



EPF Annual General Meeting 22-23 March 2016 Radisson Blu Royal Brussels - Minutes

date



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PRESENT

FULL MEMBERS

Vanessa Challinor (Alzheimer Europe), Dominik Tomek (Association for Patients' Rights Protection in Slovakia), Vladimir Tomov (Bulgarian National Patients' Organization "Confederation of Health Protection"), Stefan Radut and Radu Costin Ganescu (Coalition of Patients' Organizations with Chronic Diseases – COPAC), Vida Augustiniene (COUNCIL OF REPRESENTATIVES OF PATIENTS ORGANIZATIONS OF LITHUANIA), Michal Rataj (EAMDA), Jean-Daniel Kahn (EFAPH), Marco Greco (EFCCA), Lars Skar (EKPF European Kidney Patient Federation - CEAPIR), Bert Johnson (EUFAMI), Kirke-Anneli Kuld (Estonian Chamber of Disabled People), Luís Mendão and Brian West (European AIDS Treatment Group – EATG), Susanna Palkonen (European Federation of Allergy and Airways Diseases Patients' organization – EFA), Ingemar Farm (European Headache Alliance), Tatjana Reic (European Liver Patients' Association – ELPA), Yves Brand (European Multiple Sclerosis Platform - EMSP), Jenny Björk (European Heart and Lung Transplant Federation), Gabriela Tanasan (European Network of (Ex-)Users and Survivors of Psychiatry), Anders Olauson (EURORDIS - European Organisation for Rare Diseases), Marzena Nelken Žbik (Federation of Polish Patients), Elin Einarsdottir and Ofra Balaban (Fertility Europe), Paul Arteel (Gamian-Europe), Tunde Koltai (Hungarian Alliance of Patient Organisations), Mark Miceli-Farrugia (Malta Health Network), Stanimir Hasardzhiev (National Patients' Organization Bulgaria), Robert Johnstone (National Voices), Nicolas Philippou (Pancyprian Federation of Patients Associations and Friends - Cyprus), Juan Fuertes (PHA Europe), Christina Fasser (Retina International) and Marta Kozireva (The Latvian Umbrella Body For Disability Organizations SUSTENTO).

ASSOCIATE AND PROVISIONAL MEMBERS

Yordanka Jenzarli (Bulgarian Association for Patients Defense), Souzi Makri (ENFA), Heather Clarke (European Federation of Neurological Associations), Ian Banks (European men's health forum), Lore Dupont (Flemish Patients' Platform), Klara Zalatnai (Hungarian Osteoporosis Patient Association - HOPA) and Janet Mifsud (International Bureau for Epilepsy).

CANDIDATES FOR MEMBERSHIP

Milan Mishkovikj (The Alliance of Patients' Organisations - FYROM).

YOUTH REPRESENTATIVES

Thomas Hough (EFCCA), Polycarpus Stavrou (IDF Europe), Lembe Kullamaa (Estonian Chamber of Disabled Persons), and Aneela Ahmed (National Voices).

APOLOGIES

Rainald von Gizycki (AMD Alliance International), Monika Benson (Dystonia Europe), Cees Smit (EGAN).

Due to the tragic events that took place in Brussels on 22 March 2016, a number of participants who had registered for the event were not able to attend our meeting.

Andrea Antonovici (EMSP), Aagje Leven (EUFAMI), Karen Benn (EUROPA DONNA the European Breast Cancer Coalition), Laura Salvini (European Haemophilia Consortium - EHC), Ottfrid Hillmann (EUROPSO), Vlasta Zmazek (EURORDIS), Hilikka Karkainen (GAMIAN-Europe), Jana Moravcova (International Federation for Spina Bifida and Hydrocephalus), Katharine Wheeler (LUPUS EUROPE), Avril Daly (Retina International), Irene Oldfather (The Health and Social Care Alliance Scotland) and Mary-Lynne van Poelgest-Pomfret (World Federation for Incontinent Patients – WFIP).

Because the majority of participants had already travelled to Brussels and the quorum was reached, the EPF President and Board decided to proceed with the Annual General Meeting, with some amendments to the programme.

