



# INVOLVING YOUNG PATIENTS



europeanpatients forum

EPF 2010 Autumn Regional Advocacy Seminar for Patient Leaders

Budapest 25-27 October 2010

## Seminar Report



# Introductory remarks

Dear colleagues and friends,

We are pleased to present to you our report on the 2010 Regional Advocacy Seminar which was held on October 25-27 in Budapest. The seminar was co-hosted by the Hungarian Osteoporosis Patient Association (HOPA) and involved 50 patient leaders from Hungary, Slovakia, the Czech Republic, Greece, Estonia, Lithuania, Bulgaria, Slovenia, Romania, Poland, Italy and Portugal.

This year's overall theme was promoting the involvement of young patients in patient organisations in order for them to become strong patient advocates. The key feature of this year's was, therefore, the participation of an equal number of senior and youth representatives aged between 15 and 25 years.



EPF believes that patient organisations can do a lot for young patients, particularly by empowering them to become active partners in healthcare. This was also emphasised by Mr. Luc Giraud of the Medtronic Foundation, to which we are extremely grateful for having made this event possible through an unrestricted grant. It is for this very reason that EPF has committed to developing and integrating a young patient perspective into its future work plans with the objective of better reflecting young patients' needs in our mainstream work and promoting the involvement of young patients in our activities as well as in the activities of our member organisations. This approach builds on a preliminary EPF project involving young Swedish patients<sup>1</sup>.

The seminar had three major objectives: a) promoting stronger participation of young patients within patient organisations, b) strengthening capacity building for patient organisations' leaders on how to work and get involved in EU-level policy-making, particularly by working together in national coalitions, c) brainstorming with the youth representatives on an EPF Youth Strategy.

Seminar participants had the opportunity to contribute to workshops that looked at how patient groups can build partnerships with the EU institutions and key health stakeholders and how patient groups can establish cooperation with youth associations. Participants were also provided with an overview of youth and health policies and initiatives on the European landscape and good practices on how to become a young advocate.

I am very pleased to say that the seminar has been very successful in enhancing participants' communication and advocacy skills to influence policies that affect their lives but also the lives of their communities.

To conclude with, let me quote the words of Mr. Timo Nerrko of the European Kidney Patients' Federation (CEAPIR) and EPF Board member who emphasised that although it was the third time that EPF organised a regional advocacy seminar, this was the very first event bringing together young and more experienced patient leaders. This represents a new "milestone" in EPF's history.

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<sup>1</sup> [http://www.eu-patient.eu/Documents/Projects/YoungPatientsPerspective/Young\\_Patient\\_Perspective\\_Report.pdf](http://www.eu-patient.eu/Documents/Projects/YoungPatientsPerspective/Young_Patient_Perspective_Report.pdf)



Being an umbrella organisation, whose role is to promote a united patients' voice with the aim of making health policy more patient-centred, it is critical for EPF to work as closely as possible with patient groups from various regions of the EU, not only to listen to their needs, but also and perhaps more importantly to understand how they can contribute to EPF's work at EU level. Understanding young patients and their needs is critical to achieving this aim.

This report provides an overview of the themes discussed and summarises the main outcomes of the first two days of the seminar. The outcomes of the workshops with the youth representatives will be used to inform the EPF Youth Strategy and will be therefore summarised therein. We hope that this report will provide you with an overview of the points discussed and that the conclusions will inspire future action. All presentations given at the Seminar, including those reporting the outcomes of the parallel workshops can be accessed [here](#).

With best wishes,



Anders Olauson

President of the European Patients' Forum



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# 1. Welcome messages

## Dr. Miklós Szócska, Hungarian Secretary of State for Health



Dr. Miklós Szócska, Hungarian Secretary of State for Health

EPF was particularly pleased to welcome the Hungarian Secretary of State for Health Dr. Miklós Szócska for a key note speech that provided an overview of the upcoming Hungarian EU Presidency taking over from Belgium on January 1<sup>st</sup> 2011.

In his speech Mr. Szócska highlighted the importance the Hungarian Ministry of Health attaches to this Regional Advocacy Seminar as it is a clear indication of the strong commitment of the European Patients' Forum towards supporting Hungarian patients and their organisations.

Mr. Szócska pointed out in relation to the Presidency that the Hungarian Ministry of Health wanted to propose a topic that would start with patients. He underlined in this respect that patient-centred healthcare and patient involvement will be at the core of Hungary's Presidency approach to health.

## Ms. Klara Zalatnai, President of the Hungarian Osteoporosis Patient Association (HOPA)

Ms. Klara Zalatnai in her capacity of President of the Hungarian Osteoporosis Patient Association (HOPA) welcomed the participants and presented her organisation. HOPA, which is an EPF Associate Member, was set up in 1998 and is based in Budapest. It is an umbrella NGO with 25 member organisations and more than 2,000 patients across the country. So far HOPA has implemented a number of activities such as health education programmes and campaigns about prevention, early detection, progression of the disease, patients' involvement, lobbying and capacity-building. It is actively involved in the World Osteoporosis Day activities, an Osteoporosis Civilian Forum, and runs a Joint Programme with the Rehabilitation Section of Osteoporosis Medical Society. Klara finished by welcoming all participants warmly to Budapest, and particularly the young participants who had travelled from various places to be present.



Klara Zalatnai, HOPA

## Mr. Luc Giraud of the Medtronic Foundation

Mr. Luc Giraud of the Medtronic Foundation gave his welcome and some background about the Foundation and its support of the EPF Regional Advocacy Seminars. He emphasised the importance of empowering patients to become active partners in healthcare, and the crucial role played by patient organisations in sharing good practices and experiences and building effective partnerships, with the aim of educating the public and healthcare community about the changes needed to create patient-centred healthcare.



