

THE FA FAMILY NEWSLETTER

Newsletter Number 8

July, 1990

C/O Frohnmayer, 2875 Baker Blvd., Eugene, Oregon 97403 Phone (503) 686-0434

FIVE YEAR PLAN DEVELOPED

WELCOME FRIENDS:

This eighth semi-annual newsletter brings reports of exciting progress, as well as an agenda of hard work. We hope your families are doing well. We need your continued active help in new efforts ahead. Keep in touch! (eds.)

We are pursuing a vigorous 5-year plan to attack Fanconi anemia. We want you to know the direction of our latest efforts. Your help is obviously essential!

Our objective is to insure that the gene or genes which cause Fanconi anemia will be identified and that a cure or effective life-extending treatments will be available within five years. Here are some of the steps now underway:

1. Progress reports have been received from numerous scientific projects already supported by Fanconi Anemia Research Fund, Inc. Steady progress is evident and we may be approaching a major breakthrough! Dr. Auerbach's letter in this issue (pg. 5) sets forth her latest expectations on the RLFP analysis search for the FA gene.

Another Fund grant scientist, Robb Moses, M.D. of the Baylor College of Medicine, reported in April, 1990 as follows: "[M]y laboratory has made encouraging progress in looking at the specific DNA repair defect in FA cells using a plasmid DNA repair assay which we are developing. I am quite encouraged that this may be a new starting point for us to approach the biochemical defect in Fanconi anemia."

INSIDE

Family Fundraisers, p. 2

Growth factor trials, p. 3

Report from Arleen Auerbach, Ph.D., p.5

Treating chicken pox, p. 7

Grief and loss, pgs. 8, 9 & 10

From our families, pgs. 10 & 11

New support group families, pgs. 12,13

FA symposium questionnaire, last pg.

2. In the very near future we will re-contact the 2500 donors from all parts of this nation who first responded so generously to our fundraising appeal last year. We will send donors a brochure, informing them of progress made during the past year because of their generosity. We will request, again, a contribution to the FA Research Fund. We are

hopeful that this appeal will bring an enthusiastic response. At yearly intervals, we will recontact all prior fund contributors in the order that their responses - thanks to your efforts - were received.

3. A second fundraising brochure, informing new donors about FA and our cause, is now in the final stages of design and production. We will send you a copy of this brochure shortly. Please tell Linda Solin how many copies you will need for your fundraising purposes. You can write to Linda at the following address:

Fanconi Anemia Research Fund, Inc.
66 Club Road Suite 390
Eugene, Oregon 97401

Linda can be reached by telephone at (503) 687-4658.

4. The Board of Directors of the Fanconi Anemia Research Fund, Inc., has created a part-time paid staff position to coordinate fundraising and outreach efforts. Many thanks to Linda Solin for taking on this responsibility. Linda's knowledge of FA, and her superb organizational skills are great assets for us. (Linda's address and phone number are listed above).

5. We are now planning actively a second annual worldwide FA scientific workshop for autumn, 1990. Other affiliated FA support groups are now beginning similar encouraging workshop efforts.

Special thanks to Dr. Giovanni Pagano of our family network in Naples, Italy. Giovanni has organized a meeting of leading Italian FA researchers as this newsletter goes to press.

6. One last point deserves special emphasis. We do not have enough funds to continue essential research! Requests for dollars to continue vital projects already far exceed our resources. **We need your help now! Please contribute and involve yourselves in fundraising projects.**

FAMILIES CONTINUE TO RAISE BADLY NEEDED RESEARCH DOLLARS

Since our fundraiser began in February, 1989, forty-five families have raised an impressive \$374,098. Many thanks to all of you for the hard work, long hours and tremendous effort this represents.

Barry and Benita Bruster raised funds to offset their daughter's out-of-pocket medical expenses during a successful bone marrow transplant in Seattle. They contributed their excess funds, \$33,577.32, to the Fanconi Anemia Research Fund, Inc. We are deeply grateful for this very generous, incredibly helpful contribution!

Since our last newsletter went to press, Bill and Jackie Lucarell have raised an additional \$4,353.12 for a total of \$29,697.87. They continue to impress us with their innovative fundraisers, and their determination to do everything they can to support this effort.

Robert and Linda Scullen have now raised an incredible \$36,906.25, an increase of \$12,406.25 since our last newsletter! The effort it takes to raise such an impressive amount is tremendous indeed. We salute and thank you deeply for your commitment to this cause.

