

### IN SPOTLIGHT EPPOSI's future shaped by its Board

*EPPOSI Board members met in February to discuss the near and long-term future of our organisation. At the top of the agenda: the strategic plan, budget, recruitment and governance.*

**The strategic plan.** After further discussion and clarifications attendees approved the strategic plan that was presented during the 2009 General Assembly. This plan aims at strengthening the work that EPPOSI is performing since its creation and at developing new activities such as research on public health issues at the European level. It was agreed that its implementation, that will take some years, will request the reinforcement of EPPOSI Staff in both terms of human resources and skills.

**Budget 2010.** With an agreement on what should look the organisation like in 5 years time attendees went on to discuss the financial and management needs. The Board adopted a very ambitious budget for 2010 that is in line with the strategic plan. Indeed, this budget already lays the first stone of the plan by foreseeing the recruitment of an Executive Director for the second half of 2010, the training of current staff, and the reinforcement of communication cost needed in order to

strengthen the liaison with members.

This budget is also based on a new membership fee structure in a sense that all members to contribute to EPPOSI financial resources.

The two main reasons are



firstly, in terms of image this will strengthen the neutrality of our Platform and; secondly it will help EPPOSI to fund its development as defined in the approved strategic plan.

**Recruitment of EPPOSI Executive Director.** Profile, job description and responsibilities for the future EPPOSI Executive Director were finalised

and is available on our website.

An internal selection committee was also appointed. This committee, gathering one representative of each EPPOSI constituencies, will screen applicants and will handle first interviews with the objective of providing the Board and executive committee with a short list of pertinent candidates. The final decision will be made in close collaboration with and endorsed by the Board.

**Governance.** The discussion on tasks and responsibilities of the new Executive Director was the occasion to assess and modify the governance structure of EPPOSI. Based on remarks and recommendations made by EPPOSI members, a pre-work note was produced and presented by our executive committee for discussion. The Board agreed on any changes whose general spirit is to reaffirm the role of the Board as representing the general assembly, to simplify the internal decision making process and to empower the Executive Director.

EPPOSI is an **EU patient-led partnership between patients' organisations, science and industry**, founded in 1994 for the exchange of information and discussion of policies in EU human healthcare.

EPPOSI's **primary mission** is to **establish a strong European alliance** of patients' organisations, academic science and industry jointly working on healthcare policies towards **treatment and prevention of serious diseases**.

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## REPORT – 10th Partnering for Rare Diseases Therapy Development Workshop report is available

The report of our tenth Partnering for Rare Disease Therapy Development workshop, held in Brussels in October, is available for download from the Publications section of [www.epposi.org](http://www.epposi.org).

Each participant will receive a printed copy, and the Organising Committee also decided to send a copy to relevant key people in the new European Commission to inform them about the current situation, needs and expectations of the European rare diseases community. The report will be sent with an introductory statement kindly produced by Wills Hughes-Wilson (Genzyme).

## STAFF – Farewell to Annemie



After more than committed 10 years Annemie Vanmolkot has decided to leave EPPOSI. We would like you to join us to thank her for having handled EPPOSI's financial affairs in such a smooth and professional way for all these years. We wish her all the best in her future projects and activities!

## CURRENT ACTIVITIES

### Patients Involvement in Health Technology Assessment – Workshop

Officially launched in February, this EPPOSI project will tackle the burning issue of patients' involvement in Health Technology Assessment (HTA). The first meeting of the Organising Committee unanimously supported the need to deepen the inclusion of patients' concerns and expertise when assessing drugs and treatments. The project aims to determine the role patients could and are willing to play, and also to identify the skills and knowledge they need to do it.

Involving patients in HTA will not just change the decision-making process; the concept of HTA itself will evolve. So the Organising Committee wants to work on a broader HTA approach . one that goes beyond considering cost-effectiveness to include ethical, social and other concerns.

The first, closed, meeting will take place in Brussels (venue still to be confirmed) on 29 June 2010. It will gather around 25 experts to discuss the topics in greater depth and prepare the second meeting for a larger audience. This second meeting will take place in Brussels on 17 November 2010. For further information please contact us at [info@epposi.org](mailto:info@epposi.org) or check our website in the coming weeks.

The three co-chairs for this event are Alastair Kent, Genetic Interest Group, representing patients; Prof. Karen Facey, University of Glasgow, representing science; and Andrea Rappagliosi, GSK, representing industry.

### European Strategy for Chronic Conditions – Second Workshop

This one-day open event will focus on the challenges faced by patients with chronic diseases. It will point out the specific burdens that chronic conditions put on patients, in comparison with other acute diseases; these burdens go beyond the commonly mentioned one financial impact. Indeed, living with one . or as so often happens more than one . chronic disease has a huge impact on all aspects of their lives and those of their relatives. These specific needs call for specific solutions. Key topics would include eHealth, social and medical dimensions, and economic issues.

The workshop will take place on 9 December 2010 in Brussels (The venue is still to be confirmed). Please note that EPPOSI is working to be officially supported by the EU Belgian Presidency, which begins on 1 July and whose top priorities include tackling chronic disease. The Belgian Presidency is organising its own event on this topic

next autumn, and EPPOSI plans to discuss with officials the right moment to organise it.

For further information please contact us at [info@epposi.org](mailto:info@epposi.org) or check our website in the coming weeks.

The organising committee for the December workshop is co-chaired by Rod Mitchell, European Federation of Crohn's and Ulcerative Colitis Associations, representing patients; Bernard Maillet, UEMS (European Union of Medical Specialists), representing science; and Detlef Niese, Novartis, representing industry.

**Patients with  
chronic diseases  
call for  
specific solutions**

## 11<sup>th</sup> Partnering for Rare Diseases Therapy Development Workshop Ě Prague 2010

Preparations for the eleventh Partnering for Rare Diseases Therapy Development workshop began in February when the Organising Committee gathered for the first time. Prague was chosen as the venue after the committee stressed the importance of including eastern European countries in the rare diseases community and debate. The workshop will take place on 29 and 30 November 2010 in the Czech Senate.

More information will be soon available on [www.epposi.org](http://www.epposi.org)!

The Organising Committee is co-chaired by Lesley Greene, Children Living with Metabolic Diseases, representing patients; Prof. Milan Macek, University of Motol, representing science; and Andrea Rappagliosi, GSK . representing Industry.



An Organising Committee will be launch on the 18th of May for the preparation of a second workshop on **Registries for Rare Diseases**.

If you wish to join this committee. or one of the three other 2010 activities - please contact Jonathan at [jonathan.ventura@epposi.org](mailto:jonathan.ventura@epposi.org)

## VISIBILITY

## OUTSIDE

### CLINICAL TRIALS - EU PATIENTSPARTNER PROJECT

*Partnering for a more patient-centred healthcare and more cost-effective quality research.*



EPPOSI attended the PatientPartner Southern Europe regional workshop in Athens on 24 & 25 March. Over two days, the workshop brought together representatives of patients, sponsors and investigators to define *the needs and means for more partnership in clinical trials* in this region of European region. Delegates . from Cyprus, France, Greece, Italy, Malta, Portugal, Spain and Turkey . worked in small groups with their fellow stakeholders and more broadly to discuss the role they expect and want patientsqorganisations to play in clinical trials. This led to a broader reflection of the role of each stakeholder group, its expectations of the other stakeholders, and to consideration of what they need to play a full part in reinforcing partnership.

Delegates came out with a list of concrete recommendations, united by a common theme: the need to gain a better understanding of each other as the starting point for a more collaborative relationship between patientsqorganisations, sponsors and investigators in clinical trials.

The full reports of the three regional workshops (North-Western Europe, Central-Eastern Europe and Southern Europe) are available on the PatientPartner website, [www.patientpartner-europe.eu](http://www.patientpartner-europe.eu), along with the report of the Start-Up Workshop, held in London last year. The final workshop, with stakeholders from all over Europe, will take place in Brussels in autumn 2010.

### EPPOSI ALSO ATTENDED...

**EFGCP Annual Conference, Brussels, 26-27 January.**

The theme of this 2010 edition was %Aspects of personalised medicine for society . a challenge yet to be met+

**European Haemophilia Consortium: Ageing Haemophilia, Brussels, 23 February.**

The theme of this roundtable was %How to address the economic and medical challenges of ageing with haemophilia and support the patients?+ A summary report is available [here](#)

**EURORDISĀ Rare Diseases Day Conference, Brussels, 1 March.**

The theme of Rare Diseases Day 2010 was the added value of %bridging patients and researchers to build the future agenda for rare diseases research in Europe+

### EPPOSI APPEARED INĀ

The **European Society for Medical Oncology** published an article on our 10<sup>th</sup> workshop on Partnering for Rare Diseases Therapy Development (Brussels, 2009) on its website. The full article is available [here](#).

## CHRONIC CONDITIONS - EUROPEAN LIFE SCIENCE CIRCLE

### Patient empowerment: a policy tool to address the burden of chronic diseases in Europe?



Some years ago the European Commission's Pharmaceutical Forum stressed the need to ensure that patients receive correct information about prescription-only medicines. This led the Commission to issue a proposal (still under discussion) about how to improve this information in terms of both

form and substance. Behind this move lies the concept of patient empowerment: the more European patients are informed about possible treatments or cares, the more they will be able to play an active role in managing their disease.

In February, MEP Jorgo Chatzimakakis organised a multi-stakeholder meeting of the European Life

Science Circle (which he set up in 2006) in Brussels to address this concept, with a special focus on chronic diseases.

With the ageing European population, the burden of chronic diseases on European healthcare costs is and will be more and more a controversial issue. Policy initiatives are needed, and the new paradigm of patient empowerment

could be a key element in improving medical outcomes while reducing costs in chronic diseases. The meeting heard, among other ideas, the example of self-monitoring of blood glucose by patients with diabetes. This self-monitoring is now an important component of modern therapy for diabetes and can help to prevent hypoglycaemia.

