

# ELN FOUNDATION NEWS

No. 1 - Newsletter of the ELN Foundation - February 2010

**ELN** Foundation  
European ■ LeukemiaNet

*"Let's take action against leukemia ..."*

## **Leukemia! The challenge we face.**

More than 100.000 patients are diagnosed with leukemia in Europe each year and about 45.000 within the US. Many lives are affected and the cost to society is significant.

The challenge is to improve survival of patients and make leukemia a curable disease.

## **The ELN Foundation supports the European LeukemiaNet in its goals to**

- improve the care of leukemia patients in Europe and globally,
- ensure that patients have faster access to innovative medicines with a greater certainty about their use than currently possible,
- improve the quality of life and life expectancy of leukemia patients,
- provide physicians with up-to-date management recommendations for all forms of leukemia,
- spread excellence through rapid publication of new data and educational activities on all levels.

*... help us to make a difference"*

## The Chairman of the ELN Foundation



Dear Friend and Partner,

Leukemias are not just a challenge to society, they are also a significant cost factor due to their frequency in all age groups.

Inequalities in recognition, mortality and survival characterize leukemia management and outcome in the European Union and in the world.

Therefore, it is more important than ever to join forces to fight this disease.

At present, there are disparities in both access to treatment and quality of care. The chance to survive greatly depends on where patients are born and live, on the socio-economic groups to which they belong and on the type of leukemia from which they suffer.

The ELN Foundation is a charitable non-profit organization that was created in support of the European LeukemiaNet (ELN) to address these disparities and to improve the care of leukemia patients in Europe and globally.

The Foundation offers access to our alliance of researchers, industry, politicians, patient groups and the medical profession to better understand origin and course of leukemia and to reinvigorate the clinical development of new strategies and drugs.

The Foundation would be extremely grateful for any help you can give, as your contribution and support increases our chance of defeating leukemia.

Yours sincerely

Prof. R. Hehlmann

... Help us to make a difference”

## The ELN Foundation

The ELN Foundation is a non-profit charitable organization that was created to support the EuropeanLeukemiaNet (ELN).

The ELN is a network which to date has brought together over 100 national Leukemia study groups and their interdisciplinary partners with over a 1000 physicians and researchers, situated in 169 institutions in 33 countries, reaching across 4 continents, Europe, North America, Asia and Australia.

This collaborative activity has had a far reaching impact on the survival and quality of life for leukemia patients all around the globe.

### Mission Statement

The ELN Foundation will use the power of ELN as a grown and responsible network of excellence to build up new partnerships and ideas and join all forces to fight leukemia.

### What we offer?

The Foundation offers industry a clear advantage for cooperation by providing access to our alliance. This alliance brings together our international network of medical and interdisciplinary scientific excellence in leukemia, public and private health care institutions, profit and non-profit organisations, industry, politicians and patient groups. The aim is to enforce clinical research and to reinvigorate and accelerate the development of new leukemia drugs.

The ELN Foundation has joined the European Commissions initiative: "Action Against Cancer", to raise awareness about leukemia and to help empower patients through the provision of education about their disease.

The intention of the ELN Foundation is to use the ELN multinational network to advance leukemia research worldwide to save lives by improving medical care and treatment optimization.

### What we do?

#### ELN Foundation Activities

The Foundation will support the goals of the ELN by raising funds to allow the ELN to carry out research to investigate novel diagnostic and therapeutic procedures for leukemia patients and to establish European leukemia patient registries to thereby improve treatment and outcome of all leukemia entities.

#### Our Aim

Advance research, clinical management and sharing of best practice worldwide to make all types of leukemia curable diseases.

