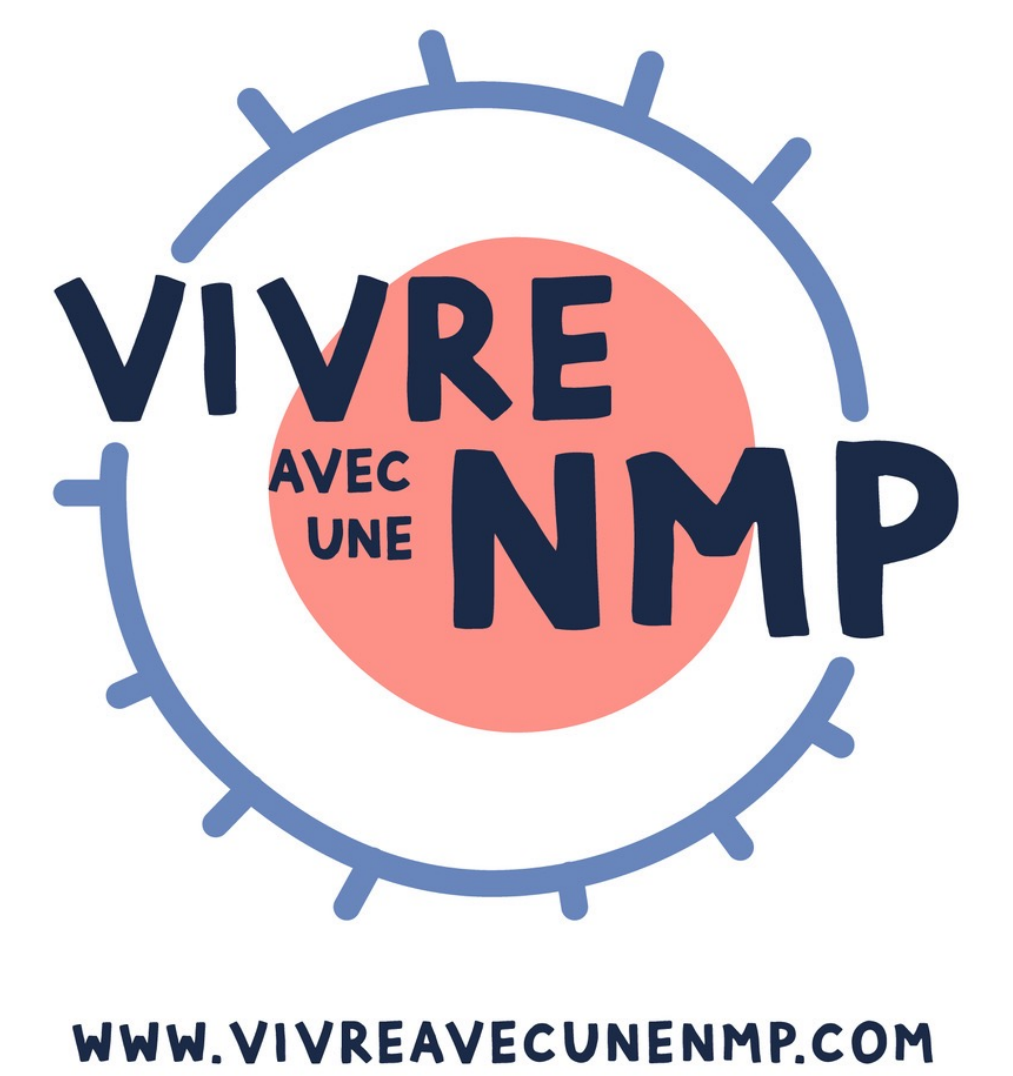


Patients organisation/ Physicians

How together best to get things moving again ?



Writers :
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Goal : Explain how, in France, our organisation collaborates with hematologists

By sharing our experience, we believe we can give everyone ideas so that doctors and patient organisations can work better together, throughout the world.

Tip 1 : A scientific council

- The choice of a scientific council or medical team that will support your organisation is **strategic**.
- It must be **composed** of clinical doctors, researchers and of course nurses because their approaches are complementary.
- It is necessary to lay the foundations of a **simple and smooth communication** (the exchanges by emails, for example, are preferred to not disturb the doctors – choose one or two interlocutors on the side of the association).



Tip 2 : Actions choices

- To carry out your various actions successfully, it is important to **involve** the scientific council.
- You can **share for approval** some of your ideas with them – especially if you are unsure about the relevance of these ideas.
- Some of your actions should highlight both the patient and the physicians, because it should not be forgotten that you need to **form a team**.
- Dare! Sometimes **the craziest ideas** can please 😊



Tip 3 : To choose a partner doctor

- The partner doctor is the one who, within your scientific council, will be involved in the actions. To be successful, he/she must be **concerned with the specific subject**.
- Keep him/her informed about **the topic progress regularly** without disturbing too much.
- In case of **media coverage**, highlight the partner doctor and systematically propose his/her contact to journalists.
- His/her notoriety will help you **move the lines**.



We did it together... in less than 3 years !