### Mr. Timo Nerkko, CEAPIR and EPF Treasurer



Timo Nerkko, CEAPIR and EPF Treasurer

Mr. Nerkko EPF Treasurer thanked Klara Zalatnai and HOPA, as well as the Medtronic Foundation, for their valuable support, and emphasised the importance of EPF advocacy seminars. He said that it is absolutely critical that EPF works as closely as possible with patient groups from different regions of the EU to understand their needs, and to understand how they can help to shape the policy work of EPF. Mr Nerkko concluded by thanking all participants, particularly the youth representatives, whose participation in the seminar will be extremely valuable as it will enable EPF to have for the first time a thorough insight into needs and expectations of young patients on the basis of which to acquire new ideas and inspiration for integrating a youth perspective into EPF mainstream work.



## 2. Involving young patients

The first day of the seminar was dedicated to looking at challenges and benefits of involving young patients in patient organisations. The discussion was enriched by concrete examples and experiences from different patient or youth-focused organisations which have been very successful in actively integrating young people in their activities as well as in their governance structures. The main issues emerged during the morning debate were then taken forward for further discussion within the small-group workshops held in the afternoon.

### 2.1. Summary of Presentations

#### 2.1.1. Setting the scene

*The European Patients' Forum, Nicola Bedlington, European Patients' Forum (EPF) Director*

Ms. Nicola Bedlington gave an overview of the EU health policy landscape, and the role played by the EPF in that context. She presented EPF's many activities, emphasising particularly VALUE+, the first EPF-led project that focused on meaningful patient involvement.



<http://www.eu-patient.eu/Initiatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/>



Ms. Bedlington stressed that an important part of EPF's mission is to form effective alliances with policy makers and other health stakeholders. EPF today has the active support of some 120 Members of the European Parliament (MEPs) and close relationships with the key rapporteurs on major health policy dossiers, works with the European Medicines Agency (EMA) in a consultative capacity, and builds alliances with health professionals' organisations, patients' organisations and other stakeholders at EU level.

Developing effective, powerful communication is a focal area for EPF, and Ms Bedlington especially invited feedback from young patients regarding EPF's youth strategy and the possibility of setting up a platform for young patient leaders to interact and network. "This is one possible way – but not the only one – in which the young patients' voice could be heard in EPF's work" said Ms. Bedlington.



### *Young People as Patients: Who decides?, Doortje Braeken, International Planned Parenthood Federation (IPPF)*

Ms. Braeken presentation was focused on the concept of “youth” to explain how young people in general are perceived in our societies to set the ground for a more in-depth analysis of some of the key challenges faced by young chronic patients. She started out her presentation showing the audience the youth work of IPPF and its experience in involving young people in institutional and programme work. In her presentation she focused on the need to move towards empowerment and to look at the social and legal context of youth, to see youth itself from a different perspective and not just as a stage of development. More work is needed to understand the evolving capacity of a young person, said Ms. Braeken.

In her presentation she discussed the concept of vulnerability. She remarked that young people are often considered vulnerable. Vulnerability is a major challenge for young chronic patients. She emphasised that one aspect contributing to this is that there are few youth-friendly services and programmes. Also, there is often no appropriate information available specific to young patients' concerns, nor about their rights.

According to Ms. Braeken, there is also a risk of abuse by the system, or by individuals. She took parental consent as an example to show how this can be problematic for many young patients. To illustrate this she gave the poignant example of a girl with terminal cancer who had to go to court to prove she had the mental capacity to decide for herself, against the recommendation of her parents and doctors, whether she wanted to have a treatment that would only extend her life for one month (she did not).

In order to address these problems, she stressed that we need to reconsider the concept of “youth”. Typing “youth” into an Internet search engine, said Ms. Braeken usually gives very disappointing results with “youth” being simply defined as “not being adult”, and not as a phase in its own right. Youth is seen as “not being there [i.e. adult] yet” – the identity as not yet fixed, the person as powerless, less responsible, dependent, while we know young people are much more than that.

On the other hand, she pointed out that we also need to find appropriate means for helping young patients to become empowered actors and better able to address their vulnerabilities.

Ms. Braeken's take-home message was *“If you want to involve young people, you need to learn about their lives, how their lives are affected in all the different aspects. Listen and then give young people a voice in your organisation”*.

## **2.1.2. Youth and health in the European landscape**

### *Youth and health – an Overview from the European Youth Forum, Laura Cottey, European Youth Forum (EYF) Working Group on Employment and Social Affairs*

Ms. Cottey introduced the European Youth Forum (EYF). EYF is a youth-led organisation representing young people bringing together over 90 National Youth Councils and international non-governmental youth organisations. EYF works for the empowerment of young people, so that they can exercise their rights and become active citizens to ensure young people have a say in the policies that affect them.



She pointed out that more attention needs to be paid to understanding and raising awareness of what empowerment actually means and, more importantly, how the empowerment of young people can be promoted within our societies.

Her take-home message was that young people have to be *“active partners rather than a ‘demographic’ to be legislated on”*. The key is youth empowerment: allowing young people to tackle the issues behind health problems, such as inequalities.

### *Health in the EU Youth Strategy, Elisa Briga, Council of Europe Youth Partnership*

Ms. Briga, representing the Council of Europe Youth Partnership, introduced the new EU Strategy for Youth: “Investing & Empowering”. This is based on youth work and evidence-based policy-making. Ms. Briga gave a general background on EU youth and health policy, which focuses strongly on prevention and the promotion of healthy lifestyles. She also introduced some specific opportunities that are relevant for young patients with chronic conditions under the “Youth in Action” programme. Because inclusion is a main objective of the programme, there are specific opportunities for people with disabilities and health problems. Examples of projects for young people have included youth exchanges, groups of young patients from different countries getting together to network and reflect on issues that concern them, to find creative solutions, and to raise social awareness.

The “Youth in Action” Programme is online at:

[http://ec.europa.eu/youth/youth/doc152\\_en.htm#sectNAS](http://ec.europa.eu/youth/youth/doc152_en.htm#sectNAS)

## 2.1.3. Young advocates – it is possible!

### *The experience of the EFCCA Youth Group, Marco Greco, European Federation of Crohn's & Ulcerative Colitis Associations*

Mr. Greco of the European Federation of Crohn's & Ulcerative Colitis Associations started his talk with the popular slogan: “Nothing about us without us”. This is a sentiment that all speakers and the audience strongly supported.

