THE FA FAMILY NEWSLETTER
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Newsletter Number 1
Winter, 1985

WELCOME!

This is a first attempt at an informal newsletter. Many of you expressed the desire to communicate in this way, and to share family experiences.

Our apologies for the delay in getting out this first issue. We waited to hear back from as many families as possible, and then got caught by the usual holiday rush.

Your contributions to the newsletter are essential. This is your vehicle for communicating and, if it is to succeed, it must be a shared project. We hope others will actually take responsibility for producing future issues.

A final disclaimer. We are not medical experts, and we cannot dispense medical advice. Any thoughts related to medical care which you may hear through your association with other FA families should always be discussed with your own doctor.

ITEMS

NOTED RESEARCHER VOLUNTEERS TO HELP AS ADVISOR FOR FA SUPPORT GROUP

Arleen D. Auerbach, Ph.D. of the Rockefeller University has generously agreed to lend assistance as an advisor to our informal group. We are deeply grateful.

Dr. Auerbach's research work on Fanconi Anemia is well known and highly respected. You or your physician may have seen her recent work on prenatal detection of FA (Pediatrics Vol. 76 No. 5 November, 1985). Dr. Auerbach has sent a brief research update reprinted inside on page 3.

NOVA SPECIAL ON GENE THERAPY

In November, PBS stations across the country broadcast a fascinating hour-long NOVA special on the potential of gene therapy. Watch for re-runs. We may be able to secure permission to get VCR copies. Write if you have an interest in viewing this program. We know that gene therapy for FA is probably many years away, but it is exciting to know of so many scientific breakthroughs.

GENETIC RESEARCH ON FA

As Dr. Auerbach's letter indicates, the ultimate goal is to "learn about the molecular basis for the disease." In addition to Dr. Auerbach's work, we are aware of a research group at Stanford University, and researchers in Canada and France who are attempting to isolate the gene or genes that cause the problems of FA. While therapies based on those discoveries may be many years away, it is heartening that this rare disorder is the subject of such distinguished research.

Seventy-fifth Anniversary

THE ROCKEFELLER UNIVERSITY HOSPITAL

1230 YORK AVENUE · NEW YORK, NEW YORK 10021-6399

An International Registry of all known Fanconi anemia (FA) patients has been established at The Rockefeller University. We are trying to obtain information on as many patients with this syndrome as possible. The information is provided by physicians treating patients with FA or by examination of patients referred for study by us at The Rockefeller University Hospital. The RU Hospital is a clinical research facility in which only patients with diseases being investigated by RU faculty members are evaluated. We believe that by gathering detailed clinical, genetic and laboratory data on a large number of patients with this rare disorder, we will be able to address questions relating to diagnosis, the natural history of the disease, prognosis, and treatment. Our ultimate goal is to learn about the molecular basis for the disease.

Data from approximately 100 carefully studied patients in the Registry are currently being analyzed. Preliminary findings indicate that the clinical diversity of FA patients is much more widespread than previously recognized. Patients may have severe, mild, or no birth defects. The anemia most commonly begins between the ages of 5 to 10 years, but may begin as early as two months, or as late as 30 years of age. This diversity makes clinical diagnosis of FA difficult to establish, and patients and their siblings should have special cytogenetic testing to confirm their diagnostic status.

We have recently developed a laboratory test for prenatal diagnosis of FA, which can be performed in either the first trimester of pregnancy, utilizing cells obtained by chorionic villus biopsy, or in the second trimester, by amniocentesis. We have now studied approximately 40 pregnancies at risk for FA, and there have been no apparent misdiagnoses.

We welcome correspondence from FA families with questions about research on this syndrome.

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

Eighteen families affected by FA have given us permission to share their names with others. These families are listed below. However, this newsletter is being sent to the nearly 30 families who responded initially. Even if you did not want your name disclosed, you may still wish to contact a listed family in your geographic area. Note: If you want your name listed in future issues so that other families can contact you, please write your permission. We did not list anyone below who did not return the postcard enclosed in our August 14, 1985 letter. WE REALLY ENCOURAGE YOU TO MAKE CONTACT WITH ONE ANOTHER. It can be very helpful to share feelings and experiences and to know that others are going through the same thing.

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601-324-3605

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