FA family newsletter

#16 A Semi-annual Newsletter on Fanconi Anemia for Affected Families, Caring Physicians and Research Scientists Summer, 1994

Gene Therapy Receives Initial Government Approval

We have witnessed a pathbreaking event! On June 9, 1994, a federal government committee approved a gene therapy protocol for the FA "C" gene. Dr. Johnson Liu and his National Institutes of Health (NIH) colleagues developed the gene therapy proposal.

The Recombinant DNA Advisory Committee ("RAC" Committee) voted unanimous approval after Liu's detailed presentation. FA parents Karilyn Kelson and Lynn Frohnmayer attended the RAC proceedings in Bethesda, Maryland at the NIH campus.

Liu and his collaborator, Dr. Christopher Walsh, must still receive approval from a wholly separate government agency, the Food and Drug Administration (FDA), before human trials can begin. FDA officials were in the RAC audience, and already have received a written submission. Every effort is being made to secure FDA approval in the immediate future.

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FA Families Unite at Camp Sunshine

Families shared thoughts and built strong emotional bonds during the fourth annual FA Family Meeting from May 30 to June 3, 1994 at Lake Sebago, Maine. Twenty-eight families from seventeen states and five nations enjoyed mild weather and the extraordinary hospitality of Camp Sunshine's founder, Dr. Larry Gould, and his caring staff and volunteers.

Children were entranced by magic shows, a costume party, arts and

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Fanconi Anemia Research Boosted by Major Federal Grants

Recent grant announcements by the National Institutes of Health demonstrate continuing gains for FA research. On June 14, 1994, Senator Mark Hatfield called your editors to report a message from Claude Lenfant, MD, Director of

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HIGHLIGHTS

MEDICAL NEWS

Early Results of G-CSF + Epo Trial

Dr. Richard Harris, Children's Hospital, Cincinnati, Ohio began treating FA patients with a combination of G-CSF and erythropoietin (Epo) while searching for unrelated transplant donors. Results are very preliminary but nonetheless encouraging.

Seven FA patients have been treated for more than three but less than six months on this combination of growth factors. All seven experienced a rapid increase in their neutrophil counts. Most had an increase in hemoglobin as well. Three patients experienced an improvement in their platelet counts. It took two to three months to see an increase in the hemoglobin and platelet counts.

To be eligible for this trial, patients had to have no clonal abnormality and have one of the following factors:

1) An absolute neutrophil count under 1,500,
2) Platelets under 75,000 or,
3) Red cell transfusion dependent.

Given the results of Dr. Rackoff's G-CSF study, Harris wonders if G-CSF alone might be responsible for the increase in hemoglobin, at least in some patients. If so, it would be preferable to use this growth factor alone. Harris is now a collaborator on the G-CSF trial. If a patient fails that trial, or during times when the G-CSF trial is closed to patient entry, Harris will use the G-CSF + Epo combination.

FA patients who have been on androgens for a prolonged period of time do less well at the time of a bone marrow transplant. Eventually, Harris would like to see growth factors take the place of androgens for FA patients. Additional trials are needed to determine the optimal dosage, and which growth factors are most beneficial. Additional data should also help physicians better assess potential risks.

Harris can be reached at 513-559-8236 or by FAX 513-559-3549, for anyone wishing to discuss these trials.

G-CSF News Encouraging

Family meeting attendees were greatly heartened by Dr. Wayne Rackoff's presentation on G-CSF (filgrastim) therapy on FA patients. A fuller account is contained in the Scientific Supplement to this newsletter.

Six patients have completed at least eight weeks of G-CSF therapy. All six patients had excellent neutrophil responses. In all patients, the original G-CSF dose was reduced while still maintaining good neutrophil counts.

Especially exciting and somewhat unexpected, at least three patients appear to have had an increase in their platelet counts as well. One patient had a dramatic increase in hemoglobin, and two other patients had less dramatic increases in hemoglobin.

