Li-Fraumeni Syndrome Workshop

November 2, 2010
Natcher Auditorium (Building 45), NIH Bethesda

Sponsored by the NIH Office of Rare Diseases Research and the National Cancer Institute

This meeting will bring together intramural and extramural clinicians and scientists to review the existing knowledge regarding Li-Fraumeni syndrome (LFS), to share current research projects, and to identify areas, such as cancer screening and risk reduction interventions, in which further research is needed. The meeting will also serve as a starting point for the creation of a LFS research consortium. Families with LFS are invited to attend in this meeting. This will be an opportunity to participate in education sessions on existing scientific knowledge, including cancer screening recommendations, and in workshops that will foster interaction and the development of a support group.

We anticipate that this meeting will be the first of several LFS-related scientific meetings. The goals of the first meeting are to bring the clinicians/scientists together to review the current knowledge and, more importantly, to foster further collaborations.

DRAFT Agenda

Tuesday, November 2, 2010, Natcher Auditorium, NIH

7:45 - 8:30  Registration

8:30 - 8:45  Welcoming remarks & meeting overview – Joseph Fraumeni

8:45 – 9:00  History and Overview of LFS – Louise Strong
Chair: Sharon Savage

9:00 - 10:00 Perspectives from Li-Fraumeni Syndrome families
Chair: Andrea Patenaude
Oliver and Jamie Wyss
Luana Locke
Von Means

10:00 - 10:15 Coffee Break

10:15 - 12:00 Clinical Aspects
Chair: Jeffrey Weitzel

The Story from Brazil – Maria Isabel Achatz
Genotype-phenotype correlations in the TP53 mutation database – Pierre Hainaut
Chompret Criteria and experience in France – Thierry Frebourg (invited)
Screening and Research from the UK – Gareth Evans
Cancer Screening: Adults – Judy Garber
Cancer Screening: Children – David Malkin

12:00 - 1:00 Genetic Counseling and Psychosocial Aspects
Chair: June Peters
Genetic counseling and testing for Li-Fraumeni Syndrome – Kathy Schneider
Psychosocial Considerations – Andrea Patenaude
Ethical concerns with testing minors – Ben Wilfond
International perspectives on psychosocial reactions – Evelyn Bleiker

1:00 - 2:00 Lunch - on your own
2:00 - 3:00  Molecular Biology of TP53  
Chair: David Malkin  
Overview of TP53 function – David Malkin  
Mitochondria and TP53 – Paul Hwang  
Telomeres and LFS – Uri Tabori  
DNA Repair and TP53 – James Ford

3:00 - 3:15  Coffee Break

3:15 - 5:00  Concurrent Sessions

A. Creating a research consortium and development of new studies  
a. Presentations on database and projects in development  

Chair: Joshua Schiffman  
Children’s Oncology Group LFS registry proposal – Simona Ognjanovic  
Collecting and managing biospecimens – Joshua Schiffman  
Studies of metformin – Philip Dennis  
Identifying a consortium-wide screening protocol – Judy Garber

b. Consortia building  
Open discussion on logistics

A. B. Family Support and Advocacy: Chaired by patient advocates with experience in family support and advocacy groups  
Kevin McQueen (Fanconi Anemia Research Fund)  
David Smith (SpeciaLove)  
Connie Lee (Angioma Alliance, Genetic Alliance)  
John Berkeley (Li-Fraumeni Syndrome Support group)  
Representatives from NIH Office of Advocacy Relations  
Discussion topics to include:  
Fostering family communication and support  
Organization of family meetings  
Fundraising  
Other issues

5:00 - 5:30  Meeting summary and report from break-out sessions

5:30  Adjourn