

Fanconi Anemia Research Fund
25th Annual Family Meeting
June 24 –29th, 2016
Camp Sunshine, Casco, Maine

Friday, June 24

3:00 pm	Check-in (Note: FA adults, teens, kids, groups and activities are listed in Camp Sunshine's schedule)
4:15 – 5:20 pm <i>Nancy's place, upstairs</i>	Parents and FA Adults New to the Family Meeting <i>Nancy Cincotta, MSW, MPhil, Psychosocial Director, Camp Sunshine</i>
5:30 – 6:50 pm	Dinner
5:30 – 6:50 pm	Families and FA Adults New to the Family Meeting Enjoy Dinner with Mentors
6:50 – 7:00 pm	Parents take kids to group
7:00 – 7:10 pm <i>Auditorium</i>	Welcome to the 25th Annual Family Meeting <i>Pamela Norr, Marie Sweeten and Suzanne Planck, Fanconi Anemia Research Fund</i>
7:10 – 7:25 pm	Camp Safety and Kids Program <i>Mike Katz, Executive Director, Camp Sunshine</i>
7:25 – 7:40 pm	Transition upstairs for the support group. Parents and adults with FA only, please.
7:40 – 9:15 pm	Support Group for Parents and Adults with FA: Introductions and What to Expect from Camp
9:15 pm <i>Nancy's place</i>	Support Group for Adults with FA <i>Nancy Cincotta, MSW, MPhil</i>

Saturday, June 25

8:00 – 8:50 am	Breakfast
8:50 – 9:00 am	Parents take kids to group
9:00 – 9:10 am <i>Auditorium</i>	Introductions: FARF Co-founder, Board Members, and Staff <i>Pamela Norr, Executive Director, Fanconi Anemia Research Fund</i>
9:15 – 10:15 am <i>Auditorium</i>	Fanconi Anemia 101 <i>Blanche P. Alter, MD, MPH, National Cancer Institute, Bethesda, MD</i>
10:15 – 10:30 am	Questions & Answers
10:30 – 10:40 am	Overview of FA Research Opportunities to Participate in at the Family Meeting <i>Brad Preston, PhD, Scientific Director, Fanconi Anemia Research Fund</i>
10:40 – 10:50 am	National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study <i>Blanche P. Alter, MD, MPH, National Cancer Institute, Bethesda, MD</i>
10:55 – 11:05 am	Early Detection of Head and Neck Squamous Cell Carcinoma in Fanconi Anemia <i>Eunike Velleuer, MD, Heinrich-Heine University, Children's Hospital, Germany</i> <i>Ralf Dietrich, Executive Director, Fanconi Anemia Patients' Organization of Germany</i>

11:15 – 11:25 am	Metabolomics; The Role of Human Papillomavirus (HPV) in People with Fanconi Anemia <i>Melinda Butsch Kovacic, MPH, PhD, Cincinnati Children's Hospital Medical Center, OH</i> <i>Sharon Sauter, MS, CCRP, Cincinnati Children's Hospital Medical Center, OH</i>
11:30 – 11:45 am	Break/Pick up kids
11:45 am – 1:00 pm	Lunch for Adults with FA Bring your lunch; childcare provided (weather permitting) <i>Nancy Cincotta, MSW, MPhil</i>
11:45 am – 1:00 pm	Lunch
12: 55 – 1:00 pm	Parents take kids to group
1:05 – 3:30 pm	Fanconi Anemia Stem Cell Transplantation Panel Center-Specific Data: Protocols, Number of FA Transplants, and Outcomes for Kids vs. Adults
1:05 – 1:35 pm	<i>Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, NY</i>
1:40 – 2:10 pm	<i>Stella Davies, MD, Cincinnati Children's Hospital Medical Center, OH</i>
2:15 – 2:45 pm	<i>Margaret MacMillan, MD, University of Minnesota Masonic Children's Hospital, MN</i>
2:45 – 3:15 pm	Questions for Panel
3:15 – 3:30 pm	Break
3:35 – 3:55 pm	New FARF Initiatives to Accelerate FA Research <i>Brad Preston, PhD, Scientific Director, Fanconi Anemia Research Fund</i>
3:55 – 4:05 pm	Questions & Answers
4:15 – 5:30 pm <i>Nancy's place</i>	Support Group for Parents <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:45 pm	Dinner
6:45 – 7:15 pm <i>Arts and Crafts room</i>	Preparation for Balloon Release
7:15 – 8:00 pm <i>Sebago Lake</i>	Balloon Release
8:15 – 9:15 pm <i>Auditorium</i>	Talent Show
9:15 – 10:15 pm <i>Nancy's place</i>	Support Group: Bereavement Group for Parents <i>Nancy Cincotta, MSW, MPhil</i>
9:15 – 10:15 pm <i>Auditorium</i>	Masquerade Ball

