

MEETING MINUTES
CML Community Advisory Board (CML-CAB) with Pfizer on March 4, 2019

Executive Summary

CAB meetings provide an opportunity to build a meaningful relationship between pharmaceutical companies and the patient community to overcome the challenges and needs associated with CML. The main objectives of this CML Community Advisory Board (CAB) meeting were to foster a mutual understanding and to take tangible actions forward for Pfizer, the patient community and both in collaboration. CAB meetings are held under confidentiality terms from all parties to allow for an open and frank discussion. These minutes have been adapted to provide a non-confidential overview for the membership of the CML Advocates Network.

Topics discussed during this CML-CAB meeting included an update on the organization and CML program at Pfizer, any access barriers relevant to bosutinib, Bosulif patient experience and an update on the Therapy-Free Remission (TFR) patient survey of the CML Advocates Network.

Pfizer recently underwent global restructuring with the aim to make the organization more agile. The patient community is interested, particularly at the local level, to know who the contacts are. Pfizer has hired a Chief Patient Officer to ensure patient engagement. Pfizer highlighted their commitment to putting patients first and briefly presented their roadmap to a more patient centric organization. Pfizer agreed to help identify country level contacts for CML patient advocacy groups (PAGs). In turn, CML PAGs will provide a list of countries in which they have network member organizations.

To help address barriers in engaging with patients, CML-CAB is open to sharing examples on how they collaborate with other companies.

The discussion around the clinical development program revealed some frustration on access, also with regard to investigator-led studies. CML patient organisations have access to large patient communities in emerging countries, including children, and can help increase access to studies there. There is a need to develop a 3-way dialogue including patients, pharma and healthcare professionals (HCPs) to discuss challenges and ways forward. Many patients worldwide lack access to treatment and PCR monitoring. Bosulif is now available in 46 countries (34 product launches & 12 Named Patient Programs, NPP) with expansion planned into emerging markets. In addition, pediatric development is ongoing. Access, however, is very important to allow patients to live with CML for many decades forward. Pfizer and CML-CAB committed to continue working closely together to identify and fill gaps.

Patient education was discussed, focusing particularly on materials to help patients and HCPs understand how to manage bosutinib-related diarrhoea. CML-CAB expressed their interest in developing material and providing patient input to help manage the problem. It was identified that physicians may inadvertently be creating roadblocks in ensuring that diarrhoea is managed appropriately. Pfizer is interested in working with patient community to change that mind-set.

It was suggested that written materials should be translated into other media, e.g. videos. Apps are seen as a great way to collect real-world evidence, but will be used by patients only if they provide a direct benefit to them.

Finally, the results of the CML Advocates Network's Therapy-Free Remission (TFR) survey results showed that at the most 5% of the global patient population are able to achieve TFR (physicians state that 20-25% of patients can achieve TFR. In reality, if Western countries account for 15-20% of the world, at the most 5% of the global patient are able to stop), with psychological concerns being an important issue along the entire TFR journey. CML-CAB noted that there is a clear need to increase the percentage of patients who can achieve TFR which would be made possible with better access to treatment (to get to TFR, and to resume treatment on TFR failure) and access to PCR testing (as stopping can't be done without close sensitive PCR monitoring and restart of therapy in case of TFR failure) worldwide.

CML-CAB also identified a need to develop treatments for patients with progressive disease. It was noted that thousands of CML patients worldwide are young patients who will not be able to continue treatment for 40 or 50 years, many of them in countries without access to treatment or monitoring. It was suggested that these be areas of focus for Pfizer. Ultimately, however, the goal is to find a real cure for CML.

Meeting moderated by:
Kathy Redmond, Moderator/Facilitator

Minutes prepared by:
Lisa Machado and Nicole Schröter (based on confidential minutes developed by Marion Alzer (Medical Writer)