

Together We Share and Learn

By the Patient, For the Patient

Promoting Adherence

Improving Compliance

Evidence Based Advocacy in India

Viji Venkatesh



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INTRODUCTION

- CML is the commonest adult leukemia in India
- Annual incidence ranges from 0.8– 2.2/100,000 population in males and 0.6– 1.6/100,000 population in females in India.
- The median age of diagnosis is 38-40 years

(Source : International Journal of Science and Healthcare Research , Vol.5; Issue: 1; Jan.-March 2020)

- Friends of Max (FOM) is The Max Foundation's patient support group arm in India.
- FOM currently has over 400+ CML patients as registered members
- All CML patients are welcome to become members and avail of various benefits FOM provides



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CHALLENGES IN MONITORING THE DISEASE

- CML patients on life-long treatment are burdened both financially and emotionally
- CML patients must regularly undergo BCR-ABL tests used to monitor treatment, recurrence or detect resistance to therapy
- Depending on various factors, the prices for each test can range anywhere between ₹4000 and ₹15000, (50\$ - 185\$) which may be unaffordable to a lot of our financially distressed patients
- The cost is even higher for people living in remote parts of the country who must incur additional expenses such as travelling and lodging
- Such factors, as we have witnessed, often lead to non-compliance at the patient's end, which may ultimately result in health complications or relapse



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FOM DIAGNOSTICS PILOT PROJECT - GOALS

- At FOM we believe, **“Failure to access BCR-ABL monitoring should not be a reason for non-compliance”**
- With this aim in mind, FOM has entered into a partnership with a leading diagnostics company to help patients access this extremely important monitoring test at no cost
- The project works on a Pan-India scale and offers the services of at-home sample collection and e-delivery of reports to all patients. Some of these may live in metropolitan cities, while a large number live in rural or remote areas
- **Goals-**
 - **Ensuring patients can avail diagnostic services irrespective of their financial condition**
 - **Raising awareness about the importance of periodic monitoring and compliance**
 - **Ensuring Right to Life as guaranteed under Article 21 of the Indian Constitution**



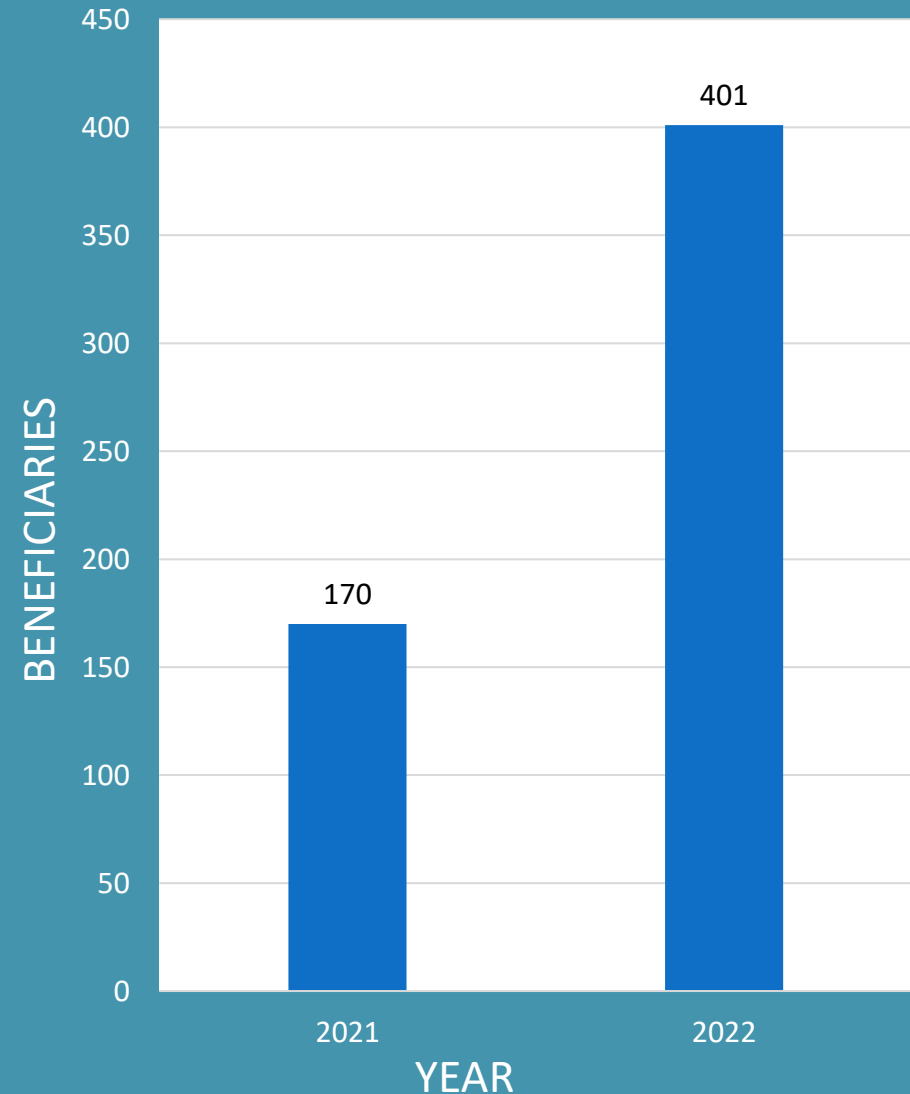
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BENEFICIARIES

