Proposal to WHO for a Stillbirth Parent Voices Initiative

Submitted by **24 March 2020** to **Pmnch-rfp@who.int**

Bid Ref: 2020/UHL/NMC/010

Part 1: Presentation of Institution

duly completed and signed by a person or persons duly authorized to represent the bidder, to submit a proposal and to bind the bidder to the terms of this RFP

Company Information to be provided by the Vendor submitting the proposal	
UNGM Vendor ID Number: n/a	
Legal Company Name: International Stillbirth Alliance (ISA)	
Company Contact: Susannah Hopkins Leisher, Board Chair	
Address: P.O. Box 14	
City: Millburn	**State**: NJ
Country: USA	**Zip:** 07041
Telephone Number: 1-973-379-4847	**Fax Number:** 1-973-379-4847
Email Address: shleisher@aol.com	**Company Website:** https://www.stillbirthalliance.org/
Corporate information: The International Stillbirth Alliance is a non-profit corporation registered in the US.	
Company mission statement: To raise awareness of stillbirth globally and to promote global collaboration in the prevention of stillbirth and provision of appropriate care for parents and other family members whose baby is stillborn	
Service commitment to customers and measurements used: Our aim is to reduce the risk of stillbirth and to enhance bereavement care of families who experience stillbirth through public awareness initiatives, community and family engagement, development and promotion of best clinical practice standards and facilitating high quality collaborative research.	
Organization structure: The ISA includes three working groups, one of which, the Stillbirth Advocacy Working Group (SAWG), is co-chaired by Susannah Leisher (ISA board chair) and Hannah Blencowe of the London School of Hygiene and Tropical Medicine, and was founded by PMNCH in 2016. The SAWG will be the ISA entity primarily involved in the implementation of the proposed projects, through an Advisory Group described below.	
Relevant experience: The ISA, and SAWG specifically, are ideally placed to respond to this RFP. Stillbirth has been a largely neglected issue to date in global public health, and ISA is currently the only international organization with the required specific expertise to address this gap at the global level. We are unique in that we bring together member organizations, bereaved family members, clinicians, researchers and policy makers, with nearly 100 members from dozens of countries on every continent. With this broad range of stakeholders, we discuss issues related to stillbirth and develop and implement strategies to advocate for reduced risk and provision of bereavement care to affected families. Founded in 2003, we have held 15 annual stillbirth-focused international conferences in Africa, Asia, North and South America, Australia, and Europe; played leading roles in key stillbirth-related research on prevention and bereavement support, including leadership on the two Lancet series on stillbirths (2011, 2016); and have served as the co-chair of the SAWG since 2016. Work undertaken by the SAWG has included developing and launching a Global Stillbirth Scorecard (see attached), annual policy analyses tracking mentions of stillbirths, monthly blog contributions on stillbirths to the Healthy Newborn Network, advocacy efforts to secure the stillbirth rate as a priority indicator for global health tracking, and regular and active participation at global RMNCAH events, including PMNCH's accountability breakfasts at UNGA, to ensure inclusion of stillbirths. We have extensive experience and expertise within our network which can be mobilized quickly to support the implementation of this proposal.	
Staffing information: ISA is led by a 12-member Board of Directors including the Chair, Susannah Hopkins Leisher of Columbia University, the Vice-Chair, Dr. Vicki Flenady of the University of Queensland's Stillbirth Centre for Research Excellence (based in Australia), the Secretary, Dr. Paula Quigley of DAI Global Health (based in Jordan), the Treasurer, Dr. Margaret Murphy of University College Cork (based in Ireland), and eight other members based in Georgia, the U.S., Australia, Canada, the UK, and the Netherlands, and including expertise in	

midwifery, obstetrics, nursing, bereavement care, epidemiology, patient/parent and community-based leadership, neonatology, general medicine, and psychology. All board members have either research and/or clinical or other work expertise in stillbirth prevention and bereavement support in low- and high-income settings, and several are bereaved parents themselves. ISA has no paid staff and is thus entirely volunteer-run.

Part 2: Technical proposal

Purpose

The objective of this initiative is to raise the voice and participation of parents bereaved by stillbirth to strengthen advocacy for stillbirth prevention and post-stillbirth bereavement support. The key purpose of this bid is twofold: 1) the development of a parent support organization registry; and 2) the development and testing of an advocacy toolkit on stillbirth advocacy. These tasks will be completed in full collaboration with the Coordinator and Executive Director of the PMNCH Secretariat.

