



# ANNUAL REPORT AND ACCOUNTS January 2016 – March 2017



Fertility Europe VZW

26.6.2017

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# FERTILITY EUROPE

## 1.1 VISION

Fertility organisations from every country in Europe to be part of Fertility Europe. We strive for a society where everyone has access to high quality, holistic fertility care and alternative parenting options to fulfil their wish to achieve parenthood.

## 1.2 MISSION

We are an umbrella NGO of infertility patient associations that aims to increase access to high-quality, holistic, equal care for infertility patients as well as to reduce infertility through education, advocacy, communication and partnerships. Fertility Europe brings fertility organisations together with opportunities for networking and sharing best practice and information on fertility and infertility.

## 1.3 INTRODUCTION AND THANKS

Fertility Europe was formalised as a legal entity based in Belgium (accordingly to Belgian Law) in May 2009. Since that time we have worked hard to both increase our reach in terms of membership, improve our governance and explored methods of diversifying our income streams.

Whilst our membership is increasing we are aware that there are still countries within Europe which are not part of Fertility Europe. We are committed to reaching out across Europe so that they can take advantage of the opportunity of sharing ideas, expertise, information and support with colleagues.

Our sincere thanks go to our wonderful volunteers who have worked hard in their various roles during the year.

The following served on the Executive Committee of Fertility Europe between January 2016 and March 2017:

▪ Elín Einarsdóttir	Chair	01/2016 – 09/2016
▪ Elín Einarsdóttir	Vice Chair	10/2016 – to date
▪ Denisa Priadková (Slovakia)	Vice-Chair	01/2016 – 03/2016
▪ Satu Rautakallio-Hokkanen (Finland)	Deputy	07/2016 – 09/2016
▪ Satu Rautakallio-Hokkanen (Finland)	Chair	10/2016 – to date
▪ Isabelle Chandler	Member	01/2016 – 11/2016
▪ Nicoleta Cristea-Brunel	Secretary	01/2016 – 09/2016
▪ Ofra Balaban	Deputy	01/2016 – 03/2016
▪ Ofra Balaban	Member	04/2016 – to date
▪ Afroditi Alexopoulou	Treasurer	01/2016 – to date
▪ Klaudija Kordic	Deputy	07/2016 – 11/2016
▪ Klaudija Kordic	Secretary	12/2016 – to date
▪ Irina Popova	Deputy	10/2016 - to date

Our Office Manager, **Kalina Nedelcheva**, continued her work for Fertility Europe until the end of 2016. New Office Manager **Anita Fincham** started at the beginning of 2017.

And of course we are more than grateful to the European Society of Human Reproduction and Embryology (ESHRE). ESHRE has once again shown their recognition and understanding of the

importance of Fertility Europe by support our Spring meetings in 2016 and 2017 and Council meeting in 2016. It is extremely difficult to generate income, especially during the financial times we are all experiencing so their support is vital to us.

## 1.4 PURPOSE OF FERTILITY EUROPE

- To build a strong cross border network among European patients and professionals in order to achieve the exchange of best practice;
- To promote education in the field of protection of reproductive health and a proactive approach to family planning
- To improve the rights of those affected by difficulties in conceiving in areas such as, inter alia;
  - ✓ Access to high quality infertility investigation, treatment, support and guidance,
  - ✓ Reduction of multiple births,
  - ✓ Full information on all assisted conception/reproduction treatment possibilities and the right to accept or reject treatment without any discrimination,
  - ✓ Cross border reproductive care

## 1.5 AIMS OF FERTILITY EUROPE

- Promoting discussion and information on the following aspects of fertility
  - ✓ Equity of access to treatment
  - ✓ Involvement of those treated
  - ✓ Community awareness
  - ✓ EU Health policy
  - ✓ Psycho-social, ethical and cultural aspects
  - ✓ Involuntary childlessness
  - ✓ Rights/welfare of children conceived through ART
  - ✓ European patients' platform/point of reference
  - ✓ Public discussion
  - ✓ Evolving ART techniques/proven results
  - ✓ Legislation
  - ✓ Professional guidelines
  - ✓ Organisation and independent functioning of patient/client/beneficiary associations and groups
- Divulging the views of patients and others experiencing difficulties in conceiving, as stakeholders in the European health care debate, by means of a broad, truly representative and independent patient group resource
- Providing patient/customer organisations with a forum so as to encourage the exchange of best practices among the national patient/customer organisations in order to enable a harmonious increase of their level of reputation, accountability, effectiveness and professional competence
- Enhancing and supporting cooperation and exchange of experience between patient/customer organisations and professionals in order to follow our mission.
- Co-operating in the formation and execution of joint projects aimed at improving awareness on fertility issues and the situation concerning the rights of those affected by difficulties in conceiving

