Harmonization Health Surveillance Recommendations for Childhood Cancer Survivors International Meeting Summary Williamsburg Lodge, Virginia June 10, 2010

Participants: Saro H. Armenian, Smita Bhatia, Richard Cohn, Louis S. Constine, Riccardo Haupt, Lars Hjorth, Melissa M. Hudson, Leontien Kremer, Wendy Landier, Gill Levitt, Renée L. Mulder, Paul C. Nathan, Kevin C. Oeffinger, Michael Sullivan, Flora Van Leeuwen, W. Hamish Wallace.

- 1. Melissa Hudson outlined the objectives of meeting. Participants uniformly expressed interest in harmonizing health surveillance recommendations for childhood cancer survivors. Full details in Attachment #1: Hudson MM_Harmonizing Health Surveillance Recommendations_Overview.
- 2. Hamish Wallace presented the background and methodology of the Scottish Intercollegiate Guidelines Network in the context of a discussion of global issues associated with evidence-based guideline development.
 - a. SIGN methodology is characterized by a systematic review of evidence that assesses the methodological quality of studies and evidence supporting screening recommendation.
 - b. SIGN addresses 5 key outcomes: growth, puberty and fertility, cardiac abnormalities, thyroid dysfunction, and cognitive and psychosocial outcomes.
 - c. SIGN is unique in its recommendations for levels of follow-up care that are based on site of malignancy, type/intensity of therapy, and age at treatment.

Dr. Wallace informed the group that plans for SIGN guideline updates and development of new guidelines related to second malignancies and renal/liver toxicity were approved in 2009. Under discussion by SIGN is a simplified scoring system for the updates: Red – not recommended, Amber – need more evidence, Green – recommended. Full details in attachment #2: Wallace WH_SIGN 76.

- 3. Gill Levitt gave an overview about the *Therapy Based Long-Term Follow-Up Practice Statement* developed by the UKCCSG, now Children's Cancer and Leukaemia Group (CCLG).
 - a. This statement was organized by late effects experts to serve as a resource to unify care of long-term survivors across the United Kingdom.
 - b. The Practice Statement includes brief summaries of exposure based outcomes related to surgery, chemotherapy and radiation therapy.
 - c. The Practice Statement also features detailed appendices pertinent to the care of specific pediatric cancers and high risk therapeutic interventions.

Dr. Levitt related that CCLG was developing care pathways for GPs to motivate adherence to screening recommendations. CCLG is also collaborating in the PanCare survivorship guideline initiative. Full details in attachment #3: Levitt G_CCLG Practice Statement.

- 4. Wendy Landier presented the background and methodology pertinent to the development of the Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers.
 - a. The COG Guidelines were developed using a hybrid model that considers the quality of the evidence linking late effects with therapeutic exposures and screening recommendations based on expert clinical experience.

b. Version 3.0 of the COG Guidelines released in 2008 includes 146 sections delineating health screening recommendations related to therapeutic exposures used for treatment of pediatric cancers, cancer screening recommendations for common adult malignancies, and references for general health screening, in addition to a variety of patient educational handouts call "Health Links"

Multidisciplinary task forces within COG monitor the late effects literature and propose modifications as appropriate for guideline content. These groups have also been active in disseminating knowledge about health risks associated with treatment for childhood cancer through a variety of review manuscripts. Full details in attachment #3: Landier W & Hudson M_COG Guidelines.

- 5. Leontien Kremer presented an overview of the Dutch Children's Oncology Group clinical guidelines.
 - a. The DCOG Guidelines addresses monitoring of selected late effects for which an ample evidence base is available, as well as employment and social consequences and organization of follow-up care.
 - b. DCOG Guideline recommendations are based on the translation of evidence derived from systematic reviews and clinical experience.

Evaluation of new evidence is planned within next 2 years. DCOG investigators are also participating in the PanCare survivorship guideline initiative. Full details in attachment #4: Kremer L_DCOG Guidelines.

- 6. Representatives from each cooperative group presented recommendations for breast cancer and cardiovascular disease surveillance. Because of time constraints, the subsequent discussion focused on breast cancer surveillance. The major differences in recommendations relate to clinical and treatment characteristics of risk groups, age at initiation of surveillance, frequency of surveillance, and surveillance modalities preferred for specific age groups.
- 7. Conclusion: Participants agreed that breast cancer surveillance recommendations among the groups had commonalities to serve as a strong basis for future discussion regarding harmonization. Review of the evidence supporting discordant recommendations would identify areas for future research and facilitate the development of harmonious recommendations. The group committed to continue discussions via e-mail communications and meet at common academic forums to consider other health surveillance recommendations. Additional long-term goals proposed include the development of a white paper to summarize the current state of the science regarding health surveillance recommendations for pediatric cancer survivors and identify priority research goals to address knowledge deficits. The efforts of this international group could also be the focus of a future conference that could serve as a forum to update progress and facilitate future research collaborations.