



26th Annual Family Meeting • June 23 –28th, 2017 • Camp Sunshine, Casco, Maine

Friday, June 23

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 26th Annual Family Meeting <i>Mark Quinlan, Executive Director, 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 <i>Nancy's place</i>	Support Group for Parents and Adults with FA: Introductions and What to Expect from Camp
9:15 pm	Support Group for Adults with FA <i>Nancy Cincotta, MSW, MPhil</i>

Saturday, June 24

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 <i>Mark Quinlan, 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>
11:10 – 11:20 am	Cutaneous Findings in Fanconi Anemia <i>Christina Boull, MD, University of Minnesota, Minneapolis, MN</i>

11:25 – 12:00 pm	Break/Pick up kids
12:00 pm – 1:00 pm	Lunch for Adults with FA Bring your lunch; childcare provided (weather permitting) <i>Nancy Cincotta, MSW, MPhil</i>
12:00 pm – 1:00 pm	Lunch
12:50 – 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>Margaret L. MacMillan, MD, Fanconi Anemia Comprehensive Care Program, University of Minnesota, Minneapolis, MN</i>
1:35 – 1:45 pm	Questions & Answers
1:50 – 2:20pm	<i>Stella Davies, MD, Cincinnati Children’s Hospital Medical Center, OH</i>
2:25 – 2:55 pm	<i>Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, NY</i>
2:55 – 3:15 pm	Questions for Panel
3:15 – 3:30 pm	Break
3:35 – 3:55 pm	CFAR : FARF Initiatives to Accelerate FA Clinical Research <i>Brad Preston, PhD, Scientific Director, Fanconi Anemia Research Fund</i>
3:55 – 4:05 pm	Questions & Answers
4:15 – 5:30 pm	Support Group for Parents <i>Nancy’s place</i> <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:30 pm	Dinner
6:30 – 7:00 pm	Preparation for Balloon Release <i>Arts and Crafts room</i>
7:00 – 7:30 pm	Balloon Release <i>Sebago Lake</i>
8:00 – 9:00 pm	Talent Show <i>Auditorium</i>
9:00 – 10:00 pm	Support Group: Bereavement Group for Parents <i>Nancy’s place</i> <i>Nancy Cincotta, MSW, MPhil</i>
9:00 – 10:00 pm	Masquerade Ball <i>Auditorium</i>

Sunday, June 25

8:00 – 8:50 am	Breakfast
8:50 – 9:00 am	Parents take kids to group
9:00 – 9:50 am	Support Group for Mothers <i>Nancy’s place</i> <i>Nancy Cincotta, MSW, MPhil</i>
10:00 – 10:45 am	Endocrine Issues in FA <i>Auditorium</i> <i>Susan R. Rose, MD, MEd, Professor of Pediatric Endocrinology, Cincinnati Children’s Hospital Medical Center and University of Cincinnati College of Medicine, OH</i>
10:45 – 10:55 am	Questions & Answers

11:00 am – 11:45 pm	Nutrition and FA <i>Kelly Costello, RD, University of Minnesota Masonic Children's Hospital, MN</i>
11:45 – 11:55 am	Questions & Answers
12:00 – 1:00 pm	Lunch
12:50– 1:00 pm	Parents take kids to group
1:05 – 1:50 pm	Gene Therapy for Fanconi Anemia: The Future is Now <i>Pamela S Becker, MD, PhD, Professor of Medicine, University of Washington and Associate Member, Fred Hutchinson Cancer Research Center</i>
1:55 – 2:15 pm	Gene Therapy in Fanconi Anemia: Industry partnership and trials in Seattle and Madrid <i>Jonathan Schwartz, MD, Chief Medical Officer, Rocket Pharmaceuticals, Ltd., NY</i>
2:15 – 2:25 pm	Questions for Gene Therapy Panel
2:30 – 3:15 pm	TGFβ inhibitors in FA treatment <i>Kalindi Parmar, PhD, Dana-Farber Cancer Institute, MA</i>
3:15 – 3:25 pm	Questions & Answers
3:30 – 3:40 pm	Break
3:45 – 5:00 pm <i>Nancy's Place</i>	Support Group for Parents <i>Nancy Cincotta, MSW, MPhil</i>
5:00 pm	Group Photo
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 26

8:00 – 8:50 am	Breakfast
8:50 – 9:00 am	Parents take kids to group
9:00 – 9:50 am <i>Nancy's place</i>	Support Group for Fathers <i>Nancy Cincotta, MSW, MPhil</i>
10:00 – 10:45 am <i>Auditorium</i>	Dermatological Care: Sun Protection for People with Fanconi Anemia (& Everyone Else Too!) <i>Christina Boull, MD, University of Minnesota, Minneapolis, MN</i>
10:45 – 10:55 am	Questions & Answers
11:00 – 11:45 am	What is New in Head and Neck Cancer Treatment <i>Bhuvanesh Singh, MD, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY</i>
11:45 – 11:55 am	Questions & Answers
12:00 – 1:15 pm	Lunch
1:15 – 1:25 pm	Parents take kids to group
1:30 – 2:15pm	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>
2:15 – 2:25 pm	Questions & Answers

Fundraising

2:30 – 3:15 pm

Kevin Gatzlaff, PhD, FA parent, FARF Philanthropy Council, IN
Mary Ann Lana, MS, FA parent, FARF Philanthropy Council, NY
Sherri Van Ravenhorst, MS, Fanconi Anemia Research Fund

3:15 – 3:30 pm

Break

3:30 – 3:40 pm

Transition to Support Group

3:45 – 5:15 pm

Support Group for Parents: Family Affairs

Nancy's place

Nancy Cincotta, MSW, MPhil

5:30 – 6:30 pm

Dinner

7:00 – 7:30 pm

Wish Boats Launch

Pond

8:00 – 10:00 pm

Celebration

Auditorium

(including presentation of the Amy Winn & Christopher T. Byrd Award)

Tuesday, June 27

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

8:00 – 9:00 am

Breakfast

9:00 – 10:00 am

Support Group for Adults with FA and Parents: Looking Forward

Nancy's place

Nancy Cincotta, MSW, MPhil

12:00 – 1:00 pm

Lunch

1:00 – 2:00 pm

FA Art (everyone with FA invited to attend!)

Nancy Cincotta, MSW, MPhil

5:30 – 6:50 pm

Dinner

Wednesday, June 28

8:00 – 9:00 am

Breakfast

11:00 am

Check-out