- All FOM Members are beneficiaries under the project
- 170 beneficiaries at the start of the project in 2021
- 401 beneficiaries as of September 2022
- All beneficiaries are eligible for as many Bcr-Abl tests as advised by their treating physician
- FOM supports all monitoring tests of patients on Treatment Free Remission



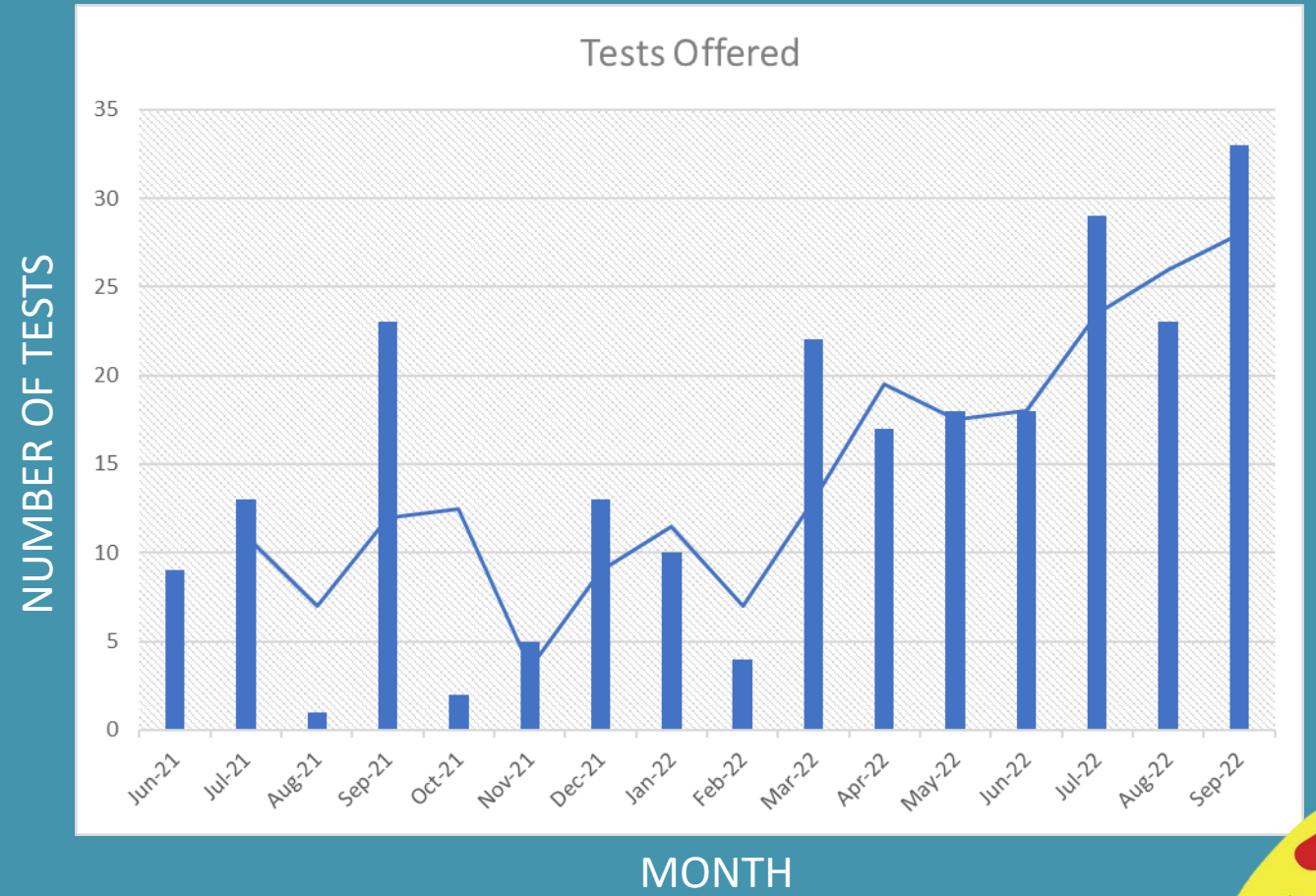
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TESTS OFFERED SO FAR

