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 therapy.

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 447-0587, 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!
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, 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!

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,

[Signature]

[Name]

President, AAFA

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<td>Senate Office Building</td>
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<td>Washington, D.C. 20510</td>
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Dear Senator:

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Dear Congressman:
Seven-year-old at risk of leukemia

KATIE FROMHAMEYER

Seven-year-old at risk of leukemia.

KATIE FROMHAMEYER

Scores offer to donate bone marrow for Fromhamyer girls.
 Abramov, Donna & Peter  
10 Simmons Drive  
East Islip  
New York 11730  
516-277-3628  

Delvalle, June A.  
Registered Occupational Therapist  
29 Blackthorn Lane  
White Plains  
New York 10606  
914-761-3504  

Burns, Larry & Sheila  
713 Lockhart Gen. Del.  
Duenweg  
MO 64841  
417-624-7059  

Gannon, Ms. Susan T.  
10 Rolling Ridge Rd.  
West Milford  
N.J. 07480  
201-728-3823  

Campbell, Joseph & Joahn  
P.O. Box 25  
Starkville, MS 39759  
601-324-3605  

Gardiepy, Mr. & Mrs Eugene  
424 East "D" Street  
Iron Mountain  
Michigan 49801  
906-774-0205  

Cereso, Gail  
6B Cedar Hollow  
Linwood, New Jersey 08221  
609-927-1327  

Grieco, Patricia & Joseph  
9 Crystal Lane  
East Northport  
New York 11731  
516-368-5778  

Cereso, Paula L.  
110 Turnwood Lane  
Winston-Salem, N.C. 27104  
919-768-9282  

Halteh, Ousama & Souha  
491 Richmond Dr. #2  
Millbrae  
CA 94030  
415-692-5432  

Connolly, Mrs. Kathleen  
12 Hubbardston Rd.  
Dorchester, Mass 02125  
617-825-5845  

Magill, Roberta & Glenn  
124 Cedarwood Drive  
Chillicothe, Ohio 45601  
614-775-3833  

Curry, Bradley & LeaAnn  
51 Oakridge Drive  
Lanesville, Indiana 47136  
812-952-3075 (Home)  
812-587-0765 (Her work)  
812-945-6623 (His work)  

Johnston, David & Martha  
6515 Arkansas Ave.  
Hammond, In. 46323  
219-844-5785  

Davis, Christine  
1120 Carmelita Ave.  
Sacramento, Calif. 95838  
916-927-7293  

Leontic, Mr. & Mrs. Alfred  
P.O. Box 4113  
Santiago  
CHILE  

Deeks, Dahne L.  
131 King Street  
Nutley, N.J. 07110  
201 661-4213 (Home)  
201-751-5555 (Work)  

Montella, Anthony & There  
38 Weiner St.  
Staten Island  
New York 10309  
718-948-8942  

Licari, Gayle  
Dee Dee Doultt  
40 Roberts Road  
Newport  
North Carolina 28570  
919-223-3110  

Logsdon, Lauri & Bruce  
614 Foxfire Circle  
Jacksonville, N.C. 28540  
919-455-1448  

MacLellan, Charles & Moir  
16 Fead St.  
Orangeville  
Ontario  
L9W1A7  
Canada  
519-941-8707
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.