

EPF Regional Advocacy Seminar - Nordic Countries

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1. About EPF

The European Patients' Forum (EPF) is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe. Our 65 members represent specific chronic disease groups at EU level or are national coalitions of patients.

Our vision is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

Our mission is to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

EPF helps to empower patients' organisations through educational seminars, policy initiatives and projects. We coordinate best practice exchanges between patients' organisations at European and national levels. Our programmes also help to strengthen their organisational and advocacy capacity.

2. Introduction

2.1 EPF REGIONAL ADVOCACY SEMINAR BACKGROUND

Organising annual EPF Regional Advocacy Seminars is the approach EPF is pursuing to engage and work with national patient organisations and their national coalitions with a view to:

- Integrating national perspectives into the European debate to have a stronger patient voice;
- Feeding policy information and policy outcomes back into national realities and contexts;
- Developing and sustaining the advocacy capacity of patient leaders.

The value of this approach has been strongly confirmed by the success of the advocacy and capacity-building seminars for patient leaders held over the previous years, for example in Romania (2011), Portugal (2012), and Croatia (2013).

While the core objective of strengthening patient leaders' advocacy capacity is the key feature of EPF's advocacy seminars, these events also represent an opportunity to address specific issues which we identify in close consultation with our members. This year's EPF Regional Advocacy Seminar was held in Lund, Sweden on 24 and 25 November 2015. Its overarching theme was "Strengthening patient involvement in European research and policy".

The participants to this seminar were representatives of national patients' organisations from the Nordic countries, namely **Denmark, Finland, Iceland, Norway** and **Sweden**.

2.2 GENERAL OBJECTIVES AND STRUCTURE OF THE SEMINAR

The overall objective of the 7th EPF Regional Advocacy Seminar was to provide patients' organisations with tools to advocate effectively at European and national level.

The Seminar had five specific objectives:

- Strengthening patient organisations' capacity in order for them to become more empowered actors in national and European health policy arena;
- Raising knowledge and awareness among national patient organisations of how to get involved in the transposition and implementation of key EU health-related policies;
- Examining opportunities of cooperation with different stakeholders (EPF; other patient organisations, health professionals, industry)
- Making sure patients have a say on the EU & national research agenda and make a meaningful contribution
- Providing an opportunity for Nordic patient organisations to network

This Seminar was an opportunity for the participants and their organisations to establish dialogues and build up partnerships with EPF and other patients' organisations and to learn and share experiences about the implications of some key EU policy initiatives for patients and national healthcare as a whole.

The methodology of the Seminar was based on interaction and active involvement of participants. The Seminar took place over one-and-a-half day and included plenary and parallel workshops, enabling interactive debate and reflections. Parallel sessions were conceived in order to let participants have a deeper focus on the chosen topic and gain learning that can be effectively used and transferred to their own patients' organisations.

The first day started with a **plenary session to "set the scene" for the seminar**. Representatives of patients' organisations from the participating countries were offered an overview on the EU Institutions, their roles, functions and interactions, as well as the legislative and policy framework on healthcare. Practical examples on patients' organisations legislative and collaborative work were presented to the audience.

The following session was dedicated to **patient involvement in research and policy**. To introduce the session, participants were presented with the rationale behind patient involvement and the key milestones in the evolution of patient involvement over the past years. During a brainstorming exercise, participants identified main barriers to patient involvement and solutions to overcome these.

Three parallel workshops took place in the afternoon of the first day with a focus on the **EUPATI Toolbox, Advocacy for patient involvement and Health Technology Assessment**. A closing plenary presented the outcomes of the parallel workshops and highlighted key conclusions.

The second day started with a **plenary session focused on patients' organisations cooperation with European patients' organisations and partnership with other patients' organisations at national level**. Case studies highlighted the main benefits deriving from partnership and cooperation. The benefits of preparing the next generation of patient advocates were presented by a Young patient leader.

Three parallel workshops followed focusing on **partnership with other stakeholders: healthcare professionals, companies and donors, and other Nordic patient organisations**. Finally, a closing plenary presented the outcomes of the parallel workshops, highlighted the key conclusions, and made proposals for the way forward.

3. Setting the scene: an overview of the EU Institutions and decision-making process

Kaisa Immonen-Charalambous, EPF Director of Policy, introduced the European Institutions and their competencies in the decision-making process in healthcare with the aim to make participants familiar with this wide topic.

She outlined how and to which extent each European institution is involved in health and explained how patients' organisations may get involved in the decision-making process.

Her key messages were the following:

- **The main EU Institutions** of interest to patients are the European Commission (Directorate-General SANTE)¹, the Council of Health Ministers², and the European Parliament, where the Committee dealing with health issues is the Committee for Environment, Public Health and Food Safety (ENVI).³

Other relevant EU institutions include the European Court of Justice, the Committee of the Regions and the European Economic and Social Committee.⁴

- **The EU competences in health are limited by the Treaty**,⁵ which reserves responsibility for the organisation of health systems and delivery of healthcare to the Member States. EU action shall complement and support national policies and must be subject to the principles of *subsidiarity* (action as close to the citizen as possible) and *proportionality* (no more action than is necessary). The EU can adopt binding legislation in some areas of exception, including quality and safety of pharmaceuticals and medical devices, whilst in other areas of health EU action is based on “soft law” and collaboration to exchange best practices.

The limited competency of the EU is being increasingly challenged both by health actors who wish to see more policy-making at European level, and by Member States' recognition that they are facing common challenges, for example in the areas of ageing, chronic disease, and healthcare systems reform.

- **The EU legislation has an impact on policies in Member States.** EU directives need to be transposed into national laws. (Regulations are directly applicable.) How a directive

¹ Home page: http://ec.europa.eu/health/index_en.htm

² Home page: <http://www.consilium.europa.eu/en/home/>

³ For a list of all committees, see www.europarl.europa.eu/committees/en/parliamentary-committees.html

⁴ For information about all the institutions of the EU, see: <http://europa.eu/about-eu/institutions-bodies/>

⁵ Article 168 of the Treaty on the Functioning of the European Union (TFEU). The Treaty in its entirety is available at <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A12012E%2FTXT>

is applied will depend on how a national government chooses to interpret it. Directives can often be quite vague, defining only objectives but not means. This process can be an opportunity for patient advocates at national level to get involved and influence the end result.

- **Patient organisations can play a role in EU decision-making:** the decision-making process gives room to patients' organisations participation, but they need to be able to exploit to the maximum extent this opportunity by providing input to consultations, setting up informal meetings with EU Commission representatives, proposing amendments and recommendations to those Members of the Parliament who are involved with specific dossiers.

Given the difficult accessibility of the Council, EPF works usually with EU Presidencies on key priority areas, while it encourages its members at national level to contact National Authorities directly and deliver coherent messages across the Member States. Patient organisations can also engage MEPs from their own country and contact them through their national offices.⁶

- **This role is different according to the nature of the patient organisation:** European patient organisations are closer to European decision-makers, while national patient organisations know about national-specific realities and legislation, and therefore have a greater potential to influence their government's priorities or positions in the Council. These two levels of action are complementary and have to work together for optimum impact.

Kaisa then illustrated the role of EPF in this decision-making process through three examples:

- **The cross-border healthcare directive.** EPF strongly advocated the patient perspective during the long negotiation process on this piece of legislation, which took two years to get an agreement between Parliament and Council. Since the adoption after directive, EPF organised a series of seminars to inform and raise awareness among patient communities in all member states. The application after directive is taking quite some time, and member states are taking different approaches – so patient organisations still have a key role in unlocking the potential benefits of the directive.⁷

⁶ Find your local MEP here: www.europarl.europa.eu/meps/en/map.html

⁷ For information on EPF's activities, see: www.eu-patient.eu/whatwedo/Policy/Patients-Mobility; for information and reports from the European Commission, see http://ec.europa.eu/health/cross_border_care/policy/index_en.htm

- **The clinical trials legislation**, where EPF asked for meaningful patient involvement in trials, including ethics review, and is working with stakeholders to develop EU guidelines for communication of the results of trial for lay people (“lay summaries”).
- **Patient safety**, as an example of non-legislative collaboration. Member States, the European Commission and health stakeholders have an established framework for collaboration through the Commission’s Expert Group where EPF is a member, as well as in the EU-funded Joint Action, PaSQ.⁸ The role of EPF and other patient organisations within these activities has been to recognise the role patients and families play in patient safety, and to advocate for increased patient involvement in the development of policies and programmes on patient safety in EU Member States.

EPF collaborates with all relevant stakeholders (public health, industry, health professionals, European Medicines Agency, etc.). It involves its members through consultations on policy dossiers and fosters their active role at national level.

⁸ www.pasq.eu; http://ec.europa.eu/health/patient_safety/policy/index_en.htm

4. Patient involvement in EU policy and research

4.1 THE RATIONALE BEHIND PATIENT INVOLVEMENT

Camille Bullo, EPF Membership Officer, gave an overview of the rationale of patient involvement and explained why it is especially relevant when it comes to research.

