












Does the reality of ERNs live up to our hopes and dreams?



Amanda Bok, ePAG member
European Haemophilia Consortium

ERN-EuroBloodNet

Patient organisations covered

	Chronic Myeloid Leukemia: CML Advocates Network	→ 112 members (51 Europe)
	Chronic Lymphocytic Leukemia: CLL Advocates Network	→ 8 members (6 Europe)
	Hemochromatosis: European Federation of Associations of Patients with Haemochromatosis (EFAPH)	→ 21 members
	Hemophilia: European Hemophilia Consortium (EHC)	→ 45 members
	Immune Thrombocytopenia: ITP Support Association	→ 1 member
	Lymphoma: Lymphoma Coalition (LC)	→ 66 members (34 Europe)
	Myelodysplastic Syndromes: International MDS Alliance	→ 22 members (15 Europe)
	Myeloma: Myeloma Patients Europe (MPE)	→ 40 members
	Myeloproliferative Neoplasms: MPN Advocates Network	→ 12 members
	Thalassemia: Thalassaemia International Federation (TIF)	→ 120 members (18 Europe)
	Waldenström's Macroglobulinemia: EWMnetwork	→ <u>14 members</u>
		= 257 European haem. patient organisations (158+99)

EuroBloodNet ePAG members

1. Jan Geissler, CML Advocates Network
2. Ananda Plate, Myeloma Patients Europe
3. Sophie Wintrich, MDS Alliance
4. Pierre Aumont, CLL Advocates Network
5. Loris Brunetta, TIF
6. Amanda Bok, EHC

Our ePAG hopes & dreams

Early diagnosis
&
Second opinions

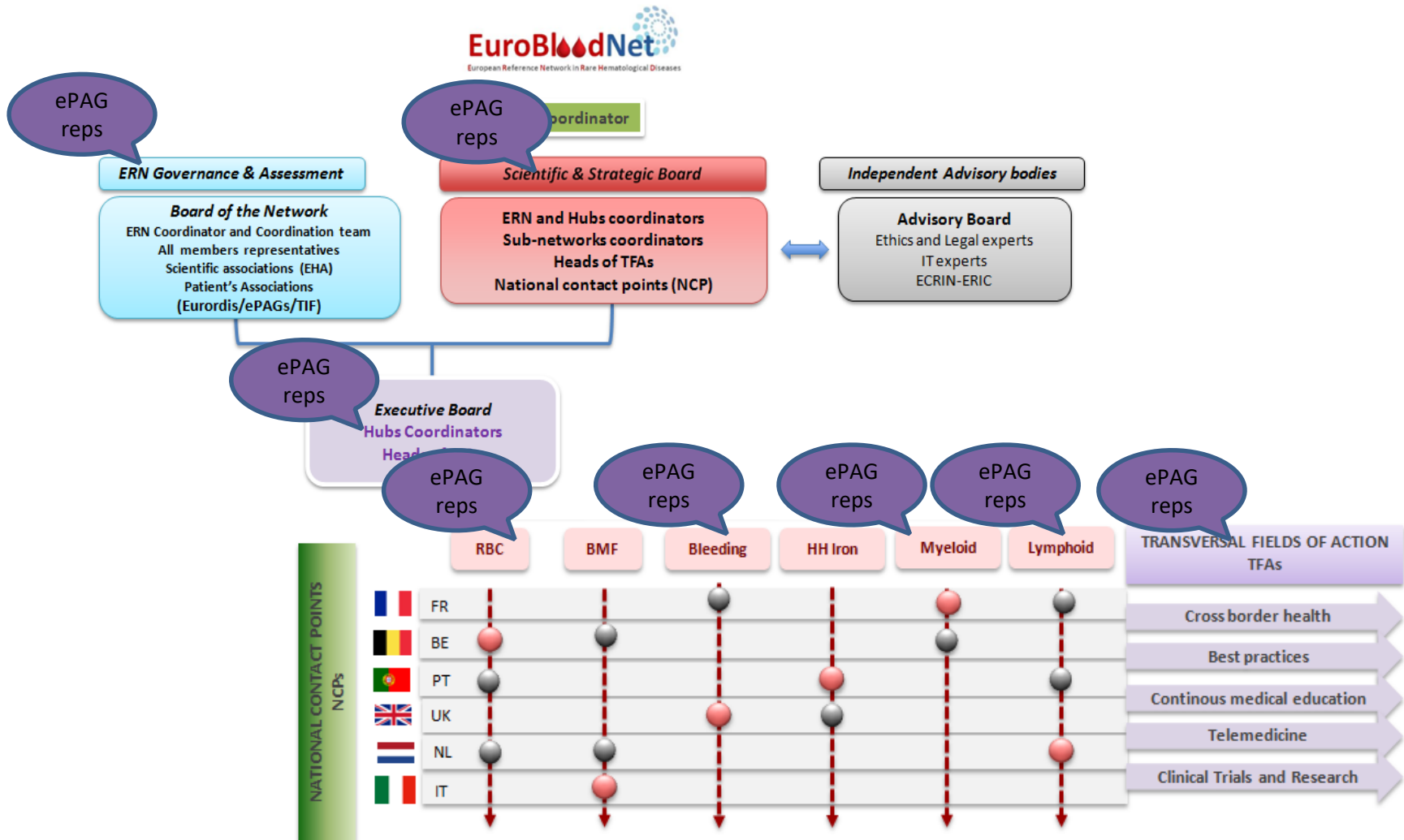
Crossing borders
So patients don't
have to

Best possible
Access to
Best possible
Treatment &
care

Genuinely
Patient-
centered
Treatment &
care



ePAG levels of involvement



Work to-date

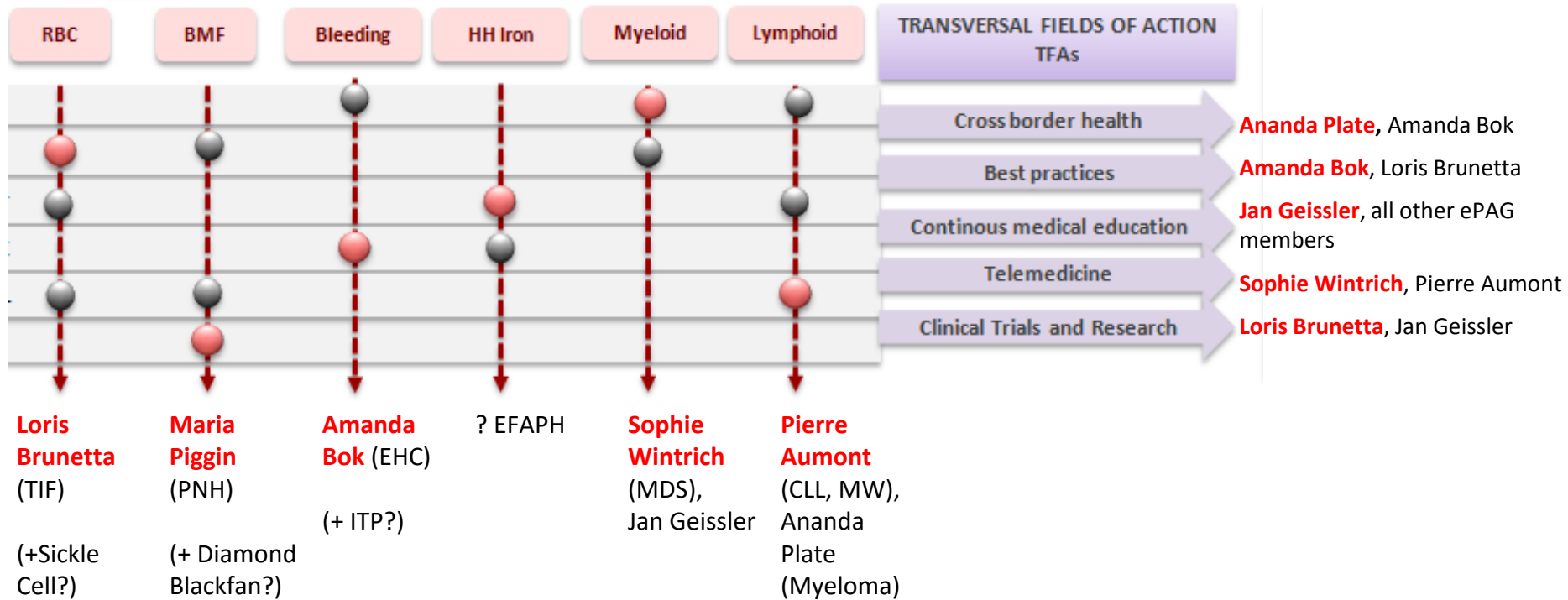
ERN

- Reviewed, commented on ERN application
- EuroBloodNet meetings
 - Pre-launch Board meeting
 - Pre-launch full ERN members meeting
 - Launch (Vilnius) Board meeting

ePAG

- Group communication
 - Group email, Dropbox, WhatsApp
- Teleconference calls
- Two in-person meetings
 - Of which one full-day strategy/operational/division of tasks & responsibilities

Currently: building TFA tandems



Plan: Extension of ePAG by 2 additional members covering Iron and BMF.

Reflection 1

Ethos & philosophy

- ERNs must beware of **facile invocation** of 'patient centricity'
- Opportunity to recognize & **lead cultural shift** towards equal & formal roles for both patients and clinicians

Reflection 2



Hearing & being heard

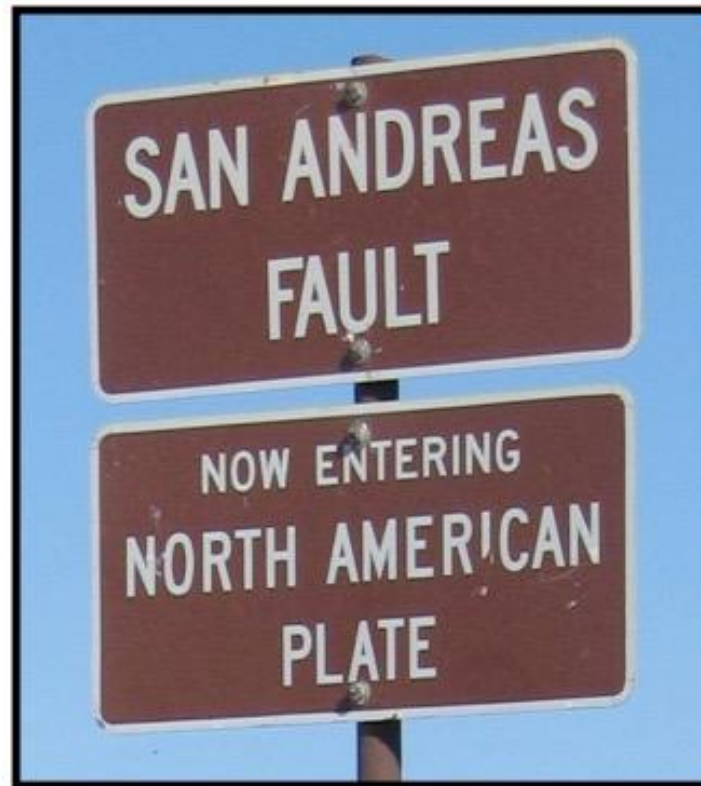
Objective	Priority			
	GLOBAL	ONCOLOGICAL	NON ONCOLOGICAL	ePAGs
Improve equal access to highly specialized healthcare delivery	5th	5th	5th	1st
Promote the best practices in prevention, diagnosis and safe clinical care	1st	2nd/3rd	1st	5th
Disseminate cutting-edge knowledge and facilitate CME	3rd	4th	3rd	4th
Provide inter-professional consultation by sharing of expertise and safe exchange of clinical information	2nd	2nd/3rd	2nd	3rd
Foster European cooperation in highly specialized procedures for diagnosis, innovative treatments and research	4th	1st	4th	2nd

Reflection 3

Management & virtual teams

- Agreed upon expectations
- Agreed upon terms of engagement
- Agreed upon roles & responsibilities
- Clear sources of administrative support

Reflection 4



Visit the fault

Impact & sustainability

- Currently unsustainable (funding) model
 - ERNs are being built on important fault lines:
 - Unpaid patient volunteers
 - Paid patient representatives
 - Even clinicians may start to face internal constraints
- For ERNs to succeed & for patients to drive and sustain their engagement: European institutions and/or others must provide operational funding

What we're building

We're building

- European standardization
 - of treatment & care
- More cohesive approach
 - to complexity of rare diseases
- More patient involvement
 - in healthcare systems & management
- Genuine patient-clinician partnership in ERN+
 - system change

Our ERN building will need

- To do more than duplicate existing links
- To be a 'networks of networks'
 - Paolo Casali, EU Joint Action on Rare Cancers
- To have will-power, passion, drive inhabit it
- To have funding to grow and sustain it

Suggestion:
Central or pooled ePAG Fund
managed by EURORDIS