## EPPOSI

## MEMBERSHIP

### Prof. Jean-Jacques Cassiman gave the Joseph Hoet Lecture at the EFGCP Annual Conference 2010

EPPOSI secretary Prof. Jean-Jacques Cassiman, from the Catholic University of Leuven, gave the Joseph Hoet lecture on ethics in clinical research at the EFGCP annual conference in Brussels in January. His talk was entitled 'Patients' needs for better treatment and the impact of personalised medicine on society: the advantages and risks of the genomic medicine'.



Pr. Cassiman receives the Joseph Hoet Medal from Pr. Frank Wells (EFGCP)

## EPPOSI MEMBERSHIP UPCOMING ACTIVITIES



### Joint EFGCP-EUCROF Workshop on Ethical Challenges in Clinical Research at Both Ends of Life: Common Lessons to be Learnt from

Paediatric & Geriatric Clinical Development  
27 & 28 April 2010, Brussels, Belgium

### Children's Medicines Working Party Annual 6th Conference & DIA 4th Paediatric Forum on Current & Future Medical Child Care: Visions, Daily Challenges, Ways Forward

28 & 29 September 2010, London, UK  
More information on [www.efgcp.be](http://www.efgcp.be)



### Future of Independent Academic Clinical Research in Europe

2 September 2010,

Brussels Belgium



### 5th European Conference on Rare Diseases

13-15 May 2010, Krakow, Poland

More information on [www.eurordis.org](http://www.eurordis.org)



### GIG Annual Conference 2010

8 June 2010, London, UK

More Information on [www.gig.org.uk](http://www.gig.org.uk)

### How can we support the development of a national strategy for Rare Disease in the UK? (Europlan conference)

16 November 2010, Manchester, UK

More information on [www.raredisease.org.uk](http://www.raredisease.org.uk)

## OTHER EVENT

### 78th EAS Congress

20 -23 June 2010, Hamburg, Germany

More information on [www2.kenes.com](http://www2.kenes.com)

## INTERESTING DOCUMENTS



Thalassaemia  
International  
Federation

### 2nd Pan-European Conference on Haemoglobinopathies

13-14 March 2010, Berlin, Germany

Press release downloadable on

[www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)

# Members

## Honorary Members

- Philippe Busquin
- Ysbrand Poortman
- Cees Smit

## Academic Sciences :

- EFB
- EFGCP
- ELSO
- EMA
- EORTC
- ESCI
- ESHGI
- INSERM /Orphanet
- UEMS

## Patients Organisations:

- EATG
- EFCCA
- EFNA
- EGAN
- EHC
- EuropaUomo
- EURORDIS
- GAMIAN Europe
- HEART EU
- Retina International
- TIF

## Industries

- Amgen
- Baxter
- BiogenIdec
- Celgene
- CSL Behring
- Genzyme
- Gilead
- GlaxoSmithKline
- Johnson&Johnson
- Merck-Serono
- Novartis
- Pfizer
- Roche
- SERVIER
- Shire HGT

## Industry Associations

- EBE
- EDMA
- EFPIA
- EUCOMED
- EuropaBio
- PPTA

## Observers

- David Bennett
- Hugo Schepens
- Peter Streng

# Objectives

- To encourage timely and regular exchange of information between patients' organisations, science and industry on the latest developments in human health care related to (bio-) medical research, policy and regulations and the ethical, social, legal and political aspects of this type of research and of biotechnology and its application to human health care
- To promote mutual understanding between patients' organisations, science, industry and the institutions of the European Union, and to contribute to equal access for all to products and services for human health care in Europe
- To encourage a timely and effective contribution of patients' organisations to the European political debate on matters that concern them
- To promote public awareness in Europe regarding the position of patients and their organisations
- To encourage a dialogue within society on progress in medical science through new technologies
- To promote the development of therapies for unmet medical needs and to facilitate partnerships within society.

## EPPOSI Board

Ségolène Aymé, Orphanet  
 Ivan C. Baines, ELSO  
 Tamás Bereczky, EATG  
 Jean-Jacques Cassiman, ESHG ( EPPOSI Secretary)  
 Avril Daly, Retina International  
 Louis Denis, EuropaUomo  
 Dolores Gauci, Gamian-Europe  
 Alastair Kent, GIG/EGAN (EPPOSI Chair)  
 Yann Le Cam, Eurordis (EPPOSI Treasurer)  
 Michael Livingston, HEART-EU  
 Bernard Mai llet, UEMS  
 Silvia Matile-Steiner , Roche  
 Rod Mitchell, EFCCA  
 Detlef Niese, Novartis  
 Karl Petrovsky, Baxter  
 Andrea, Rappagliosi GSK  
 Christian Suojanen, EFB  
 Erik Tambuyzer, Genzyme (EPPOSI Vice-Chair)

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