

Advancement Committee Report NFI Board Meeting NFI Membership Meeting Edmonton, AB, Canada – October 20, 22, 2017

Committee: J. Helm, Chair, J. Alberts, D. Buehler, S. Butler, R. Cummings, M. Daily, S. Kosta, G. McAnulty

The committee has scheduled phone meetings once or twice a month. The focus of work has been directed to development/fundraising activities and public awareness/collaborative activities.

Development/ Fundraising

Sponsors

Early emphasis was to secure and continue with current sponsors: Handi-Craft, Inc., Dr Brown's Medical and Sonicu. Both have renewed. Dr Brown's renewed their Bronze level of support for another year (Feb 1, 2017-Jan 31, 2018). Sonicu negotiated a special agreement. It is based on the Bronze level but is incremental. It was also moved to a calendar year timeline. Sonicu paid a fixed sum of support and have contributed thereafter according to their ability to exhibit at NFI events and will pay.

Work continues slowly to identify potential sponsorships from other companies or corporations.

Conferences

Advancement Committee continues to support Program activities that raise funds and increase public awareness of the NIDCAP approach. This included four 1-day conference held in New York City, NY on April 7 with presenters Jim Helm, gretchen Lawhon, Erin Ross and then in September in Seattle, Oakland, and Los Angeles with J Helm, g Lawhon, Dorothy Vittner and Kathi Frankel. Each contributed their time and services for the event that raised over \$15,000 for the NFI. Sandra Kosta, Ayn Cavicchi and Karen Helm supported this effort as well. Besides Dr Browns, Philips/Children's Medical Ventures also exhibited at the NYC conference and Dandle-LION exhibited at all three west coast venues.

Public Relations and Collaborations

Web site and communication

The NFI's website is maintained by Sandra Kosta and Deborah Buehler. The Advancement Committee also maintains the 3 google groups that are available to NFI members. These include one for the membership, one for NIDCAP Trainers and NIDCAP Training Center Directors and one for the NFI Board. They are administrated by Gloria McAnulty, Sandra Kosta and Jim Helm.

The Advancement Committee continues to support development and publication of the blogs on our website. There are several under review and it is anticipated these will all be posted over the next several months.

The NFI also maintains a Facebook page, Twitter account, Linked-In account, and a You Tube channel.

Family Advisory Council

The Family Advisory Council is co-facilitated by Mandy Daly and Samantha Buttler and continues to function mostly through email. The group has the original 11 members from 5 countries participating and is reaching out to possibly

add several new members. The Council is developing several blogs and have developed a position paper on lobbying and initiating policies that support premature infants (Mandy Daly and Silke Mader). There are plans to write a short opinion paper on how to engage families (Samantha Buttler coordinating). Further the Council continues to support the NFI's webpage in efforts to be more easily accessible for parents and is exploring ways to engage and share with other family advisory groups such as the Preemie Parent Alliance. SEE ATTACHED REPORT

Global Perspective Advisory Council

The Global Perspective Advisory Council (GPAC) consists of Bjorn Westrup. Kaye Spence, Mandy Daly and gretchen Lawhon. The purpose is to consider ways to increase the awareness, feasibility of implementing developmentally supportive care, specifically the NIDCAP approach, within a global framework, SEE DRAFT REPORT

Plans

Plans are underway to celebrate World Prematurity Day. Blogs are being developed that are anticipated to be posted over the next several months.

Discussions have started on a project to archive NFI photographs such as those taken at NIDCAP Trainers Meetings and those donated for our World Prematurity Day posters.

Respectfully submitted,

James M. Helm, PhD

James M. Helm, PhD Chair, Advancement Committee Vice President NFI Board of Directors

Family Advisory Council Report, October 2017 – Mandy Daly, ACII, DLDU

Mandy and Samantha continue to reach out to individuals with a view to expanding the membership of the Family Advisory Council (FAC). 2 new members from Australia have just confirmed acceptance of the invitation to join the council- Karen Peters and Parool Shah both from Lifes Little Treasures Foundation. Mandy continues to source an individual from Canada to join the council.

One of the main challenges in the past 6 months has been engaging with the council members. Engagement from the European members has been more positive and they have both expressed a desire to introduce NIDCAP to their countries in the future however engaging with the USA/Canadian members has been less fruitful with many emails going unanswered.

One of the current efforts to increase participation of the FAC members has been to encourage activity on the NIDCAP FB social media page and share NIDCAP FB posts on their own social media platforms and raise awareness amongst their networks. The FAC chairs are hopeful of increasing engagement through discussion and dissemination of World Prematurity Day (WPD) efforts. Currently FAC members are reporting on what they are doing to celebrate WPD 2017. The FAC would like to create a web post on the NIDCAP FB page with this information. The FAC are also boosting engagement with collaboration on a manuscript documenting the ICU experience from the parent's perspective and the importance of NIDCAP. To support this manuscript, the FAC have created a short questionnaire looking at parent perceived areas of needed improvement in the ICU. 5 responses have been collected to date.