The only toxic effect of G-CSF treatment has been mild fever in one patient. The fever resolved when the dose was reduced. To date, no patients have experienced onset of preleukemic bone marrow changes.

Future trials could include a combination of G-CSF with other growth factors to stimulate further production of all types of blood cells.

Rackoff can be reached at 317-274-8784 for additional information about this trial.

Gene Therapy

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Liu and Executive Coordinator, Linda DeSpain, are working with GTI, Inc. a privately funded biotechnology company, to secure the manufacture of adequate amounts of the healthy FA"C" gene for use in this proposed trial.

We are aware of how far we still must go. The other FA genes need to be isolated and sequenced, so that gene therapy procedures are available for all families. Healthy FA genes must be inserted into all the cells of the body, not just the bone marrow. No one pretends that this first effort will "cure" all aspects of this disease.

Yet this major step was barely imaginable a decade ago. Dr. Buchwald's isolation of the "C" gene occurred barely two years ago. Progress is accelerating. Family fund raising for research truly is continuing to make a major difference.

FA Research
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the National Institute of Heart, Lung and Blood (NHLBI). Lenfant's Institute has just awarded new multi-year FA-related grants.

We are gratified at the high quality of FA research. Because federal research dollars are so limited, only a small percentage of all scientific proposals can be funded. The successful FA projects therefore have passed a very demanding scientific peer review process.

We are also greatly heartened that FA projects and research scientists we support or have supported in the past now are receiving major federal funding. Some have labored in this field for a number of years. But with Oregon Health Sciences University in particular, our "seed money" was critically important in helping develop solid preliminary findings that led to outstanding peer reviews.

Federal support greatly magnifies the "leverage" of our research dollars, and provides us all with true success stories that we can relate back to all donors who have helped us.

Recent grant awards are:

• Robb Moses, MD, Grover Bagby, MD, Markus Grompe, MD, Oregon Health Sciences University, Portland, Oregon: $6.2 million for a major five year Program Project Grant devoted to the comprehensive study of Fanconi anemia. We have awarded seed money grants to these researchers from 1990 to the present. The FA cell repository in Portland was funded by the FA Research Fund, and was aided by families who contributed skin and blood samples at FA family meetings. Moses believes that the existence of this valuable repository greatly assisted the success of this project in receiving federal grant support.

• Dr. Alan D'Andrea, Dana Farber Cancer Institute and Harvard Medical School: A five year grant to study the normal and deranged functions of the protein encoded by the FA(C)C gene. (D'Andrea was an invited participant in our 1993 Annual FA Scientific Symposium and our 1994 Family Meeting at Camp Sunshine.)

• Arleen D. Auerbach, PhD, The Rockefeller University, New York: A three year grant: (1) to isolate and clone FA genes; (2) to determine the chromosomal location of these genes and to study their structure and expression; (3) to detect mutations in FA genes; (4) to develop screening methods using DNA technology for FA diagnosis and carrier detection. (Auerbach's work was heavily supported by the FA Research Fund in the years 1989-1991.)

Specific amounts of the D'Andrea and Auerbach grants were not available when this issue went to press.

Two other distinguished researchers, Manuel Buchwald, PhD, Hospital for Sick Children, Toronto, Canada and Ken Burtis, PhD, University of California, Davis were previously awarded multi-year federal grants for the study of Fanconi anemia. The FA Research Fund, Inc. has helped support both of these outstanding laboratories for several years.

We congratulate these distinguished researchers and wish them every success in hastening the progress of FA science. We are especially grateful to Claude Lenfant and Al Levine, PhD, Chief of the Division of Blood Diseases, NHLBI for their awareness of the broad scientific significance of FA research.

