

ACCESS TO MONITORING TESTS AT NO COST

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Advocacy Session # 1
Best practice in patient advocacy



Problem statement and background

Huge financial and emotional burden on CML patients from weaker socio economic backgrounds causing many of them to discontinue their treatment regimens in India.

Main reasons being:

- High and extended out-of-pocket expenses
- Lack of effective financial protections and mechanisms
- Lack of access to diagnostic facility & infrastructure
- Lack of information and education

Aim of the initiative

To aid and provide access to standard **BCR-ABL HOME TESTING FACILITY** to every CML patient, at no cost, PAN India.

Step 1- Identifying and Collaborating with a Reliable Diagnostic Provider

- Key features- home collection, providing online reports on whatsapp to patients located anywhere in India, July 2021
- Increasing the scope of tests to include CBC in (year), Mutation Test in April 2023 and most recently Kidney Function Test (KFT) and Liver Function Test (LFT) in September 2023
- Monitoring & Evaluation and use of technology to continuously measure impact and upgrade processes and systems

CÖRE DIAGNOSTICS
<https://corediagnostics.in/>

Step 2- Raising Funds

- Creating a concept note and proposal
- Approaching organisations for CSR funding
- Collaborating with individuals through Chai for Cancer, a unique fund raising initiative over a simple cup of tea
- Chai for Cancer Addas held every year



<https://www.worldquant.com/>

DSS Takara Bio India Pvt. Ltd.

<https://www.takarabio.com/about/international-contacts-by-region/india>



<https://chaiforcancer.org/>



Glimpses from the adda held recently on July 16, 2023, Home Adda at Kalyan, Maharashtra



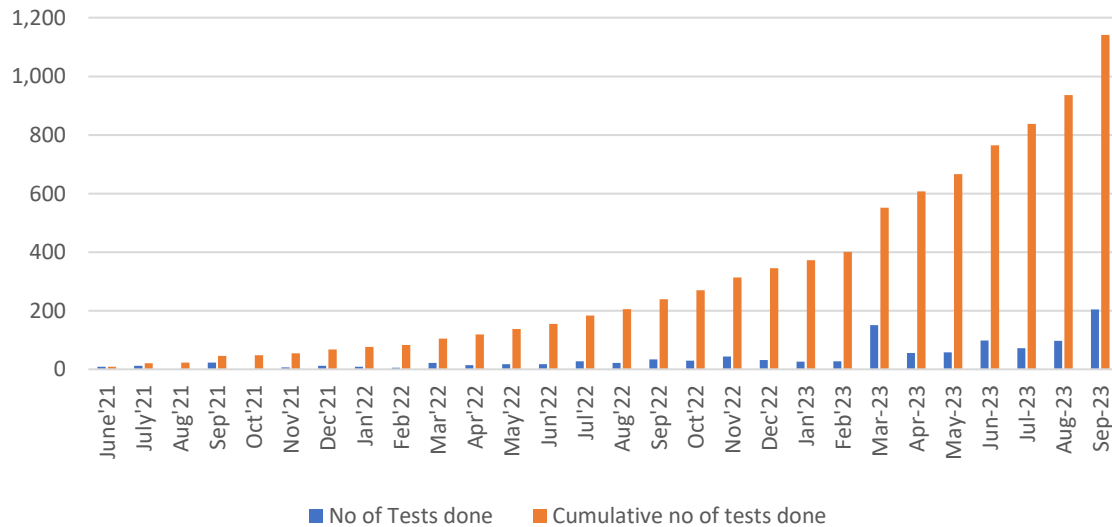
Step 3-Connecting more CML patients to the facility

- Collaborating with physician partners
- Developing a network of Patient City Chapter Leaders and Volunteers
- Creating regional patient whatsapp groups
- Tele booking of test by patients 4 days in advance
- Collection of sample by Diagnostic from patient's home
- Report sharing with patient by Diagnostic partner on whatsapp/email within 6 days of sample collection
- Arranging Monthly review meeting between FOM and diagnostic partner



Result and Impact: 100% growth

Growth in Total Number of Tests per Month



June 2021 to 30th September 2023

Total no of Tests Done	985
Total Value of Tests Done in Euros	26,519 euros
% of India covered	72%
Tests Covered	BCR-ABL, CBC, KFT and LFT

Result and Impact:

- On an average, 100 patients are availing of this facility every month
- Better treatment outcomes: Physicians are able to better manage the condition due to regular and accurate testing undertaken by patients
- Patients living in the far-flung interiors of the country are now connected to the diagnostic services
- As the facility is at no cost and from home, it ensures inclusion of patients from weaker socio-economic backgrounds (lowest in the pyramid)
- Physicians are actively recommending their CML patients for tests to FOM. Twice annually for CML patients and up to 12 tests annually for patients on remission.
- There is reduced financial burden on cancer families resulting in better cancer outcomes

Conclusion & Recommendations:

The Roles and Responsibilities of Patient Leaders and Advocates:

- As advocates we should not leave any stone unturned in ensuring all CML patients get access to treatment and guidance
- We can work on projects that will improve compliance
- We can train volunteers
- We can raise funds
- We can foster better relations with physicians and other partners



CML ADVOCACY - LEARN, SHARE, GROW
21TH INTERNATIONAL CONFERENCE FOR
ORGANISATIONS REPRESENTING PATIENTS
WITH CML



Questions

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