Janice and Ed Duffy raised \$1,250 for our research fund. They did a previous fund-raiser and sent the proceeds directly to Dr. Arleen Auerbach. Fredi and Ron Norris have contributed a very helpful \$1,000 to our effort. Sandy and Marc Weiner raised \$2,625 since our last communication with you, a total of \$4,395 since their fundraising efforts began. Donna Williams' Sunday School class gave \$600 to our research fund. They held an auction and decided to give half of the proceeds to Donna's cause. The Williams have generated a total of \$2,307 for our Fund.

Lorraine and Kevin O'Connor have now raised

a total of \$4,900.17, an increase of \$465 in the past six months. Pat and Bill Danks have raised \$300 for research, and Lauri and Bruce Longsdon have contributed \$250. All of these efforts bring badly needed financial resources to our Fund, and enable us to support our research projects.

Lynn and Dave Frohnmayer have now raised \$194,220 for FA research. This is a \$9,000 increase since the last newsletter and includes two small, successful grant applications. We have applied for several large grants which were denied. During the next few months we will continue to apply for grants, in addition to conducting a very large mailing to past and new contributors. We are committed to continuing these efforts until a cure is found for this devastating illness.

Each family's capacity to generate research dollars is different. However great or small, each effort will help us *enormously* to reach our goal. FA Research Fund, Inc. is prepared to help each family by sending sample letters, our new brochure, and ideas for raising money. We hope that each and every family will commit to doing its utmost to attack and defeat this killer disease.

NEWS FROM ABROAD

FA family groups are now actively organized in Germany and Italy, thanks to the hard work of Ralf and Cornelia Dietrich and Giovanni Pagano.

Germany

Ralf and Cornelia have located and organized more than 25 families, paid personal visits to many, established scientific advisors and published three well-organized and informative newsletters.

Italy

Giovanni Pagano has developed good publicity about FA efforts in the Italian press. He has located other Italian FA families, and has involved scientists at his own Tumor Institute in FA research. Giovanni organized an Italian national scientific meeting on FA in June in Caserta. We await reports

with eagerness.

Giovanni and Ralf Dietrich met for two days in Germany with scientists and families concerned with FA. Giovanni writes:

"Ralf is a wonderful person and impressed me deeply, with his activity and dedication. We have become like brothers, more than friends....[H]e and I have an enthusiastic agreement and great plans for our future activities."

We are delighted that Ralf and Giovanni plan to contact FA groups in France and Great Britain in the near future. These international efforts are extremely helpful to our mutual cause.

Addresses: Ralf & Cornelia Dietrich
Bockenweg 4
D 4750 Unna-Siddinghausen
Germany

Dr. Giovanni Pagano
A.I.R.F.A.
053/90
Via S. Mandato
50-80136 Naples
Italy
tel. (39)(81)34.77.21

FA THERAPIES: GROWTH FACTORS

Our prior newsletters have reported on research into hematopoietic growth factors (colony stimulating factors) such as GMCSF as possible life-extending therapies for FA patients (Issue # 5, pp 1-2, 10; Issue #7, pp 2-3).

In late May, 1990, Dr. Eva Guinan of the Children's Hospital in Boston reported that clinical trials using GMCSF for FA patients were expected to begin very soon. Dr. Guinan is seeking approximately 12 FA patients who are refractory to androgens or who have not responded to androgen therapy. If you know of a victim in this category, Dr. Guinan would welcome a call from the treating physician at (617) 732-3897.

The FA trials follow a highly successful initial pediatric study of GMCSF for aplastic ane-

mia. Results of this first study have been accepted for publication in the journal Blood.

In the future, Dr. Guinan and her colleagues are hopeful that FA patients can be treated using a promising combination of GMCSF and interleukin 3. However, because of FDA and drug company restrictions, trials may have to be completed for non-FA adult and children aplastic anemia victims before FA victims can be considered. Your editors will work with others to help speed this timetable.

FROM OUR COORDINATOR, LINDA SOLIN

Free Flights May Be Available

Corporate Angel Network (CAN) is a non-profit organization designed to arrange free air transportation for cancer patients. We have negotiated a tentative agreement to work with CAN to provide available seats to FA patients on corporate aircraft being flown on business trips. Financial need is not a requirement. By providing air transportation, CAN hopes to enable patients to obtain optimum treatment for their disease.

