



**27<sup>th</sup> 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 27<sup>th</sup> 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	<b>Early Detection of Head and Neck Squamous Cell Carcinoma in Fanconi Anemia</b> <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	<b>Eltrombopag for People With Fanconi Anemia</b> <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	<b>Quercetin Clinical Trials (Pre- and Post-Transplant)</b> <i>Stella Davies, MBBS, PhD, Cincinnati Children's Hospital Medical Center, OH</i>
12:00 – 1:25 pm	<b>Lunch</b>
12:00 – 1:25 pm	<b>Networking Lunch for Adults with FA</b> Bring your lunch (outdoors- weather permitting)
1:20 – 1:25 pm	<b>Parents take kids to group</b>
1:30 – 1:45 pm	<b>Fanconi Anemia Stem Cell Transplantation Panel, Part I</b> <i>Stella Davies, MBBS, PhD, Cincinnati Children's Hospital Medical Center, OH</i>
1:45 – 1:55 pm	<b>Questions &amp; Answers</b>
2:00 – 2:45 pm	<b>FARF-Funded Basic and Translational Research Projects</b> <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	<b>Questions &amp; Answers</b>
3:00 – 3:15 pm	<b>Break</b>
3:15 – 4:00 pm	<b>Navigating Financial Resources</b> <i>Monica Wolking, Family Financial Advocate II, Cincinnati Children's Hospital Medical Center, OH</i>
4:00 – 4:10 pm	<b>Questions &amp; Answers</b>
4:15 – 5:30 pm	<b>Support Group for Parents</b> <i>Nancy's place</i> <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:30 pm	<b>Dinner</b>
6:30 – 7:00 pm	<b>Preparation for Balloon Release</b> <i>Arts and Crafts room</i>
7:00 – 7:30 pm	<b>Balloon Release</b> <i>Sebago Lake</i>
8:00 – 9:00 pm	<b>Talent Show</b> <i>Auditorium</i>
9:00 – 10:00 pm	<b>Support Group: Bereavement Group for Parents</b> <i>Nancy's place</i> <i>Nancy Cincotta, MSW, MPhil</i>
9:00 – 10:00 pm	<b>Masquerade Ball</b> <i>Auditorium</i>

## Sunday, July 1

8:00 – 8:50 am	<b>Breakfast</b>
8:50 – 9:00 am	<b>Parents take kids to group</b>

**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	<b>Hand Differences in Fanconi Anemia</b> <i>Scott Kozin, MD, Chief of Staff, Shriners Hospital for Children, Philadelphia, PA</i>
11:45 – 11:55 am	<b>Questions &amp; Answers</b>
12:00 – 1:15 pm	<b>Lunch</b>
1:15 – 1:25 pm	<b>Parents take kids to group</b>
1:30 – 2:00pm	<b>Hematologic issues in FA</b> <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	<b>Questions &amp; Answers</b>
2:10 – 2:25 pm	<b>Metformin Clinical Trial for FA</b> <i>Elissa Furutani, MD, Boston Children's Hospital, MA</i>
2:30 – 3:15 pm	<b>Fundraising</b> <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	<b>Break/ Transition to Support Group</b>
3:45 – 5:15 pm	<b>Support Group for Parents: Family Affairs</b> <i>Nancy's place</i> <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:30 pm	<b>Dinner</b>
7:00 – 7:30 pm	<b>Wish Boats Launch</b> <i>Pond</i>
8:00 – 10:00 pm	<b>Celebration</b> <i>Auditorium</i>

## Tuesday, July 3

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

8:00 – 9:00 am	<b>Breakfast</b>
9:00 – 10:00 am	<b>Support Group for Adults with FA and Parents: Looking Forward</b> <i>Nancy's place</i> <i>Nancy Cincotta, MSW, MPhil</i>
12:00 – 1:00 pm	<b>Lunch</b>
1:00 – 2:00 pm	<b>FA Art (everyone with FA invited to attend!)</b> <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:50 pm	<b>Dinner</b>

## Wednesday, July 4

8:00 – 9:00 am	<b>Breakfast</b>
11:00 am	<b>Check-out</b>