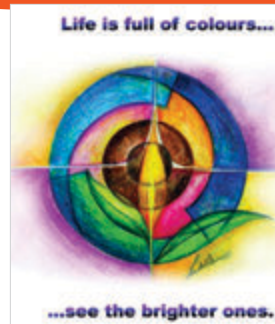




NEWSLETTER

Friends of Max

(October - December 2018)



AMMA SPEAKS

There is no doubt in our minds that it is important for FOM to be present and heard at every forum, national or international. To acquire more insights into the two rare cancers that have fascinated and challenged us in equal measure. It might surprise many that there is still not enough correct patient disease-related information reaching our patients and their caregivers. Myths and falsehoods still abound. Patients from small towns and cities flock to our meetings where access to renowned oncologists is made possible on a regular basis.

Our task is to cross boundaries, to use proven methods of communication and gently persuade hesitant, inarticulate patients to share their experiences with each other and learn from them through all forms of communication - written and oral, as well as at various forums, via social media or written literature or the spoken word.

FOM is a dynamic, flexible, knowledge-based, experience-centric platform that can only thrive and develop with new situations. Even after two decades it is a fact that so little is known of these rare cancers. That in itself is immense motivation for Friends of Max – the largest of its kind in the world – to reach out to more CML and GIST patients and caregivers, welcome them to the group and give them confidence and hope, and a chance to share and learn.

- Viji Venkatesh

FEATURE STORY: FOM as the Voice of Thousands



Leadership Summit 2018, Pune: 'The Journey Continues'

Reports on Rising Sun Cancer Summit (Malaysia), Leadership Summit 2018 (Pune) & CML Quality of Life Survey

Friends of Max continued to be present at International Meets, namely Rising Sun in Kuala Lumpur (Malaysia), as well as organise Patient Support Group Meetings in India - the most recent being the one in Aurangabad (Maharashtra)

Cities where Patient Group Meetings were held in 2018 included Mumbai, Ahmedabad, Raipur, Patna, Delhi, Kolkata, Ranchi, Madurai, Pune, Kanpur, Puducherry, Guwahati, Hyderabad and Aurangabad.

The impact of Chai for Cancer Addas (the fundraiser and advocacy platform) led to a welcome CSR (Corporate Social Responsibility) tie-up between FOM and Mandhana Retail Ventures Ltd to cover various patient-related expenses incurred by CML and GIST patients. Outside of the CSR umbrella, Chai for Cancer already enjoys the support of Society Tea, Red FM, Being Human - The Salman Khan Foundation and Mahotsav Entertainment.



Aurangabad: Art Therapy and Maximo book readings are a vital component of Patient Support Group Meetings



Dr Dinesh Bhurani of RGCI Delhi (2nd from right) at the Lamp Lighting Ceremony, FOM Leadership Summit 2018, Pune



Leadership Summit 2018 Pune (8-9 Dec 2018)

FOM delegates at a yoga session, during a short break and at an interactive session



FOM Trustees present at LS in Pune

The theme of the Leadership Summit in Pune was 'The Journey Continues'

The Summit marked an important juncture in the journey of FOM. The objective of the Meet was visually depicted in the graphic of the Railway Station. 'We will break journey at Pune and then armed with new goals and tools, but no excess baggage, continue on the journey'.

The agenda reflected chief areas deserving attention: The transition from the existing PAP to MAS, the BCR-ABL Monitoring Project, Reviewing Chai for Cancer's fundraising efforts over five years, Expanding FOM's reach in the CML and GIST community and the importance of FOM's presence at International Conferences

Excerpts from Medical Session (Q&A) Leadership Summit (Pune)

Query from a patient who was diagnosed with GIST in the small intestine in 2004 and was duly operated on for the same. Five years later he was diagnosed for GIST in the liver and has been on Glivec since then. From 2012 till today his GIST report has not changed and is stable. Can it spread in other body parts?

Answered by Dr. Hemant Malhotra:

When we do a treatment of stage four disease, the response that we get is categorized in 4 ways

Complete Response: This means after taking the medicine, when tests are done there is no detectable disease in the body. We wouldn't say there is no disease in the body but with the available imaging techniques like CT scan or PET scan, the disease is not visible anywhere in the body.

Partial Response: This means for example initially the disease was of 20 cm and you start with the medication. After 6 months of treatment the disease has reduced to 10 cm.

Stable Disease: This means for example initially the disease was of 10 cm and you start with medication. After 6 months of treatment it has reduced to 8 cm and after further 6 months of treatment also it has remained at 8 cm.

Progressive Disease: This means for

example initially the disease was of 10 cm and the patient starts taking Glivec. After 3 months when the patient does a CT scan the disease has become 18 cm.

In the case of Progressive Disease the patient should not continue with the same treatment. But in case of Complete Response, Partial Response and Stable Response, the patient may continue with the same treatment as the medicine is working on the tumor. However in situations where there wasn't a Complete Response, there is always a chance that the disease starts growing again. A tumor has many clones, many cells. Some of these clones/cells are sensitive to the drug while some clones/cells are resistant to the drug. Over a period of time the sensitive clones/cells get eradicated with the medicine, but the resistant clones/cells remain and grow. In such situation the patient needs to take care by doing regular imaging. The least invasive imaging is an ultrasound which does not produce any radiation. Also continue going to the same Sonologist every time so he knows the history. Still if at any point of time it feels that the disease is growing it can either be operated or the dosage of Imatinib may be increased if the body accepts.