- o Mutual engagement on **social media** – including X

Goal: boost communication on MPN #MPNsm

- o A **question to my hematologist**: 10 videos in 2024

Goal: to discuss questions elaborated by patients/ members



- o Free **webinars** with members from the scientific council and invite other hematologists to inform their patients

Goal: to educate patients but also doctors who do not know our pathologies

- o **Mom, what is an NMP ? - a children's book** – which will be translated into English during the last quarter of 2024

Goal: to help patients communicate their pathologies with their loved ones

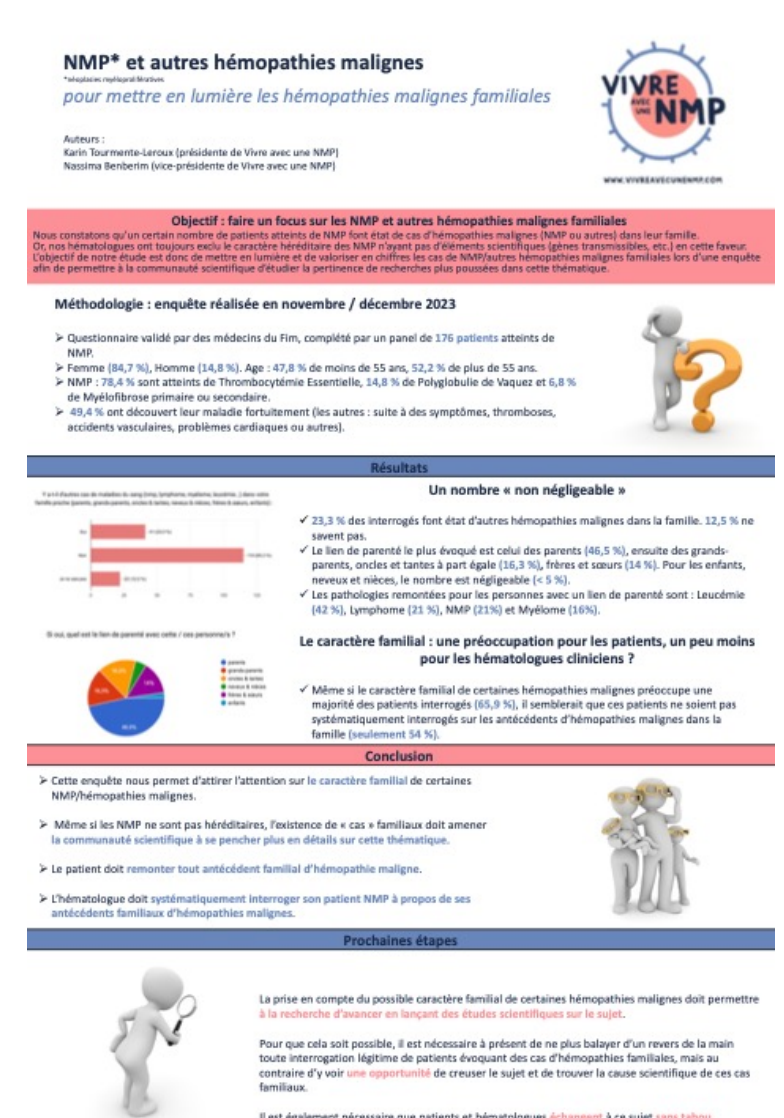


- o To invite members to **contribute to the Qualivie study** (on patients' quality of life)

Goal: to support the research

- o Survey about **MPN and other family blood cancers** survey: validation of the questionnaire by physicians

Goal: to invite hematologists to better understand our concerns and to take them into account for research



- o Feedbacks on MPN Patient life during a day of **training interns** in hematology (invitation of doctors from the scientific council)

Goal: to raise awareness among future hematologists about patient feelings

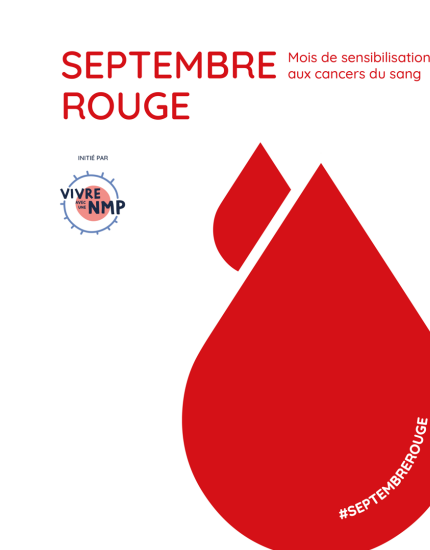


- o **Therapeutic Education Workshop**

Goal: support patients in the hospital with a medical team, collaboration to build the program (including the game: fatigue, I manage ?)

- o **Septembre rouge (Red September)**: the contribution of the scientific council

Goal: by being your medical guarantee, it will help you in the success and diffusion of your actions !



- o Patient organisation Booth during the **FIM congress** (cooperative group of MPN hematologists)

Goal: to make the patient organisation known to MPN hematologists



- o Patient organisation Booth during the **SFH congress** (French Society of Hematology) and posters presentation (approved by the scientific council)

- o September 13, 2024: **First day of association** at Saint-Louis Hospital – room loan and multi-stakeholder engagement

Goal: to make the patient organization known to non-members and allow members to meet

We'll do it together one day, because they'll figure out how to heal us:

