

## EPF Newsletter – Special Issue: 2014 Annual Review and Season's Greetings

*Welcome to this special issue of our newsletter dedicated to this year's key highlights as 2014 draws to a close. This is not an exhaustive document as more details will be available in our 2014 Annual Report but we hope to give you a real flavour of what happened at EPF over the past months.*

*First of all let us thank wholeheartedly all our member organisations, both new and old, for their contribution to much of our 2014 achievements. They participated both in person at our various events and workshops, and also through regular written communication and input to our policy and programme work. This collective investment drives the European Patients' Movement to be a strong voice for patients in Europe.*

*Similarly, we are grateful to our many allies and fellow stakeholders who work with us on a daily basis. Together we help to advance patient-centred, equitable and sustainable health systems in Europe, which is sometimes challenging in austerity times.*

*There have been some really fantastic and memorable times this year and we are proud to share some of these achievements with you. Enjoy the reading of this issue and we hope you have a restful and happy break with family and friends for the festive season.*

*We look forward to working together with you again in 2015!*



Two handwritten signatures in blue ink. The first signature is 'A.O.' and the second is 'N.B.'. They are positioned below the portrait photos.

Anders Olauson, EPF President, and Nicola Bedlington, EPF Secretary General, on behalf of the EPF board and EPF Secretariat Team

## JANUARY

### NEW STRATEGIC PLAN, DISCRIMINATION AT THE SPOTLIGHT

In January, we unveiled our [seven-year strategic roadmap](#), designed to work effectively during the [2014-2020 Health Programme](#) period, to drive better health for patients in Europe. We defined non-discrimination as one of our main goals to raise awareness of stigmas that patients continue to face in the European Union.

This topic was the focus of '*Health in Europe, making it fairer*', a landmark conference organised in March by the Directorate for Health of the European Commission ([DG SANCO](#)). We reiterated on this occasion, in a joint statement with the European Public Health Alliance ([EPHA](#)), the urgency to adopt the [Council Directive](#) on the principle of equal treatment between persons.

We closed the year by preparing a position paper called '*Healthcare for all*' to be released in early 2015. This document, developed in consultation with our members, will raise awareness about discrimination patients are still facing today and provide recommendations to EU decision-makers on how to tackle this challenge effectively.



### NEW JOINT ACTION ON CHRONIC DISEASES

January marked the official launch of the new Joint Action on Chronic Diseases, named 'EU Joint Action on Chronic Diseases and promoting healthy ageing across the life-cycle' or [CHRODIS-JA](#).

EPF will provide the patients' perspective as a partner in this three-year project that aims to confront the challenge caused by chronic disease. This collaboration builds on the policy work we did around the 'reflection process on chronic diseases' initiated by the European Commission and member states (see [paper](#), 2012).

EPF participated to the April's [Chronic Disease Summit](#) organised by the European Commission's [DG SANCO](#). The event aimed at developing a set of policy recommendations for action on how the medical, social and economic burden of chronic diseases should be tackled in the European Union now and in the years to come.

More information about CHRODIS-JA: [www.chrodis.eu](http://www.chrodis.eu).

## **PATIENT SAFETY AND QUALITY**

The EU accomplished a great deal on patient safety and quality of care this year. The [Commission Patient Safety and Quality of Care Working Group](#) met in February to discuss the 2014 agenda. Two sub-groups established in late 2013 drafted recommendations on reporting and learning systems and education of health professionals where EPF contributed, including specific sections on the role of patients and families.

This year we also continued our input into the “Patient Safety and Quality of Care” project or “[PaSQ](#)” Joint Action (JA) by evaluating the implementation of safe clinical practices in 17 countries.

EPF contributed the patients’ view to some of them. We will also produce a paper in 2015 on patient involvement and empowerment in patient safety based on the consultation with our members and the good examples contributed by the project partners and stakeholders. More information on PASQ website: [www.pasq.eu](http://www.pasq.eu).

In June, the European Commission published long-awaited reports on patient safety and quality of care – links are all available [here](#).

Later in October, the [European Commission Expert Panel on Effective Ways of Investing in Health](#) approved the “Future EU Agenda on quality of health care with a special emphasis on

patient safety” ([link](#)). As part of the working group that developed this report, EPF emphasised the importance of patient-centred healthcare systems, as patients’ views, preferences and experiences could constitute an indicator to measure the quality of care.