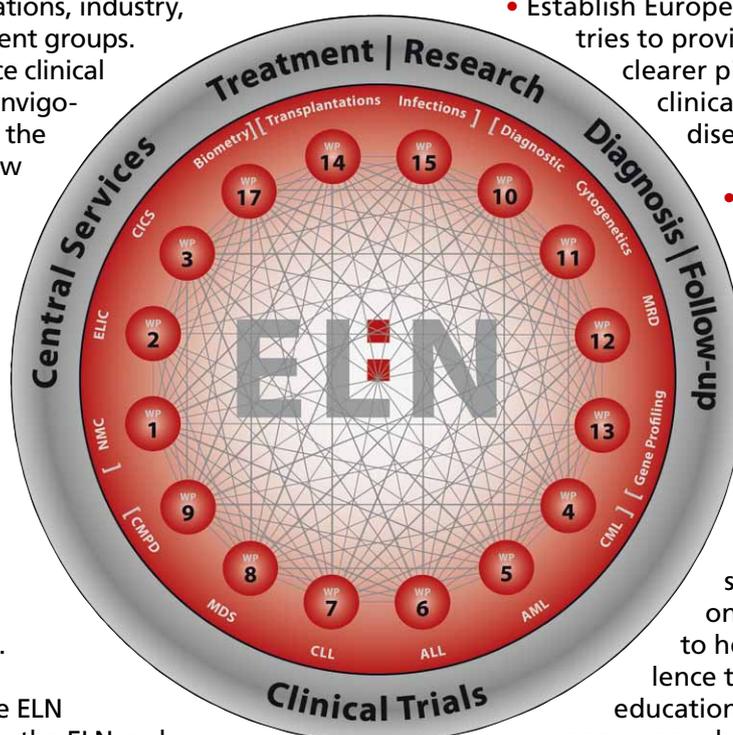
#### Our Goals

- Provide leadership for improved prevention, screening and treatment of the disease and spread excellence globally.
- Reinvigorate the clinical development of new leukemia drugs and bring more clinical research to Europe ensuring that patients have faster access to innovative medicines with a greater certainty about their use.
- Improve the standard of clinical trials, patient care and education.

- Establish European Leukemia Registries to provide clinicians with a clearer picture of the current clinical management of the disease.

- Increase life expectancy and quality of life for thousands of leukemia patients worldwide.

- Deliver a unique integrated web 2.0 solution called "My Leukemia Space" to improve communication and information structures for leukemia on an European basis; to help spread excellence through research and educational activities and to encourage sharing of best practice to improve patient care.



## The ELN Foundation Board

In 2007 the idea of forming a foundation was high on the agenda of the ELN Steering Committee. In 2008 the idea turned into a concept. An ELN Foundation Deed was developed, closely related to the goals, aims and principles written down in the original European LeukemiaNet proposal and advanced with current innovation and progress in the field.

At the ASH congress in 2008 (American Society of Hematology) and at the ELN Symposium in 2009 progress on the sustainability efforts in regards to the Foundation were presented. A number of ELN Steering Committee members agreed to be part of the new Foundation Board. Further ELN members took on responsibility to support the goals of the ELN in the future, beyond EU funding.

A critical number of 13 Founders from all over Europe was reached already in spring 2009, demonstrating the acceptance of the ELN amongst its members and their personal commitment. In June 2009 at the time of the EHA congress in Berlin (European Hematology Association) all Founders signed the ELN Foundation act and committed themselves officially to further sustain the ELN in its new legal entity. In August 2009 the ELN Foundation was legalized by the German governmental authorities (<http://www.rp-karlsruhe.de/servlet/PB/menu/1111579/index.html>).

The ELN Foundation has started up its activities, presenting its ideas and concept in this newsletter to everybody with an interest in leukemia.



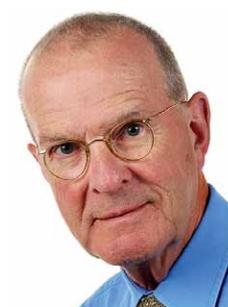
Prof. Dr. Hehlmann



Prof. Dr. Baccarani



Prof. Dr. Barbui



Prof. Dr. Büchner



Prof. Dr. De Witte



Prof. Dr. Grimwade



Prof. Dr. Guilhot



Prof. Dr. Hochhaus



Prof. Dr. Hoelzer



Prof. Dr. Niederwieser



Prof. Dr. Ossenkoppele



Dr. Saußebe



Prof. Dr. Simonsson

## Our Strategy

The ELN Foundation will offer access to its worldwide interdisciplinary leukemia research network.

It will provide knowledge and expertise in prophylaxis, diagnosis, treatment and the development, placement and conduct of early phase clinical trials.

It will supply infrastructure for larger, multi-centre clinical Trials.

