My CML story as reflection of the revolution in the last 20 years

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Gist Horizon
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Personal Journey
From Darkness to Light

• My Story Reflects on the CML Treatment Revolution that occurred in the last 20 Years.
• I was diagnosed with CML on 2/2000 and joined the IRIS trial with Professor Hochhaus in Germany.
• I started treatment with high dose Interferon + Ara c
• The outlook for the future was not good: 3-5 years survival.
• I kept my hope by setting personal goals and achieving them.
• After 7 months I was switched to STI 571 known today as Imatinib
• I became PCR negative within 9 months and kept this deep MR for 13 years
• In June 2014 I stopped Imatinib to see if “I am cured”
• I am now 7 +years on TFR with MR5 kept on all monthly PCRs.
• I decided to use my experience to help other CML patients in Israel and globally.
So Where are we going with CML?

The picture is not completely blue. There are still many clouds in the sky.

- Adherence
- Information like Pregnancy for Ex’
- Generics and Sub Standard TKIs
- QOL and Side effects management
- Access to treatments
- Resistance and relapse
CML Advocates Network: global network of leukemia patient groups

• Public directory of Chronic Myeloid Leukemia groups

• “Social media platform” to have advocates collaborate

• Build skills, coordinate campaigns, build partnerships, share knowledge

• Founded 2007 by 4 advocates

• 126 patient organisations in 95 countries
So what are we doing about these challenges?

- Research to understand patients perspectives (Adherence, TFR)
- Advisory boards with companies on improving access
- participating in new drug development as members of investigators committee
- Working closely with the CML Hematologists groups like ICMLF, EICML
- Education and empowerment of patients and advocates.
- and most important- keeping the hope and dream, yes I still have a dream
Summary

• We greatly appreciate the excellent progress made in CML therapy – thanks to well-coordinated research.

• The worldwide "CML Advocates Network" with 90 groups can be a key partner in research, recruitment and patient information.

• CML has turned into a chronic disease, but the emphasis is now on QOL issues.

• We need more! We Need a Cure!!!
I dream to organize a similar webinar within 5 years where we will be able to discuss the cure found for CML and GIST patients.
I thank my Israeli patients and the global CML advocates community for giving me the strength to continue to dream.

Thank you for listening

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