The EFCCA Youth Group was born in 1998 in Erlangen, Germany where national associations’ representatives proposed for the first time to create a special commission to take care of young patients’ concerns. EFCCA’s main challenge was to develop an environment where the young could develop their voices and policies, without paternalism, to express their creativity, and to fight for their rights.

To create the EFCCA youth committee was not an easy process, said Mr. Greco. There were many challenges and barriers to overcome. First, a committee tasked with “taking care of youth policies” was already in place but it was led by a 75-year-old person. Secondly, there was a very strong resistance to change within the organisation: the proposal for a youth-led committee was taken as sign that the young people were not mature enough to understand the problems. This was a generational gap that had to be overcome. There were also worries on the part of the older patients that investing in youth might be a waste as the young might



Marco Greco, EFCCA with “Loekie” the lion, the official mascot of the Youth Group

“disappear” once they have established their own families and careers. These and other barriers, said Mr. Greco, were successfully addressed through mediation.

The age range for the youth committee at EFCCA was defined as 18-30, determined largely by the emergence and course of the disease. In 2003 EFCCA created a Joint Commission, and in 2004 the EFCCA Youth Group (YEG) was officially set up. Its activities included a common framework for EFCCA created by the young and the older patients together, and networking with other allied bowel conditions. Concrete projects have been done: an example is “The Game”, which is a game for children available in 11 languages, to help them better understand the diseases and not be afraid of it. This is a first step towards empowerment and has an enormous impact especially at the young age. Also, summer camps are organised each year, for teenagers from all over Europe to get together.

The YEG is very active in policy, too, with activities revolving around the annual meeting. After each meeting there is a newsletter, and it also publishes an online e-magazine. Very importantly, the Youth Group has been given a dedicated seat on the EFCCA General Assembly and the organisation’s governing board. EFCCA itself has no say in the choice of young patient representatives, they are chosen by the young patients themselves. The YEG budget is agreed by the EFCCA General Assembly and managed by the Youth Group independently. The Group is only obliged to prepare a report on how the budget is used.

Some concrete initiatives of the YEG include the “YEG Pass”, an initiative that helps young patients to get acquainted with how the EFCCA works as an organisation, to see it from the inside and learn valuable skills. A young patient representative chosen by other young patients can attend all EFCCA meetings over one year, with the costs covered. Another is the Leader of Tomorrow (LOT) programme, which gives skills about how the organisation works, as well as motivation and inspiration.

Mr Greco’s story was not only that of the long journey of the EFCCA Youth Group, but also his own personal experience. Marco’s closing message to the audience was: *“The most important right for a child is to live in an environment that allows you the possibility to realise your dreams.”*

#### *A success story from IPPF EN: YSAFE – Youth Sexual Awareness for Europe Network, Katarina Glosova, International Planned Parenthood Federation European Network*

YSAFE is a network of the International Planned Parenthood Federation (IPPF), first proposed in 2005 and established in 2006. The network is based on the principle of youth participation as a right for young people, and it disseminates information about safe and emotionally stable relationships. It involves young volunteers or staff of IPPF member associations, and has over 100 members from 31 associations covering Europe and central Asia. According to Ms. Glosova, the challenge is to involve young people in member associations’ governing bodies, recruit and maintain young volunteers, and keep motivation as the young have many things going on that take their time and energy.

Ms Glosova’s important message was that young people must be involved in all aspects of an organisation’s activities, from decision to creation, implementation and evaluation – a sort of youth “mainstreaming” making youth participation normal and ordinary.

#### *A testimony from CEAPIR, Timo Nerikko, European Kidney Patients' Federation*

Mr. Nerikko talked about how CEAPIR engages with young patients. CEAPIR is not a very large organisation; it is made up of 23 member associations.



The organisation's rules do not say anything about young patients' involvement, but in 2006 a youth planning group was set up which reports each year on its activities and discusses what the young patients want from the organisation.

The Finnish kidney patients' association has around 2,000 members, perhaps 200 of whom are young patients. For CEAPIR it is important that these young patients know each other and are involved in the associations' activities. As Mr. Nerikko put it, a good and "living" organisation "needs young people".

Usually, he said, at every CEAPIR meeting there are 12-15 young patients. The participation of young patients in CEAPIR meetings and other events have been very useful for young kidney patients, as they can see what can be done together, and get to know other young patients with the same condition. Often that alone is a great boost.

Mr. Nerikko said that young patients want action and they want it fast: *"Not just talks – something should happen. They don't want to wait until 2012 to get some answers"*. Also, young people want to meet others, work together, and have a good time while doing it. CEAPIR aims that every meeting involves some "fun", and that there is a balance between work and play.

### *The example of APYN, Joao Salviano, Alcohol Policy Youth Network*

Alcohol Policy Youth Network (APYN) is a network set up in 2008 by 28 organisations with the overall objective of empowering youth organisations to develop their work in the field of alcohol policy at all levels, from local and national to EU level.

The objective is to meaningfully involve youth in the definition, development and evaluation of alcohol policy, not just as "observers". APYN aims to become a consultative body that policy-makers can interact with. It is still a young network, so it is developing partnerships with stakeholders at national and international levels – for example it is in direct communication with the World Health Organisation (WHO) but does not yet have consultative status.

APYN develops activities to address the needs identified by member organisations – for example training courses, seminars, training for trainers, advocacy courses, reports and tool kits – useful capacity-building for youth organisations to become active partners with governments and other actors, and to explore avenues to make young people's voice heard in decision-making processes and policies. APYN has prepared a number of toolkits that can be used by anyone who wants to develop own project on alcohol policy.

## **2.2. Outcomes of the discussion**

There are three major aspects which emerged in relation to the theme "Promoting stronger involvement of young patients within patient organisations in order for them to become effective advocates". These are presented below.

