The *Lancet's* Ending Preventable Stillbirths Series New York City Launch 19 January 2016

Report

I. Background of the event



The Ending Preventable Stillbirths (EPS) Series follows on from the *Lancet's* Stillbirths Series launched in 2011. The EPS Series includes five papers covering progress since the 2011 series (paper 1), new rates and risk factor data for over 180 countries (paper 2), an analysis of financial and psychosocial costs of stillbirth (paper 3), a focus on high-income country stillbirths (paper 4), and a new call to action for ending preventable stillbirths by 2030 (paper 5). The Series aims to call attention to stillbirths as a global public health issue affecting 2.6 million families each year that has not yet received the necessary focus at global and country levels. The global launch of the EPS Series was in London at the London School of Hygiene and Tropical Medicine (LSHTM) on 19 January 2016, with simultaneous launches at the Royal College of Obstetricians and Gynecologists (RCOG) in London, as well as in several other cities including Florence, Mexico City, Belo Horizonte (Brazil), Brisbane, Atlanta, and New York City.

II. Introductory speakers

Chris Blake, the CEO of co-host First Candle, welcomed guests.

Dr. Rebecca Cooney, North American editor of The Lancet, described the EPS Series in the context of the *Lancet's* other relevant series that have been or will soon be released, including midwifery, perinatal health, and breastfeeding. She pointed out that despite the 2011 Stillbirths Series' setting of global goals for action on stillbirth, as of 2015 we were still not where we want to be with regard to stillbirth prevention, and reminded the audience that the EPS series not only renews the call to action but also adds a call for action on quality bereavement care.

Nicole Alston, Founder and Executive Director of The Skye Foundation, movingly read a poem she had written describing the impact of her daughter Skye's stillbirth, thus helping to ensure that the real burden of stillbirths was fully felt in the room.

Dr. Robert Silver, Professor of Obstetrics and Gynecology at the University of Utah Health Sciences Center, Chief of the Division of Maternal-Fetal Medicine, and Co-Director of Labor and Delivery,provided a brief summary of the full Series. Since the Lancet's 2011 Stillbirths Series, there has been progress on action to prevent stillbirths, with a key change being creation of a global stillbirth rate target of 12 per 1000 births in every country. Yet much remains to be done. No stillbirth target has been set in the SDGs, only 15 of 67 national health plans mention stillbirths, and despite ODA of \$13 billion in one year, less than \$3 million is targeted for stillbirths over ten years. Also, there has been no progress on removing stigma and taboo associated with stillbirth.

The Lancet's EPS Series was written by >200 authors and investigators from >100 organizations and 43 countries, including 5 papers, 2 research articles in Lancet Global Health, 4 comments, and an Executive

Summary in English and 5 other languages. There are 2.6 million stillbirths a year, of which 98% occur in LMIC. Indeed, 10 countries account for 2/3 of all stillbirths. Half of all stillbirths take place during labor and the risk of stillbirth is 250 times higher in Pakistan and Nigeria than in Scandinavian countries. Most stillbirths are preventable (PAF for 12 potentially modifiable risk factors was shown), e.g. due to maternal infections and non-communicable diseases; just 7.4% are due to congenital anomalies.

Among high-income countries (HIC), the US has the largest number of stillbirths (11,300 in the third trimester alone, putting the US at #25 out of 186 countries ranked) but the lowest annual rate of reduction (0.4% per year as compared to Netherlands at 6.8%, putting the US at number 155 out of 159 countries ranked). These data indicate that further improvement is possible.

Investment in stillbirth prevention has a quadruple return on investment, reducing stillbirths as well as maternal and neonatal deaths, and improving child development outcomes. In LMIC there is a 25-fold return on investment via the economic and social value of surviving children. The costs of stillbirth are borne not just by mothers but also fathers, families, caregivers, and society. At least 4.2 million women are estimated to suffer depression in the aftermath of stillbirth.

The EPS series calls for 5 things to do differently to end preventable stillbirths: intentional leadership development; increasing the voice of women; increasing implementation and investment; improving indicators and metrics; and investigating critical knowledge gaps. The new call to action calls for: 12 stillbirths or fewer per 1000 in every country; setting and meeting equity goals; universal healthcare coverage; respectful care including bereavement support after death; and removal of stigma.

