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****FOR IMMEDIATE RELEASE****

On World CML Day, leukemia patients worldwide unite to address the courage and hope required to live with chronic myeloid leukemia, and call for access to best available treatment and care for all patients

Group by group, advocate by advocate, and survivor by survivor: on World CML Day on 22 September, the global patient community is raising awareness about the needs of people living with chronic myeloid leukemia (CML). Simultaneous events, publications and meetings on all continents put a spotlight on the real needs of patients and their relatives, and demonstrate the power and unity of a unique worldwide community that knows no borders. Their brand-new book "Faces of Courage and Hope" further provides an insight into the journeys of 16 CML patients in 15 countries.

Members of the CML Advocates Network, which is today comprised of 90 patient advocacy groups in 68 countries, are honoring World CML Day on September 22nd 2014 through actionable events taking place in their communities. All events worldwide aim to underscore the importance of the needs of people living with CML. The needs of patients in different regions vary largely – from basic challenges of access to treatment and care, over uncertainty on the quality of treatments, to living with cancer as a chronic disease.

Although CML is today often referred to as a model disease how blocking essential mechanisms of a tumor can bring cancer to a halt, not all that glitters is gold. Even though there has been a medical revolution in treating CML over the past decade, not every patient has access to best available treatment and care, and many patients struggle to live with cancer as a chronic, life-long disease.

There are obvious disparities in terms of access to treatment and diagnostics. We cannot turn our eyes from the fact that socioeconomic barriers are present in many countries, where patients are lost in debates around high drug prices and drug quality of copy drugs, combined with the lack of access to quality diagnostics. Just in May 2014, CML patients worldwide [called for quality and consistency when new drugs are introduced to treat their cancer](#). Since none of the new drugs provide for a cure of CML yet, even in countries where access to expensive cancer treatments is ensured, patients are facing challenges with the impact of a life-long treatment on their quality of life. The community's goal is clear: All CML patients shall have access to optimal and affordable treatment and care, giving them a quality of life as close as possible to normality. There is still a long way to go!

Key initiatives on World CML Day 2014

Again in 2014, plenty of events are being carried out by patient organizations throughout the world in order to raise awareness of the needs of people living with CML worldwide. The initiatives are



listed on the CML Advocates Network website at

<http://www.cmladvocates.net/worldcmlday2014/worldcmlday2014/initiatives>

On World CML Day 2014, the CML Advocates Network publishes an English-language book ***Faces of Courage and Hope*** that illustrates the faces and cancer journeys of 16 CML patients from 15 countries. Men and women of different ages, ethnicities and backgrounds, each share their unique experience in coping with life-altering circumstances and how they refocused their lives. The book is currently being shipped to CML patient organizations in 56 countries, and will be available on Amazon.co.uk for worldwide shipping from 22 September 2014. For more information see:

<http://www.cmladvocates.net/book-faces-of-courage-and-hope>



On 9/22, the CML Advocates Network also publishes a **patient-friendly summary of the European LeukemiaNET's CML Treatment Recommendations** in English, Italian, French, German, Hebrew, Russian, Polish, Spanish, Portuguese and Arabic. The summary will allow patients to understand the consensus recommendations provided by a global group of CML experts, coordinated by the European LeukemiaNET.

In addition, the CML Advocates Network provided buttons with the community's World CML Day logo – a total of **35.000 "World CML Day" buttons** were distributed to organizations in 34 countries on all continents to raise awareness about CML.

22 September – the global date for awareness about CML

The date chosen for World CML Day (9/22) adds symbolic significance to the campaigns of the patient community: World CML Day is honored on September 22nd because 9/22 represents the genetic change of Chromosomes 9 and 22 that is the cause of Chronic Myeloid Leukemia (CML), a rare cancer that is characterized by an unregulated growth of white blood cells. Just about 15 years ago, CML was a lethal disease for the majority of patients. Nowadays, CML is no longer a death sentence. If patients are treated effectively with recommended treatments, they can have a life expectancy similar to that of the general population.

Since 2008, patient organizations around the world have initiated events and projects on World CML Day to raise awareness of the needs of patients living with CML and to sensitize not only the public, but also politicians and medical professionals regarding CML. *"All united, all unique!"* is the theme that brings the groups together. It is a reminder of how each person and each group experiencing a rare cancer will have their own journey. As Jan Geissler, CML patient and co-founder of the CML Advocates Network shares, *"Since the first meeting of a handful of CML groups back in 2003, it is impressive to see the growth in intensity of activity in the CML patient community. Today 90 groups are members of the worldwide network. We are not only meeting once in a year at our CML Horizons conference - we are supporting each other across borders, and*



are jointly collaborating with all stakeholders, throughout the year. Working together is the key to improving support and care for CML patients in all regions”.

How can I engage in World CML Day?

No matter if you are a patient organization, a research group, or are caring for CML patients - if you or your organization is interested in joining the World CML Day campaign, here are some examples of ways to get involved:

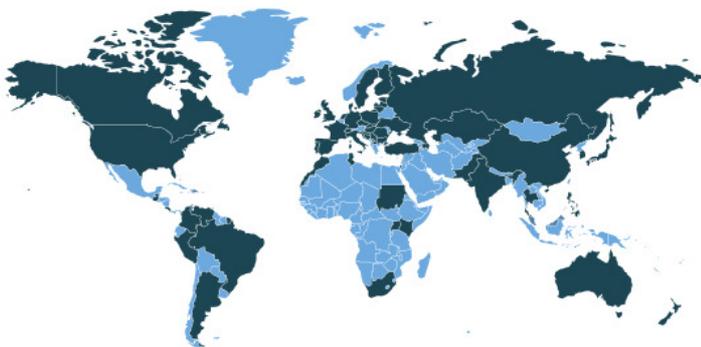
- Promoting World CML Day through your websites, events and social media channels. Visit the CML Advocates Facebook page (<https://www.facebook.com/cmladvocates>) or Twitter (<http://www.twitter.com/cmlnet>) and share our posts within your networks. You can find World CML Day logo for download at <http://www.cmladvocates.net/worldcmlday2014/worldcmlday2014/wcmlid-logo>
- Tells us about the event you are organizing on September 22nd in order to raise awareness of the need of people living with CML worldwide. We are happy to list it here: <http://www.cmladvocates.net/worldcmlday2014/worldcmlday2014/initiatives>

Thanks to all the groups around the world participating in World CML Day, together we are "All united, all unique"!

About the CML Advocates Network

The CML Advocates Network is a patient-run network and platform for patient organizations supporting patients and relatives affected by Chronic Myeloid Leukemia (CML). Launched in 2007 by four founding patient organizations, it has now grown to a network of 90 leukemia patient groups in 68 countries, offering support to patient leaders by sharing of best practice, information and advice for CML patient leaders. Individual patient support as well as country-specific policy work is being covered by its member organizations on the country level. The CML Advocates Network is hosted by the patient-driven, non-profit *Leukemia Patient Advocates Foundation* in Bern, Switzerland.

Members of the CML Advocates Network



See the list of all 90 member organizations here: <http://www.cmladvocates.net/cml-groups-list>



Contact

CML Advocates Network

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