

Fanconi Anemia Research Fund
23rd Annual Family Meeting, June 27 – July 2, 2014
Camp Sunshine, Casco, Maine

Friday, June 27, 2014

- 3:00 pm Check-in (*Note: FA adults, teens, kids, groups and activities are listed in Camp Sunshine's schedule*)
- 3:45 – 4:00 Parents take kids to group
- 4:00 – 5:00 **Fanconi Anemia 101** (Auditorium)
Blanche P. Alter, MD, MPH, FAAP, National Cancer Institute, Bethesda, MD
- 5:00 – 5:20 Questions and Answers
- 5:20 – 5:40 **Informal Gathering for Parents New to the Family Meeting** (Nancy's Place, upstairs)
Nancy Cincotta, MSW, MPhil, Psychosocial Director, Camp Sunshine
Teresa Kennedy, MA, Director of Family Support Services, Fanconi Anemia Research Fund
- 5:20 Parents pick kids up from group (except new parents; children can stay in group until 5:40 pm)
- 5:30 – 6:30 Dinner
- 6:30 – 6:40 Parents take kids to group
- 6:40 – 6:50 **Welcome to the 23rd Annual Family Meeting** (Auditorium)
Laura Hays, PhD, Executive Director, Fanconi Anemia Research Fund
- 6:50 – 7:05 **Camp Safety and Kids Program**, *Mike Katz, Campus Director, Camp Sunshine*
- 7:05 – 7:10 Transition upstairs for the support group. *Parents and adults with FA only, please.*
- 7:10 – 9:00 **Support Group for Parents and Adults with FA: Introductions and What to Expect from Camp**
Parents and adults with FA only, please. (Nancy's Place), Nancy Cincotta, MSW, MPhil
- 9:00 **Support Group for Adults with FA** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*

Saturday, June 28, 2014

- 8:00 – 8:50 Breakfast
- 8:50 – 9:00 Parents take kids to group
- 9:00 – 9:10 **Introductions: FARF Co-founders, Board Members, and Staff** (Auditorium), *Laura Hays, PhD*

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

- 9:10 – 9:25 **National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study**
Blanche P. Alter, MD, MPH, FAAP
- 9:25 – 9:40 **Early Detection of 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
- 9:40 – 9:55 **Microbial Markers of Oral Carcinogenesis**
Flavia R. F. Teles, DDS, MS, DMSc, The Forsyth Institute, Cambridge, MA
- 9:55 – 10:10 **Identification of Global and Disease-Related FA Biomarkers Using NMR-Based Metabonomics; The Role of Human Papillomavirus (HPV) in People with Fanconi Anemia**
Lindsey Romick-Rosendale, PhD, Cincinnati Children's Hospital Medical Center, Cincinnati, OH
Sharon Sauter, MS, CCRP, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Saturday, June 28, 2014, continued

- 10:10 – 10:25 Break
- 10:25 – 10:45 **Oral and Dental Health Care in Fanconi Anemia**
Flavia R. F. Teles, DDS, MS, DMSc
- 10:45 – 11:00 Questions and Answers
- 11:00 – 11:45 **Gene Therapy Clinical Trial for Fanconi Anemia (New Eligibility Criteria)**
Jennifer Adair, PhD, Fred Hutchinson Cancer Research Center, Seattle, WA
- 11:45 – 12:00 Questions and Answers
- 12:00 – 1:15 Lunch
- 12:00 – 1:15 **Lunch for Adults with FA** Bring your lunch; childcare provided (outside, weather permitting)
Nancy Cincotta, MSW, MPhil
- 1:15 – 1:20 Parents take kids to group

- 1:20 – 3:05 **Fanconi Anemia Stem Cell Transplantation Panel**
Facilitated by *Eva Guinan, MD, Dana-Farber Cancer Institute, Boston, MA*
Scientific Advisory Board, Fanconi Anemia Research Fund
- Center-Specific Data: Number of FA Transplants, Outcomes for Kids vs. Adults, and Protocols**
- 1:25 – 1:45 *Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, New York, NY*
- 1:45 – 2:05 *Stella Davies, MBBS, PhD, MRCP, Cincinnati Children's Hospital, Cincinnati, OH*
- 2:05 – 2:25 *John Wagner, MD, University of Minnesota, Amplatz Children's Hospital, Minneapolis, MN*
- 2:25 – 3:05 Questions for the panel

- 3:05 – 3:15 Break
- 3:15 – 3:55 **Long Term Follow-Up after Fanconi Anemia Stem Cell Transplantation**
Farid Boulad, MD
- 3:55 – 4:10 Questions and Answers
- 4:10 – 4:15 Transition to Support Group
- 4:10 – 5:30 **Support Group for Parents** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*
- 5:30 – 6:30 Dinner
- 6:30 – 7:00 Preparation for balloon release (Arts and Crafts room)
- 7:00 – 7:45 Balloon release (Sebago Lake)
- 7:45 – 8:45 Talent Show (Auditorium)
- 8:45 – 10:00 **Support Group: Bereavement Group for Parents** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*
- 9:00 – 10:00 Masquerade Ball (Auditorium)

Sunday, June 29, 2014

- 8:00 – 8:50 **Breakfast/Support Group for Mothers** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*
- 8:00 – 8:50 Breakfast
- 8:50 – 9:00 Parents take kids to group