### **Empowerment of young patients through involvement**

Empowerment is a complex concept and it is difficult to give a straightforward definition of what this word actually means. Empowerment includes a feeling of being capable of making one's own decisions about one's life or controlling one's own destiny. Empowerment is also related to getting certain skills that make a person feel more confident in representing and putting forward his/her own ideas.



Both speakers and participants acknowledged that we need to invest in young patients' skills and



competences if they are to become empowered partners in healthcare. In this respect, more work is needed to understand the capacity of a young person by looking beyond the age factor, and taking a holistic approach to the individual, social and legal context of youth. In empowering young patients, parental involvement is key. Young people do want their parents to be involved, but in the right way. The

challenge is, however, to get the balance right between young patient's autonomy (autonomous decisions) and protection. Inter-generational interaction needs also to be further explored. The aim should be to move from determination by adults towards more self-determination by young people.

Involving young patients in patient organisations is an effective way to empower them. Involvement, however, will not be successful if young patients do not feel the ownership of the process and the organisation. To foster ownership, young patient representatives who will participate in meetings and events of the organisation will have to be chosen by other young patients. It was also emphasised that ownership also depends on how capable a patient organisation is of giving young patients knowledge and skills about how the organisation works, as well as motivation and inspiration to want to become involved. These initiatives cost "less than you can imagine" said Mr. Greco during his presentation. Youth participation should be inherent in the work of a patient organisation. The participants agreed that there should be a sort of youth "mainstreaming" whereby youth participation is becomes the normal *modus operandi*.

There is no one single receipt for involving young patients and motivating them to participate. Each organisation must find its own way to "market" itself to be more attractive to youth – organisations need to think critically about their own image too. One cannot say tomorrow we will organise a youth group and expect it to happen overnight. The important first thing is to know that young patients are able to do many things, the next step is for them to decide what they want to do. Attending a joint activity can be a first stage towards a more comprehensive confidence building process. Peer support is an incredibly important aspect. Sometimes professional and psychological support is needed. Stigma is indeed an issue in this respect, in some disease areas more than others. The only way to convince young people to overcome that barrier is to offer an environment where they can feel protected, and feel they can realise their ambitions. This is a long process. In bowel disorders, for instance, there are still many differences between countries: in Sweden young people do not mind standing up and saying they have Crohn's – whereas in other countries there is more social embarrassment. International events and projects can help, just to show how other patients in other countries deal with these issues.

Once an organisation starts working with young patients, it is also important to have in place a child protection policy. This is not just to create a safe environment for children and young people, but also because increasingly funders and partners require it. Ms. Braeken of IPPF told the audience that they have training modules available on how to introduce such policy in an organisation.



## Communicating with young patients

A major challenge for patient organisations is to learn how to listen to young patients but also to help young patients better understand the perspective of experienced patient leaders. This is a key aspect in developing inter-generational partnership.

It is important to develop specific activities for young patients, because they are the future leaders of every patient organisation. Young patients can start work on areas that are specific to their health needs at their age – for example addressing the question of how to stay in employment and have dialogue with employers – and eventually advance to be represented on the governing bodies of the organisation and be involved in decision-making, resulting in better inter-generational interaction and partnership.



Involving young patients in patient organisations has proved to be an effective way to learn how to communicate with youngsters. Speakers from organisations which have been successful in setting up a youth group pointed out that there are benefits to this way of working. Through the direct involvement of young patients there is a better recognition and reflection of the needs and visions of young people and more awareness of the need to have dedicated services for them. Moreover, integrating a young perspective in a patient organisation

can ultimately help solve the “generational problem” that affects every national or international patient organisation.

## Youth-friendly health care

Another key point that was reiterated several times by various speakers as well as during the discussion with the participants is the fact that there are few youth-friendly health services.

Needs and expectations of young patients do not necessarily match those of adult and senior patients. Being a patient impacts on every aspect of one person’s life. For a chronically ill youngster this means that the condition and the way he/she relates him/herself with the condition have important repercussions on growing up and hence on his/her life as an adult. Chronically ill youngsters enter and go through education as patients, meaning that if they have to miss a lot of classes from school and university because of their condition, this might have strong impact on their learning process as well as on their life, particularly when it comes to entering the labour market. Moreover, being a chronically ill youngster means that a person is often perceived as ‘different’ by other young people.

These are only some major challenges young chronic patients face in their everyday life that policy makers, institutions, as well as civil society organisations working in the health sector and beyond need to take into account when developing policies, programmes or making daily decisions that might have an impact on youth.

Also, there is often no appropriate health information available specifically tailored to young patients’ concerns, nor such information exists about their rights. At a political level, there needs to



be more investment in youth-friendly services and policies for young patients and patient organisations should take the leadership of this process.

## 2.3. Outcomes of the Workshops

In the afternoon the seminar broke out into three parallel workshops. The first workshop, which was moderated by Ms. Ada Dortch of IPPF EN, dealt with the theme “*Different generations working in partnership*”. The second workshop was moderated by Ms. Laura Cottey of EYF and was held under the theme “*Building partnerships between patient organisations and youth associations*”. The third workshop was focused around the theme “*Setting up a youth group within patient organisations*” and was moderated by Mr. Marco Greco of EFCCA. Workshops were held twice to give participants the possibility to attend two different workshops.

### Workshop: 1 Different generations working in partnership

Moderator: Ms. Ada Dortch International Planned Parenthood Federation

The purpose of this workshop was to identify the major issues which hamper smooth cooperation between different generations in patient organisations. As mentioned above the so-called “generational problem” affects every patient organisation and therefore it deserves particular attention. Three key issues were identified in relation to this theme.

#### Issues and challenges

The first issue is the lack of a youth-friendly approach in education on illness.

The second barrier that was identified by the participants to this workshop is the lack of training and support of youth-adult collaboration.