Priority actions for the US include:

- Monitoring and addressing social determinants of maternal and fetal wellbeing (e.g. obesity, smoking);
- Addressing racial disparity;
- Funding and implementing high-quality perinatal audit and scale-up;
- Offering all parents high-quality autopsy and placental histopathology;
- Funding education and training of perinatal pathologists;
- Providing bereavement care training for all care providers;
- Funding research on stillbirth prediction including placental and causal pathways;
- Eliminating stigma and fatalism;
- Revising the federal standard fetal death certificate and addressing obstacles to implementation; and
- Harmonizing state data collection methodologies.

See Attachment for the pdf of the PowerPoint with the full presentation.

III. Panel 1: Global Focus: Opportunities & Lessons to Accelerate Action on Stillbirths Globally

Taona Nana Kuo, Senior Manager of the Every Woman Every Child (EWEC) Health Team in the Executive Office of the UN Secretary-General, observed that the Global Strategy for Women's, Children's, and Adolescents' Health (GS) provides an opportunity for advancement on stillbirth prevention, since it highlights the current rates of stillbirth and the potential for ending preventable

stillbirths through full implementation of the GS. The ongoing process to define the targets and indicators for the GS represents an opportunity to include a measure of stillbirths, which is not currently included in the SDGs, and which would facilitate increased attention toward and resources for stillbirth prevention. She stated that the Sustainable Development Goals (SDGs) as well as the GS are relevant for all countries—so in the context of stillbirth, the SDGs and the GS are relevant not only for the 98% of stillbirths that take place in LMIC, but also for the US, where there are different stillbirth rates (SBR) in different parts of the country. This is because the SDGs and the GS are driven by equity, calling for no mother or baby to be left behind. Nana concluded by stating that in the context of stillbirths, the aim of EWEC is to bring new stakeholders to the table to increase awareness of and resources for stillbirth prevention in the context of the continuum of care.

Joy Riggs-Perla, Director of Saving Newborn Lives (SNL) at Save the Children, described two key lessons learned since the 2011 Stillbirths Series was launched five years ago. First, we can see more clearly the importance of counting stillbirths and getting reliable data. If data is not recorded, then there is no attention paid. While there has been success on stillbirth prevention in some countries, this is largely from countries that have been collecting good data on stillbirths. SNL and LSHTM have done SBR estimates for 195 countries, but there is still a need for better quality data, especially during the intrapartum period when stillbirths are most preventable. Second, when we consider implementation of actions to prevent stillbirths at the country level, we know that high quality antenatal care (ANC) and intrapartum care (IPC) are key. Investment in high-quality care yields a quadruple return on investment, with benefits not only for reduction of stillbirths but also neonatal and maternal deaths, and improvement in child development outcomes—a reflection of the importance of integrated and high-quality care throughout the continuum of women's and children's health care. She concluded by observing that in all regions there are countries progressing more rapidly than others on stillbirth prevention; we need to learn from these and replicate their successes as well as learning from failures.

Dr. Ana Langer, Director of the Women and Health Initiative at the Maternal Health Task Force of the Harvard School of Public Health, and Professor of the Practice of Public Health in the Department of Global Health and Population, spoke about the connection between stillbirths and the maternal health agenda with respect to quality and respectful care. Maternal and baby healthcare are inextricably linked in terms of the biological, medical, and health system perspectives; the maternal mortality rate is a powerful indicator of quality of healthcare within and between countries; this is also true of the SBR and the neonatal mortality rate. High rates of death reflect, among other things, lack of timeliness and quality of care. She observed that we can look at quality of care from two perspectives: (a) technical and (b) personal/respectful. In terms of technical quality of care, when there is no access to care, the risk of stillbirth increases. This is unforgiveable because there are already known effective interventions for stillbirth prevention. Hence, the intrapartum SBR is an indicator for quality of care; and with high quality of care, the SBR will decrease. In terms of respectful quality of care, if this is lacking, low utilization of healthcare may result, causing women to miss lifesaving interventions. Also, bereaved mothers may be blamed for stillbirth. The psychosocial impact of stillbirth must be addressed, and caregivers too need support. Both technical and personal/respectful quality of care can be addressed via integration. Dr. Langer finished by calling for a Lancet series on integration.

Katie Taylor, Deputy Agency Child and Maternal Survival Coordinator and Deputy Assistant Administrator for the Bureau for Global Health at USAID, discussed the benefits of investment in integration of stillbirths within the maternal/child health continuum. USAID sees stillbirth as an integral part of this continuum, with EWEC providing an "umbrella" for programmatic action to reduce stillbirths between now and 2030. USAID agrees with the importance of metrics ("we treasure what we measure

and measure what we treasure"). USAID agrees that integration of actions to prevent stillbirths with other actions on the maternal and child healthcare continuum is vital. For instance, USAID found that the 2013 nutrition series helped facilitate a focus on critical actions for maternal and child survival and was thus key for "Ending preventable child and maternal deaths". When we consider that action to reduce maternal and neonatal mortality leads also to a reduction in stillbirths, we can expect similar positive outcomes from this series. For example, in Zambia, over 2.5 years, the "Saving mothers giving life" program found that the maternal mortality rate in target facilities reduced 53% --and despite no stillbirth focus, stillbirths also reduced by 37%. This was because the risk factors for both maternal mortality and stillbirths are greatly overlapping. It is also key to note that half of stillbirths globally (1.3 million), are intrapartum, which is also the highest-risk time for maternal and neonatal (first day of life) mortality. So if we link quality of care to mothers and newborns and fetuses, then we can have dramatic inroads on ending preventable stillbirths.

Q&A:

- Q: What are the best performers on stillbirth in each region?
 - o A: See Lancet series for data on SBR in each region.
- Q: Have we lost a lot by not getting a stillbirth target in the SDGs?
 - A: A target would help. We are looking now at the reporting framework for the SDGs.
 Measurement is so important and so any stillbirth indicator or target would be useful.

IV. Interim speaker

to work together toward common goals.

Dr. Ed McCabe, Senior Vice President and Chief Medical Officer of the March of Dimes (MOD) Foundation, expressed the MOD's pleasure in supporting the EPS. He noted that there are 2.6 million third-trimester stillbirths, with 10 countries comprising 2/3 of this burden, and much geographic and economic inequity which is mirrored in the prematurity burden. The EPS series offers hope: 1 in 4 stillbirths could be prevented through scaling up interventions that are already shown to be effective. Other necessary actions to enable reaching the 12 stillbirths per 1000 target include: increasing funding for research on causal pathways, focusing on prevention, targeting modifiable risk factors which have the potential to also reduce neonatal deaths and disability, improving data quality and ensuring complete death certificates, and better estimating the economic costs of stillbirth. Dr. McCabe pointed out that the MOD has already focused on provision of bereavement support (e.g. booklet *From Hurt to Healing*). Stillbirth is a neglected global health issue; to accelerate progress on stillbirth prevention and

V. Panel 2: US Focus: Opportunities & Lessons to Accelerate Action on Stillbirths in the U.S.

effectively engage diverse groups. The SDG era began five months ago: we must seize this opportunity

the reduction of stigma and taboo, organizations with related missions must work together and

Dr. Ed McCabe commented on how stillbirths fit into action on prematurity in the US. The MOD is now looking into prematurity in great detail, and setting goals for 2020 and 2030. Their mission is to prevent prematurity and help ensure healthy pregnancies and babies. MOD thinks stillbirth fits into <u>all</u> these efforts: stillbirth is an extension of infant mortality before birth; families suffering stillbirth have the same experience as families suffering infant death, but less support. Barriers to progress include lack of money and low visibility of the issue. Low visibility is due to taboo, because our society looks at stillbirth

differently from death of newborns. Stillbirth represents a "different kind of individual within our society". One thing that is needed is a detailed roadmap for prevention. All of us in this room must act to make stillbirths visible. The EPS series gives us an opportunity.

