

From: Prof. Khosrow Adeli – IFCC President
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Ref: New IFCC Taskforce on Global Newborn Screening

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**To: IFCC National Representatives, Regional Federations
Corporate Members**

Dear all,

Newborn screening (NBS) significantly reduces infant morbidity and mortality by initiating early detection, treatment, and management of newborns with congenital disorders. In 2015, it was estimated that **only one third of infants around the world receive screening at birth**. In alignment with the IFCC's strategic plans for 2020-2023, to directly impact healthcare and patient outcomes in developing countries, the IFCC Taskforce on Global Newborn Screening will establish a Global Newborn Screening Initiative to address this critical gap. As part of this initiative, the **IFCC will initiate NBS Pilot Projects in select developing countries** (i.e. Partner Countries). Emphasis will be placed on scientific and technical support for the development of laboratory policies and procedures, training of staff, as well as equipment required for NBS implementation.

IFCC Taskforce on Global Newborn Screening: Scope & Mandate

- Select countries for IFCC's NBS Pilot Project via a call for participation to IFCC member societies using pre-defined selection criteria. A formal call for participation by developing countries will be issued soon by the IFCC office.
- Identify potential participating centres (e.g. healthcare facilities and laboratories) and stakeholders (e.g. government ministries and/or agencies) within each Partner Country.
- Engage with these centres in order to conduct situation assessment (i.e. information in regard to NBS-related diseases as well as resources/barriers in the Partner Country).
- Identify ways in which the IFCC can provide lacking resources and support.
- Develop a detailed protocol for an initial Pilot Project specific to each Partner Country. The proposal will be presented to the Partner Country via the respective IFCC member society. The Pilot Project implementation must be conditional on the Partner Country's commitment to its continuation following IFCC's initial financial support.
- Implement the Pilot Project in participating centres in each Partner Country in collaboration with the IFCC member society and other stakeholders.
- Monitor and evaluate the progress of the overall IFCC NBS Initiative, as well as the progress of specific Pilot Projects, through data collection and on-site/virtual visits by dispatching scientific teams to each Partner Country.
- Plan for the expansion of the IFCC's NBS Initiative, as well as the expansion of each NBS Pilot Project.

Membership: The Taskforce will consist of at least a chair and 4 full members. Corporate representatives from interested companies can also be members. Members will provide expertise, plan for the development of the program and direct the scientific teams for on-site visits and training. Term of office: 3 years with the possibility of renewal for a second term.

Meeting Arrangements: 1-2 in person meetings per year, where possible, and monthly virtual meetings via Zoom. Meeting frequency can increase when appropriate.

Reporting: The Taskforce will report to the IFCC Executive Board quarterly with a document summarizing progress made within that quarter.

IFCC National Societies and corporate members are invited to nominate experts in the field of NBS to join this important Taskforce.

Please send the following information to Paola Bramati at the IFCC office by **October 30, 2020**:
(paola.bramati@ifcc.org)

- A formal letter explaining the nominee's interest in the position and the contribution that we can expect from the candidate,
- Any proposals or ideas for topics the Taskforce should address
- A short CV.

Taskforce members will be selected from nominations received from national societies and corporate members; however, **expertise in NBS as demonstrated by high quality publications in the field is the most important criterion for selection of Taskforce members**. In addition to those selected from nominations received by membership societies, the IFCC may select some Taskforce members from key experts in the field of NBS from around the world. Candidates or nominees that have not been selected can apply to become corresponding members of the Taskforce.

We look forward to nominations from national societies around the world and I am convinced that this new Taskforce will successfully strengthen the IFCC's mission towards better healthcare worldwide.

With kind regards,



Prof. Khosrow Adeli
IFCC President