
CCSS Genetics Working

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Current proposals from baseline

- Single gene diseases describing phenotype in the cohort
- LFS/LFL family history
 - 44 families
- Colon cancer history in first degree relatives
 - 139 families
 - 13 families with colon cancer and sibling with cancer
 - 6 families with sibling with colon cancer
 - All other families have colon cancer in parents and no cancers in any full sibs.
 - Proband cancers include leukemia, HD, NHL, CNS, Bone and STS, Wilms and NBL.
 - Some suggest Turcot or Lynch.
 - 25 have occurred in a parent under the age of 45 years

Current proposals using biospecimens

- MDM2 (SNP309) analysis in Hodgkin lymphoma survivors treated with radiotherapy +/- breast cancer
 - Recommendation: Replenish depleted biospecimens and consider increasing repository
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Future proposals

- GWA combined with FH for NMSC
 - GWA for Hodgkin lymphoma
 - Two stage design: Discovery; Replication
 - Primary aim etiology
 - Secondary aim SMN (or other adverse outcome with sufficient prevalence)
 - Potentially include incident cases from COG HD
 - Compare genotypes that might predict outcome or late effects in the COG group based on the CCSS group data
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Priorities for 2007 survey

- Develop web-based family history survey
 - Present baseline history
 - Probing questions for ambiguous answers
 - Ask for corrections and updates: FH of cancer, new relatives (including offspring)
- Target high yield populations first
 - Hodgkin lymphoma - SMNs
 - Sarcoma – known genetic predisposition; SMNs
 - All SMNs (w/controls matched by latency and primary diagnosis)

Questions: IT platform?

Can we update FH on deceased probands?

Expanded Cohort

- Web-based family history
 - Hypothesis that siblings, offspring with cancer and probands with SMNs enrich FH data and may form sub-population with genetic cancer predisposition
 - Inform methodology from 2007 survey
 - Biosample collection
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Additional recommendations:

Biospecimens

- Biospecimen collection
 - Existing cohort: Re-fill depleted samples
 - Expanded cohort: Early specimen collection
 - Advisory committee to be established to evaluate proposals using biospecimens followed by recommendations of biospecimens to genetics working group and other CCSS working groups
 - Material Transfer Agreement for biospecimens
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Public Use Database

■ Concerns

- ❑ Inaccuracy of data not validated or clarified
 - ❑ Potential for identification of probands based on family history
 - ❑ Could family history be provided by request?
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