



TOGETHER WE SHARE AND LEARN Celebrating World CML Day 9/22 - 2021

#AccessIsNeeded



World CML Day is celebrated every year on September 22nd (9/22), the specific date chosen as it reflects the translocation of chromosomes 9 & 22 which cause Chronic Myeloid Leukemia. This year marked the 20th anniversary of the approval of the first targeted therapy in CML which made a life changing prognosis for CML patients all over the world.

Each year, Friends of Max and The Max Foundation celebrate this day by organizing a Patient Support Group Meeting to bring together our CML brethren in India. In 2020, due to the COVID restrictions in place, we had organized a Virtual Patient Support Group Meeting.

This year Friends of Max and The Max Foundation team in India decided to take things a step further. We organized a



wide array of events to observe this special day including a "Know Your CML" Survey to gauge the disease awareness levels amongst CMLers and their caregivers, a Virtual Gathering to bring together our CML brethren in South Asia and asking our Medical Advisory Board to share their thoughts on this year's World CML Day theme - "20 years of life-changing CML therapies, but worldwide access is needed for all patients."

Amma Speaks

World CML Day is an important day for all the CML patients that Friends of Max works with. It is a day we all celebrate together, the worldwide CML community in fact – a celebration of their courage and fortitude living as they do with a life threatening condition that needs lifelong therapy, a celebration of those who work hard to bring effective treatment to the patients and a celebration of the advocates who work towards making that treatment accessible to all. I am proud to belong to the world of CML.

Today Friends of Max is the world's largest support group for CML patients. The sole objective at The Max Foundation for setting this up back in 2003 was to create a safe platform for them for sharing and learning together. Almost 20 years on this group is all that and more. On this World CML Day, I salute their spirit and zeal for being there for each other and every newly diagnosed patient.

Twenty years ago, The Max Foundation started working with CML patients and were able to provide access to thousands of them with the magic bullet – Glivec. Today, patients are still struggling which is why this year's World CML Day motto – "Access is Needed" is very important. Let us continue to work for another twenty years so that every CML patient in the world has access to the medical treatment they need.

- Viji Venkatesh,

Managing Trustee, Friends of Max and Region Head
(India & South Asia), The Max Foundation

How well do you know CML?

Friends of Max presents
"The World CML Day 2021 Survey".

Answer these simple questions and find out for yourself.

Help us serve you better!



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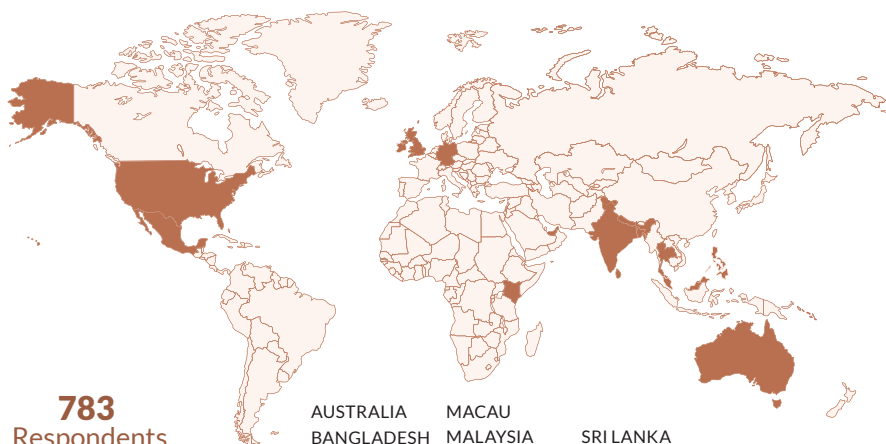
Dr Hari Menon
Medical Advisory Board,
Friends of Max

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Dr Hemant Malhotra
Medical Advisory Board,
Friends of Max

The Friends of Max World CML Day 2021 Survey and Virtual Gathering



783
Respondents

17
Countries

AUSTRALIA	MACAU	
BANGLADESH	MALAYSIA	SRI LANKA
GERMANY	MEXICO	THAILAND
INDIA	NEPAL	UAE
IRELAND	PHILIPPINES	UK
KENYA	SINGAPORE	USA

World CML Day 2021 Survey

As part of World CML Day 2021 activities, Friends of Max the support group for CML and GIST patients in India, has created a survey which seeks to identify the gaps in disease awareness amongst CML patients. This will enable us to determine the best means to address these gaps as well as the channels through which to do so in our upcoming patient education interventions. Answer these simple Multiple-Choice Questions to check how much you really know about this Leukemia that we have been living with for 20 years or more.

friendsofmax@gmail.com (not shared) [Switch account](#)

* Required

What is your name?

