

# EPF Mailing

Special Issue: Season's Greetings. EPF in 2011.

Issue 7 (41)

21 December 2011

Dear EPF Members and Allies,



As 2011 draws to a close and we start to look forward to 2012, this special issue of the EPF Mailing gives you a glimpse of some of the highlights of 2011. On behalf of the EPF board and the EPF Secretariat Team we would like to take this opportunity to thank you all very much for the excellent cooperation we have enjoyed over the past year. There have been some really fantastic and memorable times - working together with our members and our stakeholder allies to advance patient-centred, equitable healthcare across the European Union.

These relationships are extremely precious to EPF and we are so looking forward to progressing even further in 2012 on the issues that are at the heart of the European Patients' Movement – and ensuring that, in presenting the patients' perspective, we are part of a solution to secure the sustainability and quality of Europe's health systems.

Our agenda in 2012 is exciting and challenging. Policy priorities include input into the Chronic Diseases Reflection Process; the revision of the Clinical Trials Directive; enabling patients to understand what is at stake with the new Directive on patients' rights in Cross Border Healthcare, quality of care and patients' safety policy, the access to medicines platform, and the patients' place in the new Public Health Programme, HORIZON 2020 and the Structural Funds. Health Literacy and information to patients will continue to be the cornerstones of our work.

In the early New Year, with our Consortium partners we will launch EUPATI, the new major project funded under the Innovative Medicines Initiative, creating a European Patients Academy on Therapeutic Innovation.

As an associate partner, we will also be part of the launch, in January, of the SUSTAINS, a new project funded under the Competitiveness and Innovation Programme – ICT Health Strand, that

will focus on patients access to electronic health records. We will continue to invest heavily in the European Innovation Partnership on Active and Healthy Ageing, with particular emphasis on health literacy and empowerment strategies.

We are also involved as partners in the new Joint Action on Patient Safety and Quality of Care that will start in March 2012.

Intensive work will continue on CHAIN of TRUST, RENEWING HEALTH, eHEALTH GOVERNANCE INITIATIVE and INTERQUALITY (see previous EPF mailing for more information on these projects).

EPF will be partnering in two major events in 2012: the Health Inequalities Summit, led by the National Patients Association in Bulgaria ( Sofia, May), The Conference on Gender and Health Through Life, led by the European Men's Health Forum ( Copenhagen, June)

We will also organise our own conference on eHealth linked to the Chain of Trust closing event towards the end of the year. This will look at important policy advances on eHealth, including our work in the eHealth High Level Task Force and the eHealth Governance Initiative.

Our regional advocacy seminar in autumn will take place in Portugal and will bring together patient leaders from the Mediterranean countries and in April we will hold our Annual General Meeting that will include a special session to start to develop EPF's strategic plan 2014- 2020.

The final version of EPF's Annual Work Plan will be available on the EPF website by 15 January 2012.

We wish you all very restful and happy break over the festive season, with friends and family!

With our Warmest Greetings,  
EPF President Anders Olauson  
EPF Director Nicola Bedlington