IN ATTENDANCE

Nicola Bedlington (EPF Secretary General), Walter Atzori (EPF Director of Programmes and Operations), Laurent Louette (EPF Communication Officer), Camille Bullo (EPF Membership and Stakeholder Relations Manager), Danielle Flores (EPF Junior Project Officer), Žilvinas Gavėnas (EPF IT Manager), Kaisa Immonen-Charalambous (EPF Director of Policy), Stefano Tironi (EPF Assistant to Secretary General and Finance Officer), Laurène Souchet (EPF Policy Adviser), Valentina Strammiello (EPF Programme Officer), and Véronique Tarasovici (EPF Office and Events Manager).

SUPPORTING DOCUMENTS

The following supporting documents were circulated on 9 March 2016.

- Draft agenda
- Annex 0 – Letter from EPF President
- Annex 1 – Minutes of 2015 AGM
- Annex 2 – EPF Annual report 2015
- Annex 3 – EPF Charter on Patient Empowerment
- Annex 4 – Report from the auditors
- Annex 5 – Membership applications

- Annex 6 – Candidates to the board elections
- Annex 7 – EPF budget 2016
- Annex 8 – Annual work plan 2016

1 Opening of the meeting

EPF President Anders Olauson opened the meeting, announcing that despite the events of the day we needed to carry on with the proceedings as best as possible. He added that after lunch, the EPF Secretariat would have a better idea on how the meeting would proceed over the course of the two days. Anders concluded that despite the limited attendance there was a quorum, with a total of 28 participants that could vote.

He suggested a number of amendments to the agenda: since not all of the candidates were present, he proposed to put the board elections planned for that day off until the second day. He also encouraged everyone present to be sure to speak with the members of the EPF Youth Group, who were wearing special Youth Group badges.

On behalf of the board, Anders proposed a moment of silence for those who lost their lives that morning. The plenary then observed one full minute of silence.

2 2. Apologies

Due to the unfortunate events that took place in Brussels on 22 March 2016, a number of participants who had registered for the event were not able to attend our meeting.

3 Adoption of the minutes of the past AGM

The minutes from last year's AGM had been circulated electronically prior to the event date. The minutes were adopted unanimously.

4 Annual Report 2015 from the Board and the Secretariat

EPF Secretary General Nicola Bedlington presented the annual report for 2015.

Nicola presented the 2015 highlights, including EPF's work on access, empowerment, and the Capacity Building Programme.

For work on access, Nicola reported on the Riga Roadmap, the finalisation of the WeCare project, HTA, patient safety and quality of care, discrimination and access for vulnerable groups, cross-border health care, and a planned access conference in Brussels in 2017.

For work on empowerment, Nicola reported on the May campaign conference, lay summaries of clinical trials, adherence and concordance, and capacity building. Nicola also presented some statistics on EPF communications, showing strong numbers for social media presence and outreach.

Anders then called for a brief report from the Board Members on their activities in 2015 and their involvement with various EPF programmes and initiatives. Brian West recounted various cross-over activities involving EPF and said that these collaborations are always successful. Stanimir Hazzardzhiev reported on PACT, which is moving forward and promoting the patient perspective with EPF still playing a key role. He thanked the EPF Secretariat for their support. Dominik Tomek spoke of EUPATI activities in Slovakia and encouraged the establishment of EUPATI national platforms in Member States. Susanna Palkonen praised the Patient Empowerment Campaign, which she hailed as a completely new approach for EPF that is taking the organisation to the next level. Marco Greco reported on his work on pharmacovigilance and biosimilars, area where he has a lot of expertise given that EFFCA is a patient group with a high number of biosimilar usage. Robert Johnstone emphasised the importance of Medtech and of getting to know the industry and working with them more. He mentioned the Brexit issue and the possibility of his organisation being forced to leave EPF, stressing how important it is for his patient organisation to be connected to Europe. Radu Ganescu reported that he was proud to work with EPF in helping other patient organisations by giving them the tools like the EUPATI Toolkit to empower and educate.