In December, the Council of the EU adopted the conclusions on patient safety and quality of care ([link](#), PDF) which EPF welcomed positively. The text encourages the *"participation and empowerment of patients, families and their informal caregivers, as well as patient organisations, through evidence-based and unbiased provision of information and education, and promote patients' participation in decision-making in the healthcare process in order to contribute to the prevention of adverse events."*



## MARCH

### THE POWER OF PATIENT 3.0 OR PATIENT EMPOWERMENT



The March's [Careum Congress](#) 2014 entitled "The power of patients 3.0" explored ways to engage patients in future healthcare systems.

This Congress was also the second conference of the European Network on Patient Empowerment ([ENOPE](#)), in which EPF is a member. The event highlighted patient-related innovations and solutions that will shape the future of our health systems and centre on the patient.

Patient empowerment was also at the centre of the [EMPATHiE tender "EMpowering PATients in the management of chronic diseases"](#) that ended in September. EPF took part in this tender to achieve a common understanding of the concept and identify good practices, success factors and barriers.

The results of the Tender will be publicly available in 2015.

EPF will lead on a patient empowerment campaign next year that will run until mid-2016, starting with a launch conference on 20-21 May 2015. This campaign will take the European

discussions a crucial next step forward – towards concrete actions at practical and political levels, led by the

patient community in partnership with all relevant stakeholders.

It will provide an unprecedented opportunity to advance patient empowerment in a sustainable way, and create the environment to contribute towards genuine sustainability of health systems and societal 'growth'.

### HEALTH DIMENSION IN THE FINANCIAL FRAMEWORK

Long-term European programmes include the new [Multi-annual Financial Framework 2014-2020](#) which will go under review in 2015.

EPF together with the European Public Health Alliance ([EPHA](#)) expressed our views on the Europe 2020 Strategy in an open letter, raising issues linked to the poverty, education, research, and employment targets ([link](#)).

## APRIL

### PATIENTS' ROLE IN AFFORDABLE HEALTHCARE



In April the first in a series of five workshops took place under the [We Care project](#) that work “Towards a sustainable and affordable healthcare”.

As an associate partner, we played a core advisory role to ensure patients' involvement is no longer considered as a cost-driver but as the essential part of the solution for cost-effective planning.

Health literacy, patients' participation in the innovation process and an enabling healthcare environment were identified as core criteria.

[www.we-do-care.eu](http://www.we-do-care.eu)

### SPEND NOT MORE BUT SMARTER

Since December 2010, the [InterQuality project](#) investigated the effects of financing systems on the quality of healthcare.

The knowledge gained from the 4-year research provided useful input for European countries. It helps them to choose the right financing mechanisms in different areas of their healthcare systems, according to their needs and resources, and to pay not more, but smarter.

The project examined ways of funding and incentive systems affecting the quality, effectiveness and equity of access to healthcare in four areas: pharmaceutical care, hospital care, ambulatory care and integrated healthcare.



The project outcomes are available on [video](#).

[www.interqualityproject.eu](http://www.interqualityproject.eu)

## MAY

### NEW MEMBERS, NEW BOARD

We launched two members' [working groups](#) on patient empowerment and access at our [2014 Annual General Meeting](#) (AGM) in May to consolidate our work in these areas.



EPF now represents 64 patient organisations as new memberships were approved at our AGM. The [Hungarian Alliance of Patients' Organisations](#) (HAPO), the Croatian Coalition of Associations in Healthcare (CAH), the [European Aids Treatment Group](#) (EATG), and the [European Haemophilia Consortium](#) (EHC) have joined EPF as Full members, while the [Health and Social Care Alliance Scotland](#) became an Associate member.

Our members also elected new members to the [EPF Board](#). We were delighted to welcome two new members: Brian Charles West of the European AIDS Treatment Group (EATG) and Dominik Tomek of the Association for the Protection of Patients' Rights in Slovak Republic.

Anders Olauson, Susanna Palkonen and Tomasz Szelągowski were elected once again, respectively as EPF President, Vice-President and Treasurer.

Avril Daly and Philip Chircop stepped down this year and we thanked them for their great commitment.



### OUR VOTE FOR A HEALTHIER EUROPE

Our [Campaign for the 2014 EU Elections](#) ended on 25 May when the votes closed. Out of the 75 candidates who supported our Manifesto, 34 were re-elected ([link](#)) and we

will work with them to ensure that patients have the right place on the European healthcare agenda.

Together with the wider health community, EPF welcomed the European Commission President Juncker's decision in October to keep the pharmaceutical portfolio in the Directorate-General for Health and Consumers ([DG SANCO](#)). His initial intention was to give this responsibility to DG for Enterprise and Industry ([DG ENTR](#)).