## 1.6 TYPES OF MEMBERSHIP

- Fertility Europe has three types of membership for patient organisations in Europe:
  - ✓ Effective Members who fulfil the criteria for membership and have paid their

membership fees

- ✓ Candidate Members who have applied for membership and their membership is being progressed
- ✓ Associate Members who are people or organisations based in Europe with a significant background/expertise in the field of fertility and infertility

At our Council Meeting held at the ESHRE Congress in Helsinki/Finland on 4<sup>th</sup> of July 2016 there was one application for Effective membership: Nas San/Montenegro was approved unanimously. There were no terminations of memberships.

By end of March 2017 we had a total of 23 Effective Members and 1 Associate member from 22 countries across Europe.

**Effective members** at the end of March 2017:

- Adam, Czech Republic
- Amica Cicogna Onlus, Italy
- Amotat Chen, Israel
- Associao Portuguesa De Fertilidade, Portugal
- Barnlångtan, Sweden
- Cider, Turkey
- De Verdwaalde Ooievaar, Belgium
- Deti Budut, Ukraine
- Freya, Netherlands
- Fertility Network UK, United Kingdom
- Iskam bebe, Bulgaria
- Kiveli, Greece
- Lapsettomien yhdistys Simpukka ry, Finland
- Magna Mater, Greece
- Maia, France
- Nas San, Montenegro
- Nasz Bocian, Poland
- Občianske združenie Bocian, Slovakia
- Ønskebarn, Norway
- Roda, Croatia
- Sdruzhenie Zachatie, Bulgaria
- SOS Infertilitatea, Romania
- Tilvera, Iceland

**Associate members** at the end of March 2017:

- Malta Infertility Network, Malta

## 2 ACHIEVEMENTS IN JANUARY 2016 – MARCH 2017

### 2.1 MEETINGS AND TRAININGS

#### 2.1.1 EUROPEAN PATIENTS' FORUM ANNUAL GENERAL MEETING 2016

The European Patients' Forum held its Annual General Meeting in Brussels on the 22nd and 23rd of March 2016. Attending on behalf of Fertility Europe were Elin Einarsdottir and Ofra Balaban.

Unfortunately the bombings in the departure hall at Brussels airport and a bombing at the Maalbeek Metro Station happened in the morning of the 22nd and cast a shadow over the proceedings. No one involved in the meeting was harmed, a few could not attend due to diverted flights and other precautions, and an unanimous decision was made to continue with the meeting despite the horrific events.

On the agenda were the election of five board members for a 2 year term (2 new and 3 were re-elected), the election of a new President - Mr. Marco Greco, a choice of one of 4 workshops, and a roundtable discussion on "Mental Health: Fighting Stigma & discrimination". In addition EPF past President Anders Olauson was awarded the title of Honorary President.

#### 2.1.2 SPRING MEETING 16<sup>th</sup> - 18<sup>th</sup> March 2016, SOFIA, BULGARIA

The 2016 Spring meeting was held 16th-18th March in Sofia, Bulgaria. 27 participants from 15 countries came to share their experience. FE welcomed a new candidate member Nas San (Our Dream) from Montenegro. The FE Chair Elín Einarsdóttir mentioned the achievements since Lisbon:

- the establishment of the new online forum
- the Statutes Working group formed to discuss amendments in the current statutes
- the ongoing collaboration with Merck regarding a paper comparing the MAR situation in 9 European countries

A key issue in the agenda was voting for the dismissal of Denisa Priadková from the Executive Committee due to a conflict of interest. The negative MAR situation in Croatia, Poland and Romania and possible ways that FE can help were also discussed. The FE Vice-Chair Nicoleta Cristea-Brunel presented the FE Awareness project: European Fertility Awareness Week happening in November 2016.

#### 2.1.3 ANNUAL MEETING AND ESHRE CONGRESS 4<sup>th</sup> – 6<sup>th</sup> JULY 2016, HELSINKI, FINLAND

We welcomed 25 delegates from 18 organisations representing 18 countries to our Council & Members Meeting held on the occasion of the ESHRE Annual Congress in Helsinki, Finland. Our thanks once again to ESHRE for their generous support enabling us all to come together once again.

With ESHRE grant it was possible for Fertility Europe to offer a 500 € reimbursement for 6 members associations. This time the grants went to Zachatie/Bulgaria, Wanting and waiting/Malta, Nas San/Montenegro, Roda/Croatia, Freya/The Netherlands and APF/Portugal.