Dr. Tom Westover, Assistant Professor of Maternal-Fetal Medicine at the Cooper Medical School of Rowan University, Co-chair of the NJ Statewide Perinatal Safety Collaborative of the NJ Hospital Association, and Vice-Chair of the NJ American Congress of Obstetricians and Gynecologists (ACOG), discussed roadblocks to action for stillbirth prevention in the U.S. ACOG provides guidance to practitioners but can only encourage implementation. Three documents that provide guidance are: (a) U.S. Federal standard for fetal death certificates. This was last issued in 2003, but it took 10 years for all 50 states to implement; (b) ACOG document on management of stillbirth; the main performance metric is the percent of stillbirths for which placental pathology is performed and autopsy is offered; and (c) the antepartum fetal surveillance practice bulletin. Dr. Westover concluded by calling for better evidence on how we can reduce the incidence of stillbirth.

Debbie Haine Vijayvergiya, Founding Member of The ASAP Coalition and Founder of The 2 Degrees Foundation, discussed opportunities for accelerating progress on stillbirth prevention in the United States. She spoke of the need to enhance stillbirth surveillance, improve data collection, and create a greater sense of urgency around the unmet needs for stillbirth prevention in order to not only raise our social conscience on the topic but also help generate increased funding for research. She agreed with Dr. McCabe that there is now an opportunity for collaboration among key groups to accelerate progress on stillbirth prevention. She called for the following actions over the next 12 months: establish a U.S. Perinatal Task Force; key organizations to meet to identify gaps and create a plan of action; identify sponsors for a campaign to build national awareness; establish safe conversations around stillbirth in order to remove the taboo; and increase bereavement support in hospitals. She said that stillbirth is one of the most shamefully neglected areas of public health.

Q&A:

- Q: What could be done to improve support for affected families and health care providers?
 - A: Collaboration. Too often a series is launched but nothing happens afterward; we must avoid this. There is regulatory inertia at the top; we need decision-makers to commit to action.
- Q: Are any common causes found for stillbirth as a result of autopsies?
 - A: Autopsy often happens when there is already a likelihood of a congenital anomaly.
 However, often we find things we did not expect. It is also possible to learn about possible causes without doing an invasive autopsy.
- Q: A retrospective study of 400 sleep-related deaths in NYC found a significant association between adverse birth outcomes and subsequent sleep-related deaths, which is why autopsy is so key.
 - A: There are multiple reasons for lack of autopsy. We now can do MRIs in case parents do
 not want to do an invasive autopsy. The state of New Jersey (NJ) mandates autopsy
 following infant death but not following stillbirth. Perinatal pathologists in NJ can do
 placental evaluations which are covered by insurance whereas autopsy is not.
- Q: The Skye Foundation has produced a film on African-American women's losses; thanks to Debbie Haine Vijayvergiya for passing legislation (the Autumn Joy Stillbirth Research and Dignity Act) in NJ.

VI. Final speakers

Dr. Rama Lakshminarayanan, Senior Health Specialist, HNP Global Practice, World Bank, emphasized that no one person or organization can achieve the agenda laid out in the EPS series to end preventable stillbirths. It is imperative that we all collaborate and build on our collective comparative advantages. The size of the problem is significant and has multiple dimensions, including inequity, low quality of care, and heavy psychosocial and economic costs; there is a need for a focused research and measurement agenda. "Grand convergence" is the promise of the SDGs and GS. The EPS series maps out 5 key areas of action to improve outcomes for stillbirth, maternal and neonatal mortality, and child development, including the need to amplify women's voices, which relates to the SDGs on empowerment, and the need for integration and financing, which is related to the Global Financing Facility (GFF) in support of EWEC—investing in preventing stillbirths meets the criterion of smart financing (evidence-based, high-impact, cost-effective), and financing for this critical area that provides a quadruple return on investment should be scaled up and made sustainable. Dr. Lakshminarayanan explained that the H4+¹ is repositioning itself as the H6 for stronger coordination at country and global levels, and reaffirms its commitment to supporting countries in women's, children's and adolescents' health.