The flights are provided for patients (and a parent, or parents if space allows) who are traveling to or from recognized treatments, consultations, or check ups. The patient must be able to board the aircraft unassisted and several other criteria must also be followed. CAN cannot guarantee to find an appropriate flight, but will make every effort to meet patients' needs. If you feel you may qualify for an "angel flight", call Linda Solin at (503) 687-4658 to arrange for a referral.

Welcome Kris Pahle

In conjunction with the University of Oregon, Fanconi Anemia Research Fund will benefit from the placement of a Human Services student. Kris Pahle (pronounced "polly") will join the Fund beginning September 24, 1990 through June 7, 1991.

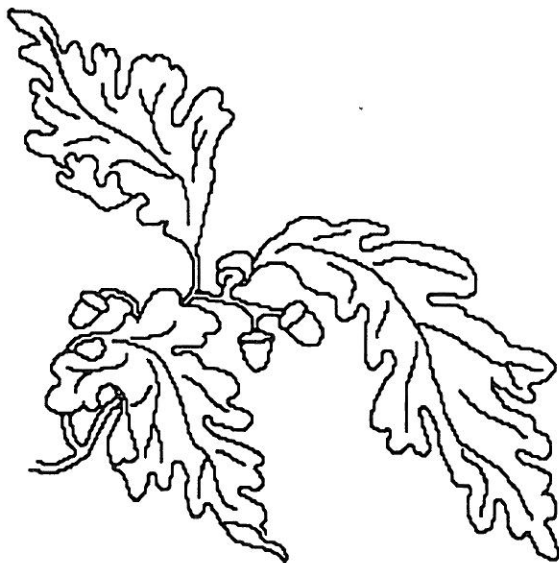
Kris is an avid outdoor sports person. She is a guide for river float trips and has been an aerobics dance instructor for our community college. Her background includes leadership in student government and she has taught sign language as a paraprofessional. She is the mother of a two year old daughter.

Kris looks forward to working with the FA families in the upcoming year.

Frohnmayers Honored

On May 24, 1990, the Oregon Chapter of the Leukemia Society of America, Inc. presented its Service to Mankind Award to Dave and Lynn Frohnmayr in recognition of their work with Fanconi anemia. Dave and Lynn have distinguished themselves nationally in their personal efforts to battle this disease.

The award was presented at a dinner at the Portland Marriott. Proceeds from the event went to support the Leukemia Society's efforts to improve the lives of thousands of children and adults who will have leukemia or a related illness diagnosed this year, and to find a cure for these devastating diseases.





THE ROCKEFELLER UNIVERSITY

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

July 2, 1990

Dear Parents:

As I write to you once again, I am optimistic about our progress in our effort to find the chromosomal location for the Fanconi anemia gene(s). As I have explained in previous newsletters, our linkage studies are a first step toward finding the gene itself. At the present time we have what is called a "strong suggestion of linkage" to a particular chromosome. We have tested 124 DNA markers for linkage to FA; 83 of these have been informative. The vast majority of the informative markers have been clearly negative in linkage analysis tests with FA, and we have been able to exclude linkage of the FA locus to approximately one-third of the genome. One particular chromosomal region has given consistently positive scores for linkage in our set of FA families, in studies in our laboratory over the last eight months. We have not been able to get high enough scores to prove conclusively that we have found the right region. There are several factors that may be causing this problem. One is that there may not be any very informative DNA markers available at the present time for the exact region on the chromosome where the FA gene is located; we are getting positive scores with several probes that are adjacent to each other, but there are large distances between these probes, and thus significant distances between the probes and the FA gene. A second confounding factor may be the existence of more than one FA gene; we may be getting high scores in some families where we have found the correct map location, but our total score would be lowered if the gene were located elsewhere in some of the families. In spite of these problems, we are fairly confident that we know the location of at least one FA gene, and hope to have more conclusive data very shortly.

Also of interest is a program we have recently developed at The Rockefeller University for providing a clinical consultation and work-up for FA patients in the Fanconi Anemia Registry. FA patients (children or adults) are admitted to our research hospital for approximately 5 days. One or both parents can stay in the room with their child, and are provided with meals. Growth hormone and other endocrine studies are done in patients with short stature. A complete hematologic work-up is done, including special studies, in Dr. Alter's laboratory, of in vitro response of progenitor cells to hematopoietic growth factors. Consultations are provided with a geneticist (Dr. Jessica Davis, N.Y. Hospital), a hematologist (Dr. Blanche Alter), an endocrinologist (Dr. Joseph Gertner, N.Y. Hospital), a nutritionist, and others as indicated. The family has an opportunity to become fully informed about all aspects of the disease. Physicians caring for a patient will be notified of the results of all of the tests, and the consultants will continue to be available to offer suggestions as the patient's condition changes. Several patients and their families have already come to New York to be admitted on this protocol, and have felt it was very helpful to them. If anyone is interested in obtaining further information regarding this, please call Mrs. Barbara Adler-Brecher, the geneticist who is coordinating the FA Registry in my laboratory. Her telephone number is 1-212-570-8862.