## 2.1.4 COUNCIL MEETING, 4<sup>th</sup> JULY 2016, HELSINKI, FINLAND

Our Council Meeting is where the official, but highly important business takes place in order to demonstrate democracy and transparency and follows the rules in our Statutes. The minutes of our Council Meeting held in Lisbon the previous year were approved.

Other approved issues were a change in the Statutes to approve electronic voting, Fertility Europe website and branding and vote on Fertility Europe recommendation paper.

We also had an election of two deputy members to the Executive Committee. Out of four candidates, two new deputies, **Klaudija Kordic** and **Satu Rautakallio-Hokkanen**, were elected and welcomed to the Executive Committee. Discussions about internal matters were lively and it was good to see the membership taking an active interest.

The Executive Committee meeting with the new deputies took place the next day. The roles of the Executive committee members remained as before.

In the afternoon we heard presentations from our host association Simpukka. Executive Manager **Johanna Repo** presented Simpukka's successful campaigns and Project Manager **Leena Tuutijärvi** presented Simpukka's project called SimpukkaCouples.

There was also discussions about Fertility Europe's use of social media and Special Families campaign, European Policy Audit On Fertility and European Fertility Week.

After the Council meeting the group enjoyed a joint dinner in Suomenlinna Fortress offered by Fertility Europe.

## 2.1.5 THE WALL OF HOPE

We had the Wall of hope again in Helsinki. It situated well inside the exhibition hall and many congress guests took a photograph of themselves in front of the Wall. There was also an info point of Fertility Europe beside the Wall. For three congress days it was manned by presenters from the Finnish Infertility Association Simpukka. Our thanks go once again to ESHRE for facilitating and making the Wall of Hope happen.



## 2.1.6 PATIENT SESSION

This year the patient session was on Tuesday, the 5th of July. The topic of the session was **Embryo and Double Gamete Donation** and four speakers were invited:

- **Anna Krawczak**, Poland  
"Should embryo donation be mandatory? Patients' perspective on Polish law on infertility treatment. "
- **Nicoleta Cristea-Brunel**, Romania  
"Comparative analysis on the situation of embryo /double gamete donation in Romania and France."
- **Caroline Spencer**, United Kingdom  
"Embryo and double gamete donation- Talking and Telling"



- **Ofra Balaban**, Israel  
“Embryo donation- new legislation - the case in Israel”

The attendance at the session was good.

The blog of **Focus on Reproduction** published an article written by Chair, **Elín Einarsdóttir**, highlighting some of the points from each speaker. Article can be found here:  
<https://focusonreproduction.eu/2016/07/06/the-patient-and-the-desire-to-have-a-child/>

## 2.1.7 TRAINING FOR SOCIAL MEDIA, LOBBYING IN BRUSSELS AND MEETING MEPs, AUGUST 26<sup>th</sup> – 27<sup>th</sup> SEPTEMBER 2016

Six members of Fertility Europe, from the ExCo, COMM and POLI working groups, were in Brussels for training arranged by Burson Marsteller. Participants were:

**Irina Popova** (Zachatie/Bulgaria), **Janis Sidovsky** (Adam/Czech), Satu Rautakallio-Hokkanen (Simpukka/Finland), Klaudija Kordic (Roda/Croatia), Elín Einarsdóttir (Tilvera/Iceland) and **Anita Fincham** (Nasz Bocian/Poland).



Monday was primarily spent on learning about the workings of the European Parliament and how lobbying – not a dirty word in this setting, but rather just a description of what’s being done, presenting and advocating for a cause or topic be it on behalf of a patient association such as ours or industry – works within its walls. This involves finding allies or someone who’s interested in the topic you’re presenting, preferably from different political parties, asking them to submit written questions or possibly organising committee debates on the topic and then taking it further.

Some time was also spent on learning how to use social media – mainly Twitter, as it seems to be one of the most used tools of MEPs.

On Tuesday, Satu Rautakallio-Hokkanen, Elín Einarsdóttir, and Irina Popova, had meetings with a MEP as well as with a number of political advisors to various other MEPs. The primary reason for doing so was to discuss a European Policy Audit on Fertility that’s being done at the moment. All of the people we talked to were interested in Fertility Europe and some were very happy and keen to help us reach our goals. In addition we were also given some practical advice on how to promote our issues in the European Parliament.

## 2.1.8 EUROPEAN FERTILITY WEEK 2016



The theme for the European Fertility Week 2016 (31st October - 6th November) was chosen at the Council Meeting in Helsinki and we decided to go with Break the Silence. Logo for the week was ordered from US based Graphic Designer Sarah Kruger.