We remain puzzled however that health technologies' dossier is transferred to the Enterprise Directorate. We expressed our concerns regarding this move together with other health stakeholders in a joint letter ([link](#)).

Vytenis Andriukaitis, a former Lithuanian health minister and doctor, began his mandate as the new EU commissioner for health and Food Safety in November. He summed up his main priorities as being 'Promotion, Prevention, and Protection' ([link](#), PDF).



## JUNE

### HEALTHCARE FOR HEALTHY AGEING

The [Uppsala Health Summit](#) in June focused on "Healthcare for Healthy Ageing". The European Union has given increased attention to this issue over the last few years, notably through the [European Innovation Partnership on Active and Healthy Ageing](#) and shared a great video this year on this ([link](#), YouTube).



EPF believes more actions from decision-makers are necessary to advance the rights of older patients. Therefore we took the opportunity of this event to reiterate our [position on the rights and needs of older patients](#).

This paper highlights important flaws that have been identified by patient organisations in the care for older people and provides recommendations for the EU institutions, Member States, and health stakeholders.

To read our position paper, please [click here \(PDF\)](#).

### June



### MORE TRANSPARENCY ON CLINICAL TRIALS

The new [EU Clinical Trials Regulation](#) entered into force on 16 June 2014. As part of this Regulation, patients can now look for clinical trials' information

on [www.clinicaltrialsregister.eu](#) as [European Medicines Agency](#) (EMA) made them publicly available since July.

This Register is the public repository of information contained in the [EudraCT database](#), the central EU database used by national competent authorities.

We were delighted with this decision as we have called for the publication of the results of all clinical trials in a timely manner, regardless of the outcomes, since the beginning of our involvement with EU clinical trials legislation and through our support of the [All Trials campaign](#).

The EMA also formally adopted in October 2014 its new [policy for the release of clinical trial data](#). EPF has released a statement to welcome it as a step forward towards greater transparency of the regulatory process on clinical trials ([link](#)).

## BUILDING AN ACADEMY OF EXPERTS WITH EUPATI

The European Patient's Academy on Therapeutic Innovation ([EUPATI](#)) hosted a workshop in July in Germany, to discuss a concrete way forward that supports meaningful patient involvement in Research and Development (R&D).

The EUPATI Expert Training Course started in October to provide patient advocates with the opportunity to receive expert-level training in medicines R&D ([link](#)).

Applications for the 2015-2016 course will be open on the [EUPATI website](#) on 19 January 2015 with the deadline for submitting applications of 31 March 2015.

One of the project's goals to facilitate its implementation is to support the creation of EUPATI National Platforms in each of the 12 participating countries. The Spanish platform was established in October following two other successful launches earlier this year in the UK and in Ireland.

[www.patientsacademy.eu](http://www.patientsacademy.eu)



## INNOVATION ON THE AGENDA OF THE ITALIAN PRESIDENCY

As from 1 July, Italy held the Presidency of the Council of the European Union until 31 December. Health-related issues represented a priority of the Italian Presidency

EPF gave a keynote speech at the conference on “Innovation systems and prospects of health” organised by the Italian Presidency in September in Italy. The event put the spotlight on ongoing initiatives to support the development of innovative medicines and making patient's access to new treatments easier.

From the patients' perspective, although access to new and improved medicines is crucial in many disease areas, innovation should not be defined purely in pharmaceutical terms. We highlighted that innovation should be based on a patient-centred approach; patient involvement is needed to determine what innovation adds in terms of real value and improvement to people's lives.

[italia2014.eu](http://italia2014.eu)



## AUGUST

### BUILDING OUR MEMBERS' CAPACITY

In August we reached a key milestone in our [Capacity Building Programme](#) with the training on fundraising for our European members. 10 of them had the opportunity to acquire more expertise and practical tools on how to diversify funding and create a viable financial structure.

The training phase will finish at the end of 2014 with the development of a toolkit on this topic, expected for late January 2015.

Earlier this year, Slovakia and Bulgaria, who joined the Programme in late 2013, entered the first phase of the Programme. At this stage, they learned more about strategic planning and how to assess their organisational capacity.

Throughout the year 18 patients' organisations from Romania and Hungary participated in the second phase of the Programme.

Much more implementation-oriented, this level consists in providing training related to operational planning. Evaluation of the first two phases of the Programme is undergoing in these two countries alongside planning for the next phase consisting of a thematic training on fundraising.