5 Patient empowerment campaign

Nicola presented on the Patient Empowerment campaign in place of Laurent Louette. Kaisa spoke up to stress that although the formal campaign would end in June, it will not be the end of the campaign messages or related activities. She emphasised that the tools of the campaign could still be used to promote the messages and goals. Kaisa then presented on the Patient Empowerment Charter, explaining that the goal was to create a simple tool on the

fundamental principles of patient empowerment. Ideally, the tool would be a poster or factsheet that could be displayed anywhere, including doctors' offices.

Anders expressed his enthusiasm for the charter. When asked about translations in all EU languages for the charter, Kaisa said that that is the goal but we are not sure how quickly it could all be done.

6 Finance and discharge of the board and auditors

Anders called on EPF Treasurer Radu Ganescu to provide an overview of the 2015 financial report. Radu presented the 2015 balance sheets, including reserves, liabilities, income, and expenditures.

Radu explained the evolution of the EPF budget. He gave details on the cash reserves, which are a surplus to last EPF 6 months in case of a sudden lack of funding.

Bert Johnson inquired about the cash reserves, asking if EPF has an investment policy where the reserve amount could be invested to generate income. Radu explained that the reserves should always be readily available and not tied up in investments. Anders added that EPF had explored this in the past but it is better to have the money available.

Nicola and Anders moved on to present the 2015 auditor's report, with Nicola giving apologies for the absence of account Johakym Laroussi. Nicola reminded the plenary that the auditor's report had already been circulated to the membership electronically. Anders read the conclusion of the report aloud, which stated that EPF had adhered to applicable accounting standards.

Anders then called for the plenary to vote on the treasurer's report and the auditor's report. The report was adopted unanimously.

This was followed by a vote on EPF's Annual Report and on the discharge of the board and auditors, with all members voting yes, with no nays or abstentions.

Membership

Nicola presented on the membership applications, stepping in for Camille Bullot, EPF Member and Stakeholder Relations Manager, who was unable to reach the hotel. There were four membership applications this year, two for full membership and two for

associate membership. The two organisations applying for full membership were Dystonia Europe and the International Federation for Spina Bifida and Hydrocephalus (IFsbh). The two organisations applying for associate membership were International Bureau for Epilepsy (IBE) and the Alliance of Patients' Organisations (FYROM). The representatives from each organisation said a few words, with Nicola speaking on behalf of IFsbh as their representative was unable to reach the hotel that day.

For all four candidate organisations, the plenary voted unanimously in favour of accepting their application for membership. Anders and Nicola thanked and welcomed the new members.

Nicola announced that the Associazione Patologie Autoimmuni Internazionale (APAI) from Italy is no longer a member of EPF. As APAI is a disease-specific organisation active only at national level, it is no longer eligible for EPF membership. Anders called for vote of approval and the plenary voted unanimously in favour of discontinuing the membership, with no nays or abstentions.

Anders confirmed that with the addition of these 4 new member organisations, EPF now has 67 members.

Youth Group

Aneela Ahmed, EPF Youth Group President, gave a short introduction on the Youth Group to the plenary and presented a slide deck with an overview of the group, recent activities, and goals.

Nicola confirmed that the Secretariat would soon be welcoming an EPF Youth Intern, who will work on a pilot basis for approximately three months. Nicola added that the issue of having Youth representation on the EPF Board is still being developed.

2016 workplan and budget

Nicola presented an overview of the 2016 EPF work plan. In the thematic area of access, she reported on work on anti-discrimination, patient safety and quality of care, the upcoming access campaign, and the upcoming access survey. Nicola added that a paper on the issue of pricing is still in development and is a very delicate political issue. Regarding EUPATI, Nicola announced that EPF is nearing the end of its involvement, as the 5-year project is coming to

an end. She promised that there would be updates in the future on the sustainability of EUPATI and of the patient's academy concept.

Radu Ganescu, EPF Treasurer reported on the 2016 budget. He confirmed that EPF would continue to receive an operating grant from the European Commission, maintaining the same funding structure as previous years with 80% EC funds, 19% industry funding, and 1% membership fees.

Anders called for a vote to approve the 2016 Work plan and the 2016 budget. Both were unanimously approved by the plenary, with no nays or abstentions.