- 242 total tests have been offered so far to CML patients under this project
- 214 beneficiaries out of the total 401 have availed of this benefit

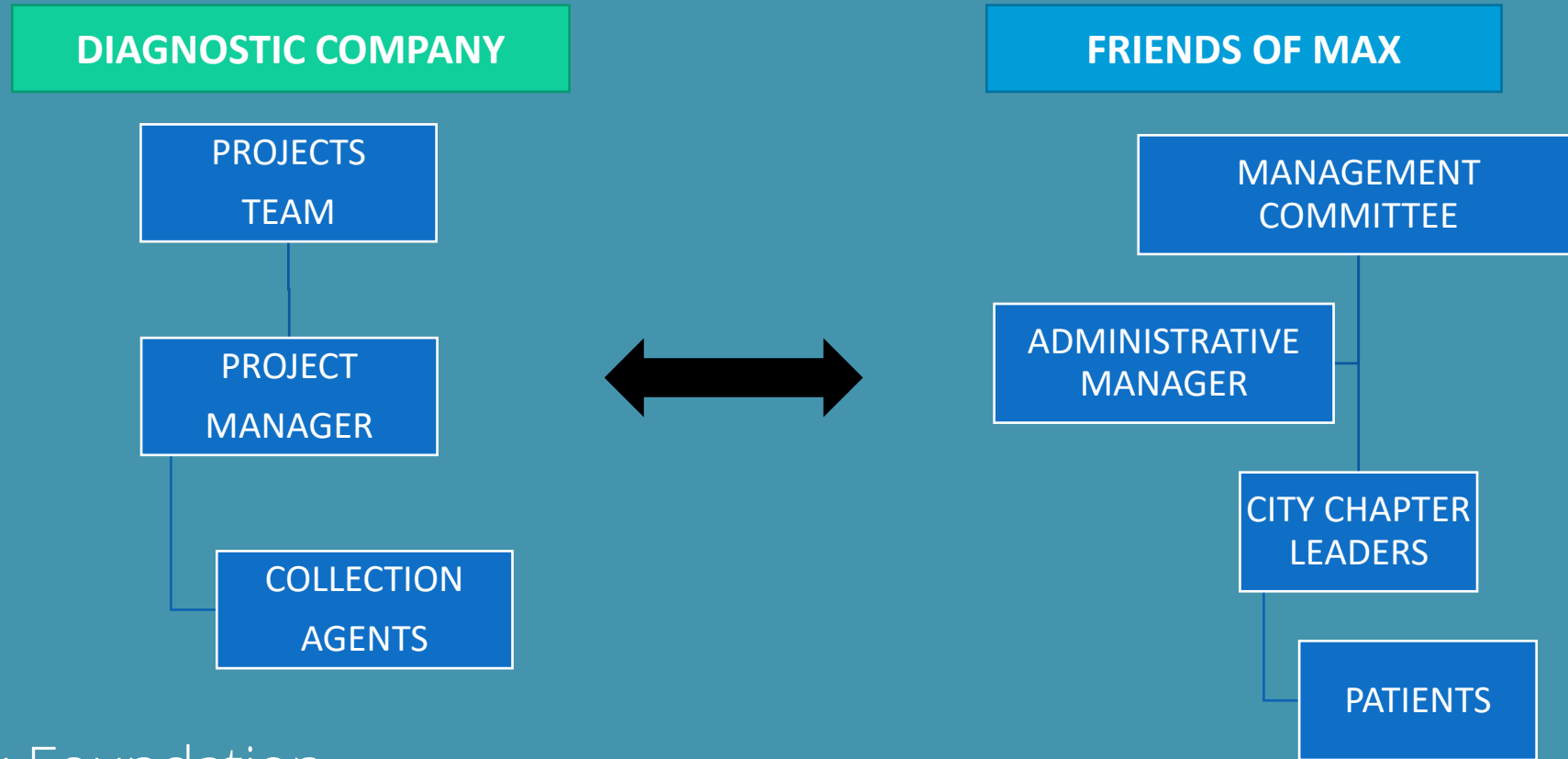


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DIAGNOSTICS PILOT PROJECT - PROCESS



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DIAGNOSTICS PILOT PROJECT - OUTCOMES

- **Improvement in Compliance** – Many patients who did not undergo any monitoring tests in the last several years due to various challenges have now undergone Bcr-Abl and CBC tests as well under this project
- **Reduction of financial strain on the patients** – Patients who underwent tests at great out-of-pocket expenses benefit from this project
- **Overcoming geographical limitations** – Patients living in rural and remote areas of the country can access these monitoring tests without the need to travel to cities
- **Democratization of the project** – The project has been put in place with the patient's needs in consideration. Patient Leaders and volunteers help in the administration of the project and the FOM Management Committee takes steps based on the feedback received from the patients

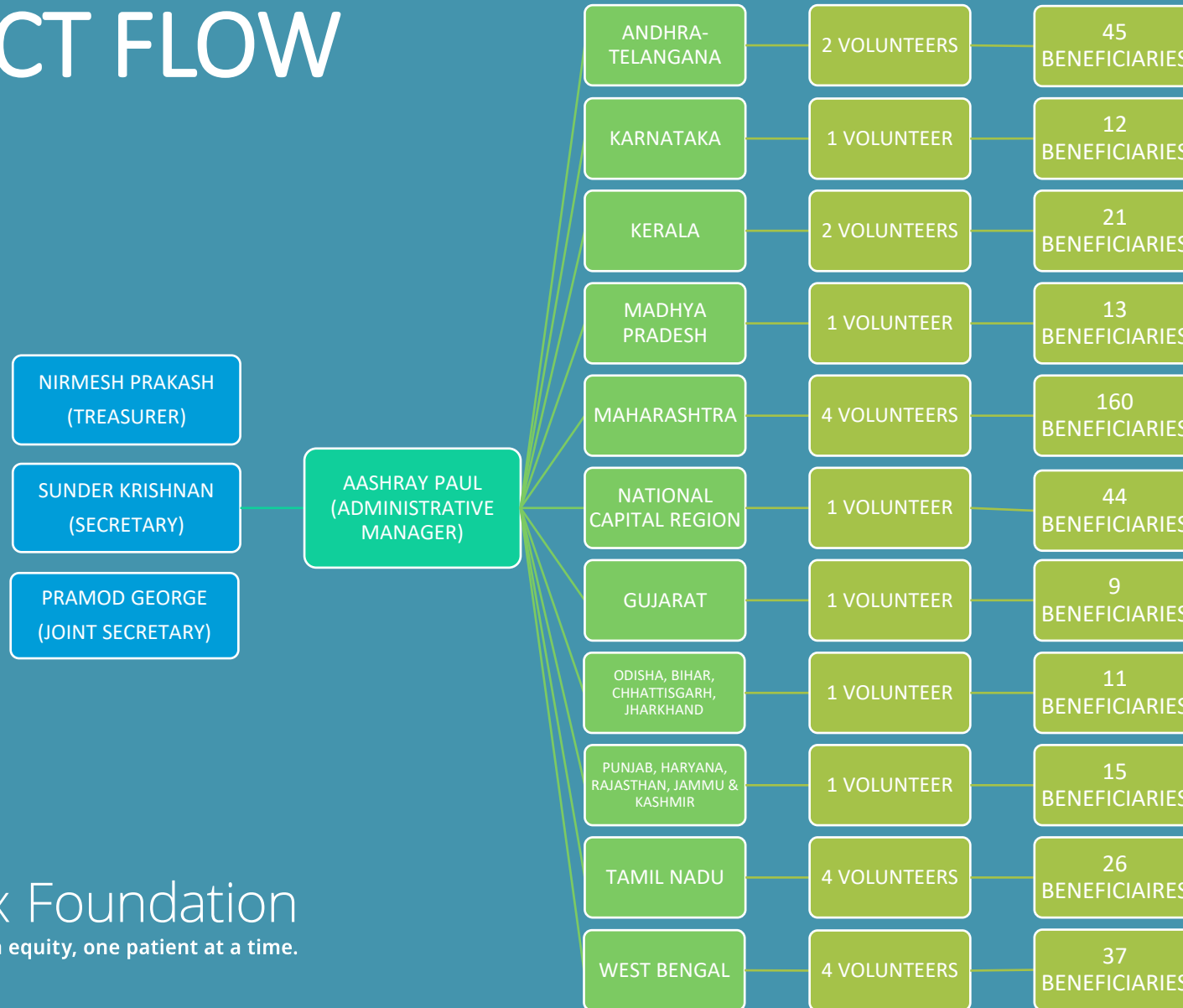


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PROJECT FLOW



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PILOT PROJECT MONITORING

- **The FOM Management Committee closely monitors this project**
- **Regular updates on the day-to-day execution are provided by the FOM Administrative Manager**
- **The progress of this project is well documented and is discussed at every Trustees' Meet**
- **Periodic meetings are also held with the City Chapter Leaders and volunteers helping with the project to get their feedback**



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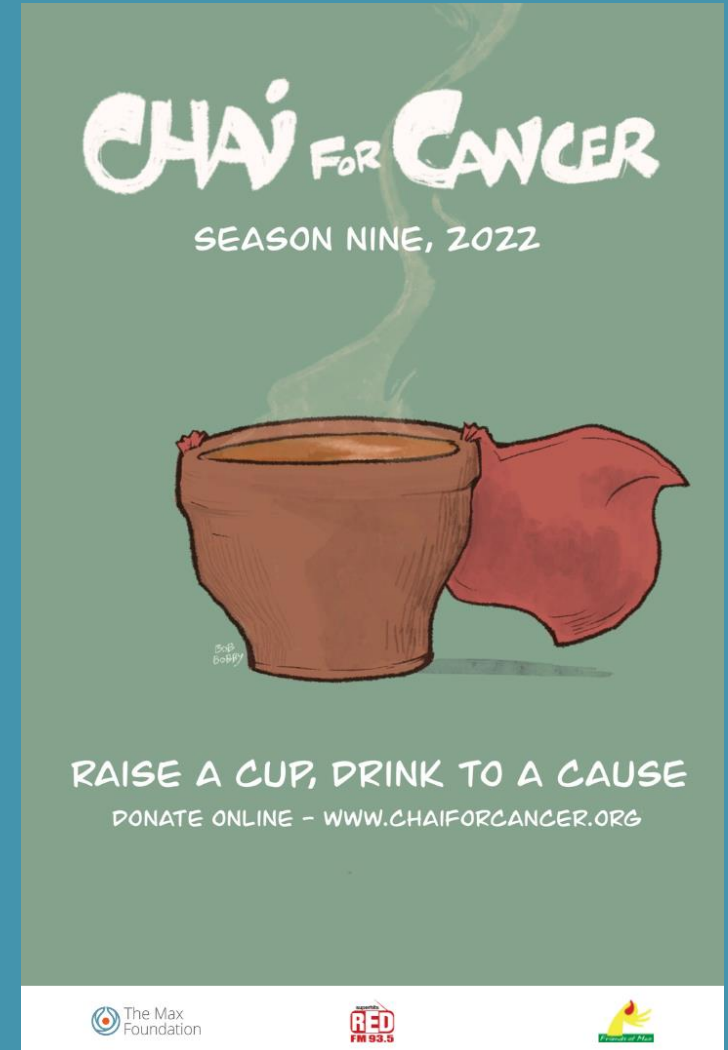


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FUNDING FOR PILOT PROJECT

CHAI FOR CANCER

- An awareness and fundraising tool created for Friends of Max to raise resources to support unmet and seemingly small needs of patients on lifelong therapy
- This Pilot Project is funded by a CSR donation from a private company that has been impressed by FOM's work in patient support



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CHALLENGES IN IMPLEMENTATION

- **Pandemic – Patients are still nervous about all invasive interventions**
- **It has been observed that many patients have not opted for a monitoring test despite paying the membership fee and being informed about the benefits**
- **Some patients have availed the test but have not opted for a follow-up test in over a year**
- **A few patients are unable to take advantage of this facility because their treating physician/hospital only accepts reports from in house labs**
- **The main source of information for the patients regarding the organization's projects are Support Group Meetings. Patients not attending these meetings or living in regions where a meeting has not been conducted recently may lack the awareness about this facility**



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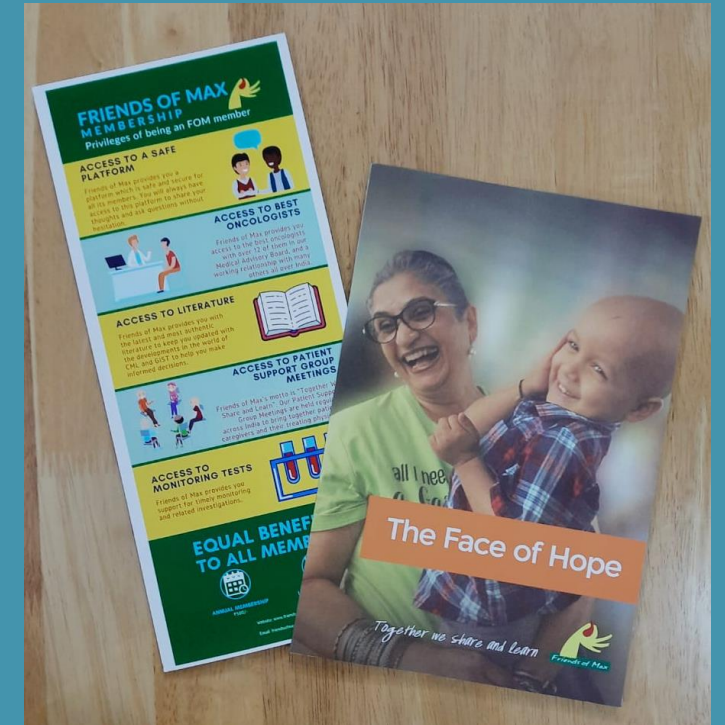
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Way forward

- There is a need to emphasize the importance of undergoing regular monitoring tests
- With things getting back to normal after the pandemic, encourage the CML patients attending the support group meetings to avail of this facility through presentations, patient testimonials and distribution of literature
- Follow-up with members who are irregular at availing this benefit and address the issues
- Work with treating physicians and patient leaders to reach out to more CML patients and bring them under the ambit of this project
- Harness the power of mass media platforms to raise awareness about this facility



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THANK YOU



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