In 2014 EPF started to support our Cypriot member (the [Pancyprian Federation Of Patients Associations and Friends](#)) in developing their first-ever strategic plan. This is part of their overall approach to raise the profile of the organisation as an equal partner in the national debate around health issues.



## SEPTEMBER

### EPF YOUTH GROUP PLANS FOR THE FUTURE

The [EPF Youth Group](#) met for its 4th Annual Meeting in September in Brussels. The young patient representatives discussed their plans for 2015-2017 and identified three main thematic areas for further discussion: discrimination, transition to adult care and capacity development.

The group wishes to sensitise civil society and policy-makers on the consequences of living as a young person with chronic conditions that may lead to discrimination. They expect policy-makers to set up a legislative framework that protects them and promotes equal opportunities.

The report of the [EMPATHY Project “Europe Meets Young Patients”](#), which consisted of a four-day seminar held in 2013 - was also made available [here](#) (PDF).



### PISCES ENHANCING SELF-CARE IN EUROPE WITH PISCE

Self-care is gaining considerable attention in the healthcare field, as patients are gradually taking a new and more active role.

EPF is involved since September in a 16-months brand new pilot project on the ‘promotion of Self-Care systems in the European Union’ called [PISCE](#).

This tender will create a platform of experts in self-care and healthcare to enhance this type of care at EU level and develop strategies to support its broader implementation.

## OCTOBER

### STRONG PATIENT REPRESENTATION IN GASTEIN

The [European Health Forum Gastein](#) (EHFG) was held in October in Austria. Many patients' representatives were present at this important European health policy event, and not only in the 'patient-focused' sessions.

We took this chance to reiterate some important messages, specifically on patient empowerment with health literacy as a key tenet, patients' access to quality healthcare and patients' involvement in research and decision-making.

This 17<sup>th</sup> EHFG conference was themed "Electing health – The Europe we want!" reflecting May's European Parliament election. We took this opportunity to mention our campaign for the 2014 EU Elections.

Our Policy Officer Laurène Souchet shared her experience on our [blog](#) of being the first patient representative in the Young Gasteiner programme.

The full and detailed report of the Gastein event is available [here](#) (PDF) and our article is available [here](#).



### A EUROPEAN TOUR ON CROSS-BORDER HEALTHCARE

The last [EPF Cross-Border Healthcare Regional Conference](#) took place in Estonia in October. This event was the

final one in a series of four on this topic. We organised them in collaboration with the European Commission to contribute to the implementation of the Cross-Border Healthcare Directive.

Patient leaders from 20 European countries now better understand the details of this legislation and its transposition at national level.

EPF will continue on this path in 2015 with national workshops organised in the eight remaining countries (Croatia, Bulgaria, Poland, United Kingdom, Ireland, Romania, Spain, and Portugal).

The European Commission will assess the implementation of the Directive in Member States in 2015 and we will ensure that grassroots patients' experiences inform it.

More information: <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>



## NOVEMBER

### IMPORTANT ACHIEVEMENTS IN THE FIELD OF MEDICAL DEVICES

In November EPF sent recommendations to the Council on the Regulation on in vitro diagnostics medical devices<sup>1</sup>. We have updated our previous position in collaboration with our members as the text is now discussed in the Council after the European Parliament's revision.

We hope that the revised law will increase transparency on the safety of this type of devices and provide better access to quality information.

In January, we held with the MedTech industry association Eucomed an interactive workshop to have an open exchange of views on the [EU Medical Devices Directive](#). The aim was to acquire a common understanding on the position of both patient groups and the medical devices industry on this.

In April the European Parliament formally [adopted](#) the report on Medical Devices ([link](#)) for which we released a position in 2013. We supported it as it ensured safer devices and more transparency.

We further wrote a letter to ex-Consumers Affairs Commissioner Neven Mimica to ensure the Commission supports this Parliament's first reading position. His office reassured us that patient safety and transparency were well taken into account in the review process.

We urged the Council to give priority to this dossier to ensure patients can benefit from provisions to improve safety of their devices, availability of information, and a better vigilance system.

In October we held with EUCOMED our 8th Dialogue meeting, a constructive platform of exchange between patients' organisations and the MedTech industry. An important item on the agenda was the release of a patient-centred checklist for companies to better involve patients in the medical devices sector ([more information](#)).



## DECEMBER

### UP AND RUNNING PATIENT-LED PARTNERSHIP ON ACCESS

Our major focus on health inequalities led us, with our Bulgarian member, the [National Patient Organisation](#) (NPO), to set up the [Patient Access Partnership](#).