I wish you all a very pleasant summer.

Sincerely yours,

Arleen D. Auerbach, Ph.D.

GENE THERAPY PROGRESS

The following article from the June 3, 1990 New York Times shows real progress in developing gene therapy technologies. It also demonstrates why our dollars for research are needed to speed discovery of the FA gene! Until the gene is isolated and cloned, this exciting progress will not be of direct help to us.

New Gene Therapy Given Vote of Confidence

By NATALIE ANGIER

In a surprising turn of events, the first proposal to treat children with a severe genetic disease by inserting new genes into their cells has received an enthusiastic vote of confidence.

A Federal subcommittee approved the proposed human gene therapy unanimously on Friday and recommended that the proposal be considered for final approval by a full committee at the National Institutes of Health on July 30.

The vote was a surprise because when the subcommittee first considered the highly experimental therapy at a meeting on March 30, panel members raised so many questions that it seemed the medical and ethical issues would take many months to resolve.

But since then the scientists have significantly altered their proposal. And the speed with which the new therapy is moving through the intricate approval process means that as early as midfall the researchers may be able to start treating children who suffer from an rare immune disorder much like the disease that killed David, the "bubble boy" from Texas.

"I thought we'd get approval, but I never thought it would be unanimous," said Dr. W. French Anderson of the National Heart, Lung and Blood Institute who is an author of the proposal.

Dr. Anderson, Dr. R. Michael Blaese of the National Cancer Institute and their colleagues have identified four children who are potential candidates for the new gene therapy.

The panel that gave its approval on Friday, the Human Gene Therapy Sub-

The approval process moves quickly for a treatment.

committee, a governing body of the National Institutes of Health, asked that several minor modifications be made to the proposal before the summer meeting of the full Recombinant DNA Advisory Committee. Dr. Anderson said the changes would be made.

Dr. LeRoy Walters, chairman of the subcommittee, who is a bioethicist at Georgetown University in Washington, said that while there were no guarantees, the full committee was likely to accept the subcommittee's recommendation. The gene therapy proposal still needs approval from the director of the National Institutes of Health and from the Food and Drug Administration, but they, too, are expected to go along and allow treatment of patients to begin.

Under the proposal, Dr. Anderson, Dr. Blaese and their colleagues will try to treat children who suffer from a lack of a critical enzyme, adenosine deaminase, or ADA. Without the enzyme, toxins in the body build up and destroy the T-cells and B-cells of the immune system, leaving the children prey to large-scale and potentially lethal infections.

The researchers will try to treat the children by isolating T-cells from the patients' blood. Placing the cells in laboratory culture dishes, the re-

searchers will infect the T-cells with a special type of genetically engineered virus that includes a copy of the ADA gene that the children lack. The virus has been carefully doctored so that it is safe and cannot cause any disease.

The researchers will return the modified immune cells to the children through a simple blood transfusion. If all goes as planned, the T-cells will propagate enough of the missing enzyme to help restore the children's immune system to normal or near-normal.

Among the changes that the researchers made to their proposal that persuaded the 14 members of the subcommittee to approve it was a guarantee that the children receiving the gene therapy would also remain on another type of therapy in which they take a synthetic form of the ADA enzyme, known as PEG-ADA.

In important new data that persuaded the subcommittee to approve the gene therapy proposal, collaborators of the researchers in Milan, Italy, and at Memorial Sloan-Kettering Cancer Center in New York showed that when defective T-cells from children with the immune disease were injected into mice, the T-cells rapidly died. But if they first inserted the gene for the ADA enzyme into the T-cells, the cells survived for months in the mouse's bloodstream.

"That's the best evidence that I know of in the world that this technique may allow the T-cells to survive inside the body for a long time and carry on the normal function of the immune system," said Dr. Walters.

NEW DRUG TO TREAT CHICKEN POX

FA victims who contract chickenpox may risk very severe health consequences. A respected consulting dermatologist recommends use of a new medication immediately when the first few blisters appear. It stops the outbreak in 24 -48 hours.