Background

The Partnership for Maternal, Newborn & Child Health (PMNCH) is the world's largest alliance for women's, children's and adolescents' health (WCAH), combining over 1,100 partner organizations from 10 diverse constituencies across 192 countries. The work of PMNCH and its members is guided by the UN Secretary General's Global Strategy for Women's, Children's and Adolescents' Health 2016 to 2030 (The Global Strategy). Since its inception, PMNCH has been working on strengthening partnerships and driving momentum towards the attainment of global targets for WCAH and has successfully kept WCAH at the heart of the global political agenda and the Sustainable Development Goals. PMNCH is supported by a small Secretariat based in Geneva, which is hosted by the World Health Organization (WHO).

Absent from the Millennium Development Goals and still missing in the Sustainable Development Goals, stillbirths remain a neglected issue, invisible in policies and programs, underfinanced and in urgent need of attention. PMNCH has identified this area as an important component of the work in 2020.
Parent voices have been largely absent from global stillbirth-related advocacy, highlighting the need for the development of an advocacy training toolkit to raise parent voices for stillbirth prevention and support. In addition, there is no single global registry of parent support organizations for stillbirths. Therefore, there is a need to gather and consolidate this information, country by country, and make it available for parents to join stillbirth advocacy efforts. It is impossible to raise voices if we do not know who is out there. The registry will also be an ongoing source of connection for parents and others all over the world.

Proposed solution and approach/methodology

1. Finding Parent Voices: Parent Registry Project

- **Deliverables**:
    - List of parent support organizations hosted on ISA website (with dropdown tabs for each region, and basic contact info on each organization or contact, links).
    - Analysis of brief online survey results with basic information from each parent support organization, including their needs related to advocacy.
- **Approach**:
    - **Phase 1: Develop tools (April-May)**
        - Project managers with support from Advisory Group to recruit Registry consultant.

    - **PARENT SUPPORT ORGANIZATION DEFINITION**: In view of the fact that there are no formal parent support organizations in many high-burden settings, keeping in view the ultimate objective to raise parent voices, and acknowledging the need we believe exists for such organizations, we use the term "parent support organization" to include both formal parent support organizations, including those which may not have been founded by parents or are not led by parents but which exist in part to provide bereavement support to parents, as well as informal groups of bereaved parents interested in parent support; we also include parent support point persons, meaning individuals in countries with no formal or informal parent support organizations, who may not be bereaved themselves, but through their professional work e.g. as midwives may be able to help facilitate informal or formal establishment of parent support organizations.
    - Methodology design will be led by Registry consultant with support from Senior Advisor and Advisory Group, and will entail (a) more specifically defining the types of organizations and individuals we seek to identify; (b) listing regions and countries to be searched in order of priority; (c) deciding what information to gather on each organization, which must include all required permissions related to gathering, retention, display and release of information. Organization-related information will include both quantitative data which will mainly be accessed from organizational websites where available, and qualitative data related to organizational history, aims and a brief needs analysis which would be accessed by a method such as a survey (using Survey Monkey or a direct email questionnaire) and potentially with some additional follow-up direct interviews if needed by skype or phone; (d) drafting the data gathering tool(s); (e) designing a search strategy; (f) piloting search strategy and data gathering tool; (g) refining and finalizing search strategy and data gathering tool.
    - Apply for ethics permission from LSHTM to enable publication of project results
    - Registry Consultant will test search strategy and data gathering tools in 2-4 countries and refine as needed
  - **Phase 2: Collect and analyze data (June-September)**
    - Registry Consultant will gather data on parent support organizations, beginning with South Asia and Sub-Saharan Africa, then other high-burden countries and regions. Process will be flexible and iterative. As organizations are identified, they will also be asked about other organizations they know of which can be contacted.
    - Data gathering including survey and/or interviews will be with parent support organizations as defined above.
  - **Phase 3: Disseminate findings (October-November)**
    - Registry Consultant will work with August99 (https://www.august99.com/), which currently provides IT support for ISA, to develop, pilot, and finalize template for online registry, to be hosted on ISA website. Only organizations agreeing to it will have their data included in the registry (this is part of the data gathering process).
    - Registry Consultant will export all data to online template (updating of registry is not included in this project)
    - Registry Consultant will write report summarizing (a) process, (b) quantitative data (eg numbers of parent organizations, sizes, staffing, budgets etc), and (c)

