



REPORT LAUNCH

POLICY AUDIT ON FERTILITY Analysis of 9 EU Countries April 2017



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THE WORKSHOP WELCOMED PRESENTATIONS BY:

Ms Isabelle Chandler, Policy and Government Relations Adviser Fertility Europe (FE),

Dr Kersti Lundin,

Chairman of the European Society of Human Reproduction and Embryology (ESHRE),

Ms Louise Brown, world's 1st IVF conceived baby,

Ms Helen Kendrew,

Ex Officio Chair Paramedical Group and Executive Committee Member, European Society of Human Reproduction and Embryology (ESHRE),

Ms Monika Bulmańska-Wingett,

Member of the WGs POLI and COMM Fertility Europe (FE)

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.

Close to 100 participants gathered together to participate in the growing debate around reproductive rights. In welcoming participants, MEP Nicolai discussed the importance of addressing the challenges posed by infertility in Europe, stressing that infertility is a medical condition that needs national legislative frameworks. She called on, not only experts and researchers, but also patients affected by infertility. Her welcome address was echoed by European Parliament Vice-President, MEP Ramón Luis Valcárcel Siso (EPP, SP), who contributed a video message to the event.

RECOGNITION OF AN ISSUE THAT AFFECTS MILLIONS OF CITIZENS IN THE EUROPEAN UNION

'The debate regarding infertility is, increasingly relevant due to demographic challenges that test our social model. MEP Ramón Luis Valcárcel Siso spoke to the necessity of tackling this challenges for the well-being of future generations, highlighting that infertility not only affects women but also men. He went on to say that both politicians and medical specialists, without forgetting patients, can do more to coordinate at the European Union level, nationally and regionally.

Moderator, Ms Tamsin Rose, facilitated an engaging debate, guiding the audience through various presentations on key issues.



To talk about fertility is to talk about life. it is to talk about family. MEP Ramón Luis Valcárcel Siso,

MEP N. Nicola

PRESENTATIONS -



Ms Isabelle Chandler, FE, presented the perspective and underlying needs of the 25 million people affected by infertility in Europe. She stressed that infertility remains a social taboo and stigma that permeates life in many ways. She went on to say that the issue remains largely underestimated and misunderstood, and that treatment access is not equitable across EU countries.

"The launch of this policy audit is a unique opportunity to put a focus on this issue. People take fertility for granted. Infertility results from a medical condition and it has professional, psychological and social consequences."

FE advocates for universal access, developments in research and a bioethics legal framework. FE needs to be supported by other stakeholders in its advocacy campaigns.



Dr Kersti Lundin, ESHRE, presented their activities and the mission of ESHRE, emphasizing that rights and an individual's ability to access treatment are not equal among EU MS (e.g. few countries have plans for reimbursements regarding treatments). A big step forward is needed to raise awareness among member states in a way that provides a clear view of the situation.

"This is a very important report showing differences regarding fertility treatments access. I sincerely hope that we can make a difference."

ESHRE's mission is to promote interest on reproductive health and science through outreach and communication with professionals, patients and policy-makers.





Mr Martin Powell introduced the world's first IVF conceived baby, Louise Brown. He recalled Louise's mother and her strong desire to have a baby.

"Leslie Brown was the real pioneer by being the first woman to successfully conceive a baby through IVF."

Ms Louise Brown, the world's 1st IVF **conceived baby**, stressed the importance of scientific advances in the field of reproductive medicine. She called for medical assistance to be provided to those who cannot conceive, because infertility is a health issue. Recalling that her mother, first went to the doctor not for her infertility issue but for depression.

"IVF is not about making babies, it is about creating families.

PRESENTATIONS



Ms Helen Kendrew, ESHRE, presented the findings of the policy audit, giving an overview of the analysis with specific examples from the UK. The study was conducted through a questionnaire, sent out to patients and doctors across the 9 EU countries.

"Infertility is defined by WHO as a medical problem, affecting 1 on 6 couples worldwide...Despite these figures there is an enormous underestimation of the psychological burden on the NHS."



Ms Monika Bulmańska-Wingett, FE, presented the patients' perspective on the policy audit.

"The most crucial issue regarding infertility and infertility policies is access to treatment and the fact that it is often limited by availability of treatments, eligibility criteria and state funding/reimbursement. Limitations are only justified when they improve safety, efficacy and fairness. They are not justified when they create discrimination against life choices, like postponing parenthood or being single, against sexual orientation and when they are based on ideology- or religion-driven decisions rather than ethics and EBM (evidence based medicine)."

The primary consequence of differences in EU MS legislations is the so-called medical tourism. This is not a problem per se, but it becomes an issue when people are forced to seek treatment in a different country because it is not provided in their home country.