Matchmaking exercise

Anders began the thematic matchmaking session for the members, with the plenary breaking out into six smaller groups for a brainstorming exercise. The report back from the session went as follows:

Patient Safety group: The group reported that the common challenges were (lack of) information and access to information, communication, including with communication with doctors but also patient communication in lay language that clearly medical risks and benefits, and empathy. Under topics for working together, the group proposed better collaboration with National Contact Points and the creation of FAQ factsheets that are by patients, for patients.

Discrimination group: The group reported that the common challenges were discriminatory policies in general and the issue of positive discrimination. Under topics for working together, the group proposed improved education (development of new glossary), improved information to the public at large, and concrete actions and activities (updates of legislation).

Empowerment group one: The group reported that the common challenges were the lack of acceptance of the expert patient by healthcare professionals, lack of initiative by some patients, and the issue of translation of educational materials at local level. Under topics for working together, the group proposed the development of patient empowerment guidelines for dissemination, utilising toolkits to optimise fundraising, mentoring programmes, and using social media and YouTube to share best practices and case studies.

Empowerment group two: The group reported that the common challenges were healthcare cost reductions, the need for training and education not just for patients but also for patient

organisations, doctors, and the general public, and representation in the decision-making process at both national and EU level. Under topics for working together, the group proposed inter-country support, ie UK supporting Cyprus as they develop their national health service, and the development of training tools. The group also emphasised the importance of empowering the young patients in patient organisations, as they don't have life experience.

Access group: The group reported that the common challenges were the holistic nature of access, the lack of a standardised measurement of access (although the PACT is working on this), the principle of subsidiarity with different levels of access in different countries, and the issues and barriers of pricing and reimbursement. Under topics for working together, the group proposed a sharing platform to share best practices, cross-disease support, and policy tools like the upcoming EPF paper on pricing.

Access group two: The group reported that the common challenges were access to innovative medical technologies and medicines, the role of EMA in the introduction of drugs into the market, and the need for a more harmonised system in approval and reimbursement of drugs. The group also mentioned the issue of buyers' clubs, coming from a lack of access but with no oversight or medical checks on these drugs. Under topics for working together, the group proposed to work together to put pressure on governments and industry for drug affordability and availability, which is leading to growing health inequalities. The group also proposed to use connections within EPF more fully.

Once the groups were done reporting back to the plenary, Anders thanked everyone for their contributions. He also noted that the report back showed the pain and struggle in the patient journey and that it is important to capture that. Nicola and Anders then closed the meeting for the day.

Opening of day two

Anders called the meeting to order and invited Nicolas Philippou from the Pancyprrian Federation of Patients' Associations & Friends to speak briefly. Nicolas spoke about the history of his organisation and explained that Cyprus does not have a national health system, but parallel public and private sectors.

He announced that a week earlier, legislature was passed to include the Pancyprrian Federation in all dialogue at national level and in all decisions on health policy. He thanked

EPF for the support and its investment in capacity-building in Cyprus, which facilitated a new structured relationship with the government and led to this achievement.

Board Elections

Camille announced that the Board elections would begin. Due to circumstances, there were several Board candidates were not able to arrive in Brussels to be at the meeting. As a solution, Anders suggested that he would read their pre-prepared answers. Anders reminded the plenary that the rule for 'present candidates' was to answer three questions, with one minute for each response.

The candidates were: Andreea Antonovici (not present) from European Multiple Sclerosis Platform (EMSP), Ofra Balaban from Fertility Europe, Ingemar Färm from European Headache Alliance (EHA), Juan Fuertes from PHA Europe, Bert Johnson from European Federation of Associations of Families of People with Mental Illness (EUFAMI), Hilikka Kärkkäinen (not present) from GAMIAN-Europe, Tunde Koltai from Hungarian Alliance of Patient Organisations, Jana Moravcova (not present) from International Federation for Spina Bifida and Hydrocephalus (IF), Susanna Palkonen from European Federation of Allergy and Airways Diseases Patients' Associations (EFA), Michal Rataj from European Alliance of Neuromuscular Disorders Associations (EAMDA), Gabriela Tanasan from European Network of (Ex-Users and Survivors of Psychiatry) (ENUSP), Dominik Tomek from Association for Patients' Rights Protection in Slovakia (AOPP), Brian West from European AIDS Treatment Group (EATG), and Vlasta Zmazek (not present) from EURORDIS.