- **Patients have a moral right** to be involvement in how research is developed, managed and evaluated;
- **Patient involvement is also a common operating principle of the EU health systems**, according to the 2006 Council Conclusions on common values and principles in the European Union Health Systems;
- Looking at research, **patient involvement also leads to better quality research results:**
 - Patients bring in a broader perspective and experiential knowledge.
 - Their priorities for research are often different: involving patient means having a better alignment of innovation with real needs;
 - Finally, patient involvement strengthen trust and acceptance of research.

4.2 THE EVOLUTION OF PATIENT INVOLVEMENT

Nicola Bedlington, EPF Secretary General, gave a short presentation on the evolution of patient involvement in research and policy-making.

Although there is today a number of opportunities for patients to be involved in clinical trials, ethic committees, contribution to health technology assessment (HTA) reports, this has not always been the case. EPF and other patient groups have relentlessly advocated for patient involvement.

From 2008 to 2010, EPF led a project called **VALUE +** which aimed at demonstrating that patients' meaningful involvement enhances health project results, which can in turn contribute more effectively to policy towards patient-centred, equitable healthcare throughout the EU. The project contributed to **raise awareness about the added-value of involving patients' organisations in projects**, as well as to increase the capacity as patients' organisations of getting involved in projects as equal partners and of applying for and managing EU supported projects through different project information tools.

The **European Medicines Agency (EMA)** is a good example of how stakeholders gradually recognised the value and insight patients bring. Indeed, since 2005, the EMA progressively implemented patient consultation mechanisms. Patients participate as full members in

several of the scientific committees, and in scientific advisory groups on an ad hoc basis. EPF and other patient organisations are permanent members of the EMA's Patient and Consumer Working Party.⁹ Unfortunately, the degree of patients' involvement at national regulatory agencies varies enormously between Member States.

This growing awareness of the importance of patient involvement translates on the political side: patient organisations are more and more invited to participate to research advisory groups that shape the health research priorities.

We are gradually shifting towards a vision where patients are seen as “co-producers” of well-being and integral actors in the health system. Still, a lot remains to be done for patient involvement to become systematic, and patient organisations have a role to play.

EPF continues to advocate for patient involvement in policy-making in different ways: through the European Patients' Academy for Therapeutic Innovation (EUPATI) programme, which trains patient representatives to become confident patient advocates; and through its current Patient Empowerment Campaign, which calls on a real EU Strategy recognising the expertise and contribution patients can make in policy-making.

4.3 OVERCOMING THE BARRIERS TO PATIENT INVOLVEMENT

This interactive session was devoted to identifying the barriers to achieving patient involvement. During one hour, participants reflected on the two following questions:

- What are the barriers to patient involvement and policy & research?
- How can we remove this? What are the enablers of patient involvement?

Participants identified the following issues as **the main obstacles to patient involvement in research and policy:**

- Lack of knowledge and awareness of opportunities to become involved;
- Lack of capacity of patient organisations to contribute; passivity of some members,
- Lack of financial resources;
- Lack of political will to involve patients;
- Too little coordination between patient organisations, resulting to a loss of visibility for patients on the European scene;
- Weight of tradition and conservatism of healthcare systems.

⁹ For information on how patients are involved in the EMA, see: www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000317.jsp&mid=WC0b01ac058003500c

The contribution patients can make varies according to the level considered: at individual level, research unit/hospital level or at system level.

Participants then offered some ideas to overcome these barriers. The following proposals were made:

- Striving for unity of the patient movement, in order to gain visibility and credibility at European level;
- Taking a more proactive approach towards stakeholders such as decision-makers, industry, and regulatory bodies;
- Working towards advancing the mentalities and the larger recognition of patients' expertise, promoting a paradigm shift to a more holistic view of healthcare
- Increasing the level of information to patients, but also to the general public (through public debates for instance);
- Launching educations programmes (such as EUPATI) where best practices of patient involvement can be promoted;
- Focusing on the local level first, where it is easier to create the conditions for a quality dialogue;
- Making patient involvement a condition for getting funds for a project.



5. Strengthening the patients' voice through Partnerships and Alliances

5.1 EUROPEAN DISEASE-SPECIFIC UMBRELLAS

Susanna Palkonen, Director of the European Federation of Allergy and Airways Diseases Patients Associations (EFA), delivered a presentation on the importance of partnerships for patient associations.



She detailed the key benefits for patient associations of being active within disease-specific umbrella organisations and of working in partnership with other stakeholders.

Her key messages were the following:

About being active in a disease-umbrella:

- Being active within a European organisation brings you credibility and helps you to be on an equal footing with health professionals;
- You do not need to share all priorities, you just need to agree on what you want to work on together;

About partnerships with other stakeholders:

- Think of partnering with NGOs beyond the health sector: the European Federation of Allergy and Airways Diseases Patients Associations cooperated with associations active in the environmental sector, as they have similar objectives.
- Partnerships increase ownership and maximise impact, but don't dilute patient perspective

What do European patient groups do?

