



Meeting for Adults with FA

Sept 26-29, 2018

Wednesday, September 26

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| 3:00 pm – 4:00 pm <i>Sequoia Foyer</i> | Room Check-in and Meeting Registration |
| 4:00 pm – 4:15 pm <i>Bay Laurel North</i> | Welcome and Introductions <i>Mark Quinlan, Executive Director, Fanconi Anemia Research Fund, Eugene, OR</i> |
| 4:20 pm – 5:00 pm | Icebreaker |
| 5:10 pm – 6:25 pm <i>Sequoia 3 & 4</i> | Support Group: Family Introductions, A Time to Share Your FA Story (adults with FA & their guests) <i>Nancy Cincotta, MSW, MPhil, Camp Sunshine, Casco, ME</i> |
| 6:30 pm – 7:30 pm <i>Orchid Terrace</i> | Dinner |

Thursday, September 27

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| 7:30 am – 8:30 am <i>Orchid Terrace</i> | Breakfast |
| 8:45 am – 9:00 am <i>Bay Laurel North</i> | Welcome and Keynote Address <i>Matt Pearl, Eureka, MO</i> |
| 9:00 am – 9:50 am <i>Bay Laurel North</i> | Overview of Research Opportunities: |
| 9:00 am – 9:15 am | National Cancer Institute: Inherited Bone Marrow Failure Syndromes Cohort Study <i>Blanche P. Alter, MD, MPH, FAAP, National Cancer Institute, Bethesda, MD</i> |
| 9:18 am – 9:33 am | Early Detection for Head and Neck Squamous Cell Carcinoma in Fanconi Anemia <i>Eunike Velleuer, MD, Children's Hospital Neuwerk, Moenchengladbach, Germany</i> <i>Ralf Dietrich, Executive Director, Fanconi Anemia Patients' Organization, Germany</i> |
| 9:35 am – 9:50 am | Cutaneous Findings in Fanconi Anemia <i>Christina Boull, MD, University of Minnesota, Minneapolis, MN</i> |
| 9:50 am – 10:05 am | Break |
| 10:10 am – 10:50 am <i>Bay Laurel North</i> | Building the FA Registry and Biorepository <i>Sudhir Borgonha, MD, Translational Science Director, Fanconi Anemia Research Fund</i> |
| 10:50 am – 11:00 am | Q & A |
| 11:05 am – 11:45 am <i>Bay Laurel North</i> | Sun Protection for People with FA (& everyone else too!) <i>Christina Boull, MD, University of Minnesota, Minneapolis, MN</i> |
| 11:45 am – 11:55 am | Q & A |
| 12:00 pm – 1:00 pm <i>Orchid Terrace</i> | Lunch |

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| 1:05 pm – 1:45 pm <i>Bay Laurel North</i> | A Researcher's Perspective: What We Learn by Studying Samples from FA Patients <i>Agata Smogorzewska, MD, PhD, The Rockefeller University, New York, NY</i> |
| 1:45 pm – 1:55 pm | Q & A |
| 2:00 pm – 2:40 pm <i>Bay Laurel North</i> | Mental Health for Adults with FA (and Those who Love Them) <i>Julia Kearney, MD, Memorial Sloan Kettering Cancer Center, New York, NY</i> |
| 2:40 pm – 2:50 pm | Q & A |
| 2:50 pm – 3:00 pm | Break |
| 3:05 pm – 4:25 pm <i>Sequoia 3 & 4</i> | Support Group: Living, Coping, Thriving and Surviving FA (adults with FA only) <i>Nancy Cincotta, MSW, MPhil</i> |
| 4:30 pm – 6:00 pm <i>Bay Laurel Central/South</i> | Scientific Symposium Opening Session- FA: Past, Present & Future Directions <i>Stella Davies, MBBS, PhD, Cincinnati Children's Hospital, OH</i> <i>Grover Bagby, MD, Oregon Health & Sciences University, Portland, OR</i> <i>Mary-Beth Johnson, Portland, OR</i> <i>Alan D'Andrea, MD, Dana-Farber Cancer Institute, Boston, MA</i> <i>Sean & Allison Breining, Saint Paul, MN</i> <i>John Wagner, MD, University of Minnesota, Minneapolis, MN</i> <i>Isis Sroka, PhD, Fanconi Anemia Research Fund, Eugene, OR</i> <i>Sudhir Borgonha, MD, Fanconi Anemia Research Fund, Eugene, OR</i> |
| 6:30 pm | Optional group outing (adults with FA and their guests) |

