



**28<sup>th</sup> Annual Family Meeting • June 21 –26, 2019 • Camp Sunshine, Casco, Maine**

**Friday, June 21**

**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, Adults with FA, Spouses & Adult Siblings 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 Adults with FA 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 28<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, Adults with FA, Spouses & Adult Siblings, only please.***

**7:40 – 9:15 pm**            **Support Group: Introductions and What to Expect from Camp**  
*Nancy's place*                    *Nancy Cincotta, MSW, MPhil*

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

**Saturday, June 22**

**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 – 11:50 am**            **Overview of FA Research Opportunities**

**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**

*Eunike Velleuer, MD, Children's Hospital Neuwerk, Moenchengladbach, Germany*  
*Ralf Dietrich, Executive Director, Fanconi Anemia Patients' Organization of Germany*

**11:15 – 11:30 am A Pilot Study of Metformin for Fanconi Anemia**

*Elissa Furutani, MD, Boston Children's Hospital, MA*

**11:35 – 11:50 am Eltrombopag for the Treatment of Fanconi Anemia**

*Andre Larochelle, MD, PhD, National Institutes of Health, Bethesda, MD*

**12:00 – 1:15 pm Lunch – Parents pick up kids**

**12:00 – 1:15 pm Lunch for Adults with FA** Bring your lunch (outdoors- weather permitting)

**1:00 – 1:15 pm Parents take kids to group**

**1:15 – 2:00 pm FARF-Funded Basic and Translational Research Projects**

*Isis Sroka, PhD, Director of Scientific Operations, Fanconi Anemia Research Fund*  
*Sudhir Borgonha, MD, Translational Science Director, Fanconi Anemia Research Fund*

**2:00 – 2:10 pm Questions & Answers**

**2:10 – 2:20 pm Break**

**2:25 – 3:15 pm Livin' La Vida FA as Adults**

*Angela Bedoya, Minneapolis, MN*  
*Amelia Hawkshaw, Sydney, Australia*  
*Duncan Nunes, Boston, MA*  
*Matt Pearl, Wanship, UT*  
*Jack Timperley, Park Ridge, IL*

**3:15 – 3:45pm Questions for panel**

**3:45 – 4:00 pm Break**

**4:00 – 5:15 pm Support Group for Parents (Parents only, please)**

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

**5:15 – 5:30 pm Break - Parents pick up kids**

**5:30 – 6:30 pm Dinner**

**6:30 – 6:45 pm Preparation for Balloon Release**

*Arts and Crafts room*

**7:00 – 7:20 pm Balloon Release**

**7:30 – 8:30 pm Talent Show**

*Auditorium*

**8:15 – 10:00 pm Support Group: Bereavement Group for Parents**

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

## Sunday, June 23

**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 – 11:45 am **Fanconi Anemia Stem Cell Transplantation Panel**  
*Auditorium Center-Specific Data: Protocols, Number of FA Transplants, and Outcomes for Kids vs. Adults*

10:00 – 10:20 am *John Wagner, MD, Fanconi Anemia Comprehensive Care Program, University of Minnesota, Minneapolis, MN*

10:25 – 10:45 am *Maria Cancio, MD, Memorial Sloan-Kettering Cancer Center, New York, NY*

10:50 – 11:10 am *Stella Davies, MBBS, PhD, Cincinnati Children's Hospital Medical Center, OH*

11:15 – 11:45 am **Questions for Panel**

11:45 – 1:00 pm **Lunch**

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

1:05 – 2:55 pm **Gene Therapy Panel**  
*John Wagner, MD, University of Minnesota, Minneapolis, MN*  
*Paula Rio, PhD, CIEMAT/CIBERER/IIS-FJD,UAM, Madrid, Spain*  
*Agnieszka Czechowicz, MD, PhD, Stanford University, CA*  
*Meera Srikanthan, MD, Seattle Children's Hospital, WA*

2:25 – 2:55 pm **Questions for Panel**

3:00 – 3:15 pm **Break**

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

5:00 pm **Parents pick up kids**

5:10 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 – 9:30 pm **Karaoke**

9:30 – 9:45 pm **Parents pick up kids**

## Monday, June 24

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 <i>Auditorium</i>	<b>Head &amp; Neck Cancer in FA</b> <i>Ann Marie Egloff, PhD, MPH, Brigham and Women's Hospital, Harvard Medical School, Boston, MA</i>
10:45 – 10:55 am	<b>Q &amp; A</b>
11:00 – 11:45 am	<b>FA Clinical Registry and Virtual Tumor Board</b> <i>Sudhir Borgonha, MD, Translational Science Director, Fanconi Anemia Research Fund</i>
11:45 – 11:55 am	<b>Q &amp; A</b>
12:00 – 1:15 pm	<b>Lunch – Parents pick up kids</b>
1:15 – 1:25 pm	<b>Parents take kids to group</b>
1:30 – 2:15 pm	<b>Cultivating Wellbeing and Resilience</b> <i>Megan Voss, DNP, RN, University of Minnesota, Minneapolis, MN</i>
2:15 – 2:25 pm	<b>Q &amp; A</b>
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> <i>Julia Wong, Family Fundraising Program Manager, Fanconi Anemia Research Fund</i>
3:15 – 3:40 pm	<b>Break/ Transition to Support Group</b>
3:45 – 5:15 pm <i>Nancy's place</i>	<b>Support Group for Parents: <u>F</u>amily <u>A</u>ffairs (Parents only, please)</b> <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:30 pm	<b>Dinner</b>
7:00 – 7:30 pm <i>Pond</i>	<b>Wish Boats Launch</b>
7:45 – 9:30 pm <i>Auditorium</i>	<b>Celebration</b>

## Tuesday, June 25

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

8:00 – 9:00 am	<b>Breakfast</b>
9:00 – 10:00 am <i>Nancy's place</i>	<b>Support Group for Parents, Adults with FA, Spouses &amp; Adult Siblings: Looking Forward</b> <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>
7:15 – 9:30 pm <i>Auditorium</i>	<b>Masquerade Ball</b>

## Wednesday, June 26

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