of Max Leveraging Social Media



- Regular postings on WhatsApp group and SM handles- FB, Twitter, Instagram and LinkedIn- newsletters, meeting reports, patient advocate of the month, impact posters
- Keeping our stakeholders informed and updated about our events including PSGMs, Addas
- Spreading the voice of FOM volunteers, patient leaders, survivors, physicians (from this part of the world) in important global events like World Cancer day , World CML Day , MPN awareness
- Fundraising via corporate funders, Chai For Cancer Program and through global patient advocacy groups



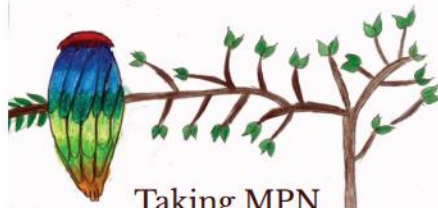
MPN Under FOM Wing



Latest News & Activities





FOM Guide to
Disease Management



Taking MPN
Under Our Wing

FAQ on
Myeloproliferative Neoplasms
Focus on Polycythemia Vera

 The Max Foundation
Accelerating health equity, one patient at a time.



MPN Horizons

Understanding the
New Complexity of MPNs

13-15 October
Zagreb, Croatia **2023.**




CHAI FOR CANCER
SEASON NINE, 2022

RAISE A CUP, DRINK TO A CAUSE
DONATE ONLINE - WWW.CHAIFORCANCER.ORG



Friends of Max
1.4K likes • 1.6K followers



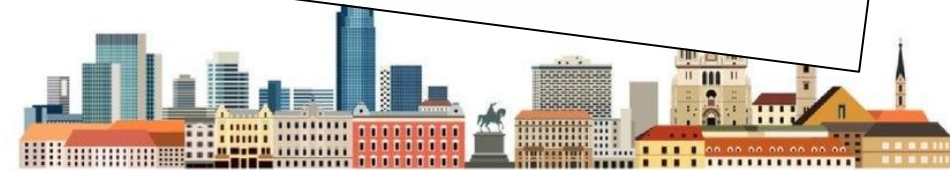
chaiforcancer Follow Message

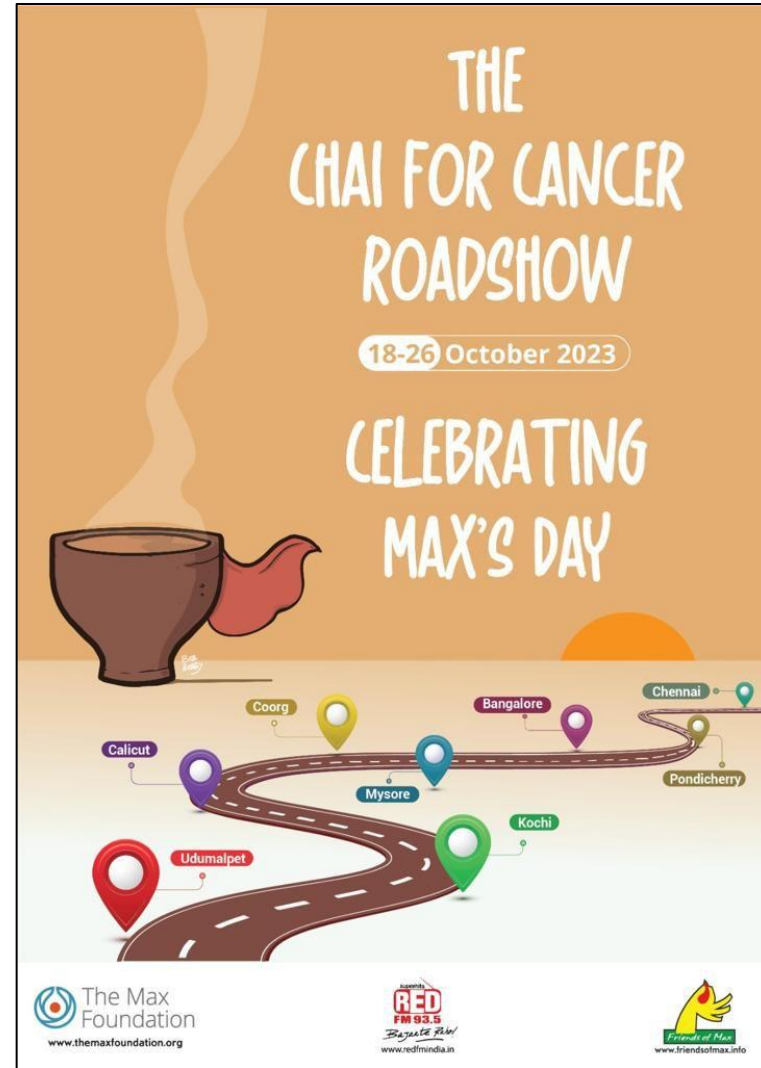
1,814 posts 1,437 followers 379 following