It will use educational activities to spread excellence in leukemia research.

## Global Future

The ELN Foundation is a world-spanning interdisciplinary leukemia network. We are an alliance of leukemia experts including physicians, scientists, health care representatives, industry, patient groups, profit and non-profit organizations and politicians.

We will spread of excellence in leukemia through educational activities. These will include training courses, exchange visits for young scientists, and information material for patients.

We aim to achieve treatment optimisation for each individual patient through the publication of recommendations and guidelines on the management of leukemia.

We offer joined round table discussions to enable new research directions in leukemia diagnosis, treatment and care through innovation and creativity.





**There are many ways in which individuals and corporations can contribute**

- Give your time, energy and expertise – can you get involved in teaching/training, etc.?
- Do you have personal contacts who may be able to help us?
- Could your organization second staff to the ELN Foundation e.g. accountants, administrators, sales & marketing executives, etc.?
- Do you think your organization would be interested in twinning opportunities with groups in the emerging or developing world?
- Could you suggest any fundraising schemes for the ELN Foundation?

The Foundation would be extremely grateful for any help you can give. Your contribution and support increase our chance of defeating this devastating disease.

*... Help us to make a difference"*

## Our Guiding Principles

- Dedication to make all types of leukemia curable diseases.
- Working ethics of accountability and independence.
- Breaking borders and fostering innovative research directions and novel treatment options by interdisciplinary research teams for the different leukemias and related disease entities.
- Improving outcomes in leukemia therapy worldwide with the resources we have been given.
- Spread of excellence on treatment, prognostic and diagnostic research and infrastructure.
- Consultation and cooperation with leukemia patient groups worldwide.
- Treating grantees as valued partners and the beneficiaries with respect.
- Effective, mission-oriented and creative mode of operation.

## Bank Account Details

**Name of the bank:** Sparkasse Rhein Neckar Nord  
**Address of the bank:** D1, 1-3, 68159 Mannheim, Germany  
**Holder of the account:** ELN Foundation  
**Account number:** 38 90 98 43  
**BLZ:** 670 505 05  
**IBAN number:** DE 68 6705 0505 0038 9098 43  
**BIC/Swift number:** MANSDE 66XXX

## Tax-free donations

The ELN Foundation is registered as a non-profit organization in Germany.

Although registered in Germany, the ELN Foundation will enable tax-free donations from anywhere in the world. Within Europe it is possible since early 2009 to pursue tax free cross-border donations, based on a European court decision (C-318/07).

From Non-European countries this is usually achieved via a promotion association or so-called "Friends of ..." organizations, which are headquartered in the donor's native country and then transfer the donations abroad taking into account the national tax specifications.

Upon request, the ELN Foundation will be pleased to provide you with detailed information on possible tax deduction in your country.

## The ELN Foundation structure and organisation

### Foundation Board

Prof. Hehlmann, Germany (Chairman)  
Prof. Baccarani, Italy  
Prof. Barbui, Italy  
Prof. Büchner, Germany  
Prof. De Witte, The Netherlands  
Prof. Grimwade, Great Britain  
Prof. Guilhot, France  
Prof. Hochhaus, Germany  
Prof. Hoelzer, Germany  
Prof. Niederwieser, Germany  
Prof. Ossenkoppele, The Netherlands  
Dr. Saußele, Germany  
Prof. Simonsson, Sweden

### Scientific Advisors

All ELN WP Leaders and International Partners

### ELN Members

All current certified members, registered via the EU are integrated

### Board of Trustees

Dr. N. Huber,  
University of Heidelberg

### Fundraising

Dr. C. Bradley

### Management

Dr. P. Schrotz-King

Everybody with an interest in leukemia is invited to join and can contact us:

## CONTACT

ELN Foundation Office  
Dr. Petra Schrotz-King  
Pettenkoferstrasse 22  
68169 Mannheim  
Germany  
Fon +49-621-383-6966  
Email: nmc@leukemia-net.org



ELN Foundation Fundraising Office  
Dr. Colm Bradley  
Lochside Cottage, West Glen Road  
Houston, Renfrewshire, PA6 7GU  
United Kingdom  
Tel: +44-777-150-8405  
E-mail: cbradley@leukemia-net.org

