



27th Annual Family Meeting • June 29 – July 4, 2018 • Camp Sunshine, Casco, Maine

Friday, June 29

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 **Parents and FA Adults New to the Family Meeting**
Nancy's place, upstairs *Nancy Cincotta, MSW, MPhil, Psychosocial Director, Camp Sunshine*

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 **Welcome to the 27th Annual Family Meeting**
Auditorium *Mark Quinlan, Executive Director, Fanconi Anemia Research Fund*

7:10 – 7:25 pm **Camp Safety and Kids Program**
Mike Katz, Executive Director, Camp Sunshine

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**
Nancy's place

9:15 pm **Support Group for Adults with FA**
Nancy Cincotta, MSW, MPhil

Saturday, June 30

8:00 – 8:50 am **Breakfast**

8:50 – 9:00 am **Parents take kids to group**

9:00 – 9:10 am **Introductions**
Auditorium *Mark Quinlan, Executive Director, Fanconi Anemia Research Fund*

9:15 – 10:00 am **Fanconi Anemia 101**
Auditorium *Blanche P. Alter, MD, MPH, National Cancer Institute, Bethesda, MD*

10:00 – 10:10 am **Questions & Answers**

10:10 – 10:25 am **Break**

10:30 – 10:35 am **Overview of FA Research Opportunities**
Isis Sroka, PhD, Director of Scientific Operations, Fanconi Anemia Research Fund

10:35 – 10:50 am **National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study**
Blanche P. Alter, MD, MPH, National Cancer Institute, Bethesda, MD
Neelam Giri, MD, National Cancer Institute, Bethesda, MD

10:55– 11:10 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 – 11:30 am	Eltrombopag for People With Fanconi Anemia <i>Neelam Giri, MD, National Cancer Institute, Bethesda, MD</i> on behalf of <i>Andre Larochelle, MD, PhD, National Heart, Lung, and Blood Institute, Bethesda, MD</i>
11:35 – 12:00 pm	Quercetin Clinical Trials (Pre- and Post-Transplant) <i>Stella Davies, MBBS, PhD, Cincinnati Children's Hospital Medical Center, OH</i>
12:00 – 1:25 pm	Lunch
12:00 – 1:25 pm	Networking Lunch for Adults with FA Bring your lunch (outdoors- weather permitting)
1:20 – 1:25 pm	Parents take kids to group
1:30 – 1:45 pm	Fanconi Anemia Stem Cell Transplantation Panel, Part I <i>Stella Davies, MBBS, PhD, Cincinnati Children's Hospital Medical Center, OH</i>
1:45 – 1:55 pm	Questions & Answers
2:00 – 2:45 pm	FARF-Funded Basic and Translational Research Projects <i>Isis Sroka, PhD, Director of Scientific Operations, Fanconi Anemia Research Fund</i> <i>Sudhir Borgonha, MD, Translational Science Director, Fanconi Anemia Research Fund</i> <i>Mark Quinlan, Executive Director, Fanconi Anemia Research Fund</i>
2:45 – 2:55pm	Questions & Answers
3:00 – 3:15 pm	Break
3:15 – 4:00 pm	Navigating Financial Resources <i>Monica Wolking, Family Financial Advocate II, Cincinnati Children's Hospital Medical Center, OH</i>
4:00 – 4:10 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, July 1

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**
Nancy's place *Nancy Cincotta, MSW, MPhil*

10:00 – 11:40 am **Fanconi Anemia Stem Cell Transplantation Panel, Part II**
Auditorium **Center-Specific Data: Protocols, Number of FA Transplants, and Outcomes for Kids vs. Adults**

10:00 – 10:30 am *Margaret L. MacMillan, MD, Fanconi Anemia Comprehensive Care Program, University of Minnesota, Minneapolis, MN*

10:35 – 11:05 am *Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, NY*

11:10 – 11:40 am **Questions for Panel**

11:45 – 1:00 pm **Lunch**

12:50– 1:00 pm **Parents take kids to group**

1:05 – 1:50 pm **Long Term Health of FA Patients: Medical and Psychosocial Aspects of Care**
Margaret L. MacMillan, MD, Fanconi Anemia Comprehensive Care Program, University of Minnesota, Minneapolis, MN

1:50 – 2:00 pm **Questions & Answers**

2:00 – 2:15 pm **Break**

2:20 – 3:05 pm **Future Opportunities in the Treatment of Head and Neck Cancer**
Bhuvanesh Singh, MD, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY

3:05 – 3:15 pm **Questions & Answers**

3:15 – 3:30 pm **Transition to Support group**

3:30 – 5:00 pm **Support Group for Parents (Parents only, please)**
Nancy's Place *Nancy Cincotta, MSW, MPhil*

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 **Adult Social and Banquet, Fundraising Recognition**
Auditorium

8:00 – 10:00 pm **Karaoke**

Monday, July 2

8:00 – 8:50 am **Breakfast**

8:50 – 9:00 am **Parents take kids to group**

9:00 – 9:50 am **Support Group for Fathers**
Nancy's place *Nancy Cincotta, MSW, MPhil*

10:00 – 10:45 am **Sunny Side of School: Helping Students with Fanconi Anemia Find Success**
Auditorium *Valerie L. Theile, MEd, School Liaison Specialist, Center for School Services, Cincinnati Children's Hospital Medical Center, OH*

10:45 – 10:55 am **Questions & Answers**

11:00 – 11:45 am	Hand Differences in Fanconi Anemia <i>Scott Kozin, MD, Chief of Staff, Shriners Hospital for Children, Philadelphia, PA</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 – 2:00pm	Hematologic issues in FA <i>Akiko Shimamura, MD, PhD, Director, Bone Marrow Failure and MDS Program, Dana-Farber/Boston Children's Hospital Cancer and Blood Disorders Center, MA</i>
2:00 – 2:10pm	Questions & Answers
2:10 – 2:25 pm	Metformin Clinical Trial for FA <i>Elissa Furutani, MD, Boston Children's Hospital, MA</i>
2:30 – 3:15 pm	Fundraising <i>McKenna Knapp, MEd, Philanthropy Director, Fanconi Anemia Research Fund</i> <i>Sherri Van Ravenhorst, MS, Communications Director, Fanconi Anemia Research Fund</i>
3:15 – 3:40 pm	Break/ Transition to Support Group
3:45 – 5:15 pm	Support Group for Parents: Family Affairs <i>Nancy's place</i> <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:30 pm	Dinner
7:00 – 7:30 pm	Wish Boats Launch <i>Pond</i>
8:00 – 10:00 pm	Celebration <i>Auditorium</i>

Tuesday, July 3

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 <i>Nancy's place</i> <i>Nancy Cincotta, MSW, MPhil</i>
12:00 – 1:00 pm	Lunch
1:00 – 2:00 pm	FA Art (everyone with FA invited to attend!) <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:50 pm	Dinner

Wednesday, July 4

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