- Advocacy: try to set the scene from the patients' perspective at European level
- Following EU legislation: writing briefings for members, consulting with them on their respective priorities, developing joint positions, writing template letters to MEPs, Council...

- In terms of methods, EFA works through working groups, trainings and visits, such as the role play “Meet and Greet the EU”, capacity-building project, and translations of briefing notes.

Susanna concluded her presentation with a call to the participants: “Nordic associations’ leaders, Europe needs you!”

5.2 NATIONAL COALITIONS

Sari Tervonen, President of POTKA, the Finnish Network of patient organisations, presented the work of this relatively young national coalition of patient organisations.

Although Finnish patient organisations have been cooperating since the seventies, POTKA was created 3 years ago, under the umbrella organisation SOSTE, which brings together around 202 Finnish NGOs working in the social and healthcare field. SOSTE advocates for NGO funding and visibility, while POTKA focuses on more specific issues of relevance for patient chronic diseases.



As many Finnish NGOs, POTKA receives funds coming from slot machine funding and redistributed by the government.

National alliances have the double advantage of increasing the credibility and representativeness of the patient movement for a given country. POTKA’ work translates primarily in the organisation of meetings for its members and the publication of statements and resolutions aimed at changing attitudes towards patients with chronic diseases. POTKA also provides advice to decision-makers and municipalities.

What about cooperation with other patient groups?

- POTKA’s interest in international cooperation lies first in getting information on what is happening at EU level and funding opportunities.
- Because the health issues Nordic countries encounter, Nordic cooperation is also among POTKA’s priorities.

- Making the voice of patients heard can happen thanks to alliances: more patient platforms are needed.

5.3 YOUTH PATIENT GROUPS

Daniel Sundstein, former leader of the European Federation of Crohn's and Ulcerative Colitis (EFCCA) gave a testimony of the importance of patient groups for young patients.

Telling his own story, he explained how he shaped the work of the EFCCA Youth Group so that it reflected the preoccupations and priorities of its members. Young patients are not ordinary patients, he explained, they are also busy building their lives. **Therefore, in order to secure the commitment of the youth group members, the work of youth patient groups must inspire motivation and a vision of your future achievements.**



The added value of youth patient groups is the complementary support they provide for their individual members: although the support of a family is invaluable, only fellow young patients can fully understand what you are going through.

The work of youth patient organisations is also crucial to prepare the next generations of patient advocates. By dedicating personal time to the activities of their association, many young patients learn skills that they will be able to apply in the future professional life or in advocating further for patients' rights.

6. Outcomes of the thematic workshops

6.1 STRENGTHENING PATIENT INVOLVEMENT THROUGH EDUCATION: EUPATI AND THE EUPATI TOOLBOX

Walter Atzori, EPF Senior Programme Officer, presented the European Patient Academy on Therapeutic Innovation (EUPATI), a five-year project funded under the Innovative Medicines Initiative (IMI)

Launched in early 2012, EUPATI aims to respond to the unmet need of patient advocates and the health interested general public to find reliable and objective information to understand and become involved in medicines' research and development.

In order to address this need, the EUPATI has three main objectives:

- developing and disseminating objective, credible, correct and up-to-date public knowledge about medicines R&D
- building competencies & expert capacity among patients & public
- facilitating patient involvement in R&D to collaborate in academic research, industry research, regulatory and HTA bodies, as well as ethics committees

The themes covered by EUPATI cover the entire medicines' journey: from the discovery of Medicines and Planning of Medicines Development to health technology assessment and the economics of medicines' development, through clinical trials and regulatory affairs.

To bring the project to life, EUPATI has developed different education materials which correspond to different target audiences:

- **The EUPATI Patient Expert Training Course:** 100 selected patient advocates, split in two cycles, follow and blended e-learning and in person training intensive course on medicines' development during a period of 14 months.
- **The EUPATI Educational Toolbox, for patient advocates:** hosting patient-friendly ready-to-use educational material on medicines' research and development in seven European languages English, Italian, Spanish, Polish, German, French and Russian is set to go live in early 2016.
- **The EUPATI Internet Library:** designed for the health-interested public, this is meant as a layman friendly internet library and glossary on medicines' and research development.

During the workshop on the EUPATI toolbox, participants had the opportunity to preview and test the EUPATI toolbox to be launched on 27 January 2016.

6.2 ADVOCACY FOR PATIENT INVOLVEMENT

This workshop was facilitated by Kaisa Immonen-Charalambous and Kirsten Lerstrøm, Chair of Lupus Europe. The objective was to reflect on the unique input patients can provide to research policies; the different levels of actions and advocacy (local, national, European); the individual and collective contribution of patients and the enablers and barriers to patients' involvement in research policies.

