



Report

European Policy and Expert Summit on Preconception Health

7-8 March 2019, Europe House, The Hague, The Netherlands

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INTRODUCTION

On 7 and 8 March 2019, international health and behavioural experts, scientists, policy makers and patient organisation representatives gathered in the ‘Europe House’¹, The Hague, The Netherlands, for the two-day “European Policy and Expert Summit on Preconception Health”. The summit was organised by the Preparing for Life Foundation, a network of international medical and behavioural professionals, scientists, patients and service clubs.

The preconception period, preceding pregnancy, offers several opportunities to prevent congenital disorders and to contribute to the health of the mother and her (future) child, and even of future generations. Nowadays, it is broadly recognized that preconception care has a positive effect on a wide range of health outcomes for mother and child. Not only can preconception care prevent pregnancy complications, reduce mother and child mortality and prevent birth defects, it also has positive long-term effects on health. Preconception care should therefore be embedded in national healthcare programs. Therefore, preconception care and preconception education are of utmost importance.

In 2007, a report by the Dutch Health Council concluded that the provision of preconception advice on diet, lifestyle, diseases, use of medication, working conditions, and genetic factors are an intrinsic part of effective care. With this report at the background, and following the United Nations Health Millennium Development Goals, the Preparing for Life consortium took the initiative to invite the World Health Organization (WHO) and partners to have an international meeting (Geneva, 2012) to develop a global consensus on preconception care. The following understanding of preconception care was used:

“The provision of biomedical, behavioural and social health interventions to women and couples before conception occurs, aimed at improving their health status, and reducing behaviours and individual and environmental factors that could contribute to poor maternal and child health outcomes. Its ultimate aim is to improve maternal and child health, in both the short and long term.”

(Source: *Meeting to Develop a Global Consensus on Preconception Care to Reduce Maternal and Childhood Mortality and Morbidity*, WHO Headquarters, Geneva, 6–7 February 2012, Meeting report²).

Furthermore, WHO advised to build capacity of regional public health programs, to implement and monitor preconception care, and to support demonstration projects on preconception care. However, although the clinical relevance is now increasingly being recognized globally, implementation of preconception health programmes at regional and national policy and executive levels is often still lacking or not organized in a sustainable manner. In many European countries, preconception health is still an emerging concept. Therefore, it is of great importance to develop an integrated European policy agenda for preconception health with explicit and feasible recommendations and/or guidelines that may facilitate implementation of national preconception health programs.

This challenge to implement the WHO-recommendations in Europe was taken up again by the Preparing for Life foundation by organising this current Summit. Despite approval of the “*Action plan for sexual and reproductive health: towards achieving the 2030 Agenda for Sustainable Development in Europe –leaving no one behind*” (Copenhagen, 2016) by 50 countries of the WHO European Region, participants of the summit noted that as of today, preconception care barely has been on the agenda in the health policies of Europe and the European countries. A ‘sense of urgency’ is needed! There was a consensus that European and national governments, as well as civil societies, need to take action urgently to integrate the international WHO-recommendations into their health policy and programs.

¹ The Europe House is the home of the Representation of the European Commission, and the European Parliament Information Office in the Netherlands: www.europarl.europa.eu/huisvaneuropa/en/europe-house.

² The meeting was organized by the WHO Department of Maternal, Newborn, Child and Adolescent Health (MCA) in conjunction with the Aga Khan University, the Bill & Melinda Gates Foundation, the March of Dimes and the Preparing for Life Initiative, www.who.int/maternal_child_adolescent/documents/consensus_preconception_care/en/).

