



EUROPEAN  
HEMATOLOGY  
ASSOCIATION



**VIENNA**

**20<sup>TH</sup> CONGRESS**

**JUNE 11 - 14 | 2015**

European Hematology Association

# **EHA 2015**

## **Patient Advocates**

# **Capacity Building Meeting**

**Vienna, 13 June 2015**



# Welcome @ EHA 2015: 48 patient advocates from 37 organisations



# Outline of collaboration of patient advocacy orgs with EHA



- EHA's Patient Advocacy Workgroup
- EHA Advocacy Session 2010-2012 -> Track 2013-2015 + exhibition booth + fellowship Programme (50 free registrations in 2013+2014+2015) – **1st time we used all**
- EHA QoL and Symptoms Workgroup
- **New! Patient speakers at SWG meetings**
- **New! Contribution to EHA Research Roadmap project**



# EHA Patient Advocacy Sessions 2010-2015

Opportunity to address „our“ key topics to hematologists and HCPs

- 2010: **Access to clinical trials**
- 2011: **Adherence**: Do your patients take their drugs as prescribed?
- 2012: **Quality of Life**: Do patients perceive it the same way you do?
- 2013: Involving patients as partners in **clinical research**
- 2014: **Generics**  
2014: **Young people with old people's diseases**
- 2015: **Access to treatment**  
2015: **Collaborating with patients for successful haematology research and for assessment of optimal benefits and risks**  
(NEW: call for topics)
- (Molecular blockbuster genetics, doctor-patient communication)

# Aim of this capacity building session:

## Follow-up actions on both Patient Advocacy Sessions

- Short summary of advocacy session on Access & Research (5-10 minutes approx. by session coordinator)
- Discuss follow-up actions, timelines, task distribution:
  - where are we today (on patient involvement in research)
  - where do we want to be
  - how do we get there  
(1-2 tangible follow-up actions with timelines & who does the work)

# Follow-up actions on session “Access to treatment”

- Summary of session on access to treatment
- Discuss follow-up actions, timelines, task distribution:
  - where are we today (on access to treatment)
  - where do we want to be
  - how do we get there / 1-2 tangible follow-up actions with timelines
- Proposed output: a joint toolkit to advocate for access to treatment (who, how and when)





# Follow-up actions on session

“Collaborating with patients for successful haematology research and for assessment of optimal benefits and risks

- Summary of advocacy session
- Discuss follow-up actions, timelines, task distribution:
  - where are we today (on patient involvement in research)
  - where do we want to be
  - how do we get there / 1-2 tangible follow-up actions (who, how and when)
- Ideas:
  - basic practical training for patient advocates on how to involve in research?
  - Your ideas?





**Thank you!**

**Group Photo!**

