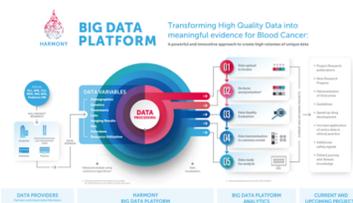


For Chronic Myeloid Leukemia Patient Group Advocates
CML Advocates Network, February 2021



More opportunity than risk: "Choosing the optimal therapy is vital for patients"

Although diagnosis and treatment methods for **blood cancers** have greatly improved in recent years, many are still incurable. For this reason and with the help of 94 partners and members, including seven patient organizations as well as pharmaceutical companies and university hospitals, **HARMONY**, as a pan-European project of the **EU Innovative Medicines Initiative** launched in 2017, gathers genomic data from thousands of patients affected by blood cancers.

To find out more about what potential does Big Data hold for health research and what role does it play in **CML**, read the following article on our website with our co-founder **Jan Geißler** explaining all details of the **Harmony Alliance** project and how we are involved to drive research for better treatment outcomes for patients.

[Big Data and CML: Read the article](#)

RARE DISEASE DAY



Rare Disease Day 2021

A rare disease, also referred to as an orphan disease, is any disorder that affects a small percentage of the population. **Chronic Myeloid Leukemia is a rare disease**, accounting for around 0.03% of all cancers diagnosed.

Rare Disease Day is a global movement that celebrates the diverse faces and experiences of the over 300 million people living with a rare disease worldwide.

On the occasion of **Rare Disease Day 2021** that takes place on the last day of February, we encourage our CML members worldwide to take part of this global awareness campaign by raising their voices amongst the general public and decision-makers about CML and its impact on patients' lives.

Know more about **Rare Disease Day** and how to get involved on 28th February 2021!

[Visit Rare Disease Day 2021 website](#)



First CMLCAB in 2021 successfully held online

Last Thursday 18 February 2021 we held our **12th CML Community Advisory Board (CML-CAB)** and **22nd CML-CAB session**. It was the 9th CML-CAB meeting with Novartis. Besides 9 company representatives mainly from the areas of Patient Engagement, Medical Affairs, Global Development, and Market Access, a multi-centennial body of experience consisting of 13 CML-CAB members and covering 241 patient or advocacy years attended this meeting.

CML-CAB members selected to attend this specific meeting were chosen out of the total group of 19 CML-CAB members (with a total of near to 340 patient or advocacy years), based on expertise on the meeting topics.

With the focus of this virtual meeting being on "**future treatments and current access**", topics discussed included the Asciminib development program (incl. PRO measures and QoL), value proposition and positioning of the drug, as well as Novartis' global access strategy for Asciminib.

We also remembered the 4 valued and engaged advocates who the CML community has sadly lost over the past 8 weeks. In a moving speech, Denis Costello, Executive Director of the CML Advocates Network and moderator of this meeting, encouraged the participants to take a moment of silence in remembrance of these four and others that who have gone before us, and also "*to remember why we are here and who we serve*".

Thanks to all attendees for the engaging discussions during this 3-hours meeting!

[Know more about CML CAB on our website](#)

DUTCH

Aanbevelingen voor de behandeling van mensen met CML

Een patiëntvriendelijke samenvatting van aanbevelingen voor de behandeling van chronische myeloïde leukemie volgens de Europese LeukemiaNet 2020.

Gepubliceerd door de
CML Advocates Network

ELN 2020 CML Treatment Recommendations

The patient-friendly summary of the ELN 2020 CML Treatment Recommendations is now available in **15 languages** including Dutch and more are coming.

While treatment guidelines and recommendations are recognized as being the standard of care by haematologists, they can be difficult for CML patients to understand at some points.

Therefore, our summary, prepared by a workgroup of patient advocates and reviewed by key CML experts, can help you to discuss your disease and treatment choices with your doctor.

[Download the ELN2020 Treatment Recommendations Summary](#)



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