

Treatment-Free Remission: The Patient's Perspective

סוף שבוע של מודעות ל- CMK
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עמותת חולי CML ישראל

CML Patient Environment

- Lack of “patient-friendly” TFR information- you cant decide stopping if you do not have the data
- Different standards at different TFR trials
- TFR done in and out of clinical trials
- Success factors are confusing and different among trials
- Companies are pushing second-generation TKIs as better option for future TFR – not really proven in real life yet

CML Patient Environment

- ▣ Canadian and UK studies showed that a large percentage of CML patients do not want to stop treatment even if eligible
- ▣ When I consulted world CML experts I received contradicting advice, from “You must be crazy to consider stopping” to “You are a perfect candidate to stop – go for it”
- ▣ Bottom line: TFR not well understood, much confusion as well as hope, excitement

TFR PHASES



TFR Patient Survey: April 2015

Facebook group for TFR patients – 175 members
Primary support resource for these patients

The screenshot displays the Facebook interface for a group titled "CML Patients in TFR (Treatment Free Remission)". The top navigation bar includes the Facebook logo, the group name, a search icon, and navigation options like "Home", "Messages", and "Notifications" (with a 56 notification badge). On the left sidebar, there is a user profile picture and "Edit Profile" link, followed by navigation options: "News Feed", "Ads Manager", "Messages" (16), "Events" (1), "Photos", and "Browse". Below these are "PAGES" (The National CML ... 9, Pages Feed 20+, Like Pages 4, Create Page, Create Ad) and "GROUPS" (Phoenix PR pros 1). The main content area features a large scenic image of a waterfall cascading over mossy rocks. Below the image are "Joined", "Share", and "Notifications" buttons. A secondary navigation bar includes "CML Patients in TFR (Treatment Fr...", "Members", "Events", "Photos", "Files", and a search box "Search this group". Below this is a post creation area with "Write Post", "Add Photo / Video", "Ask Question", and "Add File" buttons, and a text input field "Write something...". On the right, the "ABOUT" section shows "70 members" and "Closed Group" status, with a description: "This Group has been established as an exclusive home for all CML patients who are in TFR (Treatment Free Remission) for a...".

Consideration and decision

- ▣ TFR is not and should not be the main goal of CML Treatment. Good response and QOL are and should be the main targets. Patients who don't reach very deep MR should not feel they have failed.
- ▣ Lack of reliable information on TFR and conflicting standards are a big challenge.
- ▣ Many experts still recommend TFR only in a clinical trial- but trials are not available.
- ▣ Lack of standardize and reliable monitoring.
- ▣ Psychological concerns- Canadian and UK study- 40 % of eligible patients do not want to stop.
- ▣ And still- for many patients TFR is a great hope and closest possible step to CURE.

Survey: Key Reasons Seeking TFR

- 74% – Relief from side effects
- 74% – Concern about long-term effects
- 13% – Costs of treatment

“Had no quality of life due to severe side effects.”

“Taken off for side effects, chose not to return.”

“Stopped 2 months before telling doc. Great difficulty getting consultants to believe how very bad things were. It's my body and mind, I have the final say.”

Stopping – Probation Phase

- ▣ Uncertainty in first 6-9 months is the biggest.
- ▣ In many countries monthly PCR's are not available or reimbursed.
- ▣ Withdrawal Symptoms- a challenge for about 30 % of patients on TFR.
- ▣ The emotional concern from molecular reoccurrence.

Physical Impact of TFR

Mixed responses – positive and negative

- Cessation side effects worse than being on drug
- Joint pain/cardiac issues worsened, required additional medical support
- Side effects and fatigue lessened with time
- No side effects. Feel really good
- Turned down trial offer – patients report bone pain lasting weeks to years, need to manage with another drug, this is not “treatment free”

Survey: Psychological Concerns

- **Isolation:** Want to talk to other patients in TFR
- The thought of a relapse never really left my mind. It was like tempting fate going so long without treatment. **Each PCR time was terribly stressful.**

TFR failure Phase

- ▣ The emotional effect can be very difficult.
- ▣ **Response loss:**” If I lose remission, I may not be able to regain response at same level as before TFR “.
- ▣ “The news that I'd lost MMR was utterly devastating. I think I was more upset about it than I was when I was diagnosed simply because I understood this time what treatment would entail”
- ▣ Would a 2 ed TFR be possible in the future?
When?

Long Term TFR

- ▣ The need for long term strict monitoring-adherence to monitoring issues
- ▣ Late relapses as seen at EuroSki.
- ▣ **Uncertain future:** Not clear what's next. Can TFR last forever?
- ▣ Information about PCR fluctuations to ease emotional concerns.

CML Advocates Global TFR Survey

CML Advocates Global TFR survey

- ▣ We are finalizing our questionnaire of a TFR survey aimed at all 4 stages of TFR
- ▣ We aim to collect patients responses in regards
 - Reasons: why and why not?
 - Percieved risks
 - Withdrawal Symptoms and side effects.
 - Time: when and & how long
 - Response level after stopping.
 - Restart- At what point
 - Monitoring challenges
 - Psychological aspects of

TFR WORKGROUP

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Final Thoughts

- Patients have the most to gain – **and lose** – from new treatments and stopping treatment.
- There is a need of evaluating not only clinical response, but also the impact on our quality of life
- There is a need to develop a patients friendly TFR glossary- no terms like Failure or relapse, rather molecular reoccurrence .
- Doctors should share up to date knowledge on TFR with their patients, so that decisions can be shared decisions where patients voices and concerns are also listened and heard

תודה על ההקשבה

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