

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// SPECIAL EDITION: 2013 ANNUAL REVIEW

A WORD FROM EPF PRESIDENT AND DIRECTOR

Welcome to EPF's Review of 2013 which describes some of the highlights of this exciting year. It is not an exhaustive document - more details will be available in our 2013 Annual Report – but we hope it will give you a real flavour of key developments in the last 12 months.

We would like to take this opportunity to thank wholeheartedly all our member organisations, both new and old, which have contributed so much to the achievements of 2013, 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 by our members drives EPF to be a united and effective voice for patients, striving for a society for all. We are very much looking forward to working with you in 2014.

We would also like to thank our many allies and fellow stakeholders who work with us on a daily basis to help to advance patient centred, equitable healthcare in Europe. We live in very challenging times, and only by really working together will we be able to engineer the changes needed for empowerment, equity, quality and sustainability.

Our warmest greetings for the festive season and for the New Year!

Anders Olason, EPF President, and Nicola Bedlington, EPF Executive Director, on behalf of the EPF board and EPF Secretariat Team



[JANUARY](#) - [FEBRUARY](#) - [MARCH](#) - [APRIL](#) - [MAY](#) - [JUNE](#) - [JULY/AUGUST](#) - [SEPTEMBER](#) - [OCTOBER](#) - [NOVEMBER](#) - [DECEMBER](#)

~ JANUARY ~ FEBRUARY ~

ANNUAL REVIEW: FOCUS ON JANUARY

ANNUAL REVIEW: FOCUS ON FEBRUARY

UPCOMING EVENTS

29 - 30/01/2014 | [Kick-off meeting of the Joint Action on Chronic Disease](#)

Madrid, Spain

A new Joint Action on Chronic Disease will take place in 2014 under the Public Health Programme. EPF will play a key role in the Joint Action representing the patients' voice, together with partners comprising member states and other stakeholders.

19-20/02/2014 | [EPF Board Meeting](#)



The highlight in January was very much eHealth with a closing conference of our 2-year project Chain of TRUST and a main seminar on this topic. It clearly emerged from both events that patients do want to be more involved in such innovative services' policies as well as in the design, implementation, and assessment of eHealth solutions.

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In February we published our position paper on clinical trials; we achieved the first phase of data collection within the European Union Network for Patient Safety and Quality of Care (PaSQ) and we saw one of our board members selected as an alternate member to the Pharmacovigilance Risk Assessment Committee (PRAC) of the European Medicines Agency (EMA).

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... 🌲 ...
~ MARCH ~ APRIL ~

ANNUAL REVIEW: FOCUS ON MARCH



March was a big project month: SmartCare officially started, to take the deployment of integrated health and social care to an unprecedented level and the SUSTAINS project released a report on user requirements. This was based on focus groups coordinated by EPF, to assess patient empowerment as a result of using patient-accessible Electronic Health Records (EHR).

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ANNUAL REVIEW: FOCUS ON APRIL



In April we released a position paper on Medical Devices to ensure the EU Institutions are fully aware of patients' recommendations while reviewing the framework and our European Patient Academy on Therapeutic Innovation (EUPATI) held its first major conference to look ahead at the future challenges.

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... 🌲 ...
~ MAY ~ JUNE ~

ANNUAL REVIEW: FOCUS ON MAY

ANNUAL REVIEW: FOCUS ON JUNE

Brussels, Belgium

The Board of Members meet five times a year to provide political leadership and oversee the implementation of the annual work programme.

[28/02/2014 | Patient Course "Understanding clinical research in cancer"](#)

Brussels, Belgium

This course is designed specifically for European patient group leaders to provide them with a stimulating and challenging two-day training experience leading to a much greater understanding of the whole clinical trials process.

[28/02/2014 | Launch of public consultation on Patient safety and quality of care](#)

The European Commission launched a consultation on patient safety and quality of care in the EU, which will run until 28 February 2014. Results of this consultation will contribute to the reflection on the future of EU policies on patient safety and quality of care.

[17 - 18/03/2014 | 2014 Careum Congress & ENOPE Conference](#)

Basel, Switzerland

The 2014 Careum Congress, which is also the second conference of the European Network on Patient Empowerment (ENOPE), in which EPF is also a partner will start from the assumption that more and more people live longer, often with one or more chronic conditions. The event will be entitled "The power of patients 3.0" to explore ways to engage patients in future healthcare systems.

[31/03/2014 – 03/04/2014 | EUPATI series of events](#)

Warsaw, Poland

On 31 March, the Executive Committee will meet to prepare the Annual General Assembly on the following day to be followed by two workshop days.

[24/04/2014 | The InterQuality project "International Research on Quality in Healthcare" will hold its final conference to share the key findings from the project.](#)

Brussels, Belgium

The InterQuality project "International Research on Quality in Healthcare" will hold its final conference to share the key findings from the project with EU representatives, Member States and other stakeholders from international



Our members appointed new Board Members and we welcomed six new members at our Annual General Meeting. It preceded our 10th Anniversary Conference featuring 2013 European Year of Citizens and the European Month of the Brain. We also signed a Memorandum of Understanding with Eucomed, the European medical technology industry association.

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In June in cooperation with our Bulgarian member NPO we held our second conference on Health Inequalities and Access for Patients at the European Parliament, which produced high impact results. We also held our quarterly meeting with the pharmaceutical industry EFPIA to discuss EU policy issues in the area of health and innovative medical research. We changed our logo to demonstrate our evolution over the past ten years.

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organisations, industries, patient groups and academia.

~ **JULY/AUGUST ~ SEPTEMBER** ~

ANNUAL REVIEW: FOCUS ON JULY - AUGUST



Young patients had the opportunity to express their needs and concerns to European policy-makers and stakeholder actors at the EMPATHY seminar. EPF also took stock of progress to date of the EPF Capacity Building Programme with initial assessment of the outcomes. EPF welcomed the Directive on Professional Qualifications as a step forward for patients' safety.

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ANNUAL REVIEW: FOCUS ON SEPTEMBER



EPF released a position paper on In Vitro Diagnostic (IVD) medical devices. The four-year project Renewing Health where EPF participated as co-manager of the User Advisory Board came to an end with various workshops. We were glad to participate at the launch meeting of We Care -Towards a Sustainable and Affordable Healthcare, in which EPF is an associate partner.

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~ **OCTOBER ~ NOVEMBER** ~

ANNUAL REVIEW: FOCUS ON OCTOBER

ANNUAL REVIEW: FOCUS ON NOVEMBER



In October we officially launched our campaign for the 2014 EU Elections. We were also involved in various workshops and sessions at the Gastein Forum, where a new consensus paper on how to advance health literacy in Europe was launched. We organised our 6th EPF Regional Advocacy Seminar in Zagreb, Croatia, to help the participants to advocate effectively at European and National level.

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We held our Patient Evidence Workshop with several members to discuss Patient Safety, drawing from their experience and case studies. Our President Anders Olauson was appointed as member of one of the 15 groups of independent experts to advise on priorities for Horizon 2020. We also released a video to help you understand our InterQuality project.

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~ **DECEMBER** ~

ANNUAL REVIEW: FOCUS ON DECEMBER



December marked a step forward on empowerment. We formally joined the the European Network for Patients Empowerment (ENOPE) and organised our first Regional Conference on patients' rights in cross-border healthcare to encourage national patients' groups get involved and monitor the legislation

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**A STRONG PATIENTS' VOICE
TO DRIVE BETTER HEALTH IN EUROPE**

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