Query from a patient who was diagnosed with CML nearly 20 years ago. He does not remember the Sokal Score but it must have been lower at that time. If one were to postulate TFR for himself, would the absence of the initial Sokal Score, interfere with the decision making?

Answered by Dr. Pankaj Malhotra:

No, the initial Sokal score doesn't interfere much. Sokal Score is basically a guideline to understand in which category the patient falls, i. e. low risk, intermediate risk or high risk. But it is important to know the Sokal Score. Sometimes we do not know the baseline transcripts of the patients. Transcripts refers to the quantity in which the protein bcr/abl is produced in the body, it is generally 190 kilo Dalton, 210 kilo Dalton or 230 kilo Dalton. Most of the patients fall in the 210 kilo Dalton category. Hence, routine lapse of checkups are done for Transcript 210, which may come negative. It may happen that the bcr/abl of these patients is also continuously coming 0.00. However, this does not mean that the disease has been completely eradicated as we did not know the base line transcripts, whether it was 190 kilo Dalton or 230 kilo Dalton. In such cases we have to be very careful in attempting TFR. So it is necessary to know the baseline transcripts of the patients.



Excerpts from the CML Quality of Life Survey conducted by FOM

This Survey had over 600 respondents in the span of approximately a month. The Survey was not representative of the Quality of Life of our complete patient pool and not the CML community in the country. However, this was an important, focussed, first step to understand the wider experiences of the respondents, not limiting their experience as patients but capturing their broad experience of living with CML.

Impact on Life & Career

COMPLIANCE

The majority of the respondents have reported that compliance is easy. This is true of respondent groups across Age, Gender, Location and No. of Years on Medication. It is also interesting to note that the patients' location has not adversely affected their compliance. Despite access issues, respondents in small towns and villages reported to compliance being easy. This can be attributed to repeated sessions / workshops at Patient Support Group Meetings; follow-up calls and patient counselling by the Max team and most

certainly, also to the interventions of their treating physicians as well.

GIVING SUPPORT TO PEERS

75% respondents have reported that it is easy to give support to peers. This can be attributed to the vast outreach of the FOM network through multiple channels like Patient Support Group Meetings, Social Media, WhatsApp groups, Email and other means of communication. This reinforces the work done by The Max Foundation team in India and the Friends of Max volunteers for patient support and advocacy.

Aurangabad meet - November, 2018



The Rising Sun 2018 Cancer Summit (28-30 Sept 2018)

The Rising Sun Cancer Summit was held in Kuala Lumpur, Malaysia. The Summit was organised by The Max Foundation and the Rising Sun Steering Committee. The summit was made possible by the generous sponsorship of Janssen, Amgen, Novartis, Pfizer, Bristol-Myers Squibb, Otsuka and MSD. A total of 56 delegates representing 23 patient advocate groups from 18 countries across Asia Pacific and South Asia were present.

Key Learnings From The Summit:

The rising cost of healthcare is a fundamental impediment to treatment access. Prices of cancer drugs have soared in recent years, putting a heavy burden on patients and governments. To improve treatment access, healthcare stakeholders should promote policies that preserve needed innovation and competition in clinical trials, while also promoting greater transparency to reduce the price of drugs for patients.

→ **Chronic Myeloid Leukemia (CML) Management and Update:**

The choice of first line therapy in chronic myeloid leukemia (CML) management is different for each country and will depend on access, cost, patient risk stratification, and targets /outcome measures.

→ **Treatment Free Remission (TFR)** has emerged as a new goal of treatment in CML. Developed countries are moving towards TFR whereas developing

nations are still grappling with issues related to medical diagnostics, access to medication and monitoring, and the lack of adequate healthcare professionals in this specialised field.

→ **Tyrosine kinase inhibitors (TKIs) are still the safest medication in CML treatment.** Patient advocates need to equip themselves with adequate knowledge to broaden their understanding around relevant topics, including clinical trials, drug patents, and Health Technology Assessments (HTA) in order to advocate for a more constructive agenda.

→ **Need to adopt a patient-centric approach** to establish a partnership among healthcare practitioners, patients, and their families to align decisions with patients' wants, needs, and preferences.



From left to right: FOM Trustee Anil Nagpal speaking during the Summit, Dr Pankaj Malhotra during a session



Expert Opinion

What will the CML therapeutic landscape look like in Asia over the next 5 years?

Dr. Pankaj Malhotra Professor of Clinical Hematology, Postgraduate Institute of Medical Education and Research, India, raised the issue of lack of compliance to treatment in developing countries due to poor literacy and awareness. He added, developed countries are moving towards TFR whereas developing nations are still grappling with issues of access, availability of medication and compliance. He said we need access to second line TKIs. He mentioned bone marrow transplantation may be considered as the first option of treatment especially in children if access to TKIs is restricted

Source: Cancer Summit Report 2018 | Rising Sun Cancer Summit of The Max Foundation



FOM Trustees at Rising Sun (from left) Anil Nagpal, Sunder Krishnan and Pramod John George



Viji Venkatesh (third from left) and Pramod John George (second from right) with other Steering Committee members at Rising Sun

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