

MPN Horizons

**Understanding the
New Complexity of MPNs**

8th International Conference

13-15 October
Zagreb, Croatia

2023.



SEPTEMBRE ROUGE

RED SEPTEMBER

BLOOD CANCER AWARENESS MONTH IN FRANCE

KARIN TOURMENTE-LEROUX, VIVRE AVEC UNE NMP,
FRANCE

Advocacy Session #
Best practice in patient advocacy
#MPNHZ23



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Problem statement and background (I)

Created in October 2021, "Vivre avec une NMP" is a patient association, suffering from MPN myeloproliferative neoplasms, rare blood cancers.

Our goal ?

To raise awareness of these unknown and misunderstood diseases that are MPNs, to help medical and pharmaceutical research and, of course, to inform and support other patients in their procedures and their day-to-day life.



WWW.VIVREAVECUNENMP.COM

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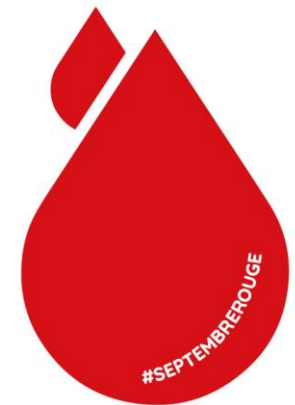
2023



Problem statement and background (II)

In many countries, September is a dedicated month for blood cancer awareness. The association "Vivre avec une NMP" decided from the first year of its existence, in 2022, to create "Septembre Rouge" (Red September), french blood cancer awareness month in order to make blood cancers known to as many people as possible.

Each year, blood cancers affect approximately **45 000 people in France, 12% of new cases of cancer!** However, blood cancers are less subject to prevention or awareness campaigns, as are certain other solid cancers: breast or prostate cancer. Beyond leukemia, lymphoma and myeloma, there are a large number of blood cancers whose evolution and treatments can be different, including rare blood cancers like **MPN (Myeloproliferative Neoplasm)**.



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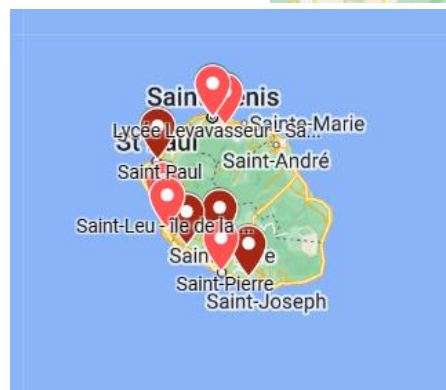


Implementation (I)

For the 1st edition, more than 25 places/cities/castle supported our campaign, and more than 50 media relayed it.

*This year, for the 2nd edition, **108 institutions, hospitals, companies...** supported us.*

Lightning monuments in Red, communicating on their tools, local actions such as a red race at Évreux air base 105... everyone was able to imagine the form that their support can take



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Implementation (II)

#SeptembreRouge also consists of 2 webconferences developed in partnership with Dis-moi Santé:

Better understanding blood cancers (malignant hemopathies) - September 1st at 6 p.m.

- understanding adult leukemia, Pr E. Raffoux, hematologist, St-Louis Hospital
- understanding lymphomas, Dr C. Rossi, hematologist, Dijon University Hospital
- understanding myeloma, Dr. A. Talbot, hematologist, St-Louis Hospital
- understanding myeloproliferative neoplasms, Pr J-J. Kiladjian, hematologist, St-Louis Hospital



MPN from A to Z - September 11 at 6 p.m.

- with Pr V. Ugo, hematologist CHU de Angers and Pr J-J. Kiladjian, hematologist, St-Louis Hospital

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Implementation(III)

Official clip of Septembre Rouge:

We had the honor this year to count among our supporters many French public figures who appear in the campaign launch clip

[Septembre Rouge 2023 - Clip Officiel - YouTube](#)

A graphic featuring the hashtag "#SEPTEMBREROUGE" in a bold, red, sans-serif font. The text is centered within a white rectangular area that has a subtle gradient and is surrounded by several small, semi-transparent red circles of varying sizes, creating a bokeh effect.

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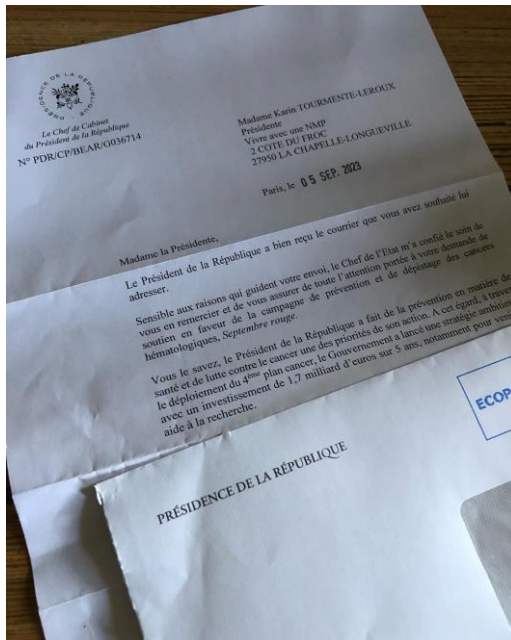
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Implementation(III)



**Support from our
French President
Emmanuel Macron**



**Support from our French
Minister of Economy,
Finance and Industrial and
Digital Sovereignty**

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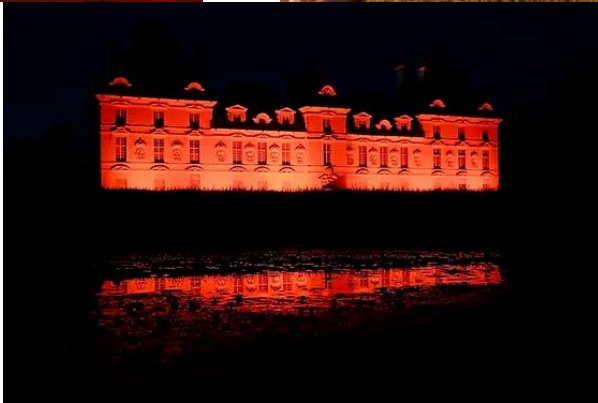
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Result and Impact (I): Picture's worth a thousand words...



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Result and Impact (II): Picture's worth a thousand words...



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Conclusion and recommendation:

- Involve the association team members to activate their own networks to get supports everywhere
- Prepare all the communication tools for the supports (media kit, press release, photos for social networks etc.)
- Look for partners and supports including health foundations, pharma, doctors association etc.
- Use a press officer in order to communicate with all medias

Our dream: one day seeing Europe in red and why not the World in red !

KARIN TOURMENTE-LEROUX, vivreavecunenmp@gmail.com