THE FA FAMILY NEWSLETTER

Newsletter Number 2
June, 1986

c/o Frohnmayer
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Welcome Again!

Forgive our delay in communication. We have had serious health problems this year, as described more fully on page 7. We deeply regret our lack of responsiveness to questions raised by some of you, but know you will understand.

The first newsletter was sent to approximately 30 known families affected by Fanconi's Anemia. We also mailed to some 75 physicians and other specialists. The response has been gratifying.

We have since heard from 11 more families. Those who have agreed to be listed since our first newsletter are noted on page 8. All members of our support group who have agreed to share their names with others, including new families, are listed on pages 9 and 10. We really encourage you to contact each other!

* SUCCESSFUL FUNDRAISER SUPPORTS FA RESEARCH

Tony and Theresa Montella report a splendidly successful fundraising benefit on behalf of their daughter Tara and other Fanconi Anemia victims. The following report appeared in the Staten Island Sunday Advance , March 23, 1986:

STATEN ISLAND SUNDAY ADVANCE
SUNDAY, MARCH 23, 1986

Tara's show

With perseverance and sufficient funds, the faulty gene causing the condition called aplastic anemia which holds Tara Montella of Tottenville and others like her in its grip, may one day be corrected by treating the bone marrow with a new technique called gene thereapy.

The South Shore Rotary Club is helping to bolster funds for research of the disease — currently underway in Rockefeller University — with a fashion show and dinner honoring the 8-year-old, April 8 in the Island Townhouse, 23 Nelson Ave., Great Kills.

According to doctors, the clinical manifestations of the disease differ with each patient, but the most common physical features are pigmentation abnormalities and short stature. In addition, a variety of severe malformations may be present at birth, such as absent or underdeveloped thumb(s), as well as kidney, heart, gastrointestinal and genital abnormalities, among others. Available methods of treatment may prolong life for a few years, but in most cases, there currently is no way of curing the disease, according to researchers.

The April 8 benefit, to be staged by Garber's of New Dorp, will feature men's, women's and children's fashions.

Tickets for the event are $25 per person and include dinner and the fashion show. Reservations may be made with **John Shall**, chairman, at 447-0507, after 6 p.m. and weekends.

The event netted more than $12,000 which has been donated to Dr. Arleen Auerbach at the Rockefeller University for research in Fanconi Anemia. We congratulate the Montellas and the generosity of the South Shore Rotary Club for this wonderful success!

See also p. 10. !!!

An update from our adviser, Dr. Arleen Auerbach (June, 1986):

THE ROCKEFELLER UNIVERSITY
1230 YORK AVENUE · NEW YORK, NEW YORK 10021

Dear FA Families:

I appreciate this opportunity to thank all of you for your cooperation with the International Fanconi Anemia Registry, and to let you know that we welcome letters with information as to how your children are doing.

One hundred and sixty-two patients diagnosed as affected with FA have had special cytogenetic studies to confirm the diagnosis, and are now entered in the Registry. A diagnosis of FA has been ruled out by these studies in 60 patients with certain clinical findings similar to FA. A detailed statistical analysis of the clinical features of these two groups of patients is currently being carried out. Interestingly, at the time of diagnosis, 30% of the patients analyzed had both aplastic anemia and birth defects, 41% had only aplastic anemia, 16% had only birth defects, and 7% had no clinical signs of FA, but had the special chromosome testing done because they had affected siblings. We have approximately equal numbers of males and females in the Registry. A preliminary analysis of our data by sex of the patient shows few differences in the clinical picture. Males have some increased chance of having certain of the birth defects associated with the syndrome, such as malformations of the genitalia, heart and short stature.

Analysis of all the data in the Registry should provide a better picture of the range of clinical variation in the syndrome, and a better idea of how to make an early diagnosis in children with certain physical signs of the disease.

Arleen D. Auerbach

Arleen D. Auerbach, Ph.D.
The Rockefeller University
1230 York Avenue
New York, New York 10021

We received the following communication from the recently-established Aplastic Anemia Foundation of America. Write if you can!

Aplastic Anemia Foundation of America

P.O. Box 22689
Baltimore, Maryland
21203

301 955-2803

May 21, 1986

Dear Friend:

The Aplastic Anemia Foundation of America needs your help. The Foundation is currently working for Congressional approval of National Aplastic Anemia Awareness Week. The week of December 1 through 7, 1986, will be one of nationwide activity designed to educate the public about aplastic anemia. Increased public awareness of the disease will provide a greater base for support to help fight and conquer aplastic anemia.

Your representatives in Washington will support the resolution creating Awareness Week if they hear from friends such as you. Please take the time to write letters to both your Senators and Congressmen expressing your interest in approval of the Week. The letters need not be long or formal; short, personal notes are most effective. Please include the following sentences in the appropriate letter (addresses below) to help your Congressmen identify the resolution.

"I support Senate Joint Resolution 329, designating December 1-7, 1986 as National Aplastic Anemia Awareness Week."

or

"I support House Joint Resolution 611, designating December 1-7, 1986 as National Aplastic Anemia Awareness Week."

If you have friends who are willing to write in support of these resolutions, please ask them to do so.

Thank you for your continued support and efforts on behalf of the Aplastic Anemia Foundation of America. With help such as yours, we will be able to conquer aplastic anemia.