Most of the Fertility Europe member organisations organised national campaigns (on online platform and in real life) to sustain the awareness-raising and advocacy efforts regarding fertility and infertility.

Some of the organisations have already a great experience in organising such campaigns; however, this year, the difference was brought by the alignment between our national efforts and the actions that have taken place simultaneously in many European countries. The campaign was promoted through common visual identity and also by using an unitary tool in the social media, under the hashtag #EuropeanFertilityWeek.



Facebook campaign was presentation of fertility myths versus truth statements and special EFW twibbon.

All the actions taking place during European Fertility Week were promoted through the communication channels of Fertility Europe (website, forum, social networks).

### 2.1.9 NEW OFFICE MANAGER

Our former Office Manager for several years, Kalina Nedelcheva, left her position due to personal reasons at the end of 2016. The Executive Committee started the process to find new Office Manager at the end of 2016 with an invitation to our members to share the job advertisement among their members.

We got 4 very good applications. The Executive Committee interviewed 3 applicants and after that the decision was made to choose Anita Fincham. Anita had been a very active member in Fertility Europe's working group and she had a long time experience as a volunteer in her own infertility association Nasz Bocian of Poland.

Anita started at the beginning of January 2017 and her contract is signed to last until the end of December 2017. She is working as a subcontractor like Kalina did earlier.

### 2.1.10 COGI

During her time as Chair, Elin Einarsdottir, was invited to speak at the 24th World Congress on Controversies in Obstetrics, Gynecology and Infertility, held in Amsterdam between the 10th and 13th of November 2016. The session was titled Alternative Perspectives on Infertility Care and her topic was What patient organisations can do for infertile couples? In her presentation she first spoke about awareness and education. Using some of the infertility myths from the first European Fertility Week to illustrate the need, not just for the people dealing with infertility but all stakeholders (friends, family, coworkers, government, etc). Moving on from there she highlighted projects such as the Wall of Hope and the Special Families Campaign as examples of what Fertility Europe is doing. She spoke about the European Policy Audit on Fertility and how it would be the first of its kind. Examples of projects being done by our members were given and in conclusion she reminded the people attending that:

Medically Assisted Reproduction does not guarantee a baby  
It only offers the chance of having one.

### 2.1.11 EXECUTIVE COMMITTEE MEETING, 24<sup>th</sup> – 26<sup>th</sup> NOVEMBER 2016, BRUSSELS, BELGIUM

The Executive Committee had its annual November meeting in Brussels. This year we extended the stay for 2 whole days. On Friday morning, the 25th we met people from Merck and Burson Marsteller for a meeting about EPAF and advocacy plans. On Friday and Saturday we had full days of Executive Committee meetings.

## 2.1.12 EXECUTIVE COMMITTEE AND THE ESHRE/FERTILITY EUROPE LIAISON GROUP MEETING

The Executive Committee usually meets with the ESHRE Liaison Group on a biannual basis. However, last year we only met once in Brussels. This is our opportunity to inform ESHRE's representatives of our work and future plans and gain their much valued feedback and advice. We are grateful for their support.

ESHRE representatives during the Liaison Meeting in Brussels on 25<sup>th</sup> November 2015 were: Dr **Kersti Lundin**- ESHRE Chair, Dr **Tatjana Motrenko** - clinician and member of the ESHRE Executive committee, **Roy Farquarson** - ESHRE Chairman elect, **Helen Kendrew** - ESHRE Chair of the Paramedical Board and **Bruno Van den Eede**, ESHRE Managing Director. The ongoing activities and budget of FE and EPAF were discussed as well as the support of ESHRE for organising the FE meetings in 2017.

## 2.1.13 SPRING MEETING AND COUNCIL MEETING FOR MEMBERS 27<sup>th</sup> – 29<sup>th</sup> MARCH 2017, BRUSSELS, BELGIUM

This year Spring Meeting was 27<sup>th</sup>-29<sup>th</sup> March in Brussels, as we needed to combine it with a launch of our European Policy Audit on Fertility in European Parliament. We were well represented, as 27 delegates arrived from 18 organisations from 16 countries.

Executive Committee held a meeting day before and enjoyed a whole day of constructive discussions face to face. It was also a first opportunity for most of the ExCo to meet the new FE Office Manager - Anita Fincham.

Monday meeting with all member delegates was all about Fertility Europe matters: Our Chair, Satu Rautakallio-Hokkanen (Simpukka, Finland) presented all that was happening in FE since Helsinki, as well as plans for the near future.

Our Vice-Chair - Elín Einarsdóttir (Tilvera, Island) reported the events of the 2016 European Fertility Week and called for ideas for a main theme for 2017 EFW, which will be held 6-12 November.