Sunday, June 29, 2014, *continued*

- 9:00 – 10:00 **Gastrointestinal, Hepatic, and Nutritional Challenges in Fanconi Anemia**
Sarah Jane Schwarzenberg, MD, University of Minnesota, Minneapolis, MN
- 10:00 – 10:15 Questions and Answers
- 10:15 – 10:30 Break
- 10:30 – 11:30 **You want me to eat what?: Improving Nutritional Behaviors**
Susana R. Patton, PhD, CDE, University of Kansas Medical Center, Kansas City, KS
- 11:30 – 11:45 Questions and Answers
- 11:45 – 1:20 Lunch
- 11:45 – 1:20 **Lunch/Support Group for Single Moms** Bring your lunch; childcare provided (Nancy's Place)
Nancy Cincotta, MSW, MPhil
- 1:10 – 1:20 Parents take kids to group
- 1:20 – 2:20 **Head and Neck Cancer in Fanconi Anemia: Risks, Prevention, Screenings, and Treatment Options**
David I. Kutler, MD, Weill Cornell Medical Center, New York, NY
- 2:20 – 2:35 Questions and Answers
- 2:35 – 3:00 **Dermatologic Issues in Fanconi Anemia**
Vinod Nambudiri, MD, MBA, Brigham and Women's Hospital Internal Medicine, Boston, MA
- 3:00 – 3:10 Questions and Answers
- 3:10 – 3:20 Break/Teens and Adults with FA arrive for the next session (*Free time for parents/guardians*)

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| 3:20 – 3:55 | Overview of Fanconi Anemia and Tips for a Healthy Lifestyle <u>Exclusively</u> for Teens and Adults with FA (raffle included). No parents, Camp counselors, researchers or others, please.
<i>Eva Guinan, MD</i> |
| 3:55 – 4:05 | Questions and Answers |

- 4:05 – 4:10 Transition to Support Group
- 4:10 – 5:30 **Support Group for Parents** (Nancy's Place)
Nancy Cincotta, MSW, MPhil
- 5:30 – 6:20 Dinner for kids
- 5:30 – 6:30 **Support Group for Adults with FA** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*
- 6:20 – 6:30 Parents take kids to group
- 6:30 – 8:00 Adults social and banquet, fundraising recognition (Auditorium)
- 8:00 – 10:00 Karaoke

Monday, June 30, 2014

- 8:00 – 8:50 **Breakfast/Support Group for Fathers** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*
- 8:00 – 8:50 **Breakfast**
- 8:50 – 9:00 Parents take kids to group
- 9:00 – 9:40 **Endocrine Issues in Fanconi Anemia**
Susan R. Rose, MD, MEd, Cincinnati Children's Hospital Medical Center, Cincinnati, OH
- 9:40 – 9:55 Questions and Answers

Monday, June 30, 2014, continued

- 9:55 – 10:35 **The Role of Aldehydes in Fanconi Anemia**
Alan D'Andrea, MD, Dana-Farber Cancer Institute, Boston, MA
- 10:35 – 10:45 Questions and Answers
- 10:45 – 10:55 Break
- 10:55 – 11:35 **Gynecologic Issues in Fanconi Anemia**
Rahel Ghebre, MD, University of Minnesota, Minneapolis, MN
- 11:35 – 11:45 Questions and Answers
Please note: Dr. Ghebre will be available until 2:00 pm for individual consultations
- 11:45 – 1:00 Lunch
- 1:00 – 1:20 Group Photo (location to be announced)
- 1:20 – 1:30 Parents take kids to group
- 1:30 – 2:00 **N-Acetyl Cysteine (NAC) and Update on the Fanconi Anemia NAC Clinical Trial**
Rabindra Tirouvanziam, PhD, Emory + Children's Center for Cystic Fibrosis Research, Atlanta, GA
- 2:00 – 2:10 Questions and Answers
- 2:10 – 2:30 **Fundraising Overview and Recent Grants Awarded by the Fanconi Anemia Research Fund**
Laura Hays, PhD
- 2:30 – 2:40 Questions and Answers
- 2:40 – 3:10 **Potential Treatments for Fanconi Anemia**
Richard Gelinias, PhD, Institute for Systems Biology, Seattle, WA
Scientific Advisory Board and Member, Board of Directors, Fanconi Anemia Research Fund
- 3:10 – 3:20 Questions and Answers
- 3:20 – 3:30 Break
- 3:30 – 4:05 **Open Forum: Ask FA Experts Your Clinical and FA Science Questions**
Blanche Alter, MD, MPH, FAAP and Rich Gelinias, PhD
- 4:05 – 4:10 Transition to Support Group
- 4:10 – 5:30 **Support Group for Parents: Family Affairs** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*
- 5:30 – 6:30 Dinner
- 6:30 – 7:15 Wish Boats Launch (Pond)
- 7:15 – 7:30 Preparation for Celebration
- 7:30 – 10:00 Celebration

Tuesday, July 1, 2014

Fun and relaxing activities planned throughout the day!

- 8:00 – 9:00 Breakfast
- 9:30 – 11:00 **Support Group for Adults with FA and Parents: Looking Forward** (Nancy's Place)
Nancy Cincotta, MSW, MPhil
- 12:00 – 1:00 Lunch
- 5:30 – 6:30 Dinner

Wednesday, July 2, 2014

- 8:00 – 9:00 Breakfast
- 10:00 am Families check-out