Your answer

What is your email ID

Your answer

Which country are you currently residing in? *

Your answer

Which state are you currently residing in? *

Your answer

As part of this year's World CML Day celebrations, Friends of Max created a simple survey to gauge the disease awareness levels amongst CMLers and their caregivers. The survey comprised of 20 questions based on topics which every CMLer ought to know. The idea was that the responses to this

survey would help us identify the information gaps that exist amongst our CML brethren and adopt a targeted approach to rectify those.

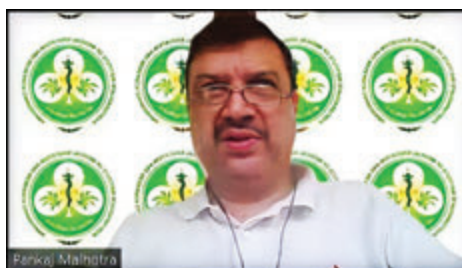
To ensure maximum participation and a reliable data set, we made use of communication and social media platforms to circulate the survey. 783 responses were

received from 17 different countries making this a massive exercise. These responses helped us gain some deep insights into the information gaps that exist among patient groups and we wanted to share our learnings with our family of CMLers. So we decided to organize a Virtual Gathering with our CML family and an expert panel to decode every question of the survey.



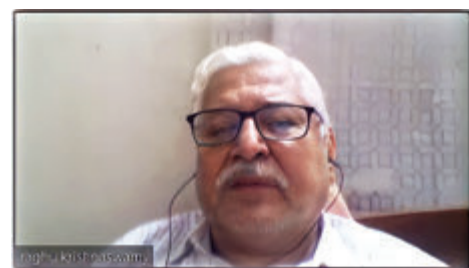
The virtual gathering was attended by over 120 patients, patient leaders, caregivers, physicians and The Max Foundation team – representing India, Nepal and Bangladesh. FOM Trustee Pramod George started the meeting with a beautiful love story of “a girl in room no. 9” who “started visiting a boy in room no. 22”, explaining why World CML Day is a day to be celebrated.

FOM Trustee Nirmesh Prakash then explained the rationale behind conducting this Survey exercise in his trademark Bhai-Bhidu format and then it was time to begin with the highlight of the evening – the Analysis segment. The segment was moderated by FOM Managing Trustee Viji Venkatesh and FOM Communications Manager Aashray Paul who presented each question to the expert panel which comprised of FOM Medical Advisory Board member Dr



Pankaj Malhotra, FOM Trustee S. Parameswaran, FOM City Chapter Leaders Dr Jude Vaz and Dr Raghu Krishnaswamy and The Max Foundation's Dr Dipanwita Maiti and Ms Beena Narayanan.

This was followed by an interactive Open Discussion segment led by the Max team's Sudha Samineni and Anshika Tandon and finally a Vote of Thanks by Priyanka Kandalgaonkar. It was heart warming to see more than half of our