Kirsten Lerstrøm gave an introductory presentation. She illustrated how medical professionals tend to see a condition through their own “speciality lens”, so rheumatologists tend to focus on hands and feet, whereas Lupus affects all of the body so for the patient the impact is much more holistic. Around half of patients are forced to give up employment within a few years of diagnosis, so it is clear that the currently available treatments are not good enough.

She presented the Lupus Europe survey “Living with lupus” as an example of how patients can strive to contribute to research policy. The survey shows the impact of the illness from the patients' point of view. With the survey lupus Europe is aiming to get the patient's voice heard by those who design research and clinical trials; it also partners with the European League against Rheumatism (EULAR), and participates several EU-funded research project and international projects.

The group then reflected on various aspects of research and related policy, from setting research priorities generally and for specific diseases, to designing clinical research and reviewing research proposal, partnering with other actors such as academic researchers, health professionals and companies, and bringing the results of research into wider dissemination. Each aspect has its own specific issues, including ethical and financial ones – so in order to find the right solutions first we need to define the type of research and objectives.

Key messages that emerged out of the discussions:

- **Research in chronic disease should always take a holistic view and value the patients' unique knowledge.** A particular challenge is how to find this knowledge and share it with researchers; in an ideal situation patient should be seen as co-researchers.
- **Public funding to patient organisations would be a concrete recognition of the value of their work.**
- **A framework or guide for patient organisations** to understand the issues related to the topic would be useful. This should include the different types of research; the stakeholders involved; how the process works; how to generate robust knowledge

(“patient evidence”); how to evaluate; and how to reach out, communicate and influence other stakeholders. The framework should be recognised also by the researchers and regulators in order to be credible.

- As a concrete suggestion, the participants felt that **EPF should develop an easy-to-use guide on the “EMA model”**, based on the work of EPF and others, which patient organisations could use to advocate for more involvement with the regulators in their own country.

6.3 HEALTH TECHNOLOGY ASSESSMENT

The purpose of this workshop was for participants to gain insight about what Health Technology Assessment (HTA) is, and the role patients can play therein.

The moderator Sophie Werkö, International Relations Manager and Project Director at the Swedish Council on Health Technology Assessment (SBU), kick-started the workshop with a short presentation of HTA.

- **A health technology assessment is a multidisciplinary process** that summarises information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased and robust manner.
- **HTA is not about technology!** Technology is understood as any health intervention: screening, vaccines, diagnostics, medicines, devices, education, rehabilitation...
- **The aim of HTA is to inform policy at national, regional or hospital level about the added-value (or lack thereof) of a technology.**

HTA agencies in the Nordic countries

Health Technology Assessment are not conducted in all countries. In some countries, there is no body in charge of HTA. These countries usually use the assessment conducted by other countries.

- [The Swedish HTA agency SBU](#) is independent, with no legislative power, and produces assessments that are then used by decision-makers. Anyone can make suggestions of technologies to be assessed by the Swedish HTA agency. The proposed topics are then prioritised.
- The Danish HTA agency was shut down some years ago. The competence was devolved to the regional level but at the current time there is not enough funding available for them to function properly.
- In Norway, HTA is the responsibility of the [Norwegian Knowledge Centre for the Health Services \(NOKC\)](#).

- In Finland, the body responsible for HTA is THL, [the Finnish Institute for Health and Welfare](#).
- Iceland has no HTA agency.

Patients' contribution to HTA

- Patients' experience of living with an illness is unique: no one knows better what it is like to live with an illness day in, day out.
- With regards to the technology, patients can express their needs and preferences, the benefits and unwanted effects they get from a technology.



Patient Group Submission Templates

The workshop then looked at the Patient Group Submission Template, a form where patients can report the impact of their condition, such as activities that are difficult, emotional and psychological issues they encounter, what their priorities are with regards to a potential new treatment, etc.

The Patient Group Submission Template is also used to report the patient experiences with currently available health interventions, and their expectations of new health interventions.

The Patient Group Submission Template is currently not used in the Nordic countries.

6.4 COOPERATING WITH HEALTHCARE PROFESSIONALS

The objective of this session was to understand how patient organisations can cooperate with health professionals at national level. The workshop was facilitated by Kaisa Immonen-Charalambous and Katrín Fjeldsted, President of the Icelandic Doctors' association and the Standing Committee of European Doctors (CPME).

Dr Fjeldsted given introductory presentation with examples of collaboration between doctors' and patients' organisations in the different Nordic countries. She felt that **stronger links should be encouraged at national level between the medical association and the patient associations**, in addition to collaboration at European level between CPME and EPF.