It consists of a patient-led multi-stakeholder partnership that will look for innovative solutions to reduce inequities in access to quality healthcare in Europe.

The inaugural Partners' Assembly meeting took place in December. The participants identified three work streams to embark on the pilot platform: they will first map existing practices and indicators of access to help develop a measurement tool which is the second step that will set standards of quality access to healthcare. This concrete deliverable will in turn inform the Platform's last phase towards shaping the national and European agenda on access.

On 27 January 2015 there will be the launch of the Interest Group on Access to healthcare in the European Parliament. This Group led by Andrey Kovatchev (ALDE, Bulgaria) ([link to blog article](#)) will play a bridging role between the multi-stakeholder platform and the European Parliament.



### PATIENT TO SHARE HEALTH DATA FOR RESEARCH

EPF has joined the '[European Data in Health Research Alliance](#)' that was officially set up in December. This alliance brings together academic,

patient and research organisations from across Europe to ensure decision-makers understand the importance of having data protections rules that facilitate research. In addition it will demonstrate that patients and researchers have the same concerns and are united on this question.

We, as patients, are increasingly aware of the value and importance of sharing our data. From our perspective, use of health and genetic data is vital to advancing health research – this includes public health research, medical research and social science research (including psycho-social research). Therefore ensuring we strike the right balance on the research and consent provisions is essential to us.

In March 2014 the European Parliament adopted a first reading position for stricter rules on consent for research. If implemented, this Regulation would harm health research by creating an obligation to seek specific consent when personal data is used ([link to more information](#)).

## EPF SECRETARIAT

### WELCOME!

EPF was glad to welcome three new staff members in our Secretariat Team this year:

**Anke Seidler** was appointed Head of the Brussels office in December. She will coordinate the EPF Secretariat team in line with the thematic approach and manage the finances of the organisation.

**Danielle Flores** also joined the team in December as an Administrative Assistant to the Policy and Programme team. She will support the operational staff to drive better policies and projects for EPF.

**Stefania Laferte** joined EPF in May 2014 as a part-time Assistant. She supports the Secretary General and Office manager.



### BYE-BYE AND ALL THE BEST!

Three staff members left the team to discover new horizons:

**Peter Windey** joined EPF in March 2012 as Finance and Operations Manager. We wish him all the best with his retirement and thank him for his dedication and professionalism.

**Brooke Aksnes** joined EPF in February 2014, firstly as a volunteer and after as an Assistant, to support our Communication activities. We wish her all the best with her studies and thank her for her great motivation and dynamism.

**Leah Cozens** joined EPF as Team Administrative Assistant in May 2014. We wish her all the best in Australia and thank her for her support.



## SAVE THE DATES OF THE 2015 EPF EVENTS!

- 1 January 2015 | [Latvian Presidency of the Council of the European Union](#)
- 19 January 2015 | Launch of the [Second EUPATI Expert Patient Training Course](#) on medicines' Research and Development
- 27 January 2015 | Launch of [MEP Interest Group on Access to Healthcare](#), Brussels, Belgium
- From January until May 2015 | [National workshops on Cross-Border Healthcare](#)

EPF will monitor the implementation of the Cross-Border Healthcare Directive in the eight countries not covered by our 2013-2014 Regional Conferences on this topic:

- 27 January 2015 | For [Croatian Patient organisations' representatives](#), Zagreb, Croatia
- 10 March 2015 | For Polish Patient organisations' representatives, Poland
- March 2015 | For Spanish and Portuguese Patient organisations' representatives, Spain
- 20 April 2015 | For Romanian Patient organisations' representatives, Bucharest, Romania
- April 2015 | For Bulgarian Patient organisations' representatives, Bulgaria
- April 2015 | For British and Irish Patient organisations' representatives, Dublin, Ireland

- Spring 2015 | [Working Groups](#) on Patient Empowerment and on Access to Healthcare, Brussels, Belgium
- 14-15 April 2015 | [WE CARE Final Conference](#), Gothenburg Sweden
- 11-13 May 2015 | [E-health Week](#), Riga, Latvia
- 19 May 2015 | [EPF Annual General Meeting](#), Brussels, Belgium
- 20-21 May 2015 | Conference on Patient Empowerment and Official Campaign Launch, Brussels, Belgium
- Early July 2015 | [EU Conference on Cross-Border Healthcare](#), Brussels, Belgium
- 30 Sept-2 October 2015 | [European Health Forum Gastein](#), Gastein, Austria