It is hoped that by inviting Jennifer Degl to the NIDCAP Trainers Meeting in Edmonton and providing her with the valuable opportunity to meet with some of the FAC members and experience the Trainers Meeting for herself that she will consider a board position in the near future. It is planned to have a gathering of the FAC at the Trainers Meeting to regroup on current efforts. Mandy and Samantha think it is important to assign specific tasks to specific individuals and working together, in person at the Trainers meeting might be a good time to begin that process.



Global Perspective Advisory Council – Report October 2017

Members: Bjorn Westrup, Mandy Daly, Kaye Spence, gretchen Lawhon

The Global Perspective Advisory Council (GPAC) is a sub group of the NFI Advancement Committee.

The purpose of the GPAC is to increase the awareness, feasibility and implementation of the NIDCAP based approach within a global framework. A global perspective refers to all newborns in low-, middle- and high-income countries.

NIDCAP is identified as the most comprehensive program of developmental care with a sound theoretical basis and a well-developed support program for systems change. Other programs or interventions may play an active role as foundation for the establishment of NIDCAP in a more global framework.

Early childhood development - what are the global challenges?

Stable social, economic, political, climatic, and cultural *contexts* are crucial factors to ensure an *enabling environment* for caregivers, families, and communities to provide *nurturing care*.

Key components of such environment are health (water, sanitation, hygiene, immunization), nutrition (breastfeeding, micronutrients, complimentary food, dietary diversity), security and safety (reduce abuse, neglect, violence, under-age marriages), responsive caregiving (responsive parenting, support emotional development, caregiver nurturance and continuity), and early learning (books, toys, play material; child care and school).

It is a well-established knowledge that early adversity and nurturing care links with brain development and function throughout the life course and the evidence now strongly suggests that parents, caregivers, and families need the above contexts and environment for providing nurturing care and protection in order for young children to achieve their developmental potential. (Black MM et al. *and* Britto PR et al. The Lancet Jan 2017)

In other words, early childhood development is determined by very complex, multifactorial, and context-dependent systems that varies enormously around the world. To complicate the picture even more, we have the almost non-conceivable global inequity in numbers and resources. Around *20 million infants* are prematurely born and/or with low birthweight every year and they could all considered to be in need of developmentally supportive care (Fig 1).



Figure 1. Global characteristics of care of the newborn

Moreover, the burden of preterm birth, impairment and disability is globally very un-evenly distributed mirroring the distribution of economic resources (Fig.2). <u>250 million children</u> younger than 5 years in low-income and middle-income countries (43%) are at risk of impaired development (proxy measures of stunting and poverty) (Black MM et al. The Lancet Jan 2017)

Figure 2. Preterm birth-associated neurodevelopmental impairment. Blencoe et al., 2013

Collaboration

In order to facilitate the work of the NFI in supporting a global spread of information, knowledge and system change for developmental care a collaboration with like-minded organizations is encouraged. Many resources have been developed through various professional groups, NGOs and consumer groups. A collaboration with these groups is a prerequisite to enhance the feasibility of global spread of best practice for developmental care and the more advanced training and educational programs. One could anticipate a joint venture to create a substantial model for a more global implementation where some groups could be working on their particular focus.

Potential groups for the NFI collaboration include, but not limited to, COINN, EADCare, EFCNI, ICM, INK, WAIMH, WAPM, WHO. These groups all have a global focus across many countries and continents.

Awareness through social media

Social Media platforms are a vital component of increasing global awareness and interest in NIDCAP We recommend that a more structured and strategic approach to managing the existing social media platforms is adopted. These platforms form the basis for all future relationship building endeavours. NFI should demonstrate mutual respect for the work of collaborators by expanding the reach and content of the platforms to include topics and subject matter not only related to NIDCAP, and should be a priority going forward. In order to raise awareness and increase traffic, it is crucial to invite the NFI membership to contribute to the content as well as to play an active role in the managing of these platforms. NFI volunteers should be delegated authority by the Advancement Committee in the Board of Directors to act on an individual and day to day basis.

A Global Perspective of Infant and Family-Centered Developmental Care

To assist the Global Perspective Advisory Committee in conceptualizing the framework for discussion with the NFI Board as well as other groups for potential collaboration the following diagram is presented (Fig 3). The target estimates for implementation of the programs/interventions are up for discussion with the various collaborating groups.



Figure 3: Diagram indicating components for a global spread of developmental care

Actions for consideration by NFI

- 1. The establishment of a task group within the GPAC to bridge the gap between organizations.
- 2. The establishment of a task group within the NFI to develop a strong profile on social media in general but also, in collaboration with GPAC, with a specific focus on the global reach of NIDCAP.

Appendix - Potential Collaborating Groups

COINN – Council of International Neonatal Nurses EADCare - European Association for Developmental Care EFCNI - European Foundation for Care of Newborn Infants ICM - International College of Midwives INKMC – International Network of Kangaroo Mother Care NFI – NIDCAP Federation International WAIMH – World Association of Infant mental Health WAPM - World Association of Perinatal Medicine WHO - Baby Friendly Initiative Others.....