Sunday, June 26

8:00 – 8:50 am	Breakfast
8:00 – 8:50 am <i>Nancy's place</i>	Breakfast Support Group for Mothers <i>Nancy Cincotta, MSW, MPhil</i>
8:50 – 9:00 am	Parents take kids to group
9:00 – 9:50 am <i>Auditorium</i>	Endocrinology <i>Anthony Hollenberg, MD, Beth Israel Deaconess Medical Center, Boston, MA</i>
9:50 – 10:00 am	Questions & Answers

10:05 – 10:50 am	Gynecologic and Reproductive Health Issues in Fanconi Anemia <i>Pam Stratton, MD, Head, Gynecology Consult Service, Eunice Kennedy Shriver NICHD, NIH, Bethesda, MD</i>
10:50 – 11:05 am	Questions & Answers
11:10 – 11:55 am	Aldehydes and Bone Marrow Function in FA <i>Alan D’Andrea, MD, Dana-Farber Cancer Institute, Boston, MA</i>
11:55 – 12:05 pm	Questions & Answers
12:05 – 1:20 pm	Lunch
1:10 – 1:20 pm	Parents take kids to group
1:20 – 2:10 pm	Head and Neck Cancer in FA <i>Bhuvanesh Singh, MD, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY</i>
2:10 – 2:25 pm	Questions & Answers
2:30 – 3:15 pm	Immunotherapy for Head and Neck Cancers <i>William N. William Jr., MD, University of Texas, MD Anderson Cancer Center, Houston, TX</i>
3:15 – 3:30 pm	Questions & Answers
3:30 – 3:40 pm	Break
3:45 – 4:30 pm	Detection of Oral Lesions and DNA Aneuploidy in Transplanted vs. Non-transplanted FA Patients <i>Eunike Velleuer, MD, Heinrich Heine University, Children's Hospital, Düsseldorf, Germany</i> <i>Ralf Dietrich, Executive Director, FA Support Group of Germany</i>
4:30 – 4:45 pm	Questions & Answers
4:45 – 5:30 pm	Free time
5:30 – 6:20 pm	Dinner for kids
6:20 – 6:30 pm	Parents take kids to group
6:30 – 8:00 pm <i>Auditorium</i>	Adult Social and Banquet, Fundraising Recognition
8:00 – 10:00	Karaoke

Monday, June 27

8:00 – 8:50 am <i>Location?</i>	Breakfast
8:00 – 8:50 am <i>Nancy’s place</i>	Breakfast Support Group for Fathers <i>Nancy Cincotta, MSW, MPhil</i>
8:50 – 9:00 am	Parents take kids to group
9:00 – 9:50 am <i>Auditorium</i>	Hand & Arm Abnormalities in FA <i>Scott Kozin, MD, Chief of Staff, Shriners Hospital for Children, Philadelphia, PA</i>
9:50 – 10:00 am	Questions & Answers
10:00 – 10:15 am	Break
10:15 – 11:00 am	FARF-funded Research, FA Clinical Trials, and Potential Treatments for Fanconi Anemia <i>Richard Gelinas, PhD, Institute for Systems Biology, Seattle, WA, Scientific Advisory Board, Board of Directors, Fanconi Anemia Research Fund</i>
11:00 – 11:10 am	Questions & Answers

11:10 am – 12:00 pm	Audiology <i>H. Jeffrey Kim, MD, FACS, Professor, Dept. of Otolaryngology, HNS Georgetown University Medical Center, Washington, DC</i>
12:00 – 12:10 pm	Questions & Answers
12:10 – 1:15 pm	Lunch
1:30 – 1:45 pm <i>TBD</i>	Group Photo
1:45 – 1:55 pm	Parents take kids to group
2:00 – 2:50 pm	Let's Put the "Fun" into Functional Foods - Eating for Taste & Health <i>Carol Ceresa, MHSL, RD, San Francisco, CA</i>
2:50 – 3:00 pm	Questions & Answers
3:00 – 3:10 pm	Break
3:15 – 4:00 pm	Fundraising <i>Sharon Schuman, PhD, Board of Directors, Fanconi Anemia Research Fund, Eugene, OR</i> <i>Sherri Van Ravenhorst, MA, Communications and Conference Coordinator, FARF, Eugene, OR</i> <i>Mary Ann Lana, MS, FA Parent, Hilton, NY</i>
4:00 – 4:10 pm	Transition to Support Group
4:10 – 5:30 pm <i>Nancy's place</i>	Support Group for Parents: <u>F</u>amily <u>A</u>ffairs <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:50 pm	Dinner
6:50 – 7:30 pm <i>Pond</i>	Wish Boats Launch
7:30 – 7:40 pm	Preparation for Celebration
7:45 – 10:00 pm	Celebration

Tuesday, June 28

Fun and relaxing activities planned by Camp Sunshine throughout the day!

8:00 – 9:00 am	Breakfast
10:00 – 11:30 am <i>Nancy's place</i>	Support Group for Adults with FA and Parents: Looking Forward <i>Nancy Cincotta, MSW, MPhil</i>
12:00 – 1:00 pm	Lunch
5:30 – 6:50 pm	Dinner

Wednesday, June 29

8:00 – 9:00 am	Breakfast
11:00 am	Check-out