        qualitative data, analyzed using a method such as thematic analysis, summarizing felt needs of parent organizations from qualitative analysis. Report will feed into the advocacy toolkit, providing guidance on the needs of parent organizations.
        - Registry Consultant will create summary ‘overview’ infographics of the report for use in advocacy.
        - Registry Consultant will provide list of potential and interested organizations for PMNCH to consider inviting as members to their CSO constituency group, in order to expand parent voice representation in their network.
    - **Post-project:**
        - Draft paper for publication (to occur after November)
- **Staffing**:
    - A Registry Consultant will be recruited to complete all work remotely.

2. Raising Parent Voices: Advocacy Toolkit Project

- **Deliverables:**
    - Brief, simple advocacy training toolkit for stillbirth parent support organizations in high-burden settings to introduce the concept and aims of advocacy related to stillbirth, learn about how to raise their voices and help to ensure their views and needs are heard within their country's health goal-setting agendas. The toolkit will also include basic guidance on how to set up a parent support organization, particularly focused on meeting the need for new groups in high-burden settings. It will be hosted on the ISA website.
    - Workshops in two high-burden settings (India and one African country) to review and revise the toolkit.
- **Approach**:
    - **Phase 1: Preparation and development of skeleton toolkit (April-May)**
        - Senior advisor to finalize selection of 2 parent support organizations, one each in India and one African country, that are interested in and able to engage with the work in the required timeframe. In view of timeframe, first consideration will be given to organizations with current links to SAWG which include groups in Ghana, Uganda and Kenya.
        - Project managers with support from Advisory Group to recruit Advocacy consultant and two in-country consultants (1 each in India and Africa).
        - Advocacy consultant to gather all relevant existing advocacy toolkits such as from UNICEF, Save the Children, EFCNI and White Ribbon Alliance, by mapping all NGO, multilateral (UN) and bilateral organizations working in the maternal, newborn, and reproductive health space, and then identify any toolkits on maternal, newborn and child health issues that they have; s/he will also ask key informants (including the Advisory Group) for suggestions. To the extent possible, s/he will link to and build on other tools developed by parent groups to support the development of new groups in high-burden settings (for instance, EFCNI has some tools/trainings).
        - In consultation with senior advisor and 2 local consultants (one in each country), advocacy consultant to draft skeleton toolkit.
        - Finalize plans for in-country work, retaining flexibility in how we would reach out to informal parent groups where no formal organization may yet exist.

- **Phase 2: In-country review, testing and adaptation of toolkit through workshops and parent organization SMART objectives (June-September)**
  - In each country: Local consultant, in consultation with senior advisor and advocacy consultant, will
    - **Adapt skeleton toolkit for in-country use**: (a) review background materials (including related to the parent organization and country-specific stillbirth-related health policy reports, data, and other information) and meet virtually with the project team, (b) design key informant interview guides to assess advocacy-related needs and status of the parent support organization, (c) plan and schedule all further in-country work in close consultation with parent support organization representatives and Senior Advisor, (d) carry out 4-6 key informant interviews (remotely if feasible and necessary due to the Covid-19 pandemic), including key individuals within the parent organization, as well as potential allies/advocates/champions for stillbirths such as nurses, midwives, and obstetricians, (e) adapt toolkit based on skeleton toolkit created by advocacy consultant
    - **Present toolkit and get initial feedback (Workshop A)**: (a) plan one-day workshop A with key representatives of the parent organization (mostly bereaved parents) and other identified key stakeholders, including midwives and policy makers, aiming to present overview of stillbirth advocacy in global and local contexts, present and get feedback on draft toolkit, and identify a single SMART advocacy objective to be attempted within the timeframe, (b) facilitate workshop, (c) revise toolkit and provide to parent support organization for their use in attempting SMART objective
    - **Test and revise toolkit (Workshop B)**: (a) plan ½ day workshop B to take place after SMART advocacy objective is accomplished, to discuss experiences and get feedback and guidance on toolkit, approximately 2-3 months after Workshop A, (b) facilitate workshop, (c) revise toolkit
  - **Senior advisor** will travel to both locations to meet with local consultant and attend workshop A in one location and workshop B in the other location, with remote participation from other team and Advisory Group members (one of these may step in if Senior Advisor cannot travel to both locations), and remote participation at workshops she cannot attend physically, to review, advise on and ensure appropriate and full integration of bereaved parents into the work at every step.
  - **Workshops:** The workshops are for bereaved parents. Workshop participants will be primarily bereaved parents, as it is for their voices and needs that the toolkit is being developed. Their review and input are the ultimate purpose of the workshops. We will also include other key stakeholders, especially including midwives, who can help to provide guidance, insight and suggestions on advocacy for stillbirth, raising parent voices, and parent organization establishment in the particular country context. The majority of workshop participants will be local, and the workshop setting should be intimate, informal, and comfortable, yet neutral. It should have the feel of a safe and comfortable meeting among friends, rather than a formal high-level workshop. The very act of parents meeting together with each other, and with other stillbirth

        stakeholders such as midwives and policy makers, may itself constitute the raising of parent voices and advocacy. This must be borne in mind when creating and revising the toolkit.
    - **SMART objectives:** In Workshop A, parents together with other stakeholders and led by in-country consultant will identify one SMART objective they can attempt, with the help of the draft toolkit, as a way of testing the utility of the toolkit. This could be a blog post they write together and post on a suitable platform; requesting a meeting with a regional health ministry official; being interviewed by a local newspaper or radio station; beginning registration as a formal organization; announcing meetings of their informal group; etc. In Workshop B, the parents will discuss their experience with the SMART objective and provide feedback to the in-country consultant and Senior Advisor. Did they succeed/fail/change their minds? Did the toolkit help or not? How could the toolkit be revised to better help support them in their SMART parent voice aims going forward?
  - **Phase 3: Finalization of toolkit (August-November to overlap with in-country work)**
    - **Finalization of in-country toolkits**: Advocacy consultant to assist local consultants with drafting and revision of adapted in-country toolkits after workshop B. At least one parent from each location should review and provide feedback during this final stage (after Workshop B).
      - Feedback from all workshop participants will be solicited on their experiences being involved with this project and recommendations for next steps
    - **Finalization of generic toolkit**: Advocacy consultant to consolidate into a single generic toolkit along with basic guidelines for adapting it to a particular country context (e.g. high-income versus low-income) and different settings (e.g. high-burden versus low-burden, urban versus rural) after conclusion of workshop B in each country. The toolkit will also include information on how to set up a parent group. Senior advisor to support Advocacy consultant in this task with input from Advisory Group members, PMNCH leadership and other key stakeholders.
  - **Phase 4: Dissemination of toolkit**
    - Toolkit to be disseminated widely and, with support from August99, posted accessibly on the ISA website and through the PMNCH network
    - Additional funds will be sought to test the toolkit in other settings.
- **Staffing**:
  - Project team will include project managers (volunteer), senior advisor, advocacy consultant, two local consultants, and the Advisory Group (volunteer).

Basic principles:

- **Parent voice:** The reason for these projects is the need to ensure that parents bereaved by stillbirth have their voices, experiences, and needs heard at all levels within policy-setting processes. While this will be challenging in settings where there are no formal parent organizations, making a leading role for non-parents essential, it is imperative that our work be informed and guided by parent experiences and voices as much as possible; this is the rationale for the Senior Advisor role on our projects
- **Country context:** We recognize country contexts are very different for bereaved parents as well as health policy processes and other relevant factors. The generic toolkit will include common

components drawn from two very different datapoints, India and one African country, and will include guidance on how to tailor for other contexts. Anticipating that also there are major differences between rural and urban contexts, we will start with a focus on urban areas.

- **Responsible, respectful contact:** Care will be taken to support the emotional wellbeing of the bereaved parents we approach. This will be also the particular role of the Senior Advisor together with in-country consultants.

Team

- Advisory Group (all volunteer)
  - Project managers will manage the project and lead the Advisory Group together:
    - Susannah Hopkins Leisher: epidemiologist, bereaved parent, International Stillbirth Alliance board chair, SAWG co-chair, member of ENAP management team, honorary research fellow and member of coordinating team for Stillbirth Centre of Research Excellence at Mater Research Institute, University of Queensland, doctoral student at Columbia University; expertise working with marginalized groups in South/Southeast Asia, sub-Saharan Africa, and other low-income settings
    - Dr Hannah Blencowe: clinical perinatal epidemiologist, Assistant Professor in Global Maternal Newborn Health at London School of Hygiene and Tropical Medicine, SAWG co-chair, Member of UN-IGME core stillbirth estimation group
  - Members: The following are all SAWG members who bring individual expertise in key relevant fields and will assist the project managers by reviewing project documents and plans, providing feedback and advice, helping with in-country planning, and other backstopping:
    - Dr Paula Quigley: based in Jordan/Germany, medical doctor and public health specialist, secretary of the International Stillbirth Alliance board, technical lead for reproductive, maternal, newborn, child and adolescent health & nutrition for DAI Global Health
    - Mary Kinney: works for Save the Children and has provided technical support primarily to country teams in Ethiopia, Malawi, Nigeria and Uganda. Some of her recent global activities include the Every Newborn Action Plan, The Lancet Ending preventable stillbirth series, The Lancet Every newborn series, and Born Too Soon: The Global Action Report for Preterm Births. She is based in South Africa.
    - Sue Steen RN: nurse, extensive expertise in bereavement support and training, field experience in Uganda, based in the US
    - Dr Neelam Aggarwal: obstetrician, has been the pioneer nodal person from WHO SEARO for starting facility-based stillbirth surveillance in India since 2011 and rolling it out since 2014, conducted trainings in Nepal, Myanmar & Maldives, contributed to WHO stillbirth surveillance guidelines for SEAR. Started a WhatsApp group for bereaved mothers in 2019 and is currently validating the tool; based in India.
    - Dr Rakhi Dandona: public health specialist, Professor in Public Health at the Public Health Foundation of India, New Delhi, and Professor of Health Metrics Sciences at IHME, University of Washington, Seattle, based in India.
    - Dr Linda Vanotoo: trained Medical Officer with certificates in applied epidemiology, Master of Tropical Paediatrics and PhD in Public Health, trained

    bereavement care provider and promoter of innovative ways to improve pregnancy outcomes. Founder of PROMISE Initiative Ghana (for promotion of survival of pregnant women and newborns) and the Hope Restoration Center to provide care to bereaved families; based in Ghana.
    - Dr Sara Nam: Midwife, epidemiologist, Technical Specialist in reproductive and sexual health for Options; providing support to MNH and SRH programmes in Africa and Asia,;member of the UN Global MPDSR TWG.
    - Trish Doherty: technical specialist at Options providing technical assistance to RMNCAH and health systems strengthening programmes across Africa and Asia. Background in research and M&E for behaviour change communication and media development.
- Consultants:
  - Senior advisor: Claire Storey: lead for parent voice in SAWG, ISA board member, based in the UK; extensive experience with parent support organizations and bereavement support.
  - Registry consultant: TBD
  - Advocacy consultant: TBD
  - Local consultants: TBD (1 each in India, Africa), who have strong knowledge of public health and especially stillbirths within the specified country, as well as public health policy, and preferably with knowledge of parent organizations. Both must be fluent in English as well as local languages. Must be able to work respectfully with bereaved parents and listen more than they talk.

Planned timeline

The work is planned to be undertaken from April 2020 to November 2020. See Technical proposal for details. Please note that due to the Covid-19 pandemic, work on Phases 2-4 of the Advocacy Toolkit depending on face-to-face contact may need to be postponed if restrictions on travel and social interactions are still in place.

Part 3: Financial proposal

Design, layout and dissemination costs will be provided as voluntary support from members of the technical department at Options Consultancy Services Ltd as part of participation in the Advisory Group, including:

- Review and design input on the parent organization registry: feedback on how this appears and operates on the website from a user-based perspective, including layout, color scheme and functionality. Oct-Nov.
- Report on the registry: provide a template, including front cover and a few graphics if needed. Oct-Nov.
- Advocacy toolkit: provide a template that will have some brand consistency with the registry and can be easily adapted to India and African location. Initial design in May and finalization in Nov.

Total requested: **US$38,873**.