Many patient organisations work quite effectively with the specialist doctors in their field, but there are wider issues relating to the healthcare system that need a different kind of collaboration. In each country, the cross-cutting issues where patients and doctors could work together effectively should be identified. In the Nordic countries, these have included for example patient safety and hospital bed shortages.

Key messages that emerged from the discussion:

- **More attention is needed on chronic disease care, as chronic conditions are long-term, often involve multimorbidity** and require a holistic view of the patient as well as ongoing monitoring and support
- **Patients can help improve services for everyone;** for example by “telling and showing” the patient experience to the professionals, through lectures at conferences, joint meetings, and participation in the development of clinical guidelines.
- **Patients and doctors can work together on information to patients;** by developing patient friendly, evidence-based information, guidance on and how to find the right information online; and by disseminating existing tools (such as guidance to patients on how to prepare for consultations) more effectively.
- **Patients should be contributing much more the professional education and training,** including to the development of training curricula. This can be addressed both at EU and national levels as there is a new framework for professional qualifications.
- Although many professionals are in favour of patient empowerment, **there is a need for wider change in medical culture.** Patients should find their “champion” professionals and use their influence to push for change in medical practices.

- **In order to avoid “tokenism” and get the best benefit out of collaboration, ethics guidelines and practical tools should be available**, such as the tools developed by Value+.¹⁰
- **National umbrella patient organisations are an important interlocutor and partner with national professionals’ organisations**, so their establishment should be encouraged. However, participants warned that national umbrellas should be as representative as possible and should not exclude other voices from being heard.

6.5 COOPERATING WITH THE INDUSTRY

The workshop on cooperating with the industry was moderated by Simona Biancu, Consultant on Fundraising. Her presentation on fundraising was followed by a lively discussion with the participants.

Here are her key messages:

- **Fundraising is about relationships with the donor first, then about the money.**
- When it comes to identifying potential donors, **think out of the box**: potential funding sources include companies, but also individuals, foundations, club services, and public funds. Ideally, a sustainable fundraising strategy includes a mix of these sources.
- There are many ways a donor can sponsor your organisation, for example payroll giving, match giving, cause-related marketing, etc...
- The first step in establishing your fundraising plan should **be identifying your prospective donors**. In order to do this, you need to find out who your constituents are. A constituent is everyone with a potential interest in your NGO (including your members, donors, volunteers, suppliers, and people interested in your cause).
- The Pareto principle also applies to fundraising: **80% of funds come from 20% of your donors**.
- **Cultivate your relationship with your donors**: inform them, involve them, and then ask for money.
- Fundraising tools range from personal meetings, to phone calls, mailing and emailing, through crowdfunding and media coverage: make sure you choose the most appropriate one to your donor’s situation.

¹⁰ The Value+ handbook, toolkit and policy recommendations are available at www.eu-patient.eu/whatwedo/Projects/ValuePlus/



During the report in plenary session, Nicola Bedlington, EPF Secretary General, added some important points on transparency and ethics in working with the industry:

- It is essential to have a clear code of conduct which will help you to keep a clear line in your cooperation with the industry;
- Know where your limits are, what is acceptable for your organisation and never compromise;
- If you receive funding from private companies, work towards getting funding from more than one: a “one-to-many” relationship is easier to manage than a “one-to-one”, and industry tends to appreciate this commitment to diversity too;
- Finally, transparency is the key: be open about your funding sources and make them public on your website and in your annual report.

6.6 RARELINK AND NORDIC COOPERATION

Rarelink, a best practice of Nordic cooperation

On the first day of the Seminar, Robert Hejdenberg, President of the Agrenska Foundation, gave a presentation of Rarelink, a great example of Nordic cooperation.

[Rarelink](#) is a Nordic website which contains a compilation of links relating to information material on rare diseases, published by organisations commissioned by the governments of Norway, Sweden, Finland, Iceland and Denmark.

In addition to direct links to the information material, you will also find links to disability organisations in the Nordic countries.

Rarelink is aimed at persons who seek information, for instance persons with a rare diagnosis, next of kin or experts who encounter or treat patients with rare diseases.

Barriers to and success factors of Nordic cooperation

The workshop on Nordic cooperation looked at the features of each of the Nordic countries, and sought to identify barriers to and elements supporting regional cooperation.

The lack of trans-nordic funding, human resources, the lack of political will from national coalitions were identified as barriers to Nordic cooperation.

