

**Fanconi Anemia Research Fund**  
**25<sup>th</sup> Annual Family Meeting**  
**June 24 –29<sup>th</sup>, 2016**  
**Camp Sunshine, Casco, Maine**

**Friday, June 24**

<b>3:00 pm</b>	<b>Check-in</b> (Note: FA adults, teens, kids, groups and activities are listed in Camp Sunshine's schedule)
<b>4:15 – 5:20 pm</b> <i>Nancy's place, upstairs</i>	<b>Parents and FA Adults New to the Family Meeting</b> <i>Nancy Cincotta, MSW, MPhil, Psychosocial Director, Camp Sunshine</i>
<b>5:30 – 6:50 pm</b>	<b>Dinner</b>
<b>5:30 – 6:50 pm</b>	<b>Families and FA Adults New to the Family Meeting Enjoy Dinner with Mentors</b>
<b>6:50 – 7:00 pm</b>	<b>Parents take kids to group</b>
<b>7:00 – 7:10 pm</b> <i>Auditorium</i>	<b>Welcome to the 25<sup>th</sup> Annual Family Meeting</b> <i>Kevin McQueen, Board President, Fanconi Anemia Research Fund</i>
<b>7:10 – 7:25 pm</b>	<b>Camp Safety and Kids Program</b> <i>Mike Katz, Executive Director, Camp Sunshine</i>
<b>7:25 – 7:40 pm</b>	<b>Transition upstairs for the support group. Parents and adults with FA only, please.</b>
<b>7:40 – 9:15 pm</b>	<b>Support Group for Parents and Adults with FA: Introductions and What to Expect from Camp</b>
<b>9:15 pm</b> <i>Nancy's place</i>	<b>Support Group for Adults with FA</b> <i>Nancy Cincotta, MSW, MPhil</i>

**Saturday, June 25**

<b>8:00 – 8:50 am</b>	<b>Breakfast</b>
<b>8:50 – 9:00 am</b>	<b>Parents take kids to group</b>
<b>9:00 – 9:10 am</b> <i>Auditorium</i>	<b>Introductions</b> <i>Kevin McQueen, Board President, Fanconi Anemia Research Fund</i>
<b>9:15 – 10:15 am</b> <i>Auditorium</i>	<b>Fanconi Anemia 101</b> <i>Blanche P. Alter, MD, MPH, National Cancer Institute, Bethesda, MD</i>
<b>10:15 – 10:30 am</b>	<b>Questions &amp; Answers</b>
<b>10:30 – 10:40 am</b>	<b>Overview of FA Research Opportunities to Participate in at the Family Meeting</b> <i>Brad Preston, PhD, Scientific Director, Fanconi Anemia Research Fund</i>
<b>10:40 – 10:50 am</b>	<b>National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study</b> <i>Blanche P. Alter, MD, MPH, National Cancer Institute, Bethesda, MD</i>
<b>10:55 – 11:05 am</b>	<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>
<b>11:10 – 11:20 am</b>	<b>Biomarkers, Skin Barrier Dysfunction, and HPV in People with Fanconi Anemia</b> <i>Melinda Butsch Kovacic, MPH, PhD, Cincinnati Children's Hospital Medical Center, OH</i> <i>Sharon Sauter, MS, CCRP, Cincinnati Children's Hospital Medical Center, OH</i>

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

## Sunday, June 26

<b>8:00 – 8:50 am</b>	<b>Breakfast</b>
<b>8:00 – 8:50 am</b>	<b>Breakfast Support Group for Mothers</b> <i>Nancy’s place</i> <i>Nancy Cincotta, MSW, MPhil</i>
<b>8:50 – 9:00 am</b>	<b>Parents take kids to group</b>
<b>9:00 – 9:50 am</b>	<b>The Endocrine System in Fanconi Anemia</b> <i>Auditorium</i> <i>Anthony Hollenberg, MD, Beth Israel Deaconess Medical Center, Boston, MA</i>
<b>9:50 – 10:00 am</b>	<b>Questions &amp; Answers</b>