Chai for Cancer

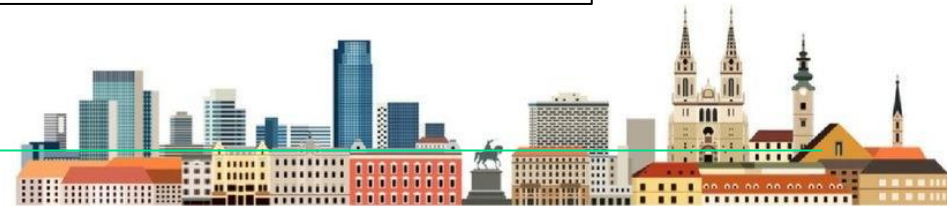
Community
A unique fundraiser and awareness campaign that looks at bringing support to cancer patients in need of emotional, financial and practical assistance

chaiforcancer.org/the-virtual-chai-for-cancer-adda-faq





Identifying Key Influencers
with online followings or engaged audiences





9/22

**World
CML Day**
22 SEPTEMBER

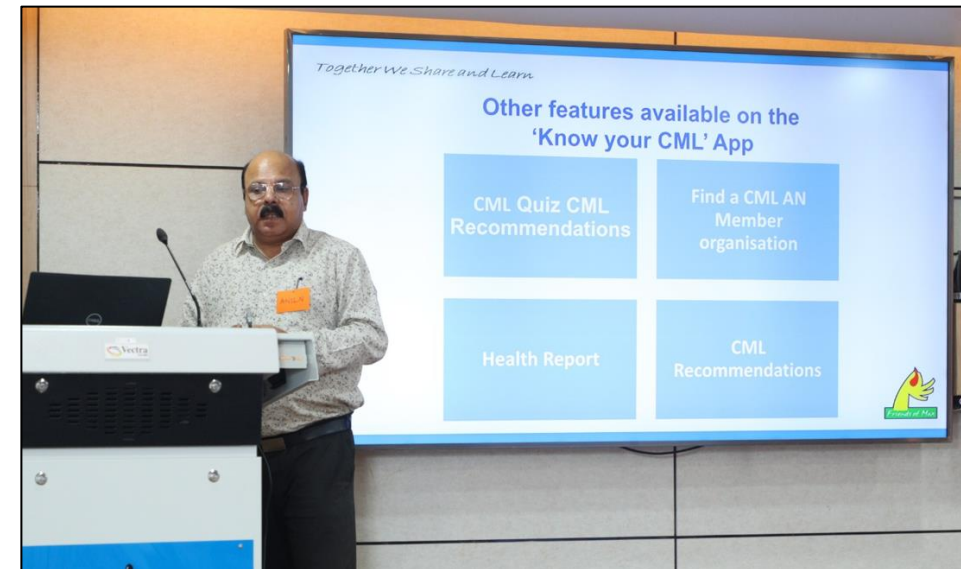
DID YOU KNOW?

More than **34,000** people around the world are diagnosed with CML*

#CureCML
#WCMLD23

*Lin Q, Mao L, Shao L, Zhu L, Han Q, Zhu H, Jin J, You L. Global, Regional, and National Burden of Chronic Myeloid Leukemia, 1990-2017: A Systematic Analysis for the Global Burden of Disease Study 2017. *Front Oncol.* 2020 Dec 15;10:580759. doi: 10.3389/fonc.2020.580759. PMID: 33384954; PMCID: PMC7770240.

Raising Awareness - Fostering Communities





Glimpses of Social Media Advocacy



MPN Horizons

Understanding the
New Complexity of MPNs


13-15 October
Zagreb, Croatia **2023.**



MPN Advocates Network
September 15 at 12:30 AM · 🌐

🔥 MPN Awareness Day 2023 🧑🌍 Take just 1 minute to enlighten yourself on these 10 intriguing facts about Myeloproliferative Neoplasms. Knowledge is power, and on this MPN Awareness Day, let's arm ourselves with insights that matter. 📖📄
#MPNAwarenessDay #KnowMPNs #PowerOfKnowledge #MakeSenseOfMPN #MPN2023

10 FACTS ABOUT MPN



1 20% of PV patients are under the age of 40.


