Fanconi Anemia Research Fund  
Family Meeting: Sessions and Confirmed Speakers  
August 10 – 15, 2012  
Camp Sunshine, Casco, Maine

Friday, August 10, 2012:
Fanconi Anemia 101  
Blanche P. Alter, MD, MPH, FAAP, National Cancer Institute, Rockville, MD

Saturday, August 11, 2012:
Welcome and Introductions: FARF Co-founders, Board Members & Staff  
Beverly Mayhew, Executive Director, Fanconi Anemia Research Fund, Eugene, OR

Overview of FA Research Opportunities to Participate in at the Family Meeting:
National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study  
Blanche P. Alter, MD, MPH, FAAP

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

Identifying Biomarkers in the Saliva of People with FA for Early Detection of Oral Cancer  
David Akin, Clinical Research Manager, UCLA School of Dentistry, Los Angeles, CA

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

General Overview of the Stem Cell Transplant Process and Risks  
Stella Davies, MBBS, PhD, MRCP Cincinnati Children’s Hospital Medical Center, Cincinnati, OH

FA Stem Cell Transplant Panel: Timing of Transplant, Protocols & Center-Specific Outcomes for Children & Adults  
Stella Davies, MBBS, PhD, MRCP, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH  
John Wagner, MD, University of Minnesota Amplatz Children’s Hospital, Minneapolis, MN

Stem Cell Transplant Survivorship Issues  
K. Scott Baker, MD, MS, Fred Hutchinson Cancer Research Center, Seattle, WA

Danazol for People with Fanconi Anemia  
Helmut Hanenberg, MD, Riley Hospital for Children, Indianapolis, IN

Navigating Your School System: Tips for Advocating for Your Child  
Renee Ortiz, MSW, City of Hope, Duarte, CA

Transition from Pediatric to Adult Care: Tips for Parents (by parents and adults with FA)  
Speakers: TBD
Sunday, August 12, 2012

Gastroenterology and Feeding Issues in Fanconi Anemia
Sarah Jane Schwarzenberg, MD, University of Minnesota Amplatz Children’s Hospital, Minneapolis, MN

Endocrine Issues: Growth and Development in Fanconi Anemia
Susan R. Rose, MD, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH

Hand Differences in Fanconi Anemia
Scott Kozin, MD, Shriners Hospital for Children, Philadelphia, PA

Head & Neck Cancer in Fanconi Anemia: Risks, Screenings, Prevention & Treatment Options
Bhuvanesh Singh, MD, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY and Scientific Advisory Board, Fanconi Anemia Research Fund

Hey, Teens & Young Adults! What You Need to Know about Head & Neck Cancer (parents are welcome, too)
Bhuvanesh Singh, MD, PhD

Biospecimen Samples for FA Research, Clinical Trials and Clinical Trials Travel Assistance Fund
Teresa Kennedy, Family Support Director, Fanconi Anemia Research Fund, Eugene, OR

Monday, August 13, 2012

Hearing Considerations in Fanconi Anemia
H. Jeffrey Kim, MD, FACS, Georgetown University Hospital, Washington, DC

Gene Therapy for Fanconi Anemia
Jakub Tolar, MD, PhD, University of Minnesota Medical School, Minneapolis, MN and Scientific Advisory Board, Fanconi Anemia Research Fund

Gynecologic Issues for Girls and Women with Fanconi Anemia
Jill Huppert, MD, MPH, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH

Pre-Implantation Genetic Diagnosis (PGD): Overview & Outcomes
Andria G. Besser, BEd, MS, CGC, The Reproductive Genetics Institute, Chicago, IL

Parent Panel: Sharing PGD Experiences
Facilitated by Andria G. Besser, BEd, MS, CGC

Identifying Biomarkers in the Saliva of People with FA for Early Detection of Oral Cancer
David Wong, DMD, DMSc, UCLA School of Dentistry, Los Angeles, CA

Fundraising for FA Research and Overview of FARF-funded Research
Beverly Mayhew
Lynn Frohnmayer, MSW, Parent, Co-founder and Board of Directors, Fanconi Anemia Research Fund
Kevin McQueen, Parent, Board of Directors, Fanconi Anemia Research Fund

Forum: Ask an FA Expert your Questions
Jakub Tolar, MD, PhD

Daily

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

(Updated 7/9/12)