<b>10:05 – 10:55 am</b>	<b>Gynecologic and Reproductive Health Issues in Fanconi Anemia</b> <i>Pam Stratton, MD, Head, Gynecology Consult Service; Eunice Kennedy Shriver, NICHD, NIH, Bethesda, MD</i>
<b>10:55 – 11:05 am</b>	<b>Questions &amp; Answers</b>
<b>11:10 am – 12:00 pm</b>	<b>Aldehydes and Bone Marrow Function in FA</b> <i>Alan D'Andrea, MD, Dana-Farber Cancer Institute, Boston, MA</i>
<b>12:00 – 12:10 pm</b>	<b>Questions &amp; Answers</b>
<b>12:10 – 1:20 pm</b>	<b>Lunch</b>
<b>1:10 – 1:20 pm</b>	<b>Parents take kids to group</b>
<b>1:25 – 2:15 pm</b>	<b>Detection of Oral Lesions and DNA Aneuploidy in Transplanted vs. Non-transplanted FA Patients</b> <i>Eunike Velleuer, MD, Heinrich Heine University, Children's Hospital, Düsseldorf, Germany Ralf Dietrich, Executive Director, FA Support Group of Germany</i>
<b>2:15 – 2:25 pm</b>	<b>Questions &amp; Answers</b>
<b>2:30 – 3:20 pm</b>	<b>Immunotherapy for Head and Neck Cancers</b> <i>William N. William Jr., MD, University of Texas, MD Anderson Cancer Center, Houston, TX</i>
<b>3:20 – 3:30 pm</b>	<b>Questions &amp; Answers</b>
<b>3:30 – 3:40 pm</b>	<b>Break</b>
<b>3:45 – 5:00 pm</b> <i>Nancy's Place</i>	<b>Support Group for Parents</b> <i>Nancy Cincotta, MSW, MPhil</i>
<b>5:00 pm</b>	<b>Group Photo</b>
<b>5:30 – 6:20 pm</b>	<b>Dinner for kids</b>
<b>6:20 – 6:30 pm</b>	<b>Parents take kids to group</b>
<b>6:30 – 8:00 pm</b> <i>Auditorium</i>	<b>Adult Social and Banquet, Fundraising Recognition</b>
<b>8:00 – 10:00</b>	<b>Karaoke</b>

### Monday, June 27

<b>8:00 – 8:50 am</b>	<b>Breakfast</b>
<b>8:00 – 8:50 am</b> <i>Nancy's place</i>	<b>Breakfast Support Group for Fathers</b> <i>Nancy Cincotta, MSW, MPhil</i>
<b>8:50 – 9:00 am</b>	<b>Parents take kids to group</b>
<b>9:00 – 9:50 am</b> <i>Auditorium</i>	<b>Hand Differences in Fanconi Anemia</b> <i>Scott Kozin, MD, Chief of Staff, Shriners Hospital for Children, Philadelphia, PA</i>
<b>9:50 – 10:00 am</b>	<b>Questions &amp; Answers</b>
<b>10:00 – 10:15 am</b>	<b>Break</b>
<b>10:15 – 11:05 am</b>	<b>FARF-funded Research, FA Clinical Trials, and Potential Treatments for Fanconi Anemia</b> <i>Richard Gelinas, PhD, Institute for Systems Biology, Seattle, WA, Scientific Advisory Board, Board of Directors, Fanconi Anemia Research Fund</i>
<b>11:05 – 11:15 am</b>	<b>Questions &amp; Answers</b>

**11:15 am – 12:05 pm**    **Ear and Hearing Manifestations in Fanconi Anemia**  
*H. Jeffrey Kim, MD, FACS, Otolologist, Dept. of Otolaryngology-HNS, Georgetown University Hospital, Washington, DC and Staff Clinician, National Institute on Deafness and Other Communication Disorders, NIH, Bethesda, MD*

**12:05 – 12:15 pm**    **Questions & Answers**

**12:15 – 1:25 pm**    **Lunch**

**1:15 – 1:25 pm**    **Parents take kids to group**

**1:30 – 2:20 pm**    **What is New in Head and Neck Cancer Treatment**

*Bhuvanesh Singh, MD, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY*

**2:20 – 2:30 pm**    **Questions & Answers**

**2:35 – 3:15 pm**    **Let's Put the "Fun" into Functional Foods - Eating for Taste & Health**

*Carol Ceresa, MHSL, RD, San Francisco, CA*

**3:15 – 3:25 pm**    **Questions & Answers**

**3:25 – 3:35 pm**    **Break**

**Fundraising**

*Sharon Schuman, PhD, Board of Directors, Fanconi Anemia Research Fund, Eugene, OR*

**3:35 – 4:20 pm**    *Lorraine McQueen, FA Parent, Midlothian, VA*

*Sherri Van Ravenhorst, MA, Communications and Conference Coordinator, FARF, Eugene, OR*

*Mary Ann Lana, MS, FA Parent, Hilton, NY*

**4:20 – 4:25 pm**    **Transition to Support Group**

**4:25 – 5:40 pm**    **Support Group for Parents: Family Affairs**

*Nancy's place*

*Nancy Cincotta, MSW, MPhil*

**5:45 – 7:00 pm**    **Dinner**

**7:15 – 7:45 pm**

*Pond*

**Wish Boats Launch**

**8:00 – 10:00 pm**

**Celebration**

## Tuesday, June 28

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

**8:00 – 9:00 am**    **Breakfast**

**10:00 – 11:30 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!)**

**5:30 – 6:50 pm**    **Dinner**

## Wednesday, June 29

**8:00 – 9:00 am**    **Breakfast**

**11:00 am**    **Check-out**