



Press Release

Leukemia Patient Groups call for improved access to cancer treatment

Baveno (Italy) 18 August 2008 · More than 50 organisations supporting patients with chronic myeloid leukaemia have signed the "Baveno CML Declaration" to call for improved access to cancer treatment and better adherence to international treatment guidelines.

The global community of organisations representing patients with Chronic Myeloid Leukemia (CML) is concerned about the growing inequality of access to adequate treatment in all countries and regions.

Patients should be treated equally regardless of race, nationality, faith, age, sex or economic status. Existing differences and delays in the way in which CML patients are monitored and treated should be overcome. International treatment guidelines should be adopted across the world. Additionally, more collaboration should happen towards the ultimate goal: finding a non-invasive cure for CML.

When the global CML community met in Italy in June 2008, more than 50 representatives of CML patient groups signed the "Baveno CML Declaration" to call for these actions. More and more groups are signing the declaration on www.cmladvocates.net today, in the hope to improve treatment for CML patients world wide.

The Baveno CML Declaration

The "Baveno CML declaration" calls upon all those responsible for the treatment and care of CML patients to:

1. Work together towards the ultimate goal: finding a non-invasive cure for CML.
2. Adhere to internationally agreed treatment guidelines to ensure that patients are treated in accordance with current international 'up to date' evidence compiled by ELN (European LeukemiaNet) and NCCN (National Comprehensive Cancer Network).
3. Ensure that patients are diagnosed promptly and accurately and are made fully aware of all clinically appropriate options.
4. Ensure equality by providing patients with optimal treatment and care regardless of race, gender, age, nationality, faith, economic status or their national or international place of residence.
5. Provide patients with the information and resources that they need to gain access to, and treatment from, clinicians specialised in the management of CML.
6. Ensure that all patients receive treatment and care in centres of excellence, preferably delivered by multidisciplinary teams. Centres and individual clinicians should participate in trials organised by international CML networks and ensure that patients gain access to the best therapy currently available.



7. Provide access to internationally standardised cytogenetic and molecular monitoring, expert pathology and mutation analysis services so that doctors and patients can make informed clinical decisions. Pharmacokinetic testing of plasma trough levels should be offered in cases of a sub-optimal response or an intolerable side effect profile.
8. Allow patients access to their health records and all laboratory results at each step along their treatment pathway regardless of any national constraints.
9. In an attempt to minimise distress caused by delay or misunderstanding of test results, educate patients so that they are better able to appreciate the interpretation of FISH, cytogenetic and PCR (Polymerase Chain Reaction) tests.
10. Facilitate access to an expert second opinion should the patient request it.
11. Provide patient advocacy groups with participation in the decision making process of research and access to treatment.
12. Provide patients with information about all relevant ongoing clinical trials and publications of trial data and support patient participation in trials across borders.
13. Ensure patients in need are provided with psychosocial support and therapy.
14. Provide access to adequate funding of current therapies so that patients do not suffer a failure to treat on economic grounds. Actions must include appropriate reimbursement of approved therapies and treatment access programmes until full reimbursement is in place.

The global community of CML patient advocacy groups will monitor the implementation of this declaration and publicise the healthcare systems that demonstrate adherence to it.

About Chronic Myeloid Leukaemia

Chronic Myeloid Leukaemia (CML) is a haematological malignancy or cancer of the blood cells. It is a rare tumour, with an incidence of 1-2 cases per 100 000 in adult populations, accounting for 15-20% of all leukaemias. It occurs in both children and adults, but is rare in persons aged 19 or younger. Just a decade ago, when no adequate treatment was available, CML was progressing into a lethal phase within just months to years after diagnosis. Due to strong progress in developing targeted therapies in recent years, CML can be treated well today, if adequate treatment is made available and applied appropriately.

About the CML Advocates Network

The CML Advocates Network is both a virtual network and an internet platform for organisations supporting patients with Chronic Myeloid Leukemia. It was launched on www.cmladvocates.net in June 2007 at an assembly of more than 80 representatives of patient organisations from 28 countries on 4 continents. It was initiated by four non-profit patient organisations Leukämie-Online (Germany), CML Support (UK), Israeli CML Patients Support Organisation (Israel) and Diagnoza CML (Czech Republic). 34 patient organisations have so far joined the network.

The main objectives of the "CML advocates network" are:

- To provide a public web directory of CML patient groups worldwide, to allow patients to find national support groups in another country.



- To provide a platform for communication and knowledge sharing between CML patient advocates, e.g. to share best practice on cancer patient advocacy.

The website was built on free software and is run by patient groups on a low-cost basis, which ensures our financial independence from any commercial interests.

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