The medication is oral acyclovir (Zovirax). It has been approved by the FDA for use in Herpes Zoster (shingles) which is caused by the same virus which causes chicken pox. It has in fact been extensively used for chicken pox, especially with children with leukemia.

If your FA child has not yet had chickenpox, you should discuss this issue with your physician at once. The medication is best started immediately after the diagnosis of chickenpox is first confirmed.

We add the usual disclaimer that your editors are not physicians. All medical issues should be discussed with your own doctors.

INSURANCE COVERAGE ISSUES: A GENEROUS OFFER!

The Leonard Riley family in our association fought for months to keep their health insurance in force for their daughter, Alaina. Regrettably, some companies try to terminate health coverage if they learn that a child has an illness requiring expensive medical treatment.

Gary Brown, the Rileys' agent, was successful in assuring continued coverage from the Rileys' insurance company. He wrote us on December 8, 1989 with this extraordinarily generous offer: "Needless to say my twenty years of experience in the industry have been enhanced by the experience of the last few months. I feel it is experience that might well be useful to others who find themselves in circumstances similar to the Rileys. Please allow me the opportunity to make that experience available to others should the need become apparent. I would accept no fee from the one in need just as I

accepted no fee from the Rileys."

Gary Brown, President
Brown and Associates Insurance Services
1616 Judson Road Suite 2
P.O. Box 1668
Longview, TX 75606
214-758-2226 (office)
214-758-2745 (residence)
214-758-4173 (fax)"

MARROW DONATION: "THE ULTIMATE GIFT"

The December, 1989 newsletter of the Aplastic Anemia Foundation of America reports a moving and happy coincidence for the family of Bob and Andrea Sacks. Daughter Danielle, an FA victim, successfully received a bone marrow transplant from her brother, Sean, several years ago.

In 1989, Bob was selected as an unrelated donor match for an aplastic anemia victim searching for a donor. Bob and his family had been HLA tissue-typed for possible donation to Danielle, and had submitted their HLA typings to the National Marrow Donor Registry. Bob terms his selection "a rare honor" and felt that the ability as a donor to give someone back life is "the ultimate gift".

Fredi Norris made a valuable point about marrow donation in a recent letter to your editors.

"I was surprised that although my whole family has been HLA typed, none of us is in any registry....It might be interesting for parents of kids with FA to learn how to register with these registries. We may not be exact matches for our own kids, but maybe we could help someone else's."

Fredi is correct on both counts! You and your relatives who have been HLA tissue-typed will not be enrolled in the National Marrow Donor Registry unless you have signed the consent form! For information on this easy process, call the National Marrow Donor Program (toll-free) at 1-800-654-1247. The Registry needs more than its present 148,000 donors. And yes, Fredi, we can help others, as Bob Sacks has proved!

DEALING WITH GRIEF AND LOSS

The past few months have witnessed the passing of several beloved children of our family network. Whether our children are lost or just threatened, our grief is powerful and cannot or should not be denied. The next four excerpts deal with this subject.

“He would want us to go on”
(taken from a letter from an FA family)

“[My wife] and I have determined to make the 1990’s a happy, productive decade. The 1980’s were very destructive to us. That decade is gone. [Our son] is gone. He would want us to go on. We have dedicated ourselves to being happy, doing good for others, and being positive in all things. We will strive to increase the asset item of ‘good will’ as much as possible.”

“I would never, never have made that trade.”
(recent letter from the mother of a teenage auto accident victim)

“If you had asked me, at any time during this last 5 months of hell - if I would trade....not having had Kami for 16 years so as not to have had to suffer to the depth of my soul - I would never, never have made that trade. The joy she gave me, over and over, and the genuine zeal with which she lived her life - Those two factors alone are justification for her to have been present on this earth for 16 years. Many people live to be 80 without giving as much to others or extracting as much enjoyment from living. That means a great deal to me as I search for answers.”

Vickie L. Simmons wrote the following poem in memory of a six year old named Alisha Marie Thomas. Alisha lost her battle against aplastic ane-

mia in May, 1988. Vickie writes “Maybe there are other parents who might find comfort in this.”

As the littlest soldier,
Was laid to rest;
The red badge of courage
Was pinned on her chest.

Not by a corporal
Or sergeant or such;
But by an angel from heaven,
Who slipped down with a touch.

The battles she fought,
Weren’t related to war;
But the littlest soldier
Still fought evermore.