FA Unrelated or Mismatched Transplant Results Show Continuing Concerns

At our recent FA Family Meeting, Dr. Richard Harris shared the latest results on bone marrow transplants for Fanconi anemia patients. Patients receiving matched sibling donor transplants have a greatly improved chance of survival than patients receiving bone marrow from unrelated donors or mismatched family or mismatched unrelated donors (see *Scientific Supplement.*)

To date, thirty-three FA patients have undergone transplantation from a fully matched, unrelated donor. Survival rate for this population is 36%. If the unrelated donor is not a 6/6 match, the survival rate has been 0%. Fifty-two patients received marrow from a relative other than a matched sibling donor. Overall survival rate for this population is 28%. The rate improves to 50% if the relative (not a sibling) is a 6/6 match (22 patients), but is only 13% if the relative is not fully matched(28 patients.)

Several transplant centers, including that of Dr. Harris, are investigating ways to reduce the incidence and severity of graft versus host disease (GVHD). GVHD is a major lethal complication responsible for many post-transplant deaths.

FAMILY NEWS

FA Patient Leads Full, Productive Life

Ronda Bierma, age 31 and her husband, Jerry, 34, are the proud parents of Tom, almost 11 and Katie, 8 1/2. Ronda has worked as a nurse's aide for Alzheimers patients. She has just been offered a new job co-teaching at a Head Start preschool, and is happy and excited about the challenge. Her life is full and productive. And for many years, Ronda has dealt successfully with some of the complications of Fanconi anemia.

Ronda is the third of four children born to Ron and Sharon Van't Hof of Hospers, Iowa. Her brother Danny died of FA in 1969, at the age of 7. Ronda has usually enjoyed good health. She has experienced some medical reversals, but has handled them with courage and a strong faith.

In September, 1983, her son Tom was born six weeks premature. After his birth Ronda required blood transfusions. In November, 1984, she had a miscarriage three months into her pregnancy. And in 1985, when she was seven months pregnant with Katie, she was diagnosed with diabetes. She took insulin for four years. Since then her diabetes has been successfully controlled through diet.

In August, 1989 Ronda had a hysterectomy and in June, 1990 her gall bladder was removed. After both operations her blood counts declined drastically but subsequently recovered on their own. This past year Ronda has been seeing a liver specialist as her liver enzyme counts were not normal. Her hematologist and kidney and liver specialists monitor her situation regularly.

Ronda enjoys reading and plays the piano. Family activities include swimming and roller skating. Life is busy and full.

Ronda adds "My perspective on all that has happened to me and all that will happen is good because I have a personal relationship with Jesus Christ. I am also very fortunate to have a Christian husband. We remind ourselves daily that God is in control and will be there for us all the time."

Tom, Katie, Jerry and Ronda Bierma

Drug Appears to Boost Counts in FA Patient

Denise Adamson, mother of Joey, age 10, reports that her son has had a strong response to cyclosporin, a drug rarely prescribed for Fanconi anemia. Our readers are referred to the Scientific Supplement for a full report from Joey's physician, Dr. Roger Vega.

By the spring of 1993, Joey Adamson was receiving platelet transfusions every other day and red cell transfusions once a month. He suffered from constant nosebleeds. He was not responding to androgen therapy and had developed liver tumors. The Adamsons knew that Joey's prognosis was extremely poor.

On May 4, 1993, Joey began cyclosporin therapy. The Adamsons were cautioned about the negative side effects of this drug, and were warned that it might increase the likelihood that he could develop a malignancy.

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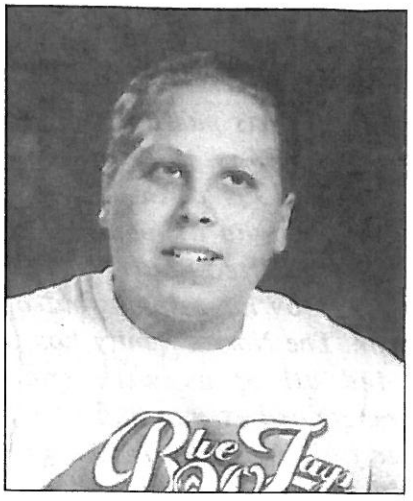
Mail continues to arrive at our old address. Remember, WE HAVE MOVED!

