



Rare!Together Network Workshop
Barcelona, 19 June 2009
What have we learned? - Where are we going?

9.00 Welcome **Rob Camp**

9.30 Discussion in ECHDO working groups

1. Statutes:

- discussion on who can be member and what does this mean?

Article 4: Membership

There will be three types of members:

- a) active membership (for patient and families organizations) > right to vote
- b) associated members (eg. Non governmental organizations) > no right to vote
- c) Honorary members > no right to vote

Article 7: Board of Directors (BOD)

Constitution of Board:

- proposal to work with existing Core group until elections at first general assembly next year (+ Belgian member since statutes will be submitted there): an official voting has to be announced in the invitation/ own topic on the agenda. A lot of things still have to be settled + not enough information available now for well-thought votes
- Later on ensure that different parties involved are included (adults and parents, eastern and western European countries...)
- We add the following sentence: "There should be at least one parent and one GUCH in the board"
- For additional comments mail to camporama@gmail.com

2. Membership fee: 200 € per annum (can possibly be decreased or waived at discretion of the BOD)

3. Collaboration with Eurordis

- ECHDO is very grateful to Eurordis and Rob for their precious help so far and hope they can continue counting on Eurordis for their further progress

- Would like to become members of Eurordis once ECHDO is settled (can be for free for new organizations)

4. Future Working groups:

Bylaws:

- a. Rob Camp, rare together, Spain
- b. Petra Ales, Slovenia
- c. Maria Escudero, Spain
- d. Anne Keatley-Clark, UK
- e. Katja Laine, Finland
- f. Hanna Milczarek, Poland
- g. Jim O'Brien, GUCH, Ireland

Further board members:

- a. Katja Laine, Finland
- b. Hanna Milczarek, Poland
- c. Jim O'Brien, GUCH, Ireland
- d. Julia Raicheva, Bulgaria
- e. Paul Willgoss, GUCH, UK
- f. Anne Keatley-Clark, UK

5. Miscellaneous:

- Translation in Belgian is necessary (office-place/ EU)
- Rights & duties of members → see By-Laws
- Next EURORDIS-meeting: May 13-15th 2010 in Krakau/ Poland

13.30 – 14.15: Wiki/internet and other work issues; D Costello, Webmaster Eurordis

- <http://raretogether.eurordis.org>
- What is Wiki: Create article about topic. Everyone can work/ comment on it
- Concrete example: working on statutes of ECHDO
- Goal: exchange on an issue and ultimately create guide(lines)
- How
 - a. Create account: fill in username and email (name is seen if you comment, email will not be published)
 - b. Use item/subitem, eg statutes
 - c. Add comment
 - i. Edit comment on page: click 'edit' and write comment
 - ii. Or use discussion page
 - d. Watch: system sends email when article is edited
 - e. Resources area: slide shows, documents, (eg Thalaessimia International Guidebook to establishing a non-profit patient support organization)
 - f. Extra tools:

- i. Article of the week: everyone can suggest
 - ii. News (about rare diseases and health issues)
 - iii. Surveys
- 2. Everyone is invited to have active input!!!

14.15 – 15.00: EU Funding of Health Research and Public Health, C Segovia, ISCIII, International Research Programmes & Institutional Relations

DG= Directorate General (=Department of European Commission)

- Research 7th framework (FP7) / DG Research & INFSO
- Public Health/DG Sanco (Food, Public health and Consumer affairs)
- Structural Funds/DG Regio

How can you have input as a patient association in EU funding?

- Work with determining actors: scientist, policy makers and have enough 'critical mass' (group together with other networks)
- National Contact points can help you to design a project

15.30 - 17.00: Advocacy Workshop, J Dart, President DEBra

Do patients have influence- how and when? - R Camp (Examples from the Aids community)

How? Be there and keep on moving together!

- Be active and flexible: it's up to us, we have to do it, be there whenever and wherever possible and needed
- Strategy: plan long term, analyze and re-adjust (who, what, why, when...) – keep on getting better
- Build partnerships, continuously
- Involvement in treatment education and monitoring (be there- from drug development to delivery and follow-up; be a watch dog)
- Effect and impact on different layers of action within your (disease) field

Consumer Activism - R Babakhanian, Patient Activist Empowering the community: How can we have power in the drug development and healthcare decision-making?

Role in Drug development process

- Good Clinical Trials => make sure CT are meaningful, effective and positive for patients from beginning to the end: in CT design, enrollment, information, conducting of CT, regulatory process, translation into available care
- How:
 - Participate: Community Advisory board (in clinical trial networks, trial sites, from drug companies...); invite drug companies and other stakeholders to a patient-led meeting/platform

- Inform the community (eg media, forums,...)
- Influence decision makers



Focus on your unique position and expertise as 'subject' in CT:
You have power as a consumer/customer

Funding by drug companies

- Can be quicker and more available than official (government/EU) funding
- 'return on investment'
- Be open-minded but transparent

Emergence, Institutionalization and Fragmentation – lessons learned from HIV activism in Barcelona G Valverde, ACTUA

Working as patient associations – be aware!

1. Terminology and language – it is a double edged tool:
 - Do not take language for granted
 - communicate non-judgmentally
2. Political and cultural context
 - a. Listen to everyone – even people who you think (or they think) they are not directly affected
3. Patient is more than disease – think beyond the biomedical; an organization must

Although we may be less organized than the government, it is a reflection of who and what we are, and quite probably we offer a relatively cost-effective service, whatever that may be. Repeating what has been done before, not because it is good, but because it is there, probably won't get us all the way to our goal.

There will be nay-sayers (to you, to the disease, to citizens' rights, etc). Understand them, accept them, move forward.

Introduction to Advocacy - How to influence policy makers Y Le Cam, CEO Eurordis

- We're no lobbyists –not defending particular interest but human, public interest; it's people and lives who are at stake = advocacy.
- Clear communication:
 - o Clear concept/issue – what are you talking about?
 - o Document your issue: facts and testimonies
 - o Clear proposal – positive, realistic, together with experts and all stakeholders
- Work together with all stakeholders: go where you want to go and work with whom you need to get there; negotiate – make people happy, eager to help you

**17.00 – 17.30
President CFE**

Resume of day / ways forward K De Rijcke,

Yes we can! Example from CF Europe

Started really actively 3 years ago- Warsaw meeting with 11 countries from Central&Eastern Europe => desperate mothers–
In 2009: 30 active associations – believe change is possible, planned, did it and had amazing achievements in 3 years time: better access to care, global awareness and stronger associations

Conclusion: Yes we can!

- What? What can be done, must be done... We can make a difference!
Believe change is possible - Right and duty to act. We can have more effect than we think - we are citizens and consumers
- Who? 'Patients' are primary stakeholders - We have to do it, together with all stakeholders (researchers, health care professionals, authorities, other associations-Eurordis...)
- How? Plan, be there, do it !
Be an active partner
Don't be afraid you're too small or weak, turn 'rare' into advantage

17.30 – 17.45

Next steps

R Camp

Please note: Eurordis Annual Meeting in Krakau, 13-15 May 2010

With the support of:

