

Go, Camp Sunshine!



FARF brings FA families together at 26th annual meeting in Casco, Maine

In July of 1991, more than 100 FA parents and children attended the very first “FA Family Symposium” in Washington, D.C. This gathering marked the beginning of what would become a cornerstone of the FA community: an annual meeting of individuals with FA, their families, and physicians and researchers with the purpose of forming connections and improving the lives of those affected by FA.

Twenty-six years later, in June 2017, nearly 230 people with FA, family members, and FA experts gathered at Camp Sunshine in Casco, Maine for five days of educational sessions, support groups, and irreplaceable bonding

opportunities. Fifty-two FA families from four countries attended. Among this group were 53 individuals with FA (including 14 adults) ranging in age from one year to 38 years. In addition, more than 100 wonderful Camp Sunshine volunteers and staff worked hard to ensure that the FA Family Meeting ran smoothly and successfully.

Each year, expert scientists and clinicians share findings from their research and updates in treatment protocols. This year, 14 speakers gave updates on transplantation (p. 4), endocrine issues (p. 9), nutrition, gene therapy (p. 1), TGFβ inhibitors in FA treatment, dermatological care (p. 10), head and neck cancer treatment,

fundraising, and currently funded FARF research and clinical trials (p. 3).

Additionally, those with FA were invited to participate in a number of

“ Words cannot describe our experience. It’s what we look forward to every year. ”

research opportunities throughout the week, including oral cancer screenings, dermatological screenings, and the



52

families



4

countries



14

speakers



53

people with FA

“Inspiring, and a fantastic place for making life-long friends and connections. I always leave wishing I had just one more day at the camp with these inspiring families and absolutely incredible volunteers.”



Fun fact: 8% of this year's FA campers are named Eli!

National Institutes of Health's Inherited Bone Marrow Failure Syndromes Study. All of this is made possible by fundraising dollars. Following the meeting, one parent remarked: "It is so awesome knowing that our family fundraising efforts are translating into progress toward a cure!"

Apart from scientific sessions, attendees are invited to participate in a number of support sessions with

Camp Sunshine Psychosocial Director Nancy Cincotta, MSW, MPhil. These support sessions are geared to specific groups such as adults with FA, spouses, children with FA, siblings, and parents (including a special group for bereaved parents).

Of course, the Family Meeting would not be complete without the many social activities such as swimming, mini golf, the ropes course, and rock

climbing wall, as well as special events like karaoke night, the talent show, masquerade ball, and sleep out.

The FA Research Fund would like to thank the Camp Sunshine team for their years of excellent coordination and tremendous job hosting Fanconi Anemia week. In the words of one attendee, "it's better than Disneyland! We wouldn't miss it and hopefully we'll never have to!"

What is the Family Meeting?

The Family Meeting is a unique event that allows families registered with FARF to attend presentations by researchers and physicians who are active in the research and treatment of Fanconi anemia (FA), to attend support groups for help in coping with the disease, to voluntarily participate in FA research projects, and to connect with other families affected by FA. Camp Sunshine volunteers provide a fun-filled program for children with FA and their siblings.

What is Camp Sunshine?

Camp Sunshine provides retreats combining respite, recreation and support, while enabling hope and promoting joy, for children with life-threatening illnesses and their families through the various stages of a child's illness. The program is free of charge to families and includes on-site medical and psychosocial support. Bereavement sessions are also offered for families who have experienced the death of a child. Learn more at www.campsunshine.org.

Who can go?

Anyone with FA and his/her family are welcome and invited to apply. There is no age limit. People from all countries are welcome. Newly diagnosed families are especially encouraged to apply. There is no cost to attend other than travel expenses. Travel scholarships are available through FARF to assist with these expenses.

How do I apply?

The FA Research Fund sends out an invitation via email in January of each year. Information will also be posted at www.fanconi.org and on the FARF Facebook page. You can also contact Family Services Director Marie Sweeten (marie@fanconi.org) with any questions. The FA session usually takes place in late June. ■