PROGRAMME OVERSIGHT

DAY 1, MARCH 7, 2019

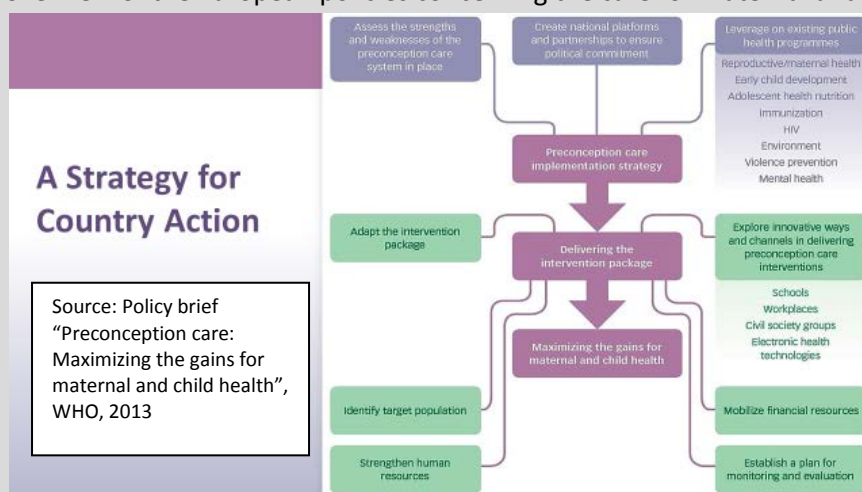
In the morning, the Summit was opened by Mr. Cor Oosterwijk, co-chair of the Preparing for Life Foundation. He gave an outline of the Preparing for Life Foundation and its objectives: raising global awareness, contributing to prevention programs, supporting governments in identifying the options for structural programs for preconception care, and bringing relevant international stakeholders together for these aims. He also summarized its past achievements: several (inter)national meetings in the Netherlands and a Dutch report of the National Health Council resulted in cooperation with WHO in the field of preconception care. Subsequently, the 2012 WHO consensus meeting became one of the major milestones, resulting in implementation conferences in several WHO-regions, among which also this European Summit.

After this introduction, the plenary presentations started:

Prof. Gunta Lazdane gave an overview of the European policies concerning the care for maternal and

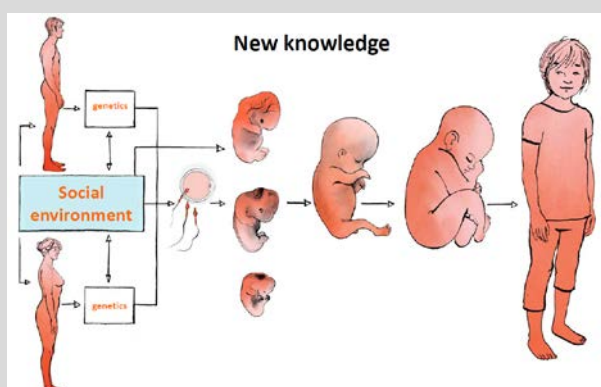
child health by WHO and the European Commission, and she scheduled the policy options for preconception health. This included the WHO Policy Brief 'Preconception care: Maximizing the gains for maternal and child health' (2013), the WHO package of preconception care interventions and the strategy for country action.

She also elaborated on other WHO-reports in the field of maternal and child health, as well European Commission' programs. *Ms. Lazdane is director of the Institute of Public Health, Professor at the Riga Stradins University, Latvia and former programme manager at WHO Regional Office for Europe.*



A Strategy for Country Action

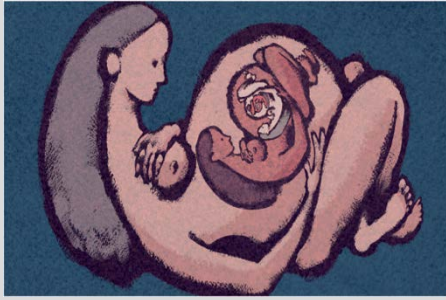
Source: Policy brief
"Preconception care:
Maximizing the gains for
maternal and child health",
WHO, 2013



A recapitulation and reconfirmation of basic principles for preconception health was presented by **Prof. Eric Steegers**. He pointed at the need for new knowledge and the sharing of it, the importance of linking medical and social domains, resulting in integrated care and a life course, tailored approach, focussing on health instead of on disease only. **He concluded that a sense of urgency is highly needed and advised that each medical professional should always ask the question:**

"Would you like to become pregnant in the next year?"

Mr. Steegers is professor of obstetrics and gynaecology at Erasmus University Medical Centre, Rotterdam, The Netherlands.



