

Friends of Max

# **Advocating for access in CML/GIST therapy**

by collaborating with Patients, Caregivers,  
KOLs, Government

Puthen Parameswaran, India



# Introduction

- Friends of Max (FOM):
  - an attempt to bring under its umbrella all CML and GIST patients, and to provide them with a platform to share and learn
- Emphasis on:
  - compliance
  - disease information
  - coping with issues related to life-long therapy
  - provide support for diagnostics
- Advocate for ideal environment, keeping all of the above in mind



# Focus

- Providing succor to one is support
- Working toward change in policy that would provide succor to all is advocacy
- FOM members have all along had great support systems provided by The Max Foundation. A majority of the members receive Glivec through the GIPAP and/or NOA.
- So there has never been any un-met need or a situation where the group has felt threatened or is in a difficult situation till now



# Advocacy

The advocacy issue – Scope of the Problem:

- In a change of policy, Government decided to **withdraw exemption of customs duty** from the life-saving cancer drug Imatinib Mesylate (Glivec)
- The potential imposition of customs duty meant that at one stroke the lives of 18,500 patients were placed at risk. The 14-year old assistance-programme essentially covers poor patients financially unable to afford the life-long dosage



# Advocacy – Key actions

- With the support of the machinery of the Max Foundation office in India, a comprehensive campaign was mounted:
- Online campaign on all platforms
- Signatures from patients and concerned oncologists at meetings in the office, at hospitals, via email, social media, “WhatsApp” and so on



# Advocacy Campaign - Goals

- Created awareness in public forums
- Explained urgency of the issue to those affected
- Bolstered confidence by offering support to our partner
- Involved key opinion leaders (KOL)
- Contacted and engaged with policy makers
- Repeated phone calls and emails until appointment was given



# Advocacy Campaign - Goals

- Appointment was secured with
  - Ministry of Health
  - Ministry of Revenue
- Officials' gave a patient hearing and agreed to do the needful
- Received a confirmation from Ministry of Health supporting for exemption of Customs Duty and notification sent to Ministry of Revenue.

The letter received are also enclosed.

3. Keeping in view the above, the drugs imported by the company for free distribution should not be taxed and the benefit of custom duty exemption should be made available even in respect of medicines supplied free of cost. In view of the above, the Department of Health and Family Welfare strongly recommends that the proposal for exemption from customs duty of cancer drug Glivec (Imatinib Mesylate) being supplied free of cost under this programme in partnership with the Max Foundation appears to be fully justified and the request should be acceded to. This concession need, however, not be extended to the drugs sold in the market which could continue to attract customs duty/other duties in the usual manner. The D/o Revenue may in view of the above consider the request of M/s Novartis for working out an arrangement to exempt Glivec (Imatinib Mesylate) supplied free of cost by Novartis through the Max Foundation in the larger interest of public health. An early action in the matter is requested.

4. This issues with the approval of the Minister, Health and Family Welfare.

Encls.: As Above.



Together We Share and Learn



To,

The Ministry of Health & Family Welfare  
Govt. of India

Honorable Sir,

We read with dismay the recent news articles on a government directive withdrawing the exemption of customs duty from some life-saving medicines for diseases including cancer.

We are a patient group of chronic myelogenous leukemia (CML) patients called Friends of Max and earnestly request you to reconsider the government decision of withdrawing exemption of customs duty on Glivec which is given as a free donation to patients in India. CML is a type of blood cancer.

Sir, there are around 18,500 patients in India who are currently suffering from this life-threatening condition who receive the drug named Glivec, completely free of cost from Novartis, through a patient assistance program run by The Max Foundation. We have been receiving this life-saving drug for around 13 years now and are living normal lives because of this wonderful assistance program. The new government order and the news appearing in the media, has created an environment of uncertainty all around and we and our family members are very worried about our future survival. This drug is as essential as the air we breathe to keep us alive.

We sincerely appeal to you to kindly continue with the exemption of customs duty granted to Glivec and help us in our desire to live longer without having to worry about where our next medicine dose will come from. Along with my fellow friends who are living with cancer and from their care givers we are certain that our cry will be heard in the corridors of power.

This act of yours will lead to countless blessings from every single one of us. Our lives are in your hands.

In solidarity

Friends of Max  
Public Charitable Trust  
Reg.No. E 24284 (B)

Secom Business Centre, A Block, Basement, Shiv Sagar Estate, Dr. Annie Besant Road, Worli, Mumbai 400 018

www.friendsofmax.info

# Petition Letter used for the advocacy campaign





**Thanks to GLIVEC,  
18500 cancer patients are ALIVE.**

**If you impose  
customs duty on GLIVEC,  
we will not be able to afford it.  
Please take back your decision.**



# **APPEAL TO THE GOVERNMENT**

**Please don't withdraw  
customs duty exemption  
on wonder drug GLIVEC.**

**18500 lives depend on it for survival.**