Participants recognised that Nordic cooperation between patient organisations would have great added-value, especially in the following areas:

- Sharing best practices, inspiration, preparing for new challenges;
- Awareness-raising: more people means a bigger voice;
- Bigger negotiation power (for example to negotiate the price of medicines);
- Advocacy;
- Education and skill-building;
- Opportunities to apply for funds (especially from the Nordic Council).



7. Conclusions and Recommendations

The conclusions of this VII Regional Advocacy Seminar highlighted the importance of networking for patient organisations to exchange ideas and keep up-to-date with the latest policy developments at the national, regional and European levels.

The recommendations made during the plenary and parallel sessions focused on two main issues that can be considered as the leitmotif of this edition of the RAS:

More education and a clearer framework for patient involvement in research

There are increasing opportunities for patients to become involved in EU policy and research. However, more education programmes and awareness-raising activities on the role patients can play in research are needed to further strengthen patient involvement in research and policy.

Increasing cooperation at individual, regional and European level

Participants thanked EPF for the organisation of the Seminar, which enabled patient organisations from the different countries to get together and exchange.

Participants also expressed their wish to pursue the dialogue with EPF initiated during these two days. For its part, EPF wishes to build a more sustainable relationship with participants from the Nordic region.

Anders Olauson, EPF President, invited the participants to stay in contact with EPF. EPF and Nordic patient organisations clearly have several common priorities in advancing a rights-based agenda with patients' communities throughout Europe. EPF's advocacy work in Brussels would be enriched by insights and knowledge from the Nordic countries, and the impact of this work, on both legislation and 'soft' policy will help Nordic patient organisations to drive their own case in a national context.

8. List of Annexes

- Agenda
- List of participants

EPF Regional Advocacy Seminar

24-25 November 2015 – Medicon Village, Lund, Sweden

Strengthening the patient's perspective in EU policy-making and research

Draft Agenda

DAY 1 – 24 NOVEMBER	
08:30-09:00	Registration
09:00-09:30	<p>Welcome and Introduction <i>Ursula Hultkvistbengtsson, Executive Vice-President, Medicon Village AB, Lund</i></p> <p>The European Patients' Forum <i>Anders Olauson, EPF President</i></p>
09:30-10:30	<p>Setting the scene</p> <ul style="list-style-type: none"> • The EU institutions' activities in healthcare and research • EPF's role in advancing patients' rights at European level <p><i>Kaisa Immonen-Charalambous, EPF Director of Policy</i></p> <p>Q&A session</p>
10:30-11:00	Coffee break
11:00-12:15	<p>Patient involvement in EU research and policy</p> <p>Moderated discussion with the participants</p> <p><i>Moderation: Camille Bullo, EPF Membership Officer</i></p>
12:15-12:30	<p>An example of Nordic cooperation: Rarelink <i>Robert Hejdenberg, Agrenska President</i></p>
12:30-13:30	Networking lunch
13:30-15:30	<p>Parallel Workshops: Strengthening patient involvement in EU policy and research</p> <p>WS 1 – Educating – EUPATI Toolbox <i>Walter Atzori, EPF Senior Programme Officer</i></p>

	<p>WS2 – Advocating – for patient-driven research policies <i>Kaisa Immonen-Charalambous, EPF Director of Policy</i> <i>Kirsten Lerström, Chair, Lupus Europe</i></p> <p>WS3 – Health Technology Assessment and the medicine journey <i>Sophie Werkö, International Relations Manager and Project Director at SBU, the Swedish Council on Health Technology Assessment</i></p>
15:30-16:00	Coffee Break
16:00-16:45	<p>Sharing key learning – Report back from working groups <i>Moderation: Nicola Bedlington, EPF Secretary General</i></p>
19:00	Dinner

<p>DAY 2 – 25 NOVEMBER Influencing national and EU policymaking through partnerships and alliances</p>	
09:00-10:00	<p>Panel Discussion – Influencing national and EU policy-making through partnerships and alliances</p> <p><i>Daniel Sundstein, Former leader of the Youth Group of the European Federation of Crohn’s and Ulcerative Colitis Associations</i></p> <p><i>Susanna Palkonen, Director of the European Federation of Allergy and Airways Diseases Patients’ Associations</i></p> <p><i>Sari Tervonen, Member of the Board of SOSTE, Finnish Society for Health and Social care</i></p> <p><i>Moderation: Walter Atzori, EPF Senior Programme Officer</i></p>
10:00-11:00	<p>Parallel Workshops: Partnerships and Alliances with Stakeholders (PART I)</p> <p>WS4 – Working with national stakeholders (national medicines’ agency, national institutions...) <i>Katrín Fjeldsted, President of the Standing Committee of European Doctors (CPME)</i></p> <p>WS5 – Cooperating with private partners <i>Simona Biancu, EngagedIn</i> <i>Nicola Bedlington, EPF Secretary General</i></p> <p>WS6 – Scandinavian regional cooperation <i>Camille Bullo, EPF Membership Officer</i></p>
11:00-11:30	Coffee Break

11:30-12:30	Parallel Workshops: Partnerships and Alliances with Stakeholders (PART II) Continuation of the parallel workshops
12:30-13:30	Networking lunch
13:30-14:30	Sharing key learning – Report back from working groups and Discussion Wrap up and closing message



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Disclaimer: The content of this *seminar* reflects only the author's views and the Executive Agency is not responsible for any use that may be made of the information contained therein.

