

General Meeting of ERIC members

Update on the 1<sup>st</sup> Global CLL Advocates Meeting

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# CLL HORIZONS 2016

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1<sup>ST</sup> INTERNATIONAL CONFERENCE FOR ORGANIZATIONS REPRESENTING PEOPLE WITH CLL  
BELGRADE • SERBIA • 11-13 NOVEMBER 2016



LEUKEMIA  
PATIENT  
ADVOCATES  
FOUNDATION



**CLLAN**  
CLL ADVOCATES NETWORK

Patient advocates from 25 countries in 5 continents

Aim

learn, share and start to think about how to help  
improve outcomes for CLL patients globally

## Agenda - Medical Sessions and Advocacy Sessions

### Medical Sessions

from the biology behind the origins of CLL, through diagnosis, watch & wait, treatment, to relapsed and refractory patients and how they can be treated now and what may be available in the future.

Advocacy topics were designed to help groups start, then manage a well-functioning patient organization.

Unique opportunity for CLL patient organization representatives to meet and network, giving them the opportunity to:

discuss issues facing CLL patients

start to think about what they could do better to help CLL patients in their communities.

## The ERIC perspective and conclusions

The meeting offered a good idea about the scope of activity of advocacy groups active in CLL

Evidently, it is early days and there is still a lot to be done in all three main areas of interest, namely

- access to medication
- education
- patient participation in care

## The ERIC perspective and conclusions

The meeting offered ERIC visibility to a wide community of patient and patient advocacy groups

It also reinforced our belief that this is a very challenging but also promising area for ERIC, relevant also from the perspective of joint funding initiatives (many of the groups attending the meeting are partners in EU-funded consortia, including HARMONY)

*an instructive example*



You wouldn't shoot an arrow if you couldn't see the target!

**TEST BEFORE TREAT!™**



CLL Society



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**TEST BEFORE TREAT!™**

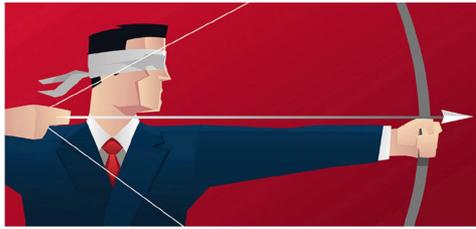


The CLL Society (CLLS) believes that **Smart Patients Get Smart Care™**. Accordingly, patients should work with their HCPs to ensure that their care is based on the best available scientific data.

Appropriate testing before treatment must guide therapy. It eliminates treatment options that are unlikely to help and that could possibly be harmful. It can improve outcomes by identifying the best data driven treatment options.

Despite increasing evidence and guidelines calling for pre-treatment testing, the CLLS knows that many patients are not offered appropriate assessment before initiating therapy.

CLLS see this as unmet need in the CLL community and plans to launch a Test Before Treat™ educational, support, and research initiative in 2017



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## Key elements include:

- Patient survey assessing knowledge and experience with predictive testing
- Focus groups for a more in depth needs assessment of the gaps in best care
- Developing an educational program
- Produce patient-friendly online resources including basic information on predictive and prognostic testing such as:
  - Overview and explanations of predictive and prognostic tests
  - Specific examples including: [FISH](#) | [Notch1](#) | [IG Mutation status](#)
- Develop well-referenced materials for patients and caregivers to share with their HCPs
- Provide online and printable tools for patients to monitor their lab values including predictive and prognostic markers

# ERIC Initiatives on Patient Empowerment

Links and discussions with Patient Groups and Patient Advocacy Groups

e.g. LEPAF, Lymphoma Coalition, Patient Power etc

Pilot programs

e.g. the Greek patient empowerment program encompassing physician communication training  
*patients show the way*

# ERIC Initiatives on Patient Empowerment

Detailed update and proposal – EHA 2017

You are welcome to make suggestions!