

IMPORTANCE OF DISEASE AWARENESS IN INDIA

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INTRODUCTION

- In India, the incidence of Chronic Myeloid Leukemia is much higher than other MPN, in contrast to reports from the West where Polycythaemia Vera is the most common.
(source: *International Journal of Epidemiology*, 2015, Vol. 44, Supplement 1)
- Friends of Max is the world's largest support group for patients diagnosed with CML and the support group arm of The Max Foundation in India.
- Disease education is a key factor in helping new patients understand their diagnosis, the risk factors and the importance of compliance and regular follow-ups.
- It is difficult to access region-specific disease education resources for MPN.
- Most patients being aged over 60 belong to the segment of population who are unable to access the internet for resources.

METHODOLOGY

- Friends of Max has partnered with supportive oncologists from renowned medical institutions to prepare disease awareness resources for the benefit of the patients.
- After the initial research on the internet, FOM compiled a list of Frequently Asked Questions (FAQ) which are most pertinent to MPN patients.
- The oncologists then used their extensive knowledge to answer the questions which was then incorporated into handy booklets, translated to regional languages and distributed among the patients, caregivers and physicians at support group meetings.
- Digital copies of the same are also freely accessible on the Friends of Max website (www.friendsofmax.info)

RESOURCES CREATED

- 50 Frequently Asked Questions on CML (2007)
- Frequently Asked Questions on CML - Focus on 2nd Generation TKIs (2021)
- Frequently Asked Question on CML - Focus on 3rd Generation TKI (2022)
- FAQ on Myeloproliferative Neoplasms - Focus on Polycythemia Vera (2022)

IN THE PIPELINE

- FAQ on Myeloproliferative Neoplasms - Focus on Essential Thrombocythemia
- FAQ on Myeloproliferative Neoplasms - Focus on Myelofibrosis

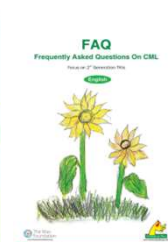
FOM Guide to Disease Management



FAQ on Myeloproliferative Neoplasms Focus on Polycythemia Vera



The Max Foundation
Accelerating health equity, one patient at a time.



CONCLUSIONS

- The information resources created by Friends of Max form an important part of our disease awareness activities.
- Access to these resources have resulted in a positive psychological impact on newly diagnosed patients and their caregivers.
- The resources have also proven to have a positive impact on the patient's lifestyle choices and an overall improvement in compliance.

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