**Regional Advocacy Seminar
24-25 November 2015
Medicon Village, Lund, Sweden**

First name	Last Name	Organisation
Helle	Andersen	HIV-Denmark
Jeanette	Andersen	SLE DK
Maude	Andersson	GYNSAM (The Gynaecological Cancer Patients National Coalition)
Minna	Anttonen	Association of Cancer Patients in Finland
Frida	Arnardottir	Neistinn, childrens heart foundation in Iceland
Walter	Atzori	European Patients' Forum
Nicola	Bedlington	European Patients' Forum
Carola	Bengtsson	Endometriosisföreningen Endometriosis of Sweden
Monika	Benson	Swedish Dystonia Association
Peter	Bernström	Sinoba (The Swedish Association for Knowledge about Urinary Incontinence and Bladder Problems)
Simona	Biancu	ENGAGEDin
Ulf	Brändström	Swedish Asthma- and Allergy Association
Camille	Bullot	European Patients' Forum
Bente	Buus Nielsen	Colitis-Crohn Association
Tove	Cassøe	Danish Rheumatism Association
Mark	Delmartino	MDM CONSULTANCY
Katrín	Fjeldsted	Standing Committee of European Doctors / Comité Permanent des Médecins Européens (CPME)
Sigrun	Grendal	HIV Iceland
Leif-Ove	Hansen	HIV Nordic
Robert,	Hejdenberg	Agrenska
Karen	Holm	Danish Haemophilia Society
Ursula	Hultkvistbengtsson	Medicon Village
Jacob	Hygen	Norwegian Blood Cancer Association
Kaisa	Immonen-Charalambous	European Patients' Forum
Karsten	Jensen	Dansk Forening for Osteogenesis Imperfecta - DFOI

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Einar	Jonsson	HIV Iceland
Marte	Jystad	The Norwegian association for children with congenital heart defects (FFHB)
Timo	Kallioaho	Mental Health Association in Seinäjoki Region
Lotte	Klim	Type1
Anders Stensbjerg	Kristensen	JDRF
Susanne	Kristiansen	Dansk Forening for Osteogenesis Imperfecta - DFOI
Ásta Sol	Kristjánsdóttir	Tilvera (eng. Existence) the Icelandic Infertility Association
Katja	Laine	Finnish Association for Heart Children and Adults
Kirsten	Lerstrøm	LUPUS EUROPE
Kärstin	Lindblom Sandqvist	BRO Bröstcancerföreningarnas riksorganisation
Marcela	Loyova	HIV Norway
Salla	Mansikkamäki	Finnish sleep federation
Erik	Mattsson	HIV Finland
Michael	Mogensen	The National Union of Hepatitis C
Peter	Nordqvist	The Swedish Childrens' Heart association
Anders	Olauson	European Patients' Forum
Susanna	Palkonen	European Patients' Forum
Dana	Paredes	Endometriosis Association Finland
Randi	Ramnefjell	WishChild (Ønskebarn)
Satu	Rautakallio-Hokkanen	Finnish Infertility Association Simpukka
Louise	Sjöbäck	The National Union of Hepatitis C
Anna	Sjöström	Families against drugs
Lasse	Skovgaard	The Danish MS Society
Rita	Slåbakk	Lung cancer association, Norway
Kolbrún	Stígsdóttir	The Endometriosis Association of Iceland
Aimo	Strömberg	The Association of Finnish Cancer Patients
Daniel	Sundstein	EFCCA (European Organisation of Colitis and Crohn's associations)
Véronique	Tarasovcici	European Patients' Forum
Sari	Tervonen	Finnish Epilepsy Association, Finnish Federation for Social Welfare and Health

Sophie	Werkö	The Swedish Agency for Health Technology Assessment and Assessment of Social Services, SBU
Niels	Westergaard	Biopeople-University of Copenhagen
Ingunn	Westerheim	The Norwegian Osteogenesis Imperfecta Association (NFOI)
Jens M.	Wilhelmsborg	Hiv-Denmark
Lars	Winborg	Disability federation in the County of Jönköping