There is a lack of commitment from both sides, while unity is very important and should be sought for. Adults need to learn how to listen to young patients but young patients equally need to be able to understand the perspective of older people, too. Good practice exists, but it is not shared as it ideally should be. It was emphasised that young people are part of the community, and one of key responsibilities of adults is to introduce young people to the work of organisations which are representing their interests.

#### Recommendations

The participants to this workshop agreed on some key recommendations.

First of all, patient organisations should adopt a youth-friendly approach in their daily practice and activities. This includes, among others, communicating in a language which can be understood by youngsters and exploiting the opportunities presented by new information and communication technology which tend to attract the young. The importance of organising regular youth events was also stressed.

Secondly, it was recommended that patient organisations should not narrowly restrict to cooperating with other patient organisations, but also consider setting up working groups consisting of patients and non patients, particularly in youth-related issues.

The third recommendation was made specifically for EPF. The participants invited EPF to play a proactive role in the area of youth and health, particularly through leading skill-building activities,



including training and support for young people involved in patient organisations. Such training should stimulate young people's coming up with ideas and should be complemented by social activities and sport events. The purpose should be to empower young patients, enhance their skills but also to raise their awareness of how they could contribute towards the work and the goal of their organisations. As a result of such events young people should think of themselves as more active and productive players in the society.

## Workshop 2: Building partnerships between patient organisations and youth associations

Moderator: Ms. Laura Coffey of European Youth Forum

The purpose of this parallel workshop was to look into how to promote effective partnerships between patient organisations and youth associations, by highlighting barriers hampering effective cooperation and making suggestions on how these barriers could be overcome in the future.

### Issues and challenges

The workshop's discussion revolved around a number of key themes. The participants emphasised that patient organisations and youth associations can complement each other and have a common interest to cooperate. Patient organisations are often too focused on the disease that may not take into account other aspects of the life of young people. Youth associations can fill this gap. Likewise, youth associations may not be able to recognise all needs of young chronic patients. By cooperating with patient organisations this gap can be bridged.

Another key challenge seems to be the lack of understanding of disease-related issues from people who are not patients, lack of knowledge about specific conditions and preconceived ideas about what such conditions really are.

### Recommendations

The participants to this workshop made a list of general recommendations addressed to both patient organisations and youth associations.

Patient organisations need to be more open to their work with youngsters, be more creative and welcome youth volunteers. Patient organisations would need to launch youth-related projects including volunteer exchanges and other activities aimed at reaching out to young patients already involved in youth associations as well as to youngsters who are not involved in any organisations. To be able to effectively reach youngsters, it is crucial to adapt communication strategies to the needs of young people. Information should be provided in any possible way, including media, TV, movies, internet, interviews, joint projects, blogs, pictures, videos, etc.

Patient organisations should try to promote themselves proactively to outsiders. Particularly, it was emphasised that patient organisations should establish continuous dialogue and relationship with youth associations and try to identify common interests, mutual benefits and areas for cooperation. There are barriers between young patients and the society. Cooperation between patient organisations and youth association should focus on finding solutions to overcome these barriers. Patient organisations and youth associations could work together for example on non-formal education programmes and activities focused not only on disease, but also on other aspects which are relevant to young patients, such as education, access to employment and services and leisure.



Emphasis should be on communicating effectively the added value of working in partnership with patient organisations. 'Creativity' is key in making this happen. It was suggested, for instance that patient organisations launch campaigns in schools and universities to involve more young patients and raise awareness about their problems, needs and expectations.

EPF was invited to explore contacts with youth organisations for partnership and create a youth network or platform, and identify funding opportunities for patient organisations-youth associations' joint projects.

### Workshop 3 Setting up a youth group within patient organisations

Moderator: Marco Greco, European Federation of Crohn's & Ulcerative Colitis Associations

The purpose of this workshop was to discuss challenges and opportunities of setting up a youth group within patient organisations drawing on the experience of patient organisations which have been successful in integrating young people in their daily activities.

#### Issues and challenges



The participants started the discussion by asking themselves a thought-provoking question: "Are we scared about the idea of creating a youth group within our patient organisation"?

There are different reasons behind such a fear. The first is the fear of change whereby the involvement of youngsters is

perceived as a negative element as it entails modifying the way an organisation works. This may lead to resistance from those who advocate the need to ensure continuity also in relation to the image of the organisation. There is also the issue of responsibility and legal liability which comes up when young people are to be involved in an organisation as it was mentioned during discussions in the plenary. Setting up a youth group entails training young people while many organisations due to budget constraints may not have enough resources to "invest" in them. The lack of support from funders and public authorities was also mentioned in this context. Adults may not trust young people. What if "they don't do the things in the right way"? In addition to that, there could be a risk that other organisations may not take young people representing a patient organisation very seriously.

On the other hand young patients themselves may refrain from being actively involved in a patient organisation because of fear of stigma. "Recruiting" young patient advocates can become a challenge for many organisations. Even when stigma does not represent a challenge, young people may not feel motivated enough to join a patient organisation as they may not perceive the added value of doing so. Moreover, young people might lack a clear understanding or sufficient awareness of what their interests really are and this can make it difficult for them to actually understand benefits of becoming an active member of a patient organisations.



## Recommendations

In order to overcome all these barriers, the participants agreed on the following recommendations.

Patient organisations should not see youngsters as a “peripheral”, but should look at benefits of involving youngsters by learning from the experience of other patient organisations where all the above mentioned challenges have been successfully turned into opportunities.

How to “face” the change?

Patient organisations should not be afraid of change. To remain successful, an organisation needs to change and adapt to changes. The issue is how to manage the change. A good way to manage the change associated with setting up a youth group is to find ways to effectively communicate to the youngsters the values of the organisations and the need to deliver against these values in order to protect “the core spirit” of the organisation. It is important that youngsters understand clearly what the values and objectives of the organisation are and realise that these objectives are also their objectives and that their contribution is fundamental to achieving them.

How to “find” young patient leaders?