Her life had a purpose
God tells us that’s true;
Just as He plans
For me and for you.

We know not why
A child is called home;
Our hearts are so empty
We feel so alone.

But if we give our burdens
To God up above;
He’ll carry them for us
And teach us to love.

We’ll remember the laughter
And think of the smiles;
The joy of those moments
When there were no trials.

As we look to the heavens
I’m sure that we’ll see;
The littlest soldier
On Jesus’ knee.

Vickie L. Simmons
May 24, 1988

Guidelines for Healing Grief, from The Compassionate Friends

1. **ACCEPT THE GRIEF** Roll with the tides of it. Do not try to be "brave". Take time to cry. This also applies to men...strong men can and do cry.
2. **TALK ABOUT IT** Share your grief within the family. Do not attempt to protect them by silence. Find a friend to talk to, someone who will listen without passing judgment. If possible find someone who has experienced a similar sorrow and talk often. If the friend tells you to "snap out of it" find another friend.
3. **KEEP BUSY** Do purposeful work that occupies the mind, but avoid frantic activity.
4. **TAKE CARE OF YOURSELF** Bereavement can be a threat to your health. At the moment you may feel that you don't care. That will change. You are important; your life is valuable—care for it.
5. **EAT WELL** At this time of emotional and physical depletion, your body needs good nourishment more than ever. If you can only pick at your food, a vitamin supplement might be helpful, but it will not fully make up for poor diet. Be good to yourself.
6. **EXERCISE REGULARLY** Return to your old program or start one as soon as possible. Depression can be lightened a little by the biochemical changes brought by exercise, and you will sleep better. An hour long walk every day is ideal for many people.
7. **GET RID OF IMAGINED GUILT** You did the best you could at the time, all things considered. If you made mistakes, learn to accept that we are all imperfect. Only hindsight is 20-20. If you are convinced that you have real guilt, consider professional or spiritual counseling. If you believe in God, you believe also in God's forgiveness.
8. **ACCEPT YOUR UNDERSTANDING OF THE DEATH** For the time being you have probably asked "why?" over and over and have finally realized that you will get no acceptable answer. But you probably have some small degree of understanding. Use that as your viewpoint until you are able to work up to another level of understanding.
9. **JOIN A GROUP OF OTHERS WHO ARE SORROWING** Your old circle of friends may change. Even if it does not, you will need new friends who have been through your experience. Bereaved people sometimes form groups for friendship and sharing.
10. **ASSOCIATE WITH OLD FRIENDS ALSO** This may be difficult. Some will be embarrassed by your presence, but they will get over it. If and when you can, talk and act naturally, without avoiding the subject of your loss.
11. **POSTPONE MAJOR DECISIONS** Wait before deciding to sell your house or change jobs.
12. **TURN GRIEF INTO CREATIVE ENERGY** Find a way to help others. Helping to carry someone else's load is guaranteed to lighten your own. If you have writing ability use it. Great literature has been written as a tribute to someone loved and lost.
13. **RECORD YOUR THOUGHTS IN A JOURNAL** if you are at all inclined toward writing. It helps to get your feelings out and it would also serve as a vehicle to record your progress.
14. **TAKE ADVANTAGE OF YOUR RELIGIOUS AFFILIATION**, if you have one. If you have been inactive in matters of faith, this might be the time to become involved again. Scripture has much to say about sor-

row. As time passes you may find that you are not so mad at God after all.

15. GET PROFESSIONAL HELP IF NEEDED

Do not allow crippling grief to continue. There comes a time to stop crying and get on with living. Sometimes just a few sessions with a trained counselor will help you to resolve anger, guilt and despair that keep you from functioning.

REMEMBER NO MATTER HOW DEEP YOUR SORROW, YOU ARE NOT ALONE. OTHERS HAVE BEEN THERE AND WILL HELP SHARE YOUR LOAD IF YOU WILL LET THEM. DO NOT DENY THEM THE OPPORTUNITY.

MARROW TRANSPLANTS: THE POSITIVE NEWS!

We have just received beautifully written accounts of two FA marrow transplant successes.

•Vickie and Darrell Simmons report the vibrant health of their daughter, Dreama Nicole after her 1987 transplant from a donor brother. (Vicki's moving poem appears separately in this newsletter, as does the Simmons' address under "new families".) This powerful family story demonstrates stamina and character at its best.