Elín Einarsdóttir, **Monika Bulmańska-Wingett** (Nasz Bocian, Poland), Klaudija Kordic (RODA, Croatia) and Ofra Balaban (Chen, Israel) told us what was happening and what is to happen within our Working Groups - COMM, POLI, MORE and FUND.

**Irena Rozic** (RODA, Croatia) organised a workshop, which aimed at finding ideas for new Fertility Europe campaigns to roll out on European level and nationally. We have now a impressive pool of ideas for projects on raising fertility/infertility awareness, fighting stigma, promoting equality of access to treatment, as well as looking after oneself during exhausting and stressful times of infertility. Some of the projects have the potential of becoming money-raising vehicles as well. Working in groups and exchanging ideas was a constructive and inspiring experience.

Monika Bulmanska-Wingett (Nasz Bocian, Poland) presented the changes to the FE Statutes, that have been proposed by the special Statutes WG. Members of the Council discussed the changes and after small amendments accepted the new Statutes. The new Statutes will become official after following a Belgian legal procedure.

The Council discussed as well possible conflict of interests of the representative of OZ Bocian, but the conclusion and voting got postponed until Council meeting in Geneva.

The representatives of Burson Marsteller **Anamaria Corca** and **Sylvia Staszak** gave us presentation about European Parliament and methods of conducting advocacy within European Parliament to get us prepared for the EPAF launch which was planned for the next day.

Tuesday was dedicated to EPAF launch at the European Parliament.

On Wednesday morning we listened to fascinating presentation by renown Belgian doctors:

- professor **Herman Tournaye** told us about medical and technical boundaries of ART
- **Petra De Sutter** focused on ethical issues, that ART presents to doctors and patients

We also listened to 3 presentations of Fertility Europe Member Associations:

- **Marijke Merckx** (De Verdwaalde Ooievaar, Belgium) presented history, achievements and plans of her organisation
- **Patrizia Ricciardone** (Amica Cicogna, Italy) told us about the struggles and achievements of her organisation in changing very restrictive law from 2004. Ban on embryo-freezing resulted in rapid fall in effectiveness of infertility treatment, but also in increase of health problems in mothers and babies caused by forced multiple transfers. Amica Cicogna did very impressive advocacy work for changing this law.
- **Donia Scicluna** (Malta Infertility Network, Malta) told us about challenges of setting up infertility patients' organisation on Malta. Malta struggles not only with restrictive law (no embryo freezing) and no medical procedures in terms of diagnostics, but also with lack of medical specialists, which forces patients to seek help abroad.

We also enjoyed constructive discussions during breaks, meals and walks. We were well looked after, courtesy of ESHRE, including dinner on Monday. We also enjoyed working dinner at Merck's office on Tuesday evening, reflecting of success of the launch and exchanging ideas on possible next steps.

We gathered afterwards feedback about the Spring Meeting through a questionnaire.

## 2.1.14 EUROPEAN FERTILITY AUDIT ON FERTILITY (EPAF)

The European Policy Audit on Fertility (EPAF) is a joint project of FE and ESHRE conducted under unrestricted grant from Merck. It is supposed to serve to collect, assess and compare up-to date information about the national fertility spectrum and policies in pre-selected European countries, identify current needs and potentially develop policy recommendations targeted at EU and national policy makers. In addition to an overview of key facts and statistics related to fertility across the 28 members of the European Union, the EPAF will include a detailed overview of policies and regulations in nine EU member states: Czech Republic, France, Germany, Italy, Poland, Romania, Spain, Sweden and UK.

### 2.1.14.1.1 LAUNCH OF EUROPEAN POLICY AUDIT ON FERTILITY, 28<sup>th</sup> MARCH 2017 AT EUROPEAN PARLIAMENT, BRUSSELS

On 28 March 2017, MEP **Norica Nicolai** (ALDE), hosted a launch event for the first Policy Audit on Fertility – Analysis of 9 EU Countries. The report, sponsored by Merck, was written by Fertility Europe (FE) and the European Society of Human Reproduction and Embryology (ESHRE), resulted in a constructive roundtable discussion addressing not only the challenges surrounding infertility, but also what can be done to solve them.

European Policy Audit on Fertility was presented in the European Parliament by ESHRE and Fertility Europe. We are very proud of our speakers **Isabelle Chandler** and **Monika Bulmańska-Wingett**, who presented the perspective and underlying needs of the 25 million people affected by infertility in Europe. They have voiced the patients' view, that access to treatment should not be anymore limited by insufficient availability of availability of treatments, unjustified eligibility criteria and lack of state funding/reimbursement. Limitations are only justified when they improve safety, efficacy, and fairness.

ESHRE Chair, Dr Kersti Lundin emphasized that the rights and an individual's ability to access treatment are not equal among EU member states. According to Lundin, a big step forward is needed to raise awareness among members states in a way that provides a clear view of the situation. ESHRE's mission is

to promote interest on reproductive health and science through outreach and communication with professionals, patients and policy-makers.

Helen Kendrew, ESHRE Chair of the Paramedical Board, presented the findings of the policy audit giving an overview of the analysis with specific examples from the UK.

Our host MEP Norica Nicolai, MEP **Beatriz Beccerra Basterrechea** and MEP **Ramón Luis Valcárcel Siso** gave us a lot of hope that there is political will to establish safe and equal access to treatment for 25 million of people facing infertility in Europe. The full text of EPAF can be read on our website with more information and videos from the event.

**Louise Joy Brown**, first IVF conceived baby, was with us to support the cause and told a moving story of the history of her family.

## 2.1.15 EUROPEAN PATIENTS' FORUM ANNUAL GENERAL MEETING 10<sup>th</sup> - 11<sup>th</sup> APRIL 2017, BRUSSELS, BELGIUM

Fertility Europe is a full member of European Patients' Forum (EPF). This year EPF specifically invited the Chairs and Presidents of their member association to participate to the Annual General Meeting. Fertility Europe Chair, Satu Rautakallio-Hokkanen represented us at the meeting.

The two day agenda consisted of AGM on Monday, the 10th of April with approval of last years minutes, Annual report and finances. In the afternoon there was election of new EPF Board members and approval of the budget and work plan for 2017.

Tuesday, the 11th was about leadership in associations. After high level speakers from European Commission, Ghent University and Institute of Health policy and Management, the participants broke in 4 groups to discuss thematic areas. The groups then discussed the assessing achievements made by EPF so far and provided insight and recommendation for the final period of the strategic plan of EPF.

# 3 FERTILITY EUROPE GOVERNANCE

## 3.1 EXECUTIVE COMMITTEE MEETINGS

The Executive Committee held fruitful face-to-face meetings in Sofia,/Bulgaria 2016, Helsinki/Finland 2016, Brussels/Belgium 2016 and Brussels/Belgium 2017 during the course of the years. During year 2016 the Executive Committee had 16 meetings. Between January 2017 and March 2017 the executive Committee had 7 meetings. All other than face-to-face meetings were Skype meetings.

The following issues were discussed during the meetings:

- Fertility Europe accounts
- Advertising Policy
- Review of Fertility Europe Statutes
- Special Families Campaign Stage 2
- Our work with ESHRE and their needs
- Members Spring Meeting in Brussels March 2017
- EPAF launch in European Parliament in Brussels March 2017
- Started planning the patient session, our Members Meeting and activities at the ESHRE Congress in Geneva in 2017
- Hiring new Office Manager
- Registration to Transparency register in EU
- Committee of advisors
- Fertility Matters -document

- Conflict of interest of an Executive Committee member
- Setting up PayPal -account and getting a credit card for the Treasurer
- Cooperation with WHO
- Fundraising
- Accountancy
- Organisational issues

## 3.2 WORKING GROUPS

### 3.2.1 COMM

COMM has been managing the social media presence of Fertility Europe, as well as updating the website, and keeping the members informed. We switched platforms for the website, it is now run on WordPress which is much more user friendly than our previous platform, and should be easier to maintain. The members Forum is accessible via the website, another new addition in communication between and with members of Fertility Europe. It is our hope that it will become a strong tool for Fertility Europe as it's a members only area where we can share sensitive information such as minutes from meetings, work in progress, and get direct feedback. COMM has been also very active in preparing and managing the first European Fertility Week 2016

### 3.2.2 FUND

It is a pity that the funding working group didn't have any meetings. The group consists at the moment of 3 members: Ofra Balaban, Elin Einarsdottir and Satu Rautakallio-Hokkanen. Since these 3 members are already working with the Executive Committee and other working groups, there is an urgent need for more members to this group. We have been asking for help from our members but unfortunately no-one has shown interest to it.

### 3.2.3 MORE

MORE working group re-established contact to the Irish patient association National Infertility Support and Information Group, to the Montenegrin association Nas San who became a member of FE in 2016, as well as continued contact to the still to be established association from Bosnia-Herzegovina Fertilitas and the local Bosnian association "BEBE. In 2016 the contact to the German Kinderwunsch association was continued esp. with regards to the EPAF project

The MORE working group had prepared the Spring meeting in Brussels 2017 and was also very helpful in supporting the EPAF launch 2017. The MORE working group consists of 3 members: Klaudija Kordic, Satu Rautakallio-Hokkanen and Susan Seenan.