0:03 / 0:55 #MakeSenseOfMPN #MPN2023

👍👎 2 1 share

Like Comment Share

Write a comment...

MPN Advocates Network
September 15 at 12:19 PM · 🌐



MPN AWARENESS DAY 2023
14th September 2023
#MakeSenseOfMPN #MPN2023

Suomen Syöpäpotilaat ry
September 14 at 11:38 AM · 🌐

Today we are celebrating MPN awareness day. The day is held annually on the second Thursday of September.

🔴 MPN refers to myeloproliferative diseases, which are... [See more](#)

⚙️ [See original](#) · [Rate this translation](#)

👍 3

Raising Awareness - Enabling Communities

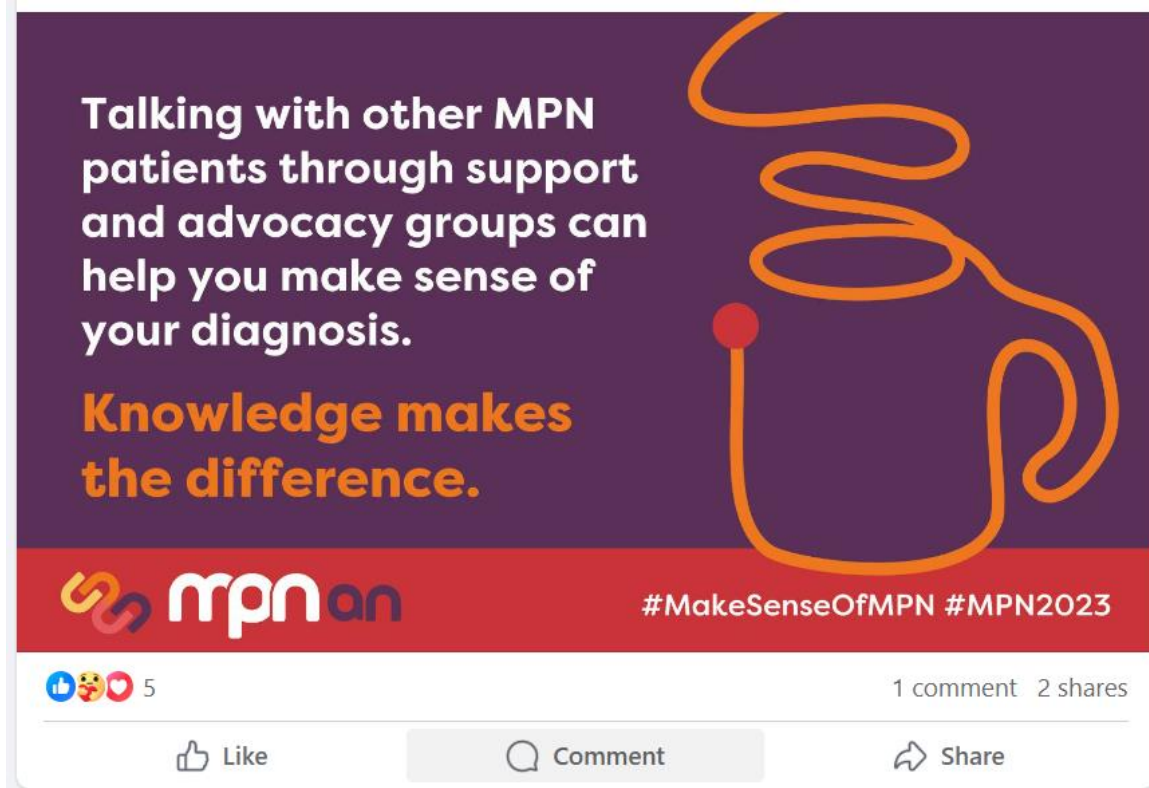


MPN Horizons

Understanding the
New Complexity of MPNs


13-15 October
Zagreb, Croatia

2023.



Talking with other MPN patients through support and advocacy groups can help you make sense of your diagnosis.

Knowledge makes the difference.



#MakeSenseOfMPN #MPN2023

5 1 comment 2 shares

Like Comment Share



MPN Horizons
MPN
Advocates
Network

MPN Advocates Network updated the group cover photo in Global MPN Advocates Network.

2d · 🌐



MPN Horizons

Understanding the
New Complexity of MPNs 2023

13-15 October 2023 • Zagreb, Croatia



1 1

Like Comment Share

Raising Awareness - Enabling Communities





Thank you

We're all in this together.

Anil Nagpal
Friends of Max
India