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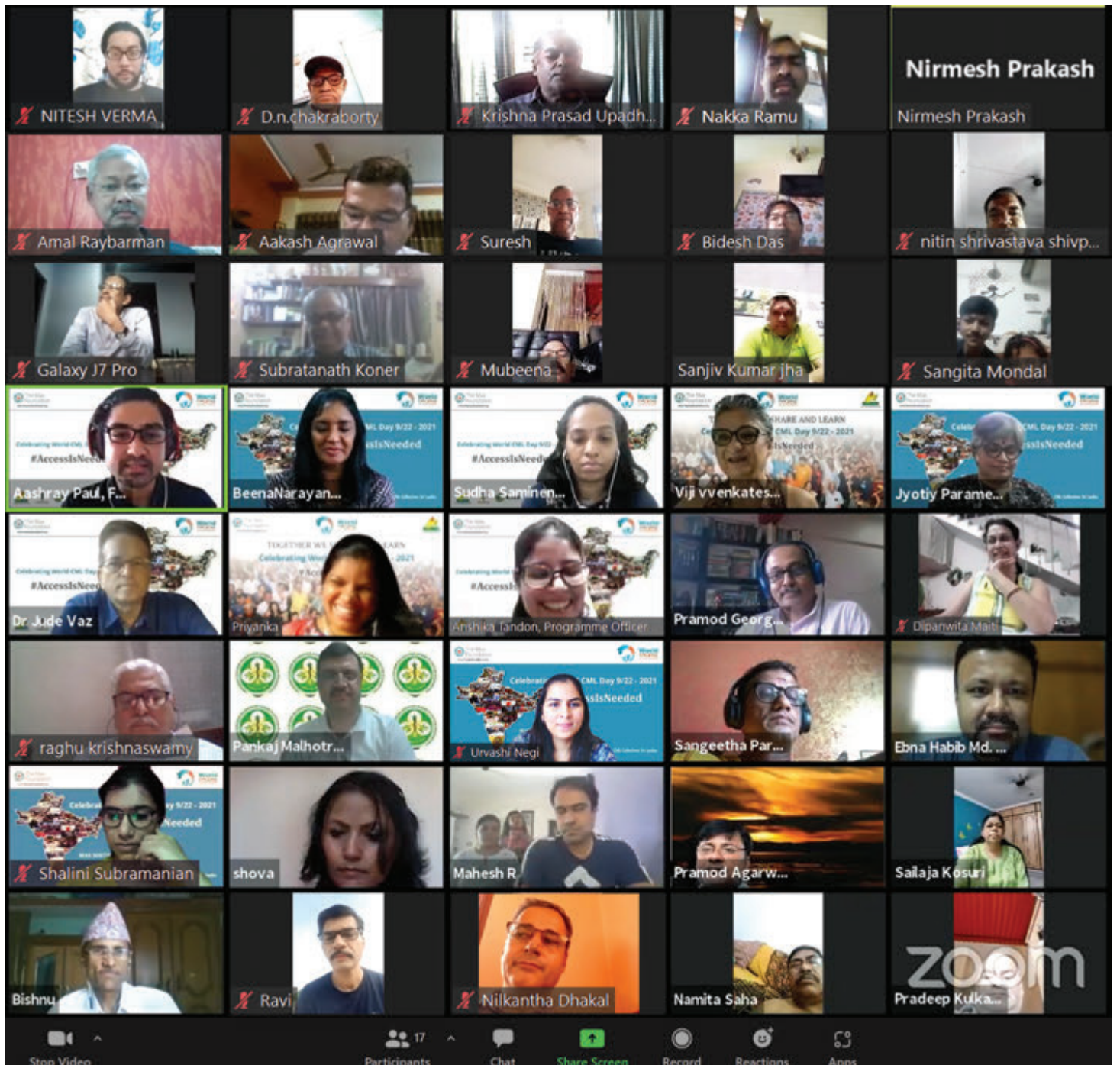
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audience watching eagerly even after 2 ½ hours, and a casual chat with them led to Viji Venkatesh starting an impromptu round of Antakshari where the sporting

Dr Pankaj Malhotra stole the spotlight once again with his rendition of "Yaara o Yaara".



The replay of Friends of Max's World CML Day Gathering can be viewed by using the QR Code

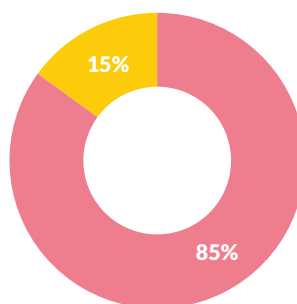


Some of the key findings of the survey and observations of the expert panel are shown below –

15 per cent of the respondents globally were found not having access to a patient support group. An identical percentage of respondents from India were also found not a part of Friends of Max.

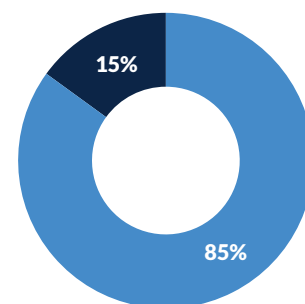
% of Respondents who are part of a Patient Support Group (Global)

● Caregivers of CML Patients
● CML Patients



% of Respondents associated with Friends of Max (India)

● No
● Yes



Respondents displayed excellent awareness in the following areas

Basic concepts and acronyms related to CML

Nature and cause of CML

Monitoring and treatment methods available

First Generation TKI



Compliance and dietary restrictions



Information gaps were revealed in the following areas

Second Generation TKI

Mutations related to CML

Drug Resistance

Stages of disease progression in CML

More technical questions about CML



Respondents displayed a tendency to avoid questions related to the following

Second and Third Generation TKI

Background of CML and its treatment

Drug Resistance



Information gaps identified through the Survey and Discussion

1. Low scores in topics already shared on FOM's social media reveal that the information is not properly being disseminated
2. There is a need to focus on topics like 2nd & 3rd Generation TKIs, CML mutations, drug resistance
3. There is a need to remove certain misconceptions regarding nutrition and spread of CML

Steps to be taken to bridge the information gaps in near future

1. Encourage patient leaders to stay updated and share relevant articles from FOM's social media pages.
2. Ask physicians and experts at the patient support group meetings to address the topics where respondents showed lack of awareness/ existence of misconceptions



The detailed analysis of Friends of Max's World CML Day Survey is available on our website

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To donate online visit www.friendsofmax.info;

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Friends of Max is registered as a Public Charitable Trust: Regn No E-24284(B) Mumbai, dated 4-7-2007