Participants to these workshops shared the suggestion made by the other two workshops as regards the need to organise specific events targeted towards young people and establishing partnerships with youth organisation schools and universities. An interesting idea could be to involve famous people to share their experience of the disease to the youngsters to help them think about their condition not in terms of what they *cannot*, but what they *can* do in their lives.



## 3. Strengthening capacity building

The second day of the seminar looked specifically at capacity building for patient organisations' leaders. Particular emphasis was placed on understanding how the EU healthcare policy-making process works, what are its mechanisms and channels for patient organisations to engage with the process. Another major theme of the second day was to explore and raise awareness about the strategic importance for patient organisations to join forces and work together in national coalitions.

### 3.1. Summary of presentations under this theme

#### 3.1.1. Patient involvement in health-related policies at European level

*Patient involvement in health-related policies at EU level, Kaisa Immonen-Charalambous, EPF Policy Officer*

Ms. Immonen-Charalambous provided the participants with valuable information on patient involvement in health-related policies at EU level. After a brief overview of the health policy-making in the EU, she shifted participants' attention to the various policy-related activities EPF has been recently involved in. She then provided concrete examples of EPF cooperation with the three most important EU institutions, i.e. the European Parliament (e.g. working with rapporteurs and involving MEPs into supporting EPF's work), various Commission Directorate Generals (e.g. Patient safety Working Group with DG SANCO, access to medicines initiative with DG Enterprise, health research and personalised medicine with DG Research) and the Council (e.g. working through successive EU Presidencies on key priority areas, see VALUE+ Final Conference in December 2009, Cross-border healthcare in December 2010).

Particular attention was paid to the various policy dossiers EPF is closely working on, such as the Pharmaceutical Package and Patients Rights in Cross Border Healthcare as well as other policy areas in which EPF is actively involved, particularly through participating in major EU projects. These areas include eHealth, telemedicine, Health Technology Assessment (HTA) and clinical trials.

She concluded by stressing the importance to strengthen the links with members to ensure their active participation in the consultation exercises that EPF regularly launches on all major policy issues (recent examples: clinical trials in third countries and initiative on eHealth). Kaisa strongly invited EPF members attending the seminar to get actively engaged in such consultation processes.

#### 3.1.2. Patient organisations working in national coalitions

After this comprehensive overview of EU level health-related policy-making the attention shifted to patient organisations working at national levels in national coalitions. Two speakers from the Baltic area representing organisations members of EPF were invited to present their experience of working in a national coalition and how this has led to a more influential patient voice in health-policy making in their countries.



### Ms Marta Kozireva, Chair person of the Latvian Umbrella Body for Disability Organisation-SUSTENTO

Ms. Kozireva spoke on behalf of SUSTENTO, the Latvian umbrella organisation representing the interests of people with disability and/or with chronic conditions made up of 31 member organisations. SUSTENTO's activities are primarily focused on protecting human rights and preventing discrimination.



Marta Kozireva, SUSTENTO and Ugne Sakuniene, LPOAT

Established in 2002, SUSTENTO represents a good practice of patient organisations and disability groups working together and joining forces at national level to have a strong position in national health and social policy-making.

Despite some early resistance, right after the establishment of SUSTENTO, all members were able to acknowledge important benefits resulting from joining forces, such as the increased ability to influence and participate in legislative matters affecting health and social welfare and the large opportunities to learn from each other and exchange good practices.

### Ms. Ugne Sakuniene, Member of the Board of the Council of Representatives of Patients' organisations' of Lithuania (LPOAT)

Ms. Sakuniene, speaking on behalf of the Lithuanian on behalf of the Council of Representatives of Patients' organisations' of Lithuania (LPOAT) presented her experience of the process that led many Lithuanian disease-specific patient organisations patients to join forces at national level.

She stressed that while the establishment of national coalitions in most Eastern Member States has been or is being pushed by top-down "pressure" coming from EU-wide patient organisations, in Lithuania it all happened as a consequence of a bottom-up process whereby national patient organisations felt the need to get together and decided to take the leadership towards the establishment of a nation-wide platform. She said that bottom-up should always be encouraged as it is far more effective because patient organisations feel the ownership of the process and are therefore much more committed to the cause.

Her take home message was a famous quote by Henry Ford *"Coming together is a beginning. Keeping together is progress. But working together is success"*.

## 3.2. Outcomes of discussions

The discussion which followed the two speakers' presentations focused on the advantages and disadvantages of patient organisations working in national coalitions.

Both the speakers and participants acknowledged that for patient organisations, there are important benefits to working in a national coalition such as the increased ability to influence and participate in legislative and policy processes affecting health and social welfare and the key opportunities to learn from each other and exchange good practices. Some participants highlighted that the overall conditions of chronic patients in their country has improved significantly after the establishment of a national coalition because of the increased ability of patient groups to get involved in the decision-



making at national level by speaking with a single stronger voice as opposed to the risk to speak with different and sometimes clashing voices. It was pointed out in this respect that working together in national platforms and speaking with a single united voice brings increased credibility for the patient movement in the eyes of other stakeholders and public officials.

There are also other major important benefits of being member of a national coalition. It was mentioned, for instance, the opportunity to gain from the valuable exchange of information between patient organisations which makes it possible for all members of the coalition to get prompt access to relevant information and react quickly when fast action is needed. It was also pointed out that joining forces in a national coalition enhances the possibility to better position patients' interests at the heart of national policy-making.

Other benefits that were thoroughly discussed are: the possibility to work together with organisations whose ultimate purposes are similar to your organisation, and, last but not least the possibility to support each other.

There are, however, some major challenges associated with establishing national platforms. Working in a national coalition requires that all organisations involved are able to strategically identify the problems that are common to all patients. This is a *condition sine qua non* for a successful national platform. In some countries patient organisations tend to narrowly focus on their own specific interests and emphasise the elements that differentiate them from other patient organisations rather than focusing on the key objectives which all patient organisations are ultimately fighting for.

