

CCSS Genetics Working Group

- Louise C. Strong, Chair
- Debra Friedman
- Nina Kadan-Lottick
- John Whitton
- Yutaka Yasui
- Gail Tomlinson
- Anna Meadows
- Ann Mertens
- John Mulvihill

Genetics WG: Activity Update

- Clarification of family history data
- Risk of cancer among twins of long-term childhood cancer survivors
- Family history of cancer among first-degree relatives: Cancer excess in sibs, especially sibs of SMN probands
RR ~ 1.5-2.5

Follow-up of FH data

- Excess cancer risk in sibs
 - HD, leukemia, Wilms, neuroblastoma, sarc
 - Not dependent on NF1, LFS, LFS-L, fam WT
- No cancer excess in parents
- Excess risk in sibs and offspring of SMN probands
- Some association of colon ca in relatives of fams with affected sibs

Concepts in Progress

- Role of genetic predisposition in SMN:
Association of second cancer risk with family cancer risk among first-degree relatives of childhood cancer survivors
 - Incidence of Li Fraumeni syndrome in survivors of childhood cancer, contribution to SMN
 - Familial cancer and SMN in pedi HD survivors
 - Familial Wilms Tumor linkage analysis
- Single gene genetic disease in childhood cancer survivors and their offspring
- Methods in genetic analysis

Priorities for Future Surveys of Initial Cohort

- Develop new tool for collection of family history data
 - new format and clarification- prefer web based probing data collection
 - family data in progeny to generate pedigrees
- Update cancer family history (only baseline available)
- Include families of deceased probands
- Develop cohort of offspring of probands

Priorities for Future Surveys of Initial Cohort

- Define needs for molecular genetic studies, DNA, tissue bank, willingness to participate, consent issues
- Interaction with SMN, reproductive outcome, molecular genetics, pathol working groups

Expanded Cohort Recommendations

- Revise family history section of baseline questionnaire-web based, probing data collection tool, data in progeny
- Initiate sample collection early in study
- Add question re ever had genetic counseling for cancer risk? Genetic testing for cancer susceptibility? Results? (list genetic syndromes)

CCSS Genetics WG: Challenges

- Family history (FH) data quality
- Follow-up of FH of deceased probands
- Consent and funding for genetic testing