

Fanconi Anemia Research Fund
24th Annual Family Meeting
June 25 – July 1, 2015 (*new families only*)
June 26 – July 1, 2015 (*returning families*)
Camp Sunshine, Casco, Maine

Thursday, June 25, 2015

- 3:00 pm **New Families and FA Adults: Check-in** (*Note: FA adults, teens, kids, groups and activities are listed in Camp Sunshine's schedule*)
- 3:50 – 4:00 Parents take kids to group
- 4:00 – 5:30 **Welcome and Support Group for 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 Dinner
- 7:00 – 9:00 Camp Sunshine Group Activity

Friday, June 26, 2015

New Families and Adults with FA

- 8:00 – 9:00 Breakfast
- 9:00 – 12:00 *FA adults, teens, kids, groups and activities are listed in Camp Sunshine's schedule*
- 12:00 – 1:00 Lunch
- 1:00 – 3:00 *FA adults, teens, kids, groups and activities are listed in Camp Sunshine's schedule*

- 3:00 pm** **Returning FA Families and FA Adults: Check-in** (*Note: FA adults, teens, kids, groups and activities are listed in Camp Sunshine's schedule*)
- 3:50 – 4:00 Parents take kids to group
- 4:00 – 5:00 **Fanconi Anemia 101** (Auditorium)
Blanche P. Alter, MD, MPH, FAAP, National Cancer Institute, MD
- 5:00 – 5:20 Questions and Answers
- 5:20 Parents pick kids up from group (except new parents; children can stay in group until 5:40 pm)

- 5:20 – 5:40** **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 Dinner

- 5:40 – 6:50** **Families and FA Adults New to the Family Meeting Enjoy Dinner with Mentors**

- 6:50 – 7:00 Parents take kids to group
- 7:00 – 7:10 **Welcome to the 24th Annual Family Meeting** (Auditorium)
Suzanne Planck, BSN, Interim Family Support Coordinator, Fanconi Anemia Research Fund
- 7:10 – 7:25 **Camp Safety and Kids Program**, *Mike Katz, Executive Director, Camp Sunshine*
- 7:25 – 7:30 Transition upstairs for the support group. *Parents and adults with FA only, please.*

Friday, June 26, 2015, *continued*:

- 7:30 – 9:15 **Support Group for Parents and Adults with FA: Introductions and What to Expect from Camp**
(Nancy's Place), *Nancy Cincotta, MSW, MPhil*
- 9:15 **Support Group for Adults with FA** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*

Saturday, June 27, 2015

- 8:00 – 8:50 Breakfast
- 8:50 – 9:00 Parents take kids to group
- 9:00 – 9:05 **Introductions: FARF Co-founders, Board Members, and Staff** (Auditorium),
Laura Hays, PhD, Executive Director, Fanconi Anemia Research Fund

Overview of FA Research Opportunities to Participate in at the Family Meeting

- 9:05 – 9:10 **National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study**
Blanche P. Alter, MD, MPH, FAAP
- 9:10 – 9:15 **Early Detection of Head and Neck Squamous Cell Carcinoma in Fanconi Anemia**
Eunike Velleuer, MD, Heinrich-Heine University, Children's Hospital, Germany
Ralf Dietrich, Executive Director, Fanconi Anemia Patients' Organization of Germany
- 9:15 – 9:20 **Metabolomics; The Role of Human Papillomavirus (HPV) in People with Fanconi Anemia**
Melinda Butsch Kovacic, MPH, PhD, Cincinnati Children's Hospital Medical Center, OH
Sharon Sauter, MS, CCRP, Cincinnati Children's Hospital Medical Center, OH

- 9:25 – 10:10 **Endocrine Issues in Fanconi Anemia**
Susan R. Rose, MD, MEd, Cincinnati Children's Hospital Medical Center, OH
- 10:10 – 10:25 Questions and Answers
- 10:25 – 10:35 Break
- 10:35 – 11:30 **Gastrointestinal, Hepatic, and Nutritional Problems in Fanconi Anemia**
Samuel Kocoshis, MD, Cincinnati Children's Hospital Medical Center, OH
- 11:30 – 11:45 Questions and Answers
- 11:45 – 1:00 **Lunch for Adults with FA** Bring your lunch; childcare provided (outside, weather permitting)
Nancy Cincotta, MSW, MPhil and *Suzanne Planck, BSN*
- 11:45 – 1:00 Lunch
- 12:55 – 1:00 Parents take kids to group
- 1:00 – 1:45 **Head and Neck Cancer in Fanconi Anemia: Risks, Prevention, and Treatment Options**
Carter Van Waes, MD, PhD, National Institute on Deafness and Other Communication Disorders, MD
- 1:45 – 2:00 Questions and Answers
- 2:00 – 2:45 **Detection of Oral Lesions and DNA Aneuploidy in Transplanted vs. Non-transplanted FA Patients**
Eunike Velleuer, MD, Heinrich Heine University, Children's Hospital, Düsseldorf, Germany
Ralf Dietrich, Executive Director, FA Support Group of Germany
- 2:45 – 3:00 Questions and Answers
- 3:00 – 3:15 Break

Saturday, June 27, 2015, *continued*:

- 3:15 – 3:55 **Families Helping Families: The Bone Marrow Transplant Process**
Mary Ann Fiaschetti, Mary Ann Lana and Marina Ravelo (FA Parents)
- 3:55 – 4:10 Questions and Answers
- 4:10 – 4:15 Transition to Support Group
- 4:15 – 5:30 **Support Group for Parents (Nancy's Place), Nancy Cincotta, MSW, MPhil**
- 5:30 – 6:50 Dinner
- 6:50 – 7:20 Preparation for balloon release (Arts and Crafts room)
- 7:30 – 8:15 Balloon release (Sebago Lake)
- 8:15 – 9:15 Talent Show (Auditorium)
- 9:15 – 10:15 **Support Group: Bereavement Group for Parents (Nancy's Place), Nancy Cincotta, MSW, MPhil**
- 9:15 – 10:15 Masquerade Ball (Auditorium)

Sunday, June 28, 2015

- 8:00 – 8:50 **Breakfast/Support Group for Mothers (Nancy's Place), Nancy Cincotta, MSW, MPhil**
- 8:00 – 8:50 Breakfast
- 8:50 – 9:00 Parents take kids to group
- 9:00 – 9:40 **Using Androgens to Stabilize Blood Counts in Fanconi Anemia**
Eunike Velleuer, MD
- 9:40 – 9:50 Questions and Answers

- 9:50 – 12:00 **Fanconi Anemia Stem Cell Transplantation Panel**
Center-Specific Data: Protocols, Number of FA Transplants, and Outcomes for Kids vs. Adults
- 9:50 – 10:20 *Michelle Lee, MD, Dana-Farber/Boston Children's Hospital, MA*
- 10:20 – 10:30 Break
- 10:30 – 11:00 *Parinda Mehta, MD, Cincinnati Children's Hospital Medical Center, OH*
- 11:00 – 11:30 *Margaret MacMillan, MD, University of Minnesota Masonic Children's Hospital, MN*
- 11:30 – 12:00 Questions for the Panel

- 12:00 – 1:20 Lunch
- 1:10 – 1:20 Parents take kids to group
- 1:20 – 2:10 **Long Term Effects and Recommended Follow-Up after Stem Cell Transplantation**
Margaret MacMillan, MD
- 2:10 – 2:20 Questions and Answers
- 2:20 – 3:05 **Mind-Body-Spirit; Simple Techniques to Manage Stress**
Richard Dickens, MS, LCSW-R, CancerCare, NY
- 3:05 – 3:20 Questions and Answers

Sunday, June 28, 2015, *continued*:

3:20 – 3:30 Break/Teens and Adults with FA arrive for the next session (*Free time for parents/guardians*)

3:30 – 4:00 **How Can I Relax, I Have FA?! Exclusively for Teens and Adults with FA (Raffle included).** *No parents, Camp counselors, researchers or others, please.*

Richard Dickens, MS, LCSW-R, CancerCare, NY

4:00 – 4:10 Questions and Answers

4:10 – 4:15 Transition to Support Group

4:15 – 5:30 **Support Group for Parents** (Nancy's Place)

Nancy Cincotta, MSW, MPhil

5:30 – 6:20 Dinner for kids

6:20 – 6:30 Parents take kids to group

6:30 – 8:00 Adults social and banquet, fundraising recognition (Auditorium)

8:00 – 10:00 Karaoke

Monday, June 29, 2015

8:00 – 8:50 **Breakfast/Support Group for Fathers** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*

8:00 – 8:50 Breakfast

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

9:00 – 9:50 **Fanconi Anemia Gene Therapy**

Jennifer Adair, PhD, Fred Hutchinson Cancer Research Center, WA

9:50 – 10:00 Questions and Answers

10:00 – 10:15 Break

10:15 – 11:00 **FARF-funded Research, FA Clinical Trials, and Potential Treatments for Fanconi Anemia**

Richard Gelinias, PhD, Institute for Systems Biology, Seattle, WA

Scientific Advisory Board and Member, Board of Directors, Fanconi Anemia Research Fund

11:00 – 11:10 Questions and Answers

11:10 – 11:40 **Open Forum: Ask FA Experts Science and Clinical Questions**

Blanche P. Alter, MD, MPH, FAAP and Richard Gelinias, PhD

11:40 – 1:10 Lunch

1:10 – 1:30 Group Photo (location to be announced)

1:30 – 1:40 Parents take kids to group

1:40 – 2:15 **Fundraising Overview**

Laura Hays, PhD

Sharon Schuman, PhD

2:15 – 2:30 Questions and Answers

Monday, June 28, 2015, *continued*

2:30 – 3:30 **Fundraising Workshop**

Moderator: *Laura Hays, PhD*

Lorraine McQueen and Cynthia Vandermeys (FA Parents)

3:30 – 3:35 Transition to Support Group

3:35 – 5:05 **Support Group for Parents: Family Affairs** (Nancy's Place), *Nancy Cincotta, MSW, MPhil*

5:05 – 5:30 Free time

5:30 – 6:50 Dinner

6:50 – 7:30 Wish Boats Launch (Pond)

7:30 – 7:40 Preparation for Celebration

7:45 – 10:00 Celebration

Tuesday, June 30, 2015 **Fun and relaxing activities planned by Camp Sunshine throughout the day!**

8:00 – 9:00 Breakfast

10:00 – 11:30 **Support Group for Adults with FA and Parents: Looking Forward** (Nancy's Place)

Nancy Cincotta, MSW, MPhil

12:00 – 1:00 Lunch

5:30 – 6:50 Dinner

Wednesday, July 1, 2015

8:00 – 9:00 Breakfast

11:00 am Families check-out