Sincerely,

Lyle L. Sensenbrenner, M.D.
President, AAFA

Senator _____
Senate Office Building
Washington, D.C. 20510

Dear Senator:

Representative _____
House Office Building
Washington, D.C. 20515

Dear Congressman:

Scores offer to donate bone marrow for Frohnmayer girls

By KATHIE DURBIN
of The Oregonian staff

More than 100 people have offered to be tested as possible bone-marrow donors in response to news accounts this week describing the plight of Katie and Kirsten Frohnmayer, who suffer from a rare, potentially fatal bone-marrow condition.

"We've had by now several dozen calls to this office," Oregon Attorney General Dave Frohnmayer, the girls' father, said Thursday. "They're just aghast; they want to know how they can help."

Frohnmayer said he had referred all calls to the Hemapheresis Department of the American Red Cross in Portland, which does the necessary blood and tissue-typing tests to find compatible bone-marrow donors.

He said he was "choked up" to learn that virtually all two dozen employees in his department's Portland office had signed up to be tested for tissue type and become regular blood donors.

Because of the high odds against finding a non-relative with compatible tissue, Frohnmayer said, "The chance that we would be helped is slim. But the chance that someone else would be helped is great."

The Red Cross has agreed to perform the $500 tissue-typing test for anyone who agrees to become a regular blood donor. The bone marrow donor will not be charged for the tests.

At the Frohnmayer home in Eugene, Lynn Frohnmayer said she had received "just a lot of very thoughtful phone calls, people expressing sympathy and empathy." Others touched by the Frohnmayers' situation have called Dave Frohnmayer's parents in Medford.

Both Katie, 7, and Kirsten, 13, suffer from Fanconi's syndrome, an inherited condition in which chromosomes in the blood are extremely fragile and susceptible to breaking. The Frohnmayers discovered 22 months ago that Kirsten had developed a form of aplastic anemia as a result of the condition. Two weeks ago they learned through a bone-marrow biopsy that Katie, who has suffered from mysterious abcesses, sores and pains since early March, may have myeloid leukemia.

Both Katie and Kirsten are under the care of Dr. Robert C. Neerhout, chief of pediatrics at Oregon Health Sciences University.

The preferred treatment for both girls is a bone-marrow transplant, but finding a compatible donor has been complicated by the fact that they have inherited an extremely rare tissue antigen from their father's side of the family.

The family has launched a search for distant relatives whose tissues contain the rare antigen. This week 23 of Frohnmayer's distant relatives, found through an exhaustive search of his family tree, were tested for tissue type to see if any of them had the rare antigen. The family hopes to get the test results soon.

Additional details on Page D2.

KATIE FROHNMAYER
Seven-year-old at risk of leukemia

KIRSTEN FROHNMAYER
Suffers from aplastic anemia

This news article from the May 5, 1986 Oregonian explains some of our health crises that have delayed this newsletter. Kirsten is now on androgen (oxymethalone) therapy and has had a strong and heartening response. (Since mid-March her hemoglobin has climbed from 4.4 to 8.5). Initially she was also on prednisone but this has since been discontinued. Platelets have gone from the 5-10,000 range to the 50-74,000 range. Side effects are minor so far and under control, and we hope that dosages soon can be tapered.

Katie's mysterious symptoms (wounds that would not heal, skin and painful bone conditions that mimicked infections, and spiking fevers) seem presently responsive to steroid (prednisone) therapy. We are still consulting physicians on the relationship of this unusual syndrome to FA or leukemia. This et of symptoms has never, to our knowledge, been associated with Fanconi Anemia.

Our bone marrow donor search in the extended family has located others who have the rare antigen (A-3,B-39,DR-7) which both Katie and Kirsten need, but so far not in a close enough match to be of help. A side benefit, though, has been the more than 50 cousins Dave never knew he had who cheerfully agreed to be tested as potential marrow donors.

We are thankful for the presently stable time we have to enjoy summer with active, happy children; to continue our donor search; and to catch our breath. We know now what it really means to treasure each day.

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In conferring with our advisor, Dr. Arleen Auerbach, and in talking with families in our support group, we have learned that Fanconi Anemia can manifest itself in very different ways. Although aplastic anemia is usually diagnosed between the ages of five and nine, there are notable exceptions.

Gail Ceresa, age 36 and her sister Paula Ceresa, age 32, are both diagnosed as having inherited the Fanconi Anemia genes. Yet neither sister has aplastic anemia and both have been able to lead very active, productive lives. Paula's blood counts are in the "low normal" range; she describes herself as "very healthy" and states that she has "never had any physical problem at all" from FA. Paula enjoys a very active, happy life. She teaches second and third grades and participates in a wide variety of sports, including golf, snow and water skiing and tennis.

Gail's white cell count has dropped during the last three years and she has experienced several staph infections. She has also had gynecological problems and minor skin cancer which was "only superficially invasive". Gail states that she and her sister have always been encouraged by their parents and doctors to lead as normal a life as they possibly can. However, she feels that it would be unwise to ignore potential health problems, and states that she has her condition monitored on a regular basis.

Gail stresses the importance of maintaining a positive attitude. She believes that "things can be overcome by your own positive attitude. It won't make your illness go away, but a negative attitude can only add to the problem. Continue to give love and support to others; this can keep you going. Don't turn away from people who are looking to you for help." Gail is a Home Economics teacher for pupils in the 5th through the 8th grades. The fact that both sisters chose the teaching profession "shows how we feel about helping other people". Both Paula and Gail would be happy to correspond or communicate by telephone with other families affected by this illness.