Anders gave a recap of the names of the candidates and reminded the plenary to vote for up to 5 members but no more, or their ballot would be voided. During the break, the Board votes were counted with Jean-Daniel Kahn and Marco Greco serving as the two tellers and Stefan Radut as observer. There was a tie between Juan Fuertes and Vlasta Zmazek, with a revote counted by the same tellers and observer. Juan was declared the winner by Anders.

In conclusion, the following board members were (re)elected: Brian West, Dominik Tomek, Michal Rataj, Susanna Palkonen, and Juan Fuertes. Anders announced that the Board would meet to elect a new President after the roundtable.

The new EPF Board now consists of : Marco Greco (elected President), Brian West (Vice-President), Radu Costin Ganescu (Treasurer); Stanimir Hasurdjiev, Robert Andrew Johnstone, Dominik Tomek, Susanna Palkonen, Juan Fuertes, Michal Rataj.

Roundtable on Mental Health

Anders spoke about the late Pedro Montellano, who was President of GAMIAN and was also elected one year ago to the EPF Board. Anders gave some background on Pedro's advocacy work and declared that Pedro was one of the most accomplished patient advocates in Portugal and in the EU overall. Anders proclaimed that the patient movement in Europe had lost a true champion and that EPF had lost a friend.

The mental health roundtable was suggested for this AGM in memory of Pedro, who had intended to promote this issue in his role as an EPF Board member. Brian West led the discussion, introducing the panel members Gabriela Tanasan, Alva Finn, Bert Johnson (sitting in for the Secretary General of EUFAMI), along with himself. Gabriela presented a slide deck on stigma and discrimination, including ENUSP suggestions for WP5 of Joint Action on Mental Health and Well-Being "Community-based approaches to Mental Health". Alva Finn from Mental Health Europe also showed a PowerPoint presentation, highlighting mental illness as comorbidity and a natural reaction to a physical condition. She stated that the MHE position is that diagnostic tools alone do not tell the whole story for patients, and MHE calls for the meaningful involvement of users, carers and civil society as equal partners with patients. Bert said that he was glad that EPF is giving so much attention to mental health, and to the connection between physical and mental problems. He stated that EUFAMI avoids taking a position on clinical matters, but he agreed with everything mentioned by the panel thus far and added that EUFAMI would like to think that service users/survivors do see carers as a natural ally in improving the patient quality of life.

Ofra asked the panel about the authority of carers to act on behalf of a patient, even if the patient does not agree or cannot consent? Bert suggested that a doctor should prioritise the needs of the patient over the carer, but Ofra points out the potential issues when the patient cannot speak for themselves. Brian added that the European Commission has no action or policy on representation, and that this is something that EPF should work on. Alva declared that the patient is always the expert of their condition and although a carer can be consulted, the relationship should always be equal and like a team. Luis (last name?) said that he was good friend of Pedro's and that they were collaborating in a project called "More

participation, Better Health”, hoping to build from that towards a national platform in Portugal. Luis said he was glad that EPF is putting mental health high on the agenda.

Brian thanked the members of the panel for their thoughtful discussion and emphasised that the themes in mental health are cross-cutting and relevant to all disease areas and conditions. He closed the panel discussion with the World Health Organisation slogan “There is no health without mental health.”

Presidential election

Marco Greco was elected as the new EPF President, with Brian West as serving as Vice President Radu Ganescu as Treasurer. Marco thanked Anders for his work and guidance over the years, proclaiming that EPF needs to be the reference point for all patients in EU. Marco guaranteed his commitment, as he has personally experiences being poorly treated as a patient, with a lack of available information.

Marco then announced the decision to invite Anders to become honorary president. The plenary stood up to applaud and approve this motion. Anders accepted and spoke about his journey as a patient advocate, his early experiences as a patient, and with other young patients.

Closing of the event

With no other business, Anders closed the meeting.