We are now located at: 1902 Jefferson St., Suite 2 Eugene, OR 97405

Healthy Attitude Keeps John Morash Going!



John Morash

Your editors received a heartwarming newspaper feature from Pleasantville, Nova Scotia about John Morash, a 13 year old "sports enthusiast". John's long bouts with steroids, needles, transfusions, pneumonia and hospital stays are part of the article on his struggle with FA.

But when John's elementary school classmates and teachers were asked recently to sign a huge get well card, many were surprised because they had not known he was sick. The feature article observes:

"It's no wonder they were in the dark. John acts anything but sick. He's part of the Dynamos gymnastics performance team. He loves basketball, baseball and soccer. He looks forward to the Wile's Lake fishing tournament in the summer and smelting in the winter. He's in Grade 6, the 'best yet', and recently finished a season of floor hockey. When John's not doing sports he watches them on television. During the World Series he stayed up every night to watch the Blue Jays. 'It was worth it,' he says with enthusiastic satisfaction."

John, his mother Shirley and family inspire us all with their positive attitude. All best wishes!

New Families Who Have Joined Our Support Group

Andrea Akins &Tony Williams
512 E. 31st Ave.
North Kansas City, MO 64116
(816) 421-0461 (H)
(816) 421-0188 (W)

Tracy & Joseph DeMarco
HER 73 Box 1090 Low
Locust Grove, VA 22508
(703) 972-2911

Mike & Rosie Gallo
860 54th Ave.
Lachine, Quebec H8T 3A6
Canada
(514) 634-2370 (H)
(514) 938-8641 (Mike's work)
(514) 938-1212 (FAX)

Timothy & Cynthia Garner
12306 Quail Woods Dr.
Germantown, MN 20874
(301) 540-1402 (H)
(301) 762-0200 (W)

Jim & Pat Graybill
Rt. 1, Box 235 T
Manchester, IA 52057
(319) 927-3827

Sheila & Tim Hood
6420 Hardup Rd
Albany, GA 31707
(912) 435-7713 (H)
(912) 435-0793 (W)

Mrs. Marion Nauss
Box 141, Mill Village
Queens Co, N.S. B0J 2HO
Canada
(902) 677-2506

Shirley Morash
R.R. 1 Pleasantville
Lunenburg Co., N.S. B0R 1GO
Canada

Tommy & Brenda Seiford
2503 Clear Ridge
Kingwood, TX 77339
(713) 358-4963

Lorne Shelson & Annette Waxberg
72 Castlewood
Toronto, Ontario M5N 2L2
Canada
(416) 489-5502 (H)
(416) 869-1571 (W)
(416) 869-1735 (FAX)

Betty Jane & Alfred Waldbaum
172 Broadlawn Drive
Elizabeth, PA 15037
(412) 751-6703 (H)
(412) 664-9379 (W)

Drug Appears to Boost Count

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They believed they had no good alternative.

Joey's last transfusion was on November 17, 1993. Over the past seven months, his counts have been safe and stable. On May 20, 1994, he had 120,000 platelets and a hemoglobin of 12.2. He feels healthy and well, and leads a full, active, normal life.

Denise would be willing to discuss Joey's situation with other families. She can be reached as follows:

PO Box 654
Red Oak, GA 30272
(404) 762-6701 (home)
(404) 762-1642 (work)