### 3.2.4 POLI

POLI group was involved in very engaging preparation of the EPAF report to be launched in European Parliament. The content of the report was created in close cooperation with FE ExCo and ESHRE; and with organisational support of Burson Marsteller and financial support of Merck. Isabelle Chandler was one of the most active members of POLI Group. Even though she resigned from the ExCo, she carried on working on EPAF report.

### 3.2.5 STATUTES

The Statutes WG consisted initially of 5 members:- Afroditi Alexopoulou (Kiveli, Greece, the ExCo member), Ella Einarsdottir (Tilvera, Iceland, the ExCo member), Irena Rozic (Roda, Croatia), Monika Bulmanska-Wingett (Nasz Bocian, Poland) and Nicole Cristea-Brunel (SOSI, Romania, the ExCo member)

and eventually got reduced to 3 members when Irena and Nicole had to quit due to personal reasons. The WG initiated its activities in October 2015 and conducted regular Skype calls for over a year. When the final proposals were ready the Statutes WG published them on the forum and sought the membership comments and opinions. After the first round of consultations the ExCo took a closer look at the amendments and after discussing their remarks within the Statutes WG, the second round of consultations was conducted. During the Spring Meeting in Brussels the proposals got voted over by the council and after minor amendments got accepted unanimously.

The new statutes will become official after following a Belgian legal procedure.

## 4 FERTILITY EUROPE RE-BRANDING, WEBSITE, SOCIAL MEDIA, NEWSLETTERS AND PROJECTS

### 4.1 FE RE-BRANDING AND CORPORATE IDENTITY

There was an obvious need for rebranding Fertility Europe logo and website. The old logo was original and dated back to many years. Also the website was on a server where Fertility Europe had no access and therefore it was extremely important to change the domain to a server where we had access and control over it.

#### 4.1.1 FE WEBSITE

The website was rebuilt by our volunteer Nicole Brunel and it was launched on the new server right after the Helsinki Council meeting in the summer of 2016. After getting the logo ready at the end of 2016, the website was updated with that and the colours according to our new style sheet. This work was done before the launch of the EPAF in March 2017. The changes were order from a Finnish designer **Caroline Melling** as an urgent minor job.

#### 4.1.2 NEW LOGO

The call for designing the new logo was published on Upworks –website in the autumn. Upworks is a website where you can ask for quotes from different kinds of professionals. We got 3 quotes from different companies from which we asked their proposals. After consideration, it was decided by the Executive Committee that we ordered the logo from a US graphic designer **Sarah Kruger**, who had already designed the EFW logo earlier and with whom we had been very content.

Sarah Kruger provided us a horizontal and vertical version of the logo including a few different sizes and black and white versions. She also provided the stylesheet of the logo.

#### 4.1.3 OTHER MATERIAL

In order to be as visible and professional as possible at the EPAF launch in Brussels, the Executive Committee acquired material for the launch. We order two roll-ups with the new logo and style from a Finnish company and we printed handouts in UK to be distributed at the launch but also at the ESHRE Congress in summer 2017. The roll-ups and the handout were again designed by Sarah Kruger. The other roll-up is with Special Families -cards and the other is informative with information about Fertility Europe.



The handout has Special Families -photos on the other side and information about Fertility Europe on the other side. We also ordered business cards for Executive Committee members and Office Manager. Those were delivered to us from Moo.com -web printing company.

#### 4.1.4 SOCIAL MEDIA

Facebook was main and very useful tool for FE last year - especially for running the EFW and EPAF campaigns.

EFW presented on FB 'Myths&truths' about infertility and series of informative notes regarding development of infertility treatment. We were also sharing the events and posts from the national fanpages of FE members.

EPAF campaign was supported by a media plan from Burston Marsteller, which enabled Office Manager to run a professional daily update on FB and Twitter for nearly a month before and during EPAF launch.

The number of followers on Twitter increased to 137, while FE facebook page has 1353 fans.

Facebook group with over 600 members, that belonged to Fertility Europe, but was run by Denisa Priadkova, was unfortunately taken over by her despite arranging with the Executive Committee, that the group should be closed.

#### 4.1.5 NEWSLETTERS

At the beginning of 2017 Fertility Europe decided to send a quarterly Newsletter to the Members and fans (in February, May, September and December) informing them about the events, actions and plans.

Newsletter is prepared by Office Manager with cooperation of ExCo and WG leaders. The first one was published in February 2017.

#### 4.1.6 SPECIAL FAMILIES CAMPAIGN

The situation of Special Families campaign, photos and website got challenging after the change of the website server. The site where you could download and upload cards didn't work anymore and no help with that was available. This was a very unfortunate situation considering the amount of money and work Fertility Europe had put on to it. Some of the members were also using the campaign and the cards very actively.

Due to a fact that no help was provided despite asking for it from the previous administrator, it was the decision of the Executive Committee to put the campaign aside. The decision was not easy, but the Executive Committee concluded that trying to find a solution to revive the page was frustrating and too time consuming. It is however possible for all members to use the cards in the future too, but producing new ones is not possible anymore.



## 5 FERTILITY EUROPE FINANCES JANUARY 2016 – MARCH 2017

Fertility Europe is extremely grateful to ESHRE for supporting our meetings in 2016-2017. The Executive Committee, our volunteers, and our members look forward to achieving even greater success in 2017-2018.

- Initiatives FE have undertaken to generate income:
  - ✓ Membership subscriptions
  - ✓ Supported the ESHRE under the slogan “Run Baby Run”, the Fun run was held at the ESHRE Congress in Helsinki and raised money for Fertility Europe. The Fun run will take place once again at the ESHRE Congress in Geneva on Monday, 3rd of July 2017 and will once again support Fertility Europe.
  
- Funding will be one of the major points to develop next year. The main acquisitions in January 2016 – March 2017 were:
  - ✓ The continuous services of a part-time Office Manager Kalina Nedelcheva (end of 2016) and Anita Fincham (beginning of 2017)
  - ✓ The services of our accountants ABConsult
  - ✓ Printing of handouts, roll-ups, new website, Special Families postcards for the Booth and business cards

### 5.1 BANK FRAUD

On 14/1/2017 the Treasurer's (Afroditi Alexopoulou) email received email from the Chair (Satu Rautakallio-Hokkanen) to make two payments for the launch event in Brussels. There was attached invoices for a certain company. After many emails and questions between the Treasurer and the alleged Chair, the treasurer made the 2 payments (2\* 4 769,43€). Because there was a bad feeling for that transaction the Treasurer spoke on the phone with the Chair and realised that the Chair had never sent those emails. The email address of the Chair was forged in order to send emails to Treasurer asking to pay false invoices. The Treasurer immediately called the KBC bank and managed to get back the second payment of 4 769,43€. After that the Treasurer went to the authorities to report the internet crime and sent the official report to the FE Bank.

We are still waiting for the result, unfortunately both sides (Police and Bank) told us that these crimes take a lot of time to solve.

## 5.2 FINANCIAL STATEMENT JANUARY 2016 – MARCH 2017

<b>FERTILITY EUROPE</b>			
<b>FINANCIAL STATEMENT JANUARY 2016 – MARCH 2017</b>			
ACCOUNT NR	ACCOUNT NAME	AMOUNT €	DESCRIPTION AND COMMENTS
<b>INCOME</b>			
700001	Carried forward from previous year	86.575,27 €	Bank account KBC Bank
700100	Membership fees	3.700,00 €	Membership fees from members
751520	Financial income	1.000,00 €	ESHRE fun run Lisbon
751521	Financial income	14,27 €	Vat refund (Atlantis)
	<b>TOTAL INCOME</b>	<b>91.289,54 €</b>	
<b>EXPENDITURE</b>			
611400	Sub-contracts	8.400,00 €	office manager(Kalina-Anita)
612100	Legal advice	1.211,00 €	Lawyer for domain+domain transfer)
612400	Accountancy fees	1.811,78 €	accounts
612700	Publishing	536,00 €	(New logo EFW+FE)
615800	Membership fees	100,00 €	EPF
616650	Travel	1.519,56 €	Working Groups travel expenses-
616650	Travel	8.667,83 €	EXCO members-office manager
656000	Bank charges	104,62 €	monthly costs, Visa-card
	Meeting expenses	2.277,00€	Helsinki dinner-brussels exco meeting
	Office costs	878,12€	Internet, postage, laptop transfer, kalinas babies gift etc
	Printing	70,68€	SF cards for wall of hope
	Web hosting services	150,26€	FE page, SF domain
	Fraud	4.769,43€	Fraud invoice for EPAF launch event
	<b>TOTAL EXPENDITURE</b>	<b>30.496,28€</b>	
	<b>BALANCE</b>	<b>60.743,26 €</b>	

On behalf of Fertility Europe Executive Committee,

Satu Rautakallio-Hokkanen

Chair

Fertility Europe VZW