

# CML PATIENTS' UNMET NEEDS

**Bar David Yair**

**The Israeli CML Patients Organization**

**Israel**



***The project was implemented by in depth 90 minutes interviews by a professional company.***

- The interviews included 25 CML patients and 5 caregivers.*

Age group	Females	Males
20-40	7	2 (1)
41-65	6 (1)	5 (2)
66+	3	2 (1)
Total (%)	17 (57 %)	13 ( 43 %)

- On Generic Imatinbiv- 2, Glivec- 10, Nilotinib- 8 , Dasatinib- 10*
- 8 females and 4 males age of fertility,*
- 20 are still working (66 %)*
- All caregivers were females*
- Bias- we are aware that all participants were members of our PO*



## ***Some of the important findings:***

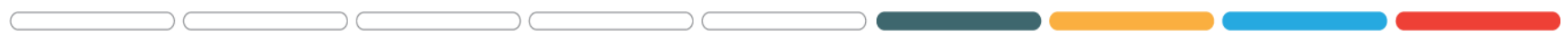
- Most patients were not involved in the decision of their treatment*
- Initial diagnosis and information given mainly at emergency rooms and was lacking*
- Main challenges of treatment were side effects management*
- Main influence of diagnosis and treatment were on- routine and life plans (mainly for young females), work and career, family functioning, leisure activities.*
- 26 (87%) patients said that side effects affect QOL, only 4 said it doesn't (13 %).*
- The most affected group are young females at the age of fertility.*

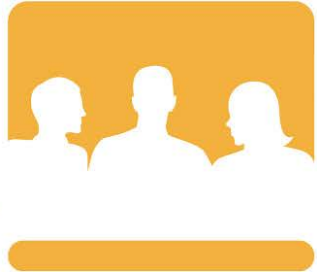




## ***Result and Impact:***

- *Gaps between what is available and what is desirable*
- *Sources of support for patients-*
- *Hematologist main treating address but some are not happy with time allocated for them during visits.*
- *Patients Organization is the main and only reliable source for information and support, but not always and not for everyone. The younger group feels outsiders and do not participate at most activities.*
- *All caregivers were very involved with the management of the patient's disease, and felt it is a physical and emotional burden. No one of them received any specific support.*





## ***Conclusion and recommendation:***

- Improve support for side effects management, drug interaction, comorbidities , patients rights especially with governments agencies.
- Find solutions and activities that suits the unique needs of the special groups especially younger patients and caregivers. This will be implimented at our upcomming CML awareness weekend in September.
- Create training program for hematologists to better understand the needs of CML patients and understand the importance of making shared decisions.





## ***Conclusion and recommendation:***

- There is a need for more regional activities to allow better participation of patients. We are reviewing the use of webinars and live facebook chats for the group of younger patients.
- The PO must improve Patients access to our educational meterial both online and at treatment centers.
- The PO must improve our outreach to nurses and social workers and to CML specialists.
- There is a need to start a systematic peer to per support.

Sharf Giora- [giora1@inter.net.il](mailto:giora1@inter.net.il)

