

Dear Family and friends,

January 3, 1991, was the beginning of an incredible journey filled with so many mixed emotions. The day our daughter was born should have been filled with ONLY pure joy. After Jeff followed Carrie to the NICU, watching as she was attached to tubes, wires, and oxygen, he came back to join me. Together as a couple, we shared our shock, love, fears, amazement, and disbelief. Wondering how and what we would say, our first parental decision was filled with trepidation as we called our own parents to share the news. We could not have anticipated what would happen over the next 4 1/2 years, specifically when Carrie was re-diagnosed, when we chose to go through transplant, and certainly not when faced with her impending death at the young age of 8.



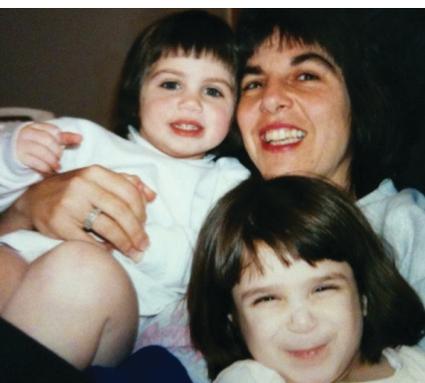
It never ceases to amaze us, what with all of the research and how far the world of Fanconi anemia has come, that we still are not able to save all of our FA children from death-- even in 2016! So many more FA children now survive transplant, only to later face cancer, leukemia, and more. Each year we are filled with more hope, as our efforts raise funds for further research, for which WE, the FA families, must be responsible.

This past summer, Jeff and I were filled with pride, excitement and joy, as our youngest daughter (Carrie's only sibling), Kira, received her Bachelor of Science degree in Nursing! The icing on the cake was her passing her licensing exam, becoming a Registered Nurse, and earning a position at her first choice pediatric hospital. We know Carrie is watching over Kira with delight and awe.

We know many of you have faced your own challenges this year, and we pray for you and your families to have the strength to carry on. We understand that some days are harder than others. May you have more positive days from this point forward, and a very healthy, happy 2017.

Please, if you are able, find it in your heart to make a donation to the Fanconi Anemia Research Fund, so that no other family has to face the loss of their child to this devastating disease. We sincerely appreciate your kindness, in honoring the memory of our angel, Carrie.

Blessings,
Beth, Jeff and Kira Janock



2016 FARF HIGHLIGHTS

The Fund hosted the **28th Annual Scientific Symposium** in Bellevue, Wash., **gathering 190+ researchers and clinicians**, Fund board members, and family representatives **from 17 countries**.

In 2016, FARF awarded more than **\$1.9 million in new research grants**.

The 25th annual **FA Family Meeting** brought together **51 families from four countries** for a week of festivities, bonding activities, research opportunities, psychosocial support, and informative sessions at Camp Sunshine in Casco, Maine.

Together, **Families and donors have contributed nearly \$2 million** in 2016 to date to fund scientific research and family services!

FARF co-sponsored the **7th International FA Gene Therapy Working Group** meeting in Madrid, Spain, attended by more than **40 scientists and clinicians** from Europe, South America, and the United States.

The Fund has been **ranked "exceptional"** (four stars) by **Charity Navigator**, the largest independent reviewer of charitable organizations in the US.

MISSION

To find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide

*The Fund is a 501(c)(3) tax-exempt organization
All donations are tax deductible*

For every \$100 donated, \$71 goes to research, \$12 goes to family support and education services, \$8 goes to fundraising efforts, \$9 goes to administration

HOW TO HELP

1 Donate online at www.fanconi.org

2 Send a check to Fanconi Anemia Research Fund at: 1801 Willamette Street, Suite 200 Eugene, OR 97401

3 Call FARF at 541-687-4658