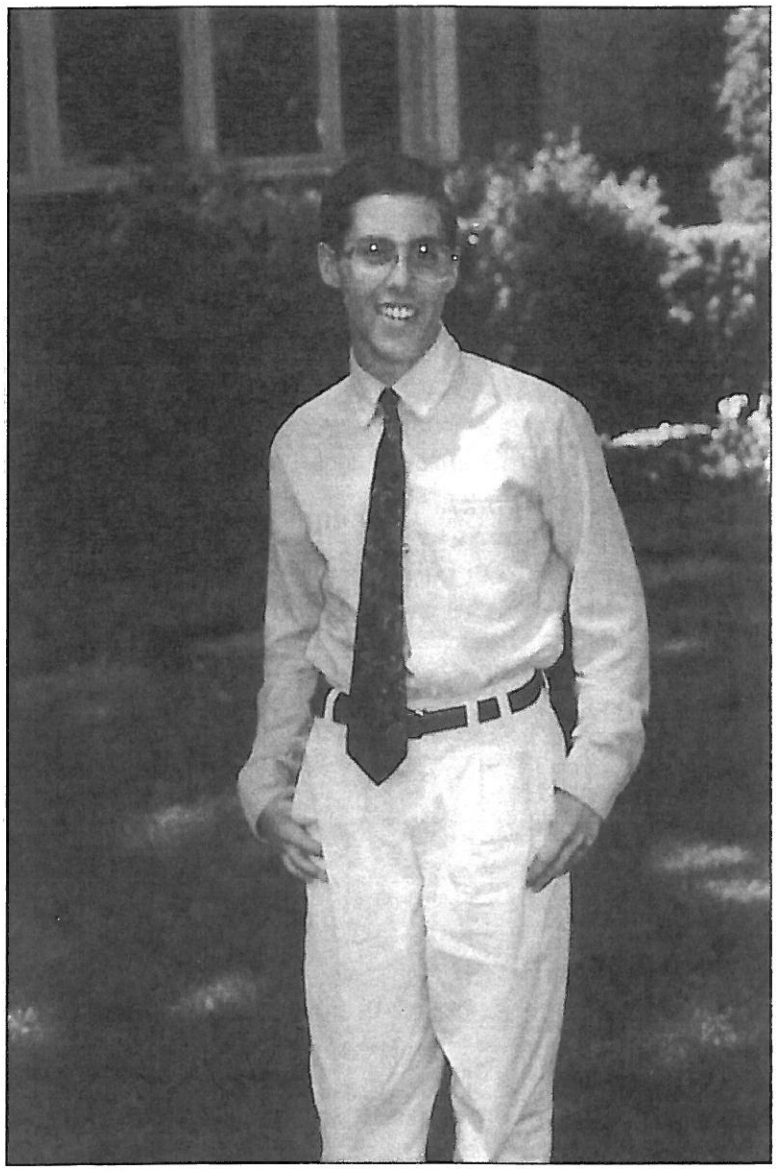
A Tribute to Alex

Alex Norris passed away from complications of leukemia on March 5, 1994 at the age of 16. Everyone who came in contact with this gifted young man was touched by his talents and optimism. The Norris family has provided all of us with special strength and extraordinary help in our fight against FA. We grieve with them.

Fredi Norris kindly shares the eloquent words of tribute she read at the service for Alex.

Our Alex was a very special young man. He was magic. Over the years Ronnie and I watched him touch the lives of so many for he was infused with the spirit of God. He was loving and kind and cared deeply for things.

Alex loved life. He was a doer. He made things happen. And he was a true hero—he was brave and courageous and fought a battle for years with a will and a dignity few adults possess. And through it all he thought he was a pretty lucky guy. He had a family who surrounded him with love and he was blessed with some strong and special bonds of friendship. Lindsay and Stephanie... you should always know that you were truly a blessing to him in both love and friendship.



Alex loved to sing... and I often told him his voice was a gift from God. I don't know where he got it because none of us can sing. Some of his happiest times were spent singing with the Chamber Singers.

Equally happy moments were spent on or near a basketball court. Everyone knows Alex's passion for basketball. He could talk about it with the best of them. His love of Larry Bird, the Celtics, and the North Carolina Tarheels was legendary.

Alex was also passionate about making his world fair and right and a better place. He fought for justice and he believed strongly that you should fight for what is right. He brought love and understanding to those around him. Alex had a great sense of humor and he made us smile and he made us laugh. Alex hated for anyone to be sad.

We will all miss him very much but I think he would