Fanconi Anemia Research Fund’s
20th Annual Family Meeting, Confirmed Speakers
June 24 – June 29, 2011
Camp Sunshine, Casco, Maine

Friday, June 24, 2011:

Fanconi Anemia 101
Blanche P. Alter, MD, MPH, FAAP, National Cancer Institute, Bethesda, MD

Saturday, June 25, 2011:

Introductions: FARF Founders, Board Members, Staff and Camp Sunshine’s Staff
Beverly Mayhew

Overview of Research Opportunities to Participate in at while at the Family Meeting

National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study
Blanche P. Alter, MD, MPH, FAAP
Lisa Leathwood, RN, BSN, National Cancer Institute, Bethesda, MD

Early Detection for Head and Neck Squamous Cell Carcinoma in Fanconi Anemia
Eunike Velleuer, MD, Heinrich Heine University, Children's Hospital, Düsseldorf, Germany
Ralf Dietrich, Executive Director, Fanconi Anemia Patients’ Organization of Germany

Microbial Markers of Oral Carcinogenesis
Flavia R. F. Teles, DDS, MS, DMSc, The Forsyth Institute, Boston, MA

A Research Study of Human Papillomavirus (HPV) in People with Fanconi Anemia
Melinda Butsch Kovacic, MPH, PhD, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH

Treatment and Management Considerations of Hematologic Complications of Fanconi Anemia
Akiko Shimamura, MD, PhD, Fred Hutchinson Cancer Research Center, Seattle, WA

Nutrition: Eating Well for Taste and Health
Carol Ceresa, MHSL, RD, San Francisco VA Medical Center, San Francisco, CA

Factors Contributing to Longevity in Adults with FA/Head & Neck Cancer in Adults with FA
Detlev Schindler, MD, PhD, University of Wuerzburg, Wuerzburg, Germany

Challenges, Coping and Quality of Life in Adults with FA: Summary of Findings
Amy Frohnmayer, MA, Oregon Health & Science University, Portland, OR

Fanconi Anemia Research Updates
Akiko Shimamura, MD, PhD

Fundraising for Fanconi Anemia Research
Beverly Mayhew
Kevin McQueen, Fanconi Anemia Research Fund, Member, Board of Directors and FA Parent

- (continued) -
Sunday, June 26, 2011:

**NDRI/OHSU/Clinical Trials & Clinical Trials Scholarship**
*Teresa Kennedy*, Family Support Director, Fanconi Anemia Research Fund, Eugene, OR

**Social, Educational and Psychological Considerations Before, During and After BMT**
*Julia Kearney M.D.*, Memorial Sloan-Kettering Cancer Center, New York, NY

**Chromosome Changes: What Are They and What Do They Mean?**
*Betsy Hirsch, PhD*, University of Minnesota Medical School, Minneapolis, MN

**General Overview of Fanconi Anemia Stem Cell Transplant Process and Risks**
*Margaret MacMillan, MD*, University of Minnesota Medical School, Minneapolis, MN

**Stem Cell Transplantation Panel: Timing of Transplant, Protocols and Center-Specific Outcomes**
*Margaret MacMillan, MD*
*Leslie Lehmann, MD*, Children’s Hospital, Boston, MA
*Wolfram Ebell, MD*, Charité-Universitätsmedizin, Berlin, Germany

**Parent Panel: To Transplant, or Not to Transplant, That is the Question: Sharing Experiences**
*Facilitated by Akiko Shimamura, MD, PhD and Nancy Cincotta, MSW, MPhil*

Monday, June 27, 2011

**Head & Neck Cancer in People with Fanconi Anemia: Overview, Treatment Options & Screening**
*David I. Kutler, MD*, Weill Medical College of Cornell University, New York, NY

**Fertility & Fertility Preservation in Males and Females with Fanconi Anemia**
*Rahel Ghebre, MD*, University of Minnesota, Minneapolis, MN

**Gynecologic Issues for Girls and Women with Fanconi Anemia**
*Rahel Ghebre, MD*

**Understanding the Genetics of FA: Carriers, Complementation Groups & Cancer Risks**
*Heather Zierhut, MS, CGC*, University of Minnesota Medical Center, Minneapolis, MN

**Overview of Preimplantation Genetic Diagnosis (PGD)**
*Heather Zierhut, MS, CGC*

**Parent Panel: Sharing PGD Experiences**
*Facilitated by Heather Zierhut, MS, CGC and Nancy Cincotta, MSW, MPhil*

Daily

**Support Groups** (For parents (mothers, fathers and single parents), adults with FA, children with FA, siblings of children with FA and bereaved parents)
*Nancy Cincotta, MSW, MPhil*, Psychosocial Director, Camp Sunshine

*Updated 5/17/11*