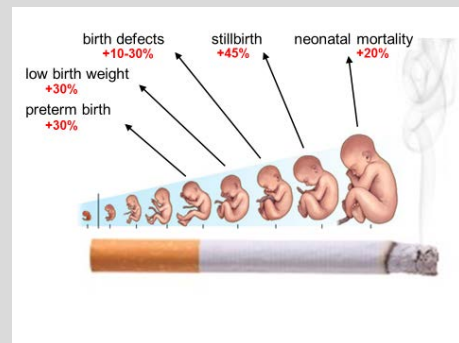
An assessment of European needs and barriers was given by **Prof. Judith Stephenson**, based on the Report on 'International comparisons of health and wellbeing in adolescence and early adulthood (Nuffield Trust, February 2019). She depicted the need for new definitions of the preconception period, including biological, individual and public health needs. She stated that some degree of pregnancy 'planning' is nowadays more common than recognised. **Therefore, she advised a dual strategy: Identifying individuals contemplating pregnancy and**

population initiatives (e.g. to reduce smoking and obesity and improve nutrition) irrespective of pregnancy planning. Judith Stephenson is the Margaret Pyke Professor of Sexual & Reproductive Health at UCL and Programme Director for Maternal Health, UCL Partners, London, UK.

In the afternoon, in several pitches, local good practices were presented to inspire preconception health policy and programs in Europe:

The pitch of **Dr. Jasper Been** was entitled: 'Enabling a smoke-free generation'. He presented convincing data on the devastating effects of smoking on pregnancy outcomes, as well as the positive impact that tobacco control policies and cessation services have on pregnancy outcomes. He also commented upon national progress that is being made in this field in The Netherlands.

Dr. Been is consultant neonatologist ErasmusMC Sophia Children's Hospital, Rotterdam, The Netherlands.



Dr. Ashna Hindori-Mohangoo presented Perisur (<https://perisur.org/>), a perinatal-intervention-based program in a middle income country Suriname. Although preconception care was successfully implemented sustainability of this successful combination of needs assessment, media campaign

and preconception services is a major concern and specific target groups still need to be reached.

Dr. Hindori-Mohangoo is the intervention developer at the foundation for Perinatal Interventions Suriname (Perisur), an adjunct associate professor at Tulane University School of Public Health and Tropical Medicine, New Orleans, USA, and Research Scientist Child Health at TNO, Leiden, The Netherlands

Ms. Salimah Walani presented on the use of digital / social media for promoting preconception health, using the March of Dimes #BlanketChange Campaign as an example.

Ms. Walani is Vice President of Global Programs, March of Dimes, Arlington, VA, USA.





Ms. Eleonora Hristova presented a survey among newly married couples regarding premarital medical examination and genetic counselling. She concluded that prevention of hereditary and rare diseases and early preconception identification of patients for genetic counselling should be a major priority in health policy and family planning. *Ms. Hristova is a researcher at the Faculty of Public Health, Medical University of Plovdiv, Bulgaria.*

The main observations, conclusions and recommendations of this first summit-day were then worked out in several workshops to develop a roadmap towards European preconception health, focussing on political and policy aspects, interventions, communication and education as well as ethical societal and cultural aspects.

DAY 2, MARCH 8, 2019

March 8 is the International Women's Day. This inspired the summit participants to stress the need of informing the generation of young women on the relevance of preparing for a healthy pregnancy, as well as the need for their involvement in advocacy.

The international scope of the day was also visible in the two plenary morning presentations:

Examples of global practices and services by midwives were presented by **Ms. Franka Cadée**. She stressed the important role midwives all over the world can have, and already have, in preconception care and education. She recommended to take an active role in supporting the development of appropriate services for women which enable them to plan their pregnancies and prevent unwanted pregnancies. Also, to seek to influence the education of midwives to ensure that they have the evidence-based knowledge, understanding and appropriate skills to meet the needs of women in planning their pregnancies.

Ms. Cadée is president of the International Confederation of Midwives (ICM).



The Voice of Rare Disease Patients in Europe

how important patient support for EURORDIS European policy had been, resulting in several Regulations from the European Commission. This close interaction with the grassroots is now also the guiding principle for working with WHO and UN. Planning such an advocacy roadmap stepwise and freeing human resources are important factors for success.

Mr. Yann Le Cam is Chief Executive Officer at EURORDIS, Paris, France, and member of the Management Board of the European Medicines Agency (EMA).

The audience was then instructed by **Mr. Yann Le Cam** on how to advocate for the good sake. He stressed

After these two presentations, the outcomes of both days were discussed and consensus was reached, resulting in the following outcomes:

OUTCOMES

The draft outcomes of the workshops of the first summit day were presented to the participants on the second day, subsequently discussed in a second round of workshops and finalised. The consensus-based outcomes are as follows:

Evidence-based interventions

The participants stressed the fact that a broad scale of effective preconception and inter-pregnancy interventions are clearly and sufficiently described in the 2012 WHO-report and require more intensive follow-up and implementation in the international community. However, it was noted that the issue of chronic diseases and the importance of targeted communications needed further working-out. Therefore, it was agreed upon that an update of the WHO-report, also including recent scientific developments, is needed.