There is also a problem of transparency. Joining and working in a national platform entails the delegation of decision making powers to people who do not belong to your organisation and who may not be fully aware of the issues the constituency that you represent is most concerned about. Moreover, some patient organisations fear that national coalitions may eventually tend to shift away from their original aim to pursue their own interest and, in doing so they may live down to patients' expectations the fulfilment of which should be the primary concern of any patient organisation. To prevent these things happening, it was highlighted that when considering establishing a national platform mutual trust, transparent commitment from all organisations involved and focus on key goals will always need to be put at the very heart of this process. If you fail to do so chances are that that the platform will never succeed in delivering against goals and expectations that were originally set.

The need to continuously motivate all organisations involved was also identified as a major challenge, particularly for newly establish national platforms. It was pointed out that in order to ensure that all members are equally committed and contribute fairly towards the work and the objectives of the national platform, benefits of working in partnerships and ownership of the process should be always clearly perceived by all organisations involved. At the same time it was stressed that we need to be realistic about benefits of establishing and joining a national coalition in order to avoid early disappointments, bearing in mind that such benefits may need time to be realised.

Last but not least it was highlighted that a key challenge is leadership. A national platform without a good leader will be highly unlikely to succeed in achieving its goals.

Good leadership and strong commitment are challenges that can be overcome as the remarkable achievements of many national coalitions in various EU countries clearly demonstrate.



### 3.3. Outcomes of the workshops

In the afternoon the seminar broke out into three parallel workshops. Each workshop took forward a specific theme that was already discussed in the morning session. The first workshop, which was moderated by Ms. Nicola Bedlington, Director of EPF, dealt with the theme “*Getting Involved in a Consultation Process*”. The second workshop was moderated by Ms. Kaisa Immonen-Charalambous, EPF Policy Officer and was held under the theme “*Working with Members of the European Parliament*”. The third workshop was focused around the theme “*Working with Healthcare Stakeholders*” and was moderated by Ms. Liuska Sanna, EPF Programme Manager.

#### Workshop 1 Getting involved in a consultation process

Moderator Nicola Bedlington, EPF Director

The aim of this workshop was to identify challenges associated with the involvement of patient organisations in policy or legislative consultation processes and make concrete recommendations on how to overcome these challenges and transform them into opportunities.

##### Challenges



The participants to this workshop identified a number of challenges in relation to this topic.

The first challenge is how to overcome the poor communication between local NGOs, including patient organisations and national governments. Without smooth and transparent communication the participation of patient organisations whether through consultations or more inclusive methods in health policy-making

will never become common practice.

Getting involved in a consultation is regarded as a highly time-consuming process which entails huge commitment and investment from patient organisations in terms of time and staff resources which often goes beyond what many patient organisations can realistically afford.

Another obstacle is to overcome the widespread disappointment resulting from previous participation in consultation exercises. Many patient organisations regret that there is poor evidence of usefulness of participating in consultation processes as real possibilities to influence decisions are marginal and any effort is perceived as not worthwhile.

##### Recommendations

EPF launches regularly consultations with its membership to develop a position on a specific issue and/or to respond to an EU-level consultation. It was highlighted that it is sometimes difficult for national patient organisations to respond to such consultations because they do not have the background knowledge required and, as mentioned beforehand, they lack internal resources to participate in EPF consultations. To facilitate all this, it was suggested that EPF uses a single electronic format for consultation similar to the one used by the European Medicines Agency (EMA).

EPF should also come up with a consistent consultation framework highlighting the main critical issues in a consultation process which can be clearly and easily identified by those who are invited to contribute.

There should be also a standardised two-way communication channel between patient organisations and EPF, but also between EPF and EU institutions to allow for proposals coming from the grassroots (bottom up) to be discussed with EPF through collaborative processes before a joint input is delivered to the EU.

Participants also recommended that EPF makes a clear distinction between what is to be dealt with at national level and what is to be decided at EU level. This should be used as a framework for national patient organisations for understanding what can be done and achieved through EPF support and what is to be handled through national channels. Quality healthcare is a clear cross-cutting issue that should be handled at EU level with the strategic coordinating role of EPF. Non-discrimination legislation is another area where EPF should seek involvement.

The participants also called upon EPF to participate in more local lobbying events to understand problems and barriers for local patient organisations, provide support, and put pressure on local institutions.

## Workshop 2 Working with Members of the European Parliament

Moderator Kaisa Immonen-Charalambous, EPF Policy Officer

The purpose of this workshop was to explore how national patient organisations perceive the opportunities to work with Members of the European Parliament (MEP) directly or indirectly through EPF. The participants also discussed what could be done to strengthen the involvement of patient organisations in EU-policy making through effective collaboration with the European Parliament.

### Challenges

There seems to be a certain lack of knowledge about what the European Parliament actually does, how the work and activities undertaken by this institution are related to the wider EU-policy making process, and, last but not least, what procedures apply at various stages of the policy making process.

The participants also underlined that national health policies and EU-level health policy making are extremely different. Working at EU level requires some knowledge of health issues and healthcare systems in other EU countries. The lack of comparative information about national laws and health issues represents a barrier.

Moreover, it is not always clear to everybody what the competence of the EU are in the area of health, but more importantly it seems to be not easy to understand how single decisions made at EU level will affect national legislation and practice that is to say how a specific decision will eventually impact on patients' daily lives and access to healthcare.

In addition to these challenges, the participants pointed out that whereas the effort made by EPF to involve national patient organisations in working with the European Parliament is very much appreciated, the communication from EPF does not always reach the grassroots. There is a lack of



visibility of how EPF works with various MEPs and this makes it extremely difficult for individual patient organisations to contribute to this work.

### Recommendations

The participants agreed on some key recommendations all addressed to EPF, whose role is critical in ensuring the smooth connection between the work of national patient organisations and EU level policy-making.



Firstly, EPF was invited to strengthen its support to patient organisations by providing capacity building and ad-hoc advocacy training focused on how to participate in EU policy-making process, possibly with the participation of Members of the European Parliament and the European Parliament Secretariat.