# EPF IN 2011 - PICK A MONTH

JAN

FEB

MAR

APR

MAY

JUNE

JULY

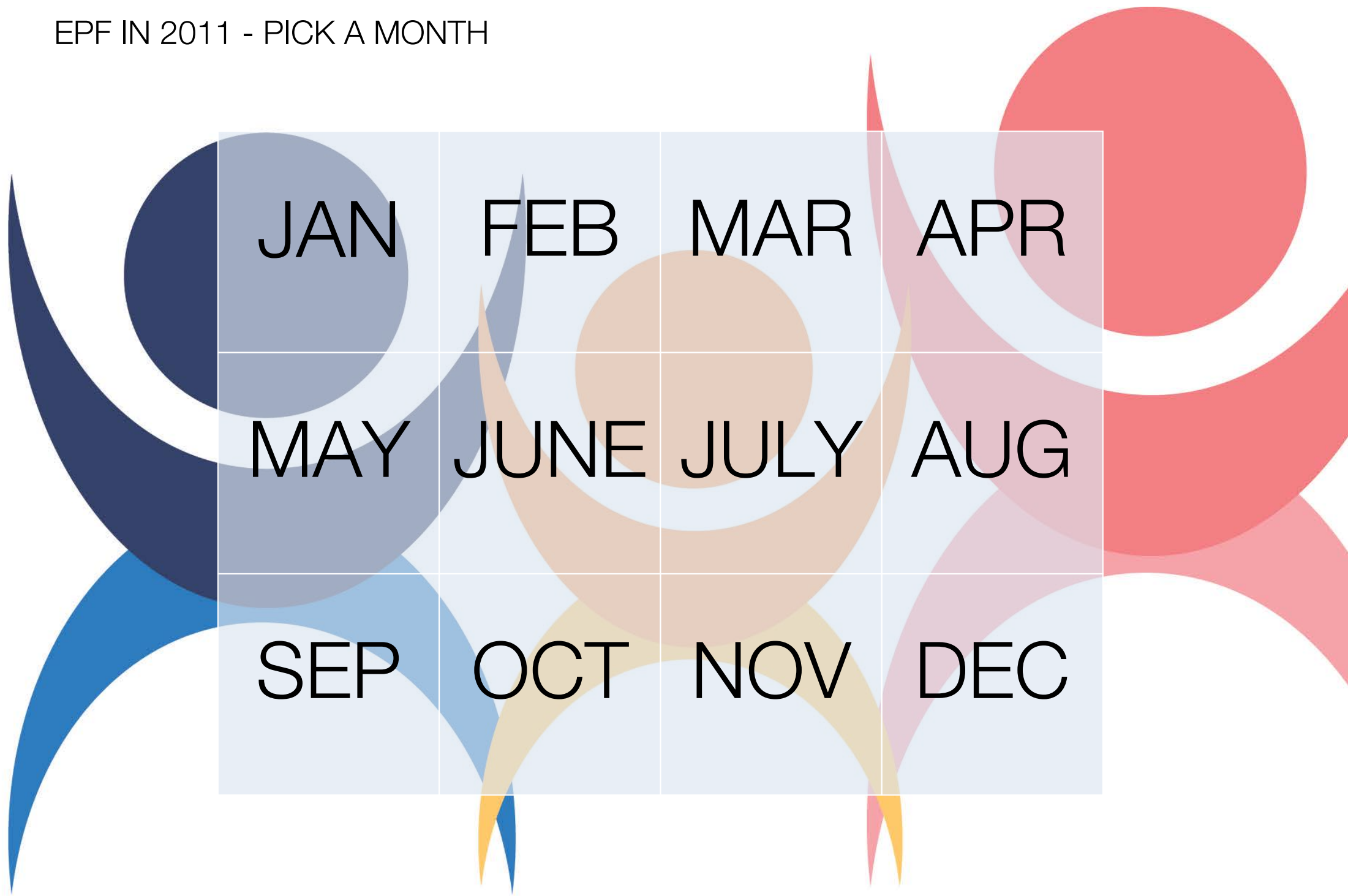
AUG

SEP

OCT

NOV

DEC



# January 2011

## 1. Interquality Project



Officially started in December 2010, the project **InterQuality** (FP7-Health 2010-2013) held its kick-off meeting in Warsaw on 18-19 January 2011.

As our readership will remember this project aims to **investigate ways of funding and incentive systems affecting the quality, effectiveness and equity of access to healthcare**, develop practical integrated models of health care financing, and determine the feasibility and effectiveness of the developed models for the determinants of the health systems in the countries of the project partners.

EPF is involved as an associate partner and leads the work related to dissemination of project progress and results as well as research on the governments' communication strategies of health reforms.

For more information on InterQuality, please visit the project web-page within the [EPF website](http://www.epf.eu), or the official project website at: [www.interqualityproject.eu](http://www.interqualityproject.eu)





## 2. Chain of trust

The Chain of TRUST consortium met in Brussels on January 31st and February 1st for the project kick-off meeting.

The paramount objective of this project which is led by EPF is to advance the empowerment of patients, health professionals and national health authorities across the EU in their understanding and effective use of telehealth services.

The innovative aspect of the Chain of Trust project is that it represents the first attempt ever made to bring together the key leading pan-European organisations representing direct telehealth users, namely patients, doctors, nurses and pharmacists in order to explore and assess users' view of and attitudes towards telehealth at both European and national level.

Updates on project progress were provided in the previous six EPF Mailing Issues.

For more information please visit the project website at [www.chainoftrust.eu](http://www.chainoftrust.eu)



### 3. Patients' Rights in Cross Border Healthcare

On the 28th of February the Council formally adopted the Directive 2011/24/EU on the application of patients' rights in cross-border healthcare. As our readers will remember, the European Patients' Forum has had a long standing, intense involvement in the draft Directive, working closely with the EU institutions, up until the last stage of negotiations with the EPF High level roundtable under the Belgian Presidency on 1st December 2010. The Directive marks a milestone for european patients, as we had highlighted in our [special feature](#).

In 2012, EPF will share with its membership toolkits to help patient organisations engage in the implementation of the Directive. We will continue to closely monitor the transposition phase, and give input on implementation measures.



## 4. eHealth Governance Initiative (eHGI)

The eHealth Governance Initiative (eHGI) started officially in March 2011. The eHGI aims to create a permanent platform for cooperation between Member States and health stakeholders on eHealth and supports the setup of a European eHealth environment for the benefit of European patients (e.g. support and guidance for implementation, deployment and use of eHealth services throughout national health care systems, increasing patient safety and quality, better use of health care resources).



For more information please see the [webpage](#) of the initiative and EPF mailings in [April](#) and [November](#) 2011.

## 5. Health Inequalities

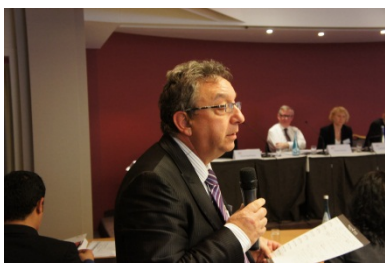
On 8th of March 2011, the European Parliament adopted a resolution on reducing health inequalities in the EU. This non-binding text highlights the commitment of the European Parliament to take action to tackle health inequalities. It recognizes that patients with chronic illness form a vulnerable group, calls on Member States to ensure that these groups have equitable access to healthcare, and recommends putting in place targeted programmes. EPF gave input to MEPs and welcomed the resolution, as access to high quality affordable healthcare for all patients is a core priority.

In 2012, EPF and EPF member National Patients' Organisation of Bulgaria (NPO) will organise a summit on health inequalities in Sofia Bulgaria.



# April 2011

## 6. EPF Annual General Meeting and Spring Seminar



## 7. Falsified medicines

On 27th May 2011 the Council adopted [the directive aimed at preventing falsified medicines from entering into the legal supply chain](#). EPF welcomed this text which contains provisions to tackle illegal online sales of medicines, as we had called for throughout the legislative process. It also establishes a unique safety feature for better traceability of prescription medicines. For more detailed information please read our [April issue](#).

In 2012, EPF will continue to engage in the implementation of the Directive, as we believe that the meaningful involvement of patient organisations is key to ensure the success of policies and campaigns to tackle this issue.



EU Fights fake medicine video: <http://ec.europa.eu/health/human-use/videos>



# May 2011

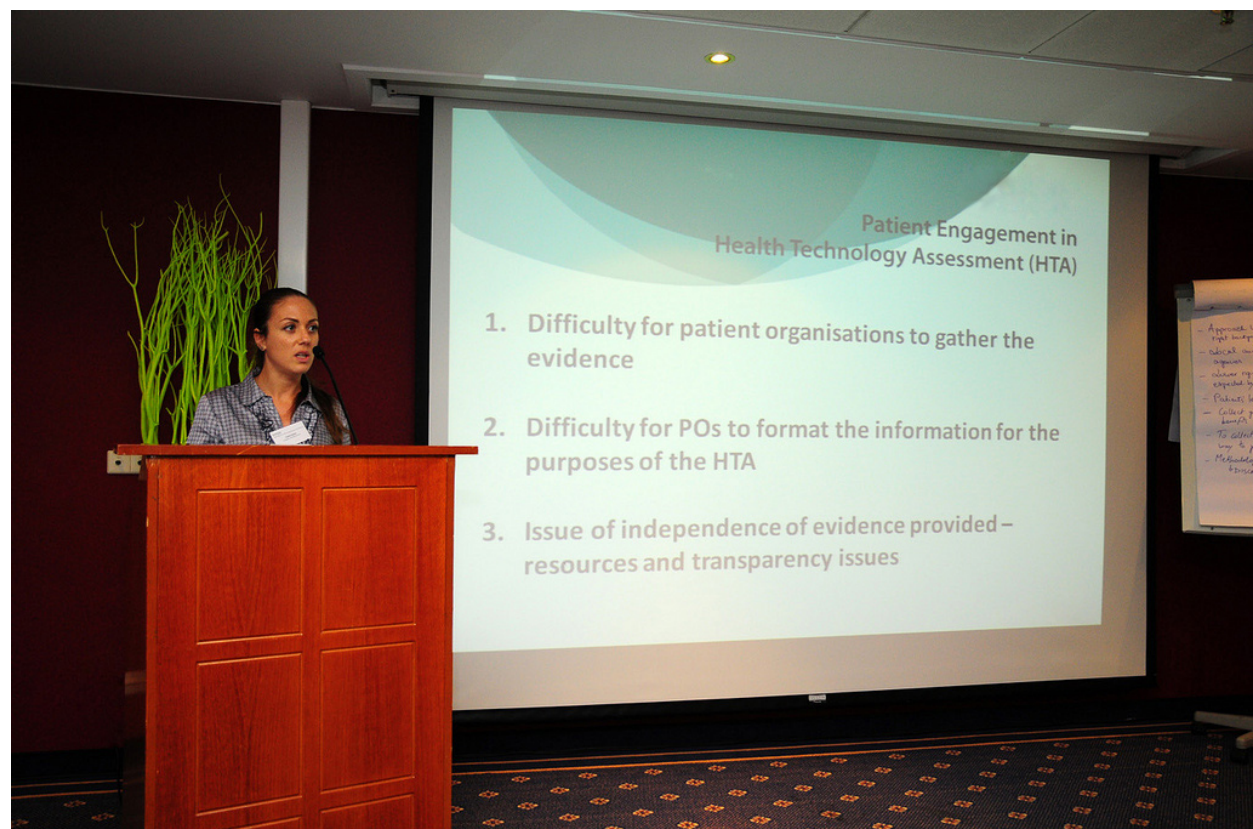
## 8. EPF HTA Initiative

In May 2011 EPF published the results of the first phase of the HTA initiative, whose aim is to understand the involvement of lay patients, informal carers and patient organisations in all the EU member states and to contribute this knowledge to inform HTA – research, policy, and practice.

EPF started conducting a three-stage research on patient involvement in HTA in November 2010 as a follow up of the recommendations of EPF Seminar on HTA in May 2010, with the aim of understanding better the involvement of lay patients, informal carers and patient organisations in the EU Member States.

The three-staged survey was conducted with (1) HTA agencies and/or national bodies responsible for HTA, (2) healthcare decision-makers who use evidence from HTA reports, and (3) patient organisations interested in providing patient perspectives/evidence to HTA.

For more information please see the [EPF website](#).



## 9. Medical Devices

The Council of the European Union adopted [Conclusions on innovation in the medical device sector](#) in June 2011. EPF gave input which was well reflected in the final conclusion. The Council stresses that patient safety must be a core priority in EU regulation for medical devices, and that innovation should be increasingly patient and user-centred.

In 2011 EPF and EUCOMED have put in place the first ever structured dialogue between patient organisations and the Medical Device Industry to exchange views on potential areas of common interests (see our June and November issue).

In 2012, the recast of EU legislative framework for medical devices will be one key dossier for EPF. The Commission has recently highlighted that the recast will be composed of:

- a proposal for a regulation on medical devices
- a proposal for a regulation on in vitro diagnosis medical devices
- a Communication regarding the innovation in medical devices for the benefit of patients, consumers and healthcare professionals



# July 2011

## 10. Respect project

The final meeting of the RESPECT project (Relating Expectations and Needs to the Participation and Empowerment of Children in Clinical Trials, FP7 2008-2011) was held in Gothenburg, Sweden on 21st July 2011.

The overall objective of the RESPECT project was to empower children participating in clinical trials and their families.

The final report of the RESPECT project will be published soon in the project's website at: [www.patientneeds.eu](http://www.patientneeds.eu)



# RESPECT patient needs



## 11. Conference on Rights and Needs for Older Patients - Poland



Please read [this EPF Mailing](#) issue for full event Report.



## 12. EPF Youth Group

The first meeting of the EPF Youth Group took place on 19-21 August 2011.

The EPF Youth Group is the main pillar of EPF's Youth Strategy, which was launched in early 2011 with the overall goal of enabling EPF to recognise, understand, meet and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment.

For more information on the EPF Youth Strategy and the Youth Meeting, please have a look at the articles included in the April, June, July, and October Mailings.



# September 2011

## 13. Adherence to therapies: EPF and allies call for concrete action at EU level

On September 2011, EPF co-organised in a lunch debate held at the European Parliament in Brussels with CPME, PGEU and EFPIA , to bring together the perspectives of patients, doctors, community pharmacists and the research-based pharmaceutical industry to explore the challenge of adherence to therapies. The event was hosted by MEPs Linda Mc Avan (S&D/IE), Cristian Silviu Buşoi (ALDE/RO) and Christofer Fjellner (EPP/SE).

For more information please read the special feature of our October mailing.





## 14. IV Regional Advocacy Seminar

The fourth EPF Autumn Regional Advocacy Seminar, organised in cooperation with the Coalition of Patients' Organisations with Chronic Diseases in Romania (COPAC), member of EPF, took place in Bucharest, Romania on 27-28 October 2011.

The overall objective of this year's EPF Regional Advocacy Seminar was to strengthen trust and mutual understanding between patient and health professional organisations in order to foster their cooperation in the national health policy arena. Approximately 60 representatives of patients' and health professionals' organisations (general practitioners, specialist doctors, nurses, and pharmacists) from Bulgaria, Romania, Estonia and Hungary attended this event.

During the two days the participants had the opportunity to build up new partnerships and explore new possibilities for enhancing patient-professional cooperation, especially in national health policy-making, while learning more about some major recent European health policy developments and understanding how to get involved and cooperate in the transposition and implementation of such policies.

For more information on the event please visit the event's [webpage](#).



## 15. European Health Policy Forum Gastein

In October EPF was again active during the European Health Policy Forum Gastein, with representatives attending many of the sessions, giving presentations, participating in panel discussions and, as usual, gathering information and insights. Read our comprehensive Gastein report in the [November issue](#) of this Mailing!

- Presentations from Gastein are now available here: [www.ehfg.org/index.php?id=programme2011](http://www.ehfg.org/index.php?id=programme2011)





## 16. Renewing Health

On November 30th 2011, the RENEWING HeALTH project held its mid-Term Workshop in Brussels.

The RENEWING HeALTH project started in February 2010 with the objective of implementing large-scale real-life test-beds for the validation and subsequent evaluation of innovative telemedicine services for patients with chronic conditions in nine European regions.

EPF is involved - together with EHTEL (European Health Telematics Association) - in the management of the User Advisory Board (UAB) whose primary mission, as defined in the UAB Terms of Reference, is to operate as a standing advisory committee to advise and provide on-going feed-back to the project team on the needs of users of the piloted telemedicine services.

For further information please visit the project's website at [www.renewinghealth.eu](http://www.renewinghealth.eu)



## 17. Clinical Trials

On 21 November, a number of EPF members met in Brussels to discuss the EU Clinical Trials Directive with representatives of the European Commission. The revision of the Clinical Trials Directive will be one of EPF's key priorities in 2012 and the Secretariat will update all the members on this process and EPF's position in the early part of the year.





# December 2011

## 18. SUSTAINS

As announced in the previous email the SUSTAINS (Support USERS To Access INFORMATION and Services on patient access to Electronic Health Records) project will officially start in January 2012.

SUSTAINS will provide a rich basket of services based on giving citizens online access to their electronic health records. This project should ultimately contribute to the empowerment of patients, better medical results, and more efficiency in the provision of healthcare services. EPF will play a key role in this project, especially in the areas of user requirements and assessment of patient empowerment before and after the trials.

The kick-off meeting of the SUSTAINS project will be held in Uppsala (Sweden) on 9-10 January 2012.

For more information please see the November issue of EPF Mailing.

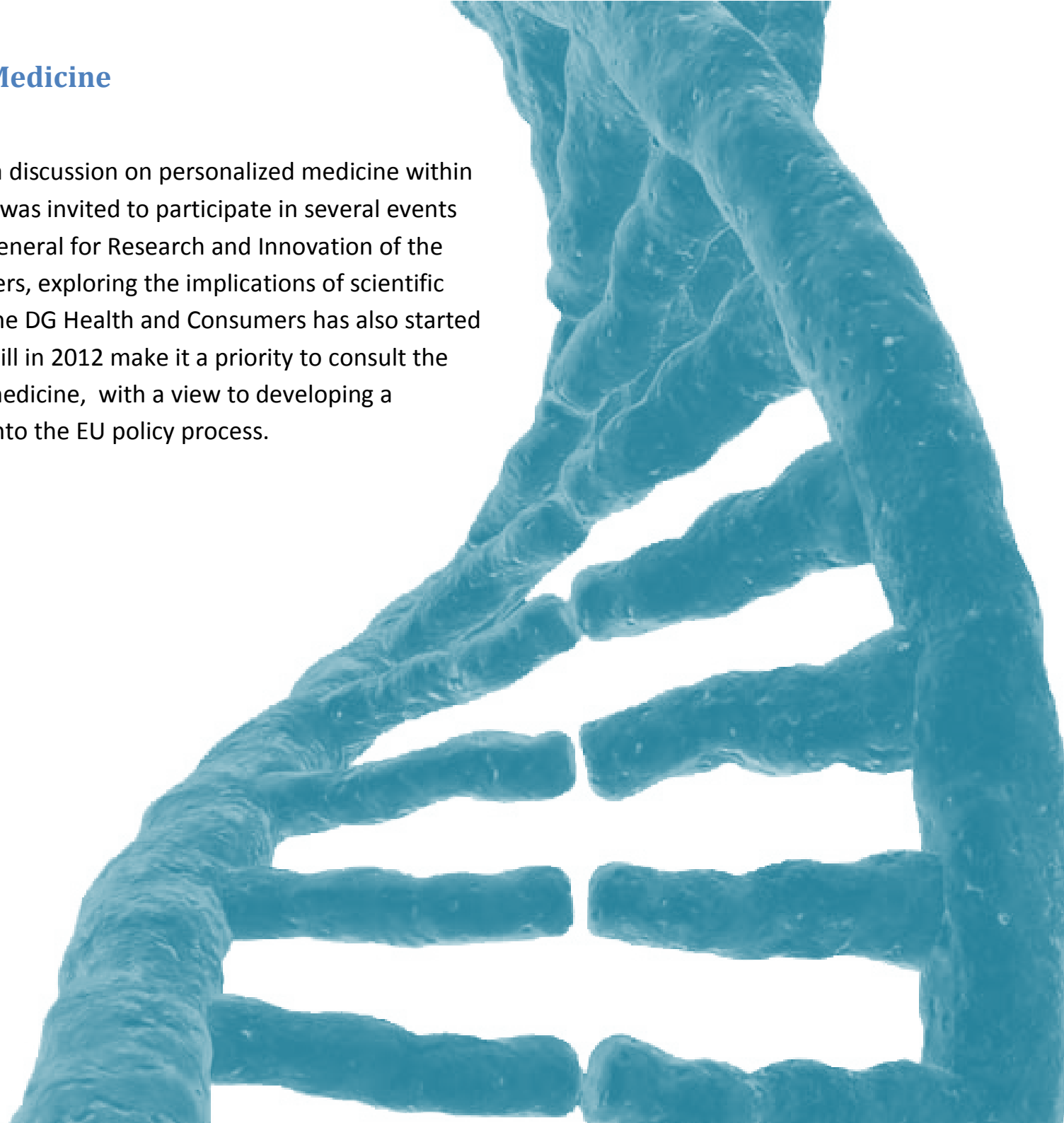
## 19. EUPATI

The EUPATI project, which is aimed at creating better education and information tools for patients on pharmaceutical research and led by the European Patients' Forum, will also start in early 2012.

The EUPATI academy will educate patient representatives and the lay public on personalised and predictive medicine, design and conduct of clinical trials, drug safety and risk/benefit assessment, pharmaco-economics as well as patient involvement in drug development. For more information please see the project's webpage in the EPF website.

## 20. Personalised Medicine

During 2011, EPF has initiated a discussion on personalized medicine within the Policy Advisory Group, and was invited to participate in several events organised by the Directorate-General for Research and Innovation of the European Commission and others, exploring the implications of scientific developments in the area. As the DG Health and Consumers has also started a reflection on this topic, EPF will in 2012 make it a priority to consult the membership on personalized medicine, with a view to developing a formal position paper to feed into the EU policy process.



*We wish you all very restful and  
happy break over the festive season,  
with friends and family!*

