

**New article: Results of the TFR for CML patients' research published in Leukemia**

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Chronic myelogenous leukemia

**Treatment-free remission in chronic myeloid leukemia: the patient perspective and areas of unmet needs**

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**"The psychological well-being of CML patients should be a consideration of healthcare professionals and addressed at all stages of the treatment-free remission journey"**

- **CML Advocates Network**, the global network connecting 125 CML patient organisations in 93 countries, has published a paper in the prestigious journal *Leukemia*, considered one of the leading journals in hematology and oncology.
- The study, the main author of which is Giora Sharf, himself a CML patient, has identified chronic myeloid leukemia (CML) patients' unmet needs during the treatment-free remission (TFR) journey.
- The results of the study published on the paper **"Treatment-free remission in chronic myeloid leukemia: the patient perspective and areas of unmet needs"**<sup>1</sup> indicate that there are points in the TFR journey where patients do not always get all the advice, information or support they want around psychological issues and tyrosine kinase inhibitors (TKIs) withdrawal.

**Background**

Whilst recommendations exist about the technical management of stopping and re-starting therapy and the clinical aspects of TFR are very well known today, much is still unknown about the experiences of those considering and undertaking TFR. CML patients have specific concerns and informational needs and this study sought to obtain the patient perspective, identify areas of unmet needs and create recommendations for improvements.

**Results of the TFR for CML patients' research**

**Fifty-six percent of patients reported fear or anxiety during treatment discontinuation**, whereas only 7% of patients were asked if they needed psychological support during this period. **Where patients re-initiated treatment, 59% felt scared or anxious, and 56% felt depressed.** Twenty-six percent of re-initiated patients received psychological and/or emotional support at this time. Sixty percent of patients experienced withdrawal symptoms whilst discontinuing treatment. **However, 40% of patients who experienced withdrawal symptoms reported that they were not fully supported by their doctor in managing all the symptoms.**

**Statements of CML patients**


**Giora Sharf**, co-founder of the CML Advocates Network, CML patient for 20.5 years and on treatment-free remission for the last 6 years.

"Our research and the TFR paper were aimed to understand the patients perspective on stopping treatment for chronic myeloid leukemia, which are not always understood and addressed by health care provider (HCPs).

We believe that by producing a strong evidence based data of more than 1000 patients from 68 countries, we will help bridge the gaps and improve the communication between patients and their HCPs, making the process of stopping taking lifesaving drug-easier."



**Jan Geissler**, co-founder of the CML Advocates Network, Vice-President of Lepaf and co-author of the Leukemia publication.

"Being able to stop treatment in deep, stable remission after years of therapy is a blessing for chronic myeloid leukemia patients, getting rid of side effects and the daily reminder about having cancer.

However, taking such a decision is not easy, as stopping treatment doesn't work for everyone who is given the option.

To make sure patients' needs are addressed and that they feel safe at any stage, our research has revealed unique data about the patients' perspectives that help to best tailor the consultation and care of patients towards therapy-free remission."



**Sarūnas Narbutas**, Chair of the CML Advocates Network, President of the Lithuanian Cancer Patient Coalition (POLA).

"This is our third publication in a peer-reviewed journal and it is a testament that the patient community has the capacity to conduct quality research with impactful findings that capture the attention by global CML experts and top-tier scientific journals.

In several months we will mark 20 years since targeted therapies for CML has disrupted approach to treating cancer. This has given birth to a thriving and knowledgeable global patient community empowered to drive patient-led evidence generation and is already laying the ground for the next research project."

**Conclusions of the TFR for CML patients' research**

Healthcare professionals should further consider how they monitor the psychological well-being of patients who are discontinuing or re-initiating treatment, and review what support is offered in response to identified concerns.

The study therefore shows that surveillance of withdrawal symptoms should be a priority during treatment discontinuation, along with how healthcare professionals assist in the management of these.

**About chronic myeloid leukemia (CML)**

Also known as chronic myelogenous leukemia, it is a type of cancer that starts in the blood-forming cells of the bone marrow and invades the blood. About 15% of leukemias in adults are CML<sup>2</sup>. In CML, treatment-free remission (TFR) refers to having a stable deep molecular response without the need for ongoing tyrosine kinase inhibitor treatment.

**About the CML Advocates Network**

The CML Advocates Network is an active network specifically for leaders of chronic myeloid leukemia (CML) patient groups worldwide. The network is run by CML patients and carers and its aim is to facilitate and support best practice sharing among patient advocates across the world. [www.cmladvocates.net](http://www.cmladvocates.net)

**About the Leukemia Patient Advocates Foundation**

The Leukemia Patient Advocates Foundation (Lepaf) is a patient-led non-profit foundation in Switzerland. Its mission is to improve the lives & survival of patients affected by leukemia. Lepaf collaborates with all stakeholders involved in research, policy, treatment and care. It also acts as a platform for patient organisations – concentrating on educating, connecting and supporting patient group leaders. The foundation acts as a legal platform for self-sustained patient advocacy networks such as the CML Advocates Network. <https://www.cmladvocates.net/about-lepaf>

**References**

1. Sharf, G., Marin, C., Bradley, J.A. et al. Treatment-free remission in chronic myeloid leukemia: the patient perspective and areas of unmet needs. *Leukemia* (2020). <https://doi.org/10.1038/s41375-020-0867-0>
2. American Cancer Society, *Chronic Myeloid Leukemia, Key statistics about Chronic Myeloid Leukemia 2020.*

**Download the TFR for CML patients' Leukemia paper**

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