Betsy McCallon, Executive Director of the White Ribbon Alliance, closed the event by stating that parent and civil society action and demand is what will make the difference. She reiterated the new EPS call to action and asked all present to please sign on at the WRA website:

- intentional leadership at all levels;
- increased voice and culturally appropriate protocols after death;
- implementation of integrated interventions, especially support for midwives (who were absent today) and caregivers;
- need for indicators to measure stillbirth; and
- clarification of knowledge gaps for both prevention and bereavement.

VII. Next steps for action in the US

Following on from the NYC launch, next steps for action in the US to prevent stillbirths and improve post-stillbirth support include those presented by Dr Silver (see above).

Below is a table with the EPS call to action and in the second column, questions we might pursue to figure out how it might be "translated" into a US-specific call to action.

Global call to action	Ending preventable stillbirths in the US (EPS-US)	
Mortality targets by 2030	Mortality targets by 2030	
• 12 stillbirths or fewer per 1000 total births	National target achieved	
in every country		

¹ "The H4+ is a joint effort by the United Nations Population Fund (UNFPA), the United Nations Children's Fund (UNICEF), the United Nations Programme on HIV/AIDS (UNAIDS), the World Health Organization (WHO), the World Bank, and UN Women with the aim to improve the health of women and children by reducing maternal and newborn mortality. These organisations assist in accelerating the implementation of commitments already made to the United Nations Secretary-General" https://wcaro.unfpa.org/public/cache/offonce/pid/14727;jsessionid=860CC18DB0E2B2C16C838FD448B 4C659.jahia01

•	All countries set and meet targets to close equity gaps and use data to track and prevent stillbirths	•	What are sources of national SBR data? What are the gaps in data? Quality and timeliness of the data? What should EPS-US stakeholders call for? What equity SBR target should EPS-US call for? What data do we need in order to set and meet target(s)? (How) could this be made an official target?	
Universal health care coverage targets			Universal health care coverage targets	
•	Family planning: by 2020, 120 million more women and girls with access to contraceptives; by 2030, universal access to sexual and reproductive health-care services and integration of reproductive health into national strategies and programs	•	What is the status of access to sexual and reproductive healthcare in the US? To what extent is it responsible for inequity in SBR? Based on this information, what changes should EPS-US stakeholders call for?	
•	Antenatal care: by 2030, universal quality of care and comprehensive antenatal care (ANC) for all women	•	What is the status of quality of and access to ANC for all women in the US? To what extent is it responsible for (inequity in) SBR? Based on this information, what changes should EPS-US stakeholders call for?	
•	Care during labor and birth: by 2030, effective and respectful intrapartum care (IP care) to all women in all countries	•	What is the status of effective, respectful IP care in the US? Based on this information, what changes should EPS-US stakeholders call for?	
Mil	lestones	Milestones		
•	Every Newborn global and national milestones met by 2020, including the Measurement Improvement Roadmap	• •	Global milestones not relevant for the US National milestones: see below*	
•	Respectful care, including bereavement support after a death: by 2020, global consensus on a package of care after a death in pregnancy or childbirth for the affected family, community, and caregivers in all settings	•	What would a US contribution to such a consensus look like? What would the nature of US involvement in such a consensus statement be?	
•	Reduce stigma: by 2020, all countries to identify mechanisms to reduce stigma associated with stillbirth among all stakeholders, particularly health workers and communities	•	What are the first steps toward achieving this goal in the US?	

*National milestones by 2020 (from the ENAP, http://www.everynewborn.org/Documents/Full-action-plan-EN.pdf, page 43)

<u>National plans</u>: Review and sharpen national strategies, policies, and guidelines for RMNCAH
(reproductive, maternal, newborn, child and adolescent health) in line with the goals, targets, and
indicators in Every Newborn action plan, including clear focus on care around the time of birth and
small or sick newborn care.