The key question is how people can be reached at the right time with the right interventions. This should be done through a life course approach, starting at young age, embedded in sexual and reproductive health education and more focussed at times that people are considering to have children. For this, a stratified needs assessment, a bottom-up and top-down approach, and targeted strategies to find the 'sweet spot' are needed.

It was recommended to develop a practical toolkit of existing effective interventions and make it available via a digital platform to different professional stakeholders.

Societal awareness

Preconception health and healthy pregnancy education should be integral part of early health literacy, and should include sex education, healthy reproduction, relationships, life plan and family planning. Preconception education should also be part of a more general education on 'how to be a good parent' and should bring a positive message.

Making the planning of pregnancy more of a habit, for both parents-to-be and parents, will create better chances for preconception health. Politicians and opinion makers bringing the topic of planning pregnancy into the open, and not only in relation to family planning but also in relation to a healthy pregnancy and healthy offspring, will help to get rid of a possible taboo in certain cultures.

To create more societal awareness, the message should also be addressed to, and forwarded by civil society, including patient organisations, teachers and youth groups. The creation of a youth movement with social rewards, the use of ambassadors, peer support, peer to peer education, video's and modern media, smart digital solutions and apps could help to spread the message as well. Stratification and adaptation of communication to different age, groups/ social economic status is required. One shouldn't hesitate to also use emotional messages.

In this way, a bottom-up demand will be created for which policy makers are especially sensitive.

Awareness amongst health care professionals

The Preparing for Life consortium feels the responsibility to encourage and facilitate international and national medical societies in bringing and keeping the subject of preconception health improvement on the agenda.

A concise 'call to action' could already be sufficient for such organisations to take action for (further) implementation of preconception care. Furthermore, the topic of preconception health and care could be, without much effort, be put on the programmes of international professional conferences.

Data to promote awareness

Accurate data in the field of preconception health are lacking. This concerns:

1. data on negative pregnancy outcomes for mother and child that could have been prevented if preconception care had been offered;
2. data on the outcomes for mother and child in case preconception care was offered;
3. data on public and political awareness.

This lack of data hampers ways to benchmark or to measure improvement. Policy makers need figures, a baseline and measurable goals. However, these data are important for all kind of stakeholders, but nobody feels responsible, there is no sense of urgency.

Awareness of two facts is especially lacking:

1. the very early influence – even long before conception - of many kinds of factors on maternal and child health;
2. their long term effects later in life.

Framing the message is needed to achieve the intended goal. With respect to several risk factors, strong evidence exists on their causal relationship with perinatal outcomes. For example, good stories, cases reports and statistics related to the use of folic acid and the effects of anti- smoking and anti-alcohol campaigns may be available.

Communication and education by healthcare professionals

All health care providers involved in the care of women of reproductive age should be educated in the importance of preconception health as it relates to their profession. It should be emphasized that preconception risk factors should be identified and addressed before a woman becomes pregnant.

Knowing all factors that influence preconception health, they should tailor the message as much as possible. This means to focus on the (one) issue(s) that are most relevant in a way that appeals most to the target group and to consider if, how and when other possible risk factors can be communicated.

All means to stimulate early preparing for pregnancy should be used and ‘parent preparedness’ normalised, focusing on, and visualising healthy behaviour before and during pregnancy.

It is advised to reach out to health care professionals in the region, especially primary physicians and midwives, and to consider to set up a preconception counselling specialist or multidisciplinary group of experts within the regional community that can be consulted by e-health and (for free) tele-consultations.

Other recommendations for sustainable and long-lasting implementation of preconception health within healthcare communities:

- train the trainers;
- engage young professionals;
- broaden the curricula of young medical and nursing students;
- have a regional ‘medical / health champion’;
- involve midwives in promoting preconception care.

Some cultural aspects

In many cases, the cultural and social differences that are relevant in relation to preconception care, are unknown. This includes the influence of region and culture on risk perception and dealing with risks. Community dialogues and interviews are then recommended.

Elements that may or may not require normalisation, will differ between cultures and regions.

On the African continent for example, normalisation of having an HIV infection is important since this is not a rarity, but rather prevalent in the African population.

Should the interaction in the context of preconception health be with the woman in the first place, or with the couple together? In many cultures, it may be necessary to empower women to deal with this issue independent of the opinion of their partners or family, to avoid social pressure and stigmatization. Such empowerment should already start early in schools.

Some ethical aspects

The ethics of preconception health includes life style aspects and genetic aspects.

Life style aspects (including sexual health and HIV infection) are 'actionable' for the parents(-to-be). This allows for a directive way of informing, educating and counselling. The ethical accountability to address people who mostly did not ask for this kind of information, is based on the fact that (practically)all parents feel responsible for the health and well-being of their children. When realising that the health of their future unborn child is also influenced by the preconception period, they will acknowledge that this proactive approach is in full agreement with their own values. A strong message at population level referring to the health of the future child, is therefore allowed. At an individual level however, advisors and counsellors should use their influence wisely adapted.

The relevance of ethics of preconception health in relation to genetics, becomes more and more prominent because of fast developments in genetic sequencing and genetic screening, like preconception (population) carrier-screening. Genetic data may also be of value for lifestyle, but in general this kind of data is non-actionable for the parents to be, apart from reproductive decision making. In that case, the advice should be non-directive and reproductive autonomy, informed autonomous decision making, non-directive advise and counselling, and personal attitudes and values should be respected. This therefore means: very balanced information on the possible consequences of the parental choices for the child.

Political awareness and responsibility in Europe.

It's the responsibility of national governmental policy makers to:

- make preconception health an integral part of public health policy; when new legislation / regulation / policy on environmental and life-style subjects (e.g. tobacco) is foreseen or under construction, include the preconception and pregnancy period;
- facilitate and fund research, including social research, to offer effective, targeted preconception care services in populations with different socio-economic and cultural characteristics, and research on Health Technology Assessment (HTA) to show the economic impact of preconception care;
- set up or facilitate preconception health campaigns and websites and/or make preconception health part of related campaigns (e.g. on sexual health, smoking, obesity);
- create awareness on correct and misleading preconception information.

The Preparing for Life consortium was also advised to be present and active in the WHO and other European and global meetings.

National implementation

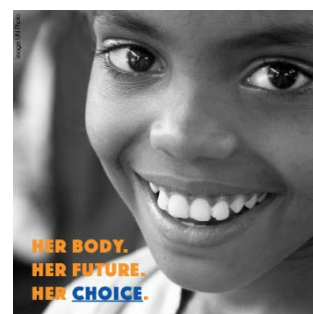
The WHO-consensus declaration (Geneva, 2012) actually is the formal (inter)national commitment for the sake of preconception health, as well as the WHO Action plan for sexual and reproductive health (Copenhagen, 2016). This commitment cannot be ignored and must be followed by the development and implementation of national strategies, in analogy to the National Plans for Rare Diseases, an initiative of the European Commission. For acquiring evidence on best practice and effectiveness of national health programs, explicit outcome parameters must be included.

The summit participants encourage the European Commission to act in a similar pro-active way in the field of preconception health, to recommend action plans or strategies to its Member States that include clearly defined responsibilities and allocated sources of funding for improvement of information and services during the preconception period.

The international sharing of success stories will help to raise competition.

Next step

Among the participants was also a delegation from the African continent. In the afternoon session, chaired by Ms. Helen Malherbe, the African delegation, the board of Preparing for Life and some other participants (Ms. Kyomuhendo Sylvia and Mr. Okello Harrison from Uganda via internet) explored the needs and barriers in the field of preconception health in the South East African Region. It was decided to have the next Preconception Health Summit in this WHO-region, in 2020.



LIST OF PARTICIPANTS



Participant

Affiliation

Mr. Jasper Been, MD, MPH, PhD	Consultant Neonatologist Erasmus MC-Sophia Children's Hospital, Rotterdam, The Netherlands; Honorary Research Fellow, Usher Institute, The University of Edinburgh, UK.
Ms. Franka Cadée	President International Confederation of Midwives (ICM).
Mr. Yann le Cam	Chief Executive Officer at EURORDIS, Paris, France, member of the Management Board of the European Medicines Agency (EMA).
Ms. Martina Cornel, MD, PhD	Professor of community genetics and public health genomics, VU University Medical Center Amsterdam, The Netherlands.
Ms. Matty Crone, PhD	Associate Professor Public Health, Leiden University Medical Center, The Netherlands.
Ms. Symone Detmar, PhD	Principal advisor Child health and prevention at TNO, The Hague, The Netherlands, Co-chair Preparing for Life Foundation.
Ms. Martina Ens-Dokkum, MD, PhD	Retired Paediatrician, governing board member Preparing for Life.
Ms. Hilary Goeiman, RD(SA), PhD	Deputy Director: Integrated Nutrition Programme at Health Department, Cape Town, South Africa.
Ms. Hanne Hegaard, PhD	Midwife, Associate Professor Obstetric Clinic & Research Unit for Women's and Newborn Health, Rigs hospitalet Copenhagen, Denmark.
Ms. Eleonora Hristova, MD	Assistant Professor, Department of Social Medicine and Public Health Medical University, Plovdiv, Bulgaria.
Mr. Okello Harrison	Co-Founder & CEO at Infants' Health Foundation, Uganda (participating via internet).
Mr. Leo ten Kate, MD, PhD	Emeritus professor of clinical genetics, VU University Medical Center Amsterdam, The Netherlands.

Participant

Affiliation

Mr. Jan Lucas Ket, MD	Retired Paediatrician, Rotary International Director (elect), governing board member Preparing for Life.
Ms. Gunta Lazdane, MD, PhD	Prof. Reproductive Health, Dep Obstet & Gynecol, Director Institute of Public Health, Riga Stradins University, Latvia. She worked at the WHO Regional Office for Europe as the programme manager for Sexual and Reproductive Health in the Division of Noncommunicable Diseases and Promoting Health through the Life-Course.
Ms. Helen Malherbe, PhD	Chair Governing Board Genetic Alliance, South Africa.
Ms. Gileard Masenga, MD	Obstetrician and Gynaecologist, Executive Director at Kilimanjaro Christian Medical Centre, Tanzania.
Ms. Madelon Meijer-Hoogeveen, MD, PhD	Policy Officer Preconception Care, VSOP Dutch Patient Alliance for Rare and Genetic Diseases, Soest, The Netherlands, Secretary General Preparing for Life, Youth Healthcare Physician, The Netherlands.
Ms. Janneke Kreijen-Meinesz, MD, PhD	Paediatrician / neonatologist, Haaglanden Medical Center, The Hague, The Netherlands.
Ms. Ashna Hindori-Mohangoo, MPH, PhD	Program Manager/Intervention Developer at the Foundation for Perinatal Interventions Suriname (Perisur), Paramaribo, Suriname; Adjunct Associate Professor at Tulane University School of Public Health and Tropical Medicine, New Orleans, USA, and Research Scientist Child Health at TNO, Leiden, The Netherlands.
Mr. Cor Oosterwijk, PhD	Director VSOP, Dutch Patient Alliance for Rare and Genetic Diseases, Soest, The Netherlands, Co-chair Preparing for Life Foundation.
Mr. Ysbrand Poortman	Board Member of the European Forum for Good Clinical Practice (EFGCP), past chair and founder Preparing for Life Foundation, The Netherlands.
Mr. Eric Steegers, MD, PhD	Professor of obstetrics and gynaecology at Erasmus University Medical Centre, Rotterdam, The Netherlands.
Ms. Eva van Steijvoort	PhD Student, Interfaculty Centre for Biomedical Ethics and Law, KU Leuven, Belgium.
Ms. Judith Stephenson, MD, PhD	Margaret Pyke Professor of Sexual & Reproductive Health at UCL and Programme Director for Maternal Health, UCL Partners, London, UK.
Ms. Kyomuhendo Sylvia	Founder & Director at Infants' Health Foundation, Uganda (participating via internet).
Ms. Janneke Verkaik, PhD	Nutrition scientist/epidemiologist, National Institute for Public Health and the Environment (RIVM), Bilthoven, The Netherlands.
Ms. Pauline Verloove, MD, PhD	Emeritus professor of preventive and curative healthcare for children, The Netherlands.
Ms. Salimah Walani, PhD, MPH, RN	Vice President of Global Programs, March of Dimes, Arlington, VA, USA.
Ms. Laura Yates, MD, PhD	President of the European Network of Teratology Information Services (ENTIS), UK Teratology Information Service (UKTIS), Newcastle upon Tyne, UK.