•Brad and Lea Ann Curry have returned from Paris with FA daughter, Natalie. Natalie's successful and medical history-making umbilical cord blood transplant . . . the second ever . . . was reported in FA newsletter #7. A summary cannot remotely do justice to the well written and informative story about how Brad and Lea Ann planned and executed their cure for Natalie.

Brad and Lea Ann conclude, with their typical optimism and generosity "If we can help any of you, please call. 812-952-3075"

We have reprinted both accounts for our group.

Please contact Linda Solin (address and telephone number on page 2) and she will send you the full texts.

"A Star She Wants to Hang On To"

Carmen Apollo's sibling marrow transplant in January, 1989 has resulted in the restoration of perfectly normal blood counts. Carmen's mother, Sharon, reported at length about their 5 month stay at the Fred Hutchinson Cancer Research Center in Seattle. Carmen, who was receiving frequent transfusions, was treated and transplanted as a "preleukemic" patient.

Carmen now is determined to pursue a career as a medical assistant. She has enrolled for training in this profession in St. Louis. Carmen told Sharon that she can help children in peril better know "how it is". This transplant "has changed her life 180 degrees. Carmen has a new look on life. She sees a star she wants to hang on to!"

Sharon Apollo has founded and supported a group in St. Louis for families of children at risk. SAC (Sharing and Caring) involves 20-30 people meeting at regular intervals.

Sharon has heard from numerous FA families, especially those looking for or considering marrow transplants. Sharon welcomes FA family calls at 314-285-4236.





Lacey and Lindsey Melancon

First allow me to say that being able to read the many personal letters published in the FA family newsletter has not only allowed us to gain knowledge of the therapies being used on other children, but has also left us knowing that we are not alone in this battle for our children's lives.

Our youngest daughter, Lindsey, was diagnosed with FA in June of 1986, at the age of three. During a hospital stay for pneumonia, we questioned the amount of bruising on her. Routine blood work showed that her platelet count was not normal. Through the course of the next few weeks, a chromosome study revealed that she had FA.

We searched frantically for some positive news on the disease, reading whatever we could find and trying to find someone who could tell us more. Oddly enough, family members told us of a couple living only three miles from our home who had a child with FA. We contacted them and became close friends. Their son has since died from post-bone marrow transplant complications. Those dear friends referred us to Dr. Dahlia Kirkpatrick, a hemotologist/oncologist with Tulane Medical Center in New Orleans, Louisiana. She has since become Lindsey's principal treating physician, working closely with our family doctors in our home town.

From the time Lindsey was first diagnosed until November, 1988, she was able to lead a relatively normal life without the aid of drugs. In November she was put on lithium because of a reduction in her blood counts. The lithium boosted all of her blood counts to an average range of 30,000-40,000 platelets, 8.0-9.5 hemoglobin and ANCs ranging from 500-1500. This therapy was used until the fall of 1989 when her blood counts began to drop drastically.

Lindsey was hospitalized because of her disease in October 1989. She has since been on daily doses of 50mg of oxymethalone and 1.5ml of cyclosporine (0.75 ml in the morning and 0.75 ml at night). Recently she added another medication, 2.5 mg of prednisone, which is taken every other day. Her blood counts are presently: 10,000-25,000 platelets, 8.5-9.8 hemoglobin and 750-1,300 ANCs. The blood counts do vary from week to week. She has also had whole blood and platelet transfusions between the 1989 hospital stay and now.

We have one other child, Lacey, who is 9 years old and in perfect health. Unfortunately, Lacey is not an HLA match. We have unsuccessfully searched all of the registries attempting to find a compatible donor. Tissue typing and MLCs are currently being done on family members.

We do not know what the future holds for Lindsey. We know, however, that the Lord has her in His hands and knows what is best for all of us. One thing is certain. Lindsey has deeply touched the heart and lives of many of our family and friends within our small community.

In closing, we would like to express our desire to hear from other parents and discuss the current treatments being used on their loved ones and to share their experiences.

Sincerely yours,

Craig & Stephanie Melancon
113 Juniper St.
Thibodaux, LA 70301
(504) 446-5049



FA SURVIVORS MEET

Your editors were pleased to hear of the personal weekend meeting early last fall of two long-term FA survivors. Donna Williams (age 32) and Paula Ceresa (age 35) learned of each other through our group network. They met, attended church services, toured the city and countryside and became fast friends in a short time. Since that initial meeting they have maintained close contact with each other. Donna's mother writes "thanks to the support group for this togetherness".