- <u>Data</u>: Count every newborn by improving and using programmatic coverage data and equity, quality gap assessments. Institutionalise civil registration and vital statistics, adapt and use a minimum perinatal dataset, implement maternal/perinatal death surveillance and response.
- Quality: Adopt Every Mother Every Newborn Quality Initiative standards of quality and indicators for assessing quality of maternal/newborn care at all levels of health system; and ensure access to essential commodities for RMNCAH.
- <u>Investment</u>: Develop or integrate cost of human resources for health strategy into RMNCAH plans, ensure sufficient financial resources are allocated.
- <u>Health workers</u>: Ensure the training, deployment, and support of health workers, in particular midwifery personnel, nurses, and community health workers.
- <u>Innovation and research</u>: Develop, adapt, and promote access to devices and commodities to
 improve care for mothers and newborn babies around the time of birth; and agree on, disseminate,
 and invest in a prioritized and coordinated research agenda for improving preterm and newborn
 health outcomes. Particular focus is needed for stillbirths, who have been left out and left behind.
- <u>Engagement</u>: Involve communities, civil society representatives, and other stakeholders to harness the power of individuals, families, and communities ensuring access and coverage of essential maternal and newborn care.
- <u>Parent voices, champions</u>: Shift social norms so that it is no longer acceptable for babies to die needlessly, just as it has become unacceptable for women to die giving birth.

Annex 1: Organizations represented

46 people registered to attend the NYC launch, representing the following organizations (including speakers):

- Government-see Bilaterals below (otherwise none)
- Multilaterals
 - Global Health Alliance
 - o EWEC
 - UNICEF
 - o UNFPA
 - H4+/World Bank Group
- Bilaterals
 - o USAID
- Non-profit/civil society—excluding parent organizations
 - o SICD (Sudden Infant and Child Death) Resource Center of Public Health Solutions
 - o GAPPS
 - o White Ribbon Alliance
 - o ISA
 - First Candle
 - Save the Children
 - World Youth Parliament
 - March of Dimes
- Non-profit/civil society—Parent organizations
 - o The 2 Degrees Foundation Fund
 - o The Action for Stillbirth Awareness and Prevention Coalition (ASAP)
 - o Knot My Baby, Inc.
 - Reconceiving Loss
 - The Skye Foundation
 - Kelly Ryan Foundation
- Research and universities
 - o NYU
 - Cooper Medical School of Rowan University
 - o Rutgers New-Jersey Medical School
 - Harvard School of Public Health
 - o Southern Hospital affiliated with Southern Medical University (China)
 - MHTF of Harvard
- Media
 - The Lancet
- Private sector
 - o Rabin Martin
 - ES Art & Culture Consulting Group
- Unaffiliated individuals

Annex 2: Examples of US and other HIC national stillbirth reports

- US: Fetal and Perinatal Mortality: United States, 2013 (by the Division of Vital Statistics) http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64 08.pdf
- Canada: Perinatal Health Indicators for Canada 2013: A Report from the Canadian Perinatal Health Surveillance System (by the Public Health Agency of Canada) http://publications.gc.ca/collections/collection 2015/aspc-phac/HP7-1-2013-2-eng.pdf
- New Zealand: Ninth Annual Report of the Perinatal and Maternal Mortality Review Committee (by the Health Quality and Safety Commission New Zealand)
 https://www.hqsc.govt.nz/assets/PMMRC/Publications/Ninth-PMMRC-report-FINAL-Jun-2015.pdf
- **Australia**: Stillbirths in Australia 1991-2009 (by the Australian Institute of Health and Welfare) http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548877

Annex 3: EPS-US 2030 task force

	Proposed member of EPS US	To be kept informed only
Saving Newborn Lives/Save the		Joy Riggs-Perla
Children		
The ASAP Coalition	Debbie Haine Vijayvergiya	
March of Dimes	Chris Howson	Ed McCabe
Maternal Health Task Force		Ana Langer
The Skye Foundation	Nicole Alston	
EWEC		Nana Kuo
USAID		Katie Taylor
White Ribbon Alliance		
International Stillbirth Alliance	Susannah Hopkins Leisher	
ACOG	Dr Tom Westover	
First Candle	Chris Blake	
Others to be added		

The task force will convene as a group of interested parties to create a matrix of work that is going on in the US and list and prioritize next steps to ensure clarity, consistency & collaboration between the many different groups & activities as well as ensuring progress on reducing stillbirths and improving bereavement care after stillbirth in the US.

Attachment: pdf of Lancet EPS Series powerpoint