Friday, September 28

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| 7:00 am – 8:30 am <i>Bamboo Garden</i> | Breakfast |
| 8:50 am – 9:30 am <i>Bay Laurel North</i> | Good Nutrition, Good Foods, and Helpful Nutrients for Adults with FA <i>Donna Behlke, MS, RDN, LD, Iowa City, IA</i> |
| 9:30 am – 9:40 am | Q & A |
| 9:40 am – 10:00 am | Break |
| 10:05 am – 11:05 am <i>Bay Laurel Central/South</i> | Scientific Symposium- Head and Neck Squamous Cell Carcinoma panel <i>John Wagner, MD, University of Minnesota, Minneapolis, MN</i> <i>Joel Greenberger, MD, UPMC Hillman Cancer Center, Pittsburgh, PA</i> <i>Carter Van Waes, MD, PhD, NIDCD/NIH, Bethesda, MD</i> <i>Ruud Brakenhoff, PhD, Amsterdam UMC, Netherlands</i> |
| 11:10 am – 12:25 pm <i>Sequoia 3 & 4</i> | Support Group: Fanconi Anemia: A Family Affair, Ever-changing Dynamics (adults with FA and their guests) <i>Nancy Cincotta, MSW, MPhil</i> |
| 12:30 pm – 1:40 pm <i>Bamboo Garden</i> | Lunch |
| 12:30 pm – 1:40 pm <i>Sequoia 3 & 4</i> | Support Group for Partners (Partners of adults with FA only. Bring your lunch) <i>Nancy Cincotta, MSW, MPhil</i> |

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| 1:45 pm – 2:10 pm | Fundraising |
| <i>Bay Laurel North</i> | <i>McKenna Knapp, MEd, Philanthropy Director, Fanconi Anemia Research Fund, Eugene, OR</i> |
| 2:10 pm – 2:20 pm | Q & A |
| 2:25 pm – 3:05 pm | Optimizing the Health of Adults with Fanconi Anemia |
| <i>Bay Laurel North</i> | <i>Margaret L. MacMillan, MD, Fanconi Anemia Comprehensive Care Program, University of Minnesota, Minneapolis, MN</i> |
| 3:05 pm – 3:15 pm | Q & A |
| 3:15 pm – 3:25 pm | Break |

3:25 pm – 4:55 pm **FARF Tank**
Bay Laurel Central/South

5:00 pm – 6:15 pm **Support Group: Fanconi Anemia: a Personal Journey (*adults with FA only*)**
Sequoia 3 & 4 *Nancy Cincotta, MSW, MPhil*

6:30 pm – 7:25 pm **Support Group for Parents (*parents of adults with FA only*)**
Sequoia 3 & 4 *Nancy Cincotta, MSW, MPhil*

7:00 pm – 7:15 pm **Group Photo of Adults with FA**
Location TBA

7:30 pm – 9:30 pm **Symposium Banquet**
Bay Laurel Central/South *With presentation of the 2018 Amy Winn and Christopher T. Byrd Award for Adults with FA*

Saturday, September 29

7:00 am – 8:30 am **Breakfast**
Bamboo Garden

10:00 am – 11:30 am **Reflections and Resilience: Growing Forward (*adults with FA and their guests*)**
Sequoia 3 & 4 *Nancy Cincotta, MSW, MPhil*

12:00 pm **Checkout**
(unless you're staying an extra day)

12:00 pm – 1:30 pm **Lunch**
Bamboo Garden

12:45 pm – 2:00 pm **Remembering Those We've Lost (*Optional, informal group.*)**
Sequoia 3 & 4 *Nancy Cincotta, MSW, MPhil*

Scientific Symposium
See Symposium agenda for details

7:30 pm – 9:30 pm **FAMily Dinner**
Bay Laurel North *Adults with FA and their guests are welcome to attend*