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# LIVING WITH CML

Patient stories to help better understand  
daily life with  
Chronic Myeloid Leukemia (CML)

CML  
Advocates  
Network

The global network for  
Chronic Myeloid Leukemia  
(CML) patient groups



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**Basil Jacobs** is 75 years old and lives in Boksburg, South Africa. He previously worked in field of procurement management but is now retired. Basil was diagnosed with CML in 2003 and he is thankfully in remission.

Basil is the co-founder of a CML patients support group on Facebook for people living with CML on treatment-free remission (TFR), the "CML Patients in TFR" private group.

He also belongs to a local Cancer Support Group, with many cancer survivors.

The logic behind the initiative is to provide a private platform so that CML patients who are in TFR or starting on a trial, whether individual or in groups, can exchange their trials and tribulations while being off their TKI treatment.

He is actually wearing a gold pennant around his neck to remind him each day of how blessed he has been on his own TFR journey. This simple action motivates him.



"My story living on treatment-free remission begins ten years and nine months ago, on 30 April 2009, when I stopped taking Imatinib 400 mg per day. I had been PCRU (Polymerase Chain Reaction test Undetectable) since our first RT-QPCR test result in South Africa, in March 2005.

My side effects disappeared within two weeks and none have emerged since. I did have a few very low level detectables thereafter but I feel it was more test-related as we were using a new laboratory.

I was also diagnosed with rectal cancer in August, 2018. It was operated on and removed in September, with chemotherapy and radiation following. Eighteen months later, I remain in remission: I keep on monitoring my PCR with my hematologist six monthly, my BCR/ABL tests have remained undetected to date and my immune system was not compromised during this period.”



*December 2010. Basil celebrating life with his family*

## Inspiring CML patients

"TFR has become the aim of most CML patients. Unfortunately, statistics show that the probability of remaining in TRF on a Trial to stop taking TKI's is limited percentage-wise.

I sometimes wonder if TFR candidates and their doctors are not too hasty taking the decision to stop TKI's. Until we know more about the suppression of BCR/ABL by the immune system or other factors, that remains unanswered."



In Basil's words, "the TFR Group was founded in November 2013 with Barbara Meunier and myself as the only members. Since then we have grown to 417 members and counting. There are a few notable doctors as members who follow our posts but do not respond as it could be regarded as unethical for them to do so.

CML patients must be in TFR or on a clinical trial to stop. We have numerous applications from patients just curious to find out about TFR. This information is available on other CML groups or by Googling TFR ( Treatment-Free Remission) We are not an advocacy group and therefor leave those decisions to the medical professionals.

Most of the leading CML groups also are represented by an administrator who can act as the conduit linking the groups. I have started a +10 years TFR subdivision and we have five members presently: we are in unchartered territory and find it exciting to be so blessed.

Also, running the Facebook Group "CML Patients in TFR" along with Barbara is tremendously uplifting to know that the combined personal experience of all the "seasoned" members can help others cope who are new to treatment-free remission."



"As is well-known, side effects, if any, can vary from patient to patient. Approximately 30% of patients do experience mild to severe withdrawal symptoms when starting TFR.

Often these side effects are not fully understood by their treating physician, oncologist or hematologist and the group gives us an opportunity to interact with members who may have or are experiencing similar issues and what they have found to minimize their discomfort.

These issues can be discussed and personal decisions made on their own prognosis. This information should then be discussed with their medical specialist and solutions decided on."



Happy 75th Birthday our beautiful Dad!

"What I'm trying to achieve is just to inspire other CML patients and serve as an example that there is life beyond a CML diagnosis.

We all must be very grateful for the research and development are done by Dr. Brian Druker in the nineties. He gave us hope, life and a future that would not have possible without Imatinib.

But then I can also mention Dr. Francois-Xavier Mahon and the French STIM (Stopping Imatinib) trials. This event was ground-breaking and the results directly responsible for my "one only trial" in South Africa in May 2003.

So my grateful thanks to both oh these gentlemen. The one initially gave me life and the other a life off my TKI.

I really hope that we can meet someday in the future.

**Life is for living, don't waste a moment!**

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