Furthermore, severe limitations are imposed on single women in many EU MS. Ms Bulmańska-Wingett pointed out the next steps to be taken:

To recognise and follow up on the patients' needs;

To be inclusive and fight discrimination; To provide universal, fair and safe treatment;

To develop scientific research;

To promote dialogue with all the stakeholders and to boost stakeholders' support towards patients. "Limitations are only justified when they improve safety, efficacy and fairness of treatment for all involved."



MEP N. Nicola

MEP B. Becerra Basterrechea

Nicole Brunel, SOS Infertilitatea Romania, was glad that Romania was included in the audit and she raised the issue of the Romanian situation regarding fertility policies. Up until 2008, there was a different legislative framework in place in Romania. Advocacy organisations in Romania have developed many campaigns to raise awareness about infertility problems and invested a lot in education and communication, also through social media.

The moderator, Tamsin Rose, invited the national representatives to intervene to the debate with experiences and insights from their countries. The Permanent Representations of Romania and Italy to the EU provided their contribution to the debate.

Mr Stefan Staicu, Health Attaché Permanent Representation of Romania to the EU, expressed his gratitude for the work that is being done. He stressed that there is room for improvement in Romania, but it is also important to recognise the results achieved so far in his country, in terms of legislative framework addressing fertility issues.

"Romania faces many demographic challenges and more efforts need to be put in place to invert the decreasing trend in population growth."

Dr Pasqualino Rossi, Health Attaché Permanent Representation of Italy to the EU also commented, reporting insights on the debate in Italy, steaming from religious influences in the political arena. Another issue of concern in Italy is represented by the conscientious objectors' phenomenon, which complicates the situation.

An FE representative drew attention to the difficulties people affected by infertility encounter in the workplace. There is lack of support for people undergoing fertility treatment, putting them at a greater risk of discrimination in the workplace.

Marc Scheijven welcomed the policy audit and expressed his surprise at the results of the audit; not expecting so much variation amongst EU MS legislations. He also introduced the issue of anonymity, stating a child's right to know their genetic origin.

The moderator, Tamsin Rose, also invited the representative of DG SANTE, Mr Catalani, to take the floor and explain the current situation from the Commission perspective.

"DG SANTE is aware of the discrepancies in legal frameworks among the Member States."

The Commission has started an evaluation process of the existing legislation and will launch an open consultation (spring 2017) on the Directive on Human Tissues and Cells and corresponding directives.





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To conclude the roundtable session, MEP Beatriz Becerra Basterrechea (ALDE, ES), contributed to the debate with her insights. The idea of family has changed. Science and society are evolving and the law needs to keep up. The role of the MEPs is to find solutions to citizens' problems.

She suggested a few ways of addressing the issue of infertility at the EU level:

Given its psychological impact, infertility could be addressed through EU mental health policies;

Infertility should be included in the EU public health agenda as well as in the gender equality and employment agenda;

Through a better coordination among countries to improve fertility policies and in particular to abolish discrimination and existing barriers;

To address infertility with a holistic approach, accounting for its many health, social, and economic factors;

To promote awareness campaigns and to engage decision makers, institutions and stakeholders;

To recognise that infertility is not an individual problem but it affects the whole society and it is closely related to economy and welfare;

To respect and guarantee sexual health and reproductive rights as human rights. ►

MEP B. Becerra Basterrechea

MEP Beatriz Becerra Basterrechea (ALD<u>E, ES)</u>

stressed the need to raise awareness and engage with different stakeholders and she welcomed the engagement of Merck. She referenced a written question on EU action in the field of reproductive medicine. The answer was that competence in this field is with the member states. The EU can support the action of Member States. Particularly in the field of reproductive medicine, the EU acted with the Directive on quality and safety of human tissues and cells. She also highlighted the need to talk about employment policies regarding infertility, and the need for better coordination to abolish the existing barriers to non-discriminatory working environments. Lastly, she raised the issue of surrogacy, an issue that requires addressing.

FINAL GOALS:

- Raise awareness to combat stigmatization of patients affected by fertility issues.;
- To secure state-funded fertility treatment in all EU countries.

Media coverage was provided by:

Euronews: euronews. http://www.eu

http://www.euronews.com/2017/03/28/numerousbarriers-in-accessing-eu-infertility-services



Euractiv:

http://www.euractiv.com/section/health-consumers/ video/worlds-first-ivf-baby-addresses-infertilityhold-until-image-insert/

Suddeutsche Zeitung:

Süddeutsche Zeitung http://www.sueddeutsche.de/leben/kuenstlichebefruchtung-zu-besuch-beim-ersten-retortenbabyder-welt-1.3441928



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