



28th 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 28th 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>	Head & Neck Cancer in FA <i>Ann Marie Egloff, PhD, MPH, Brigham and Women's Hospital, Harvard Medical School, Boston, MA</i>
10:45 – 10:55 am	Q & A
11:00 – 11:45 am	FA Clinical Registry and Virtual Tumor Board <i>Sudhir Borgonha, MD, Translational Science Director, Fanconi Anemia Research Fund</i>
11:45 – 11:55 am	Q & A
12:00 – 1:15 pm	Lunch – Parents pick up kids
1:15 – 1:25 pm	Parents take kids to group
1:30 – 2:15 pm	Cultivating Wellbeing and Resilience <i>Megan Voss, DNP, RN, University of Minnesota, Minneapolis, MN</i>
2:15 – 2:25 pm	Q & A
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> <i>Julia Wong, Family Fundraising Program Manager, Fanconi Anemia Research Fund</i>
3:15 – 3:40 pm	Break/ Transition to Support Group
3:45 – 5:15 pm <i>Nancy's place</i>	Support Group for Parents: <u>F</u>amily <u>A</u>ffairs (Parents only, please) <i>Nancy Cincotta, MSW, MPhil</i>
5:30 – 6:30 pm	Dinner
7:00 – 7:30 pm <i>Pond</i>	Wish Boats Launch
7:45 – 9:30 pm <i>Auditorium</i>	Celebration

Tuesday, June 25

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

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

Wednesday, June 26

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