In order to address the lack of awareness of health issues in different EU Member States, EPF was encouraged to collect comparative information from its various members and share it with other patient organisations. It was suggested, for instance, that EPF set up an on-line interactive database with information from different disease-areas and countries.

The participants also invited EPF to improve the communication and cooperation with its members and between members and their members in the context of consultations. The establishment of a networking platform possibly using social media was also suggested.

## Workshop 3 Working in partnership with health stakeholders

Moderator Liuska Sanna, EPF Programme Manager

The focus of this workshop was to discuss some of the key issues involved once a patient organisation is to cooperate with other healthcare stakeholders, whether be healthcare professionals, industry or public sector officials.

### Challenges

The participants have identified a number of barriers hampering the smooth cooperation between national patient organisations and other healthcare stakeholders.

The first barrier is the lack of sensitiveness and knowledge of patients' needs by other healthcare stakeholders. As far as health policy makers, for instance, it was emphasised the lack of time, will and interest in working in partnerships with patient organisations and when they show some interest patient organisations are certainly not the priority on their busy agenda.



The second issue is the fact that each stakeholder, including patients and patient organisations, tends to narrowly focus on its own interest without trying to understand how decisions or proposals will affect other stakeholders. Being able to see the big picture and not just pieces of it is a critical challenge for all stakeholders involved in the health policy arena. Concerted action and collaborative work cannot happen if each individual stakeholder group is not able to critically recognise what the common interest for all stakeholders might be.



Linked to the foregoing is the need for patient organisations to understand that they cannot overlook other health stakeholders in their daily actions. On the one hand, patient organisations need to effectively tell other stakeholders that if it is true that patients need other stakeholders, healthcare stakeholders in turn need the patients if they are to effectively achieve their goals. The key challenge here is to identify what the common interests and issues for all health stakeholders are and understand how working in partnership can help all stakeholders to better address them.

### Recommendations

On the basis of the issues that were identified in the first part of the workshop the participants made some recommendations for both EPF and patient organisations in general on how to better work and cooperate with other healthcare stakeholders.

As far as the recommendations addressed to EPF are concerned the participants highlighted that EPF should organise multi-stakeholder meetings in the framework of its regular annual events to give patient organisations the opportunity to discuss with other stakeholders about relevant issues and identify common interest and areas for possible cooperation. It was pointed out that this would attach even more added value to EPF advocacy seminars.

EPF was also invited to play an active role in identifying and collecting good practice on effective healthcare stakeholders' cooperation and share this with other patient organisations, especially those working at national level.

As to patient organisations in general, the participants called upon both patient organisations and health stakeholders to build partnerships in a transparent way.

National multi-stakeholder platforms should be created based on existing multi-stakeholder platforms which have been recently set up at EU level, i.e. ehealth User Stakeholder Group, Open Health Policy Forum and the various Joint Actions.



## 4. Next steps

The Budapest Advocacy Seminar represented the very first opportunity for EPF to bring young patients and senior patient advocates from different EU countries together to discuss: a) how to promote the meaningful involvement of young patients within patient organisations and; b) how young patients' needs can be better recognised and formulated by patient organisations through the meaningful involvement of young advocates in these organisations. It was built on some preliminary work undertaken by young patients in Sweden<sup>2</sup>.

Looking at the feedback and the outcomes produced through the stimulating interaction between young and senior patient representatives we are very pleased to say that this seminar has been indeed a very successful and rewarding exercise. We are particularly pleased to know that all participants have learnt a lot from this seminar, particularly from the experience of other organisations which have succeeded in engaging with youngsters. Many participants have pointed out that not only was the seminar a very enriching and thought-provoking experience, but they have also emphasised that they would return back home with new ideas, stimulus and motivation to move things forwards towards building up a more “youth-friendly” organisation.

EPF has certainly learnt a great deal from this experience. We have learnt that young patients' involvement in patient organisations is indeed a challenge, but there are many ways in which this challenge can be turned into opportunity. The successful experience of young patients' involvement in patient organisations which were shared with us by various speakers during the seminar not only gave us inspiration on how to implement some of the ideas within EPF and its membership, but they encouraged and motivated us to look into the opportunity to concretely engage with young patients and put a young patient perspective at the very heart of our future work and activities.

This seminar represented in this respect the first step towards the development of a “Youth Strategy” which we aim to implement alongside our future work plans starting from 2011. The outcomes of the plenary sessions and parallel workshops together with the outcomes of the workshop with the young representatives held on the third day of the seminar will be used, therefore, to inform the development of the EPF Youth Strategy.

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<sup>2</sup> [http://www.eu-patient.eu/Documents/Projects/YoungPatientsPerspective/Young\\_Patient\\_Perspective\\_Report.pdf](http://www.eu-patient.eu/Documents/Projects/YoungPatientsPerspective/Young_Patient_Perspective_Report.pdf)



## About the European Patients' Forum

The European Patients' Forum was set up in 2003 to become the collective patients' voice at the European level, manifesting the solidarity, power and unity of the European Union patients' movement. EPF is a not-for-profit, independent organisation and umbrella representative body for patient organisations throughout Europe.

We currently represent 49 member organisations that consist of chronic disease specific patient organisations working at the European level and national coalitions of patient organisations. In total, we reflect the interests of an estimated 150 million patients affected by various diseases in the EU.

EPF's vision is to establish patient-centred equitable healthcare through the European Union. Our core values emphasise a patient-centred approach to healthcare, inclusiveness, non-discrimination, patient empowerment, consultation and independence and transparency. We adopt a holistic interpretation of healthcare to include prevention, and the social, economic, environmental, cultural and psychological aspects of health.

EPF acts as a catalyst and consultative partner for positive change in EU healthcare systems and as a "watchdog", closely monitoring EU policy and legislative initiatives. We offer our members EU healthcare intelligence, and baseline patient rights policy responses to enable them to focus on disease specific responses.

We support dialogue and negotiation among a broad range of EU level health stakeholders and facilitate the exchange of good practice and challenges of bad practice on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at the European and Member State level.

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