<Donna Williams and Paula Ceresa

CHANGES IN ADDRESS

1. Vicki Ware & Tony B. Gonzales
50 NW Meadow Dr.
Beaverton, OR 97006
503-641-3212
2. Joseph & Joahn Campbell have moved
Does anyone know their present
address?

NEW FAMILIES TO ADD TO FA SUPPORT GROUP

1. Lauren Armstrong
84-28 124 St.
Kew Gardens, New York 11415
718-441-4719
2. Larry & Janice Aucoin
RR 3, Box 860
Morgan City, LA 70380
504-631-0938

3. Carol Ceresa
9 Mt. Rainier Drive
San Rafael, CA 94903
415-479-2208 (H)
415-750-6036
4. Darby & Bill Combee
3251 Ham Brown Rd.
Kissimmee, FL 34746
407-847-2722
5. Dr. D.M. Halepoto
6, College Road
Woking, Surrey
GU22 8BT
England
0483-724860
6. Nora Herren
36879 S. Twin Hawk Lane
Marana, AZ 85653
602-682-3150 (H) 602-622-7611 (W)
7. Nancy & Lester Jansen
44 Old Wharf Rd.
N. Chatham, MA 02650
508-945-4577

8. Irene & John Kalman
556 Franklin Ave.
Stratford, Connecticut 06495
203-375-6817
9. Leardon Keleher
Okishinmachi 27-2
Prezeal Kanaya 202
Kurashiki-shi, O Kayama-Ken
〒 710 JAPAN
81 864 27 1922
10. Lila Keleher
1536 Towhee Lane
Naperville, IL 60565
708-355-4265 (H)
708-510-2793 (W)
11. Bob & Frances Lamb
7757 Jackson Raymond Rd.
Raymond, MS 39154
601-857-5507
12. Trudy & Terry Lee
Rt. 4, Box 712 1/2
Dunn, NC 28334
919-892-8986
13. Bruce & Lauri Logsdon
5891 Spring Rock Circle
Columbus, OH 43229
614-899-0095
614-899-6200 (Work: T-Th)
14. Deane Marchbein & Stuart Cohen
33 Robbins Rd.
Arlington, Mass. 02174
617-646-2330 (H)
508-683-4000 Ext. 2311 (W)
15. Craig & Stephanie Melancon
113 Juniper St.
Thibodaux, LA 70301
504-446-5049
16. Fredi & Ronald Norris
1592 Rockwin Rd.
Rockville Centre, NY 11570
516-378-0687 (H)
516-485-4400 (W)
17. Alain & Sylvette Silverston
10, rue Emile Zola
94400 VITRY, FRANCE
33-1-46801083
33-1-46843681 (W)
18. Vickie & Darrell Simmons
Rt. 9 Box 158
Parkersburg, WV 26101
304-485-2729
19. Judy & Edward Szos
309 Old Country Way
Wauconda, IL 60084

To All Fanconi Anemia Families:

Dr. Vicki Athens of our support group has offered to assume a leadership role in organizing a weekend symposium for Fanconi anemia families. She is asking that all families in our support group return the following questionnaire, indicating level of interest in this idea. Our deepest gratitude to Vicki for spearheading this exciting opportunity.

An interesting idea has come up for all of us. Below is a questionnaire directed to Fanconi Anemia families, relatives, doctors, or interested persons. I would like to organize a Fanconi Anemia Family Symposium for a weekend (perhaps at a holidome type setting, etc.). This symposium would allow families to meet, discuss and learn more about Fanconi Anemia. An agenda has not been made nor has a location been chosen. Please fill out the questionnaire below and return it to me. Dr. A. Auerbach has expressed an interest in being present for this symposium. Thanks VAA.

- Yes, We are interested in a Fanconi Anemia symposium.
 No, No interest in this meeting.

Western US	<input type="checkbox"/>	Fall	<input type="checkbox"/>
Midwest	<input type="checkbox"/>	Winter	<input type="checkbox"/>
East US	<input type="checkbox"/>	Spring	<input type="checkbox"/>
Southern US	<input type="checkbox"/>	Summer	<input type="checkbox"/>

Name: _____
Address: _____
Phone: (____) _____ - _____

Topics you would like to hear discussed:

- | | |
|----------|----------|
| 1. _____ | 2. _____ |
| 3. _____ | 4. _____ |
| 5. _____ | 6. _____ |

- Yes, I would like to help organize.
 I would like to help but I can not.

Other recommendations:

Return to: Dr. Vicki A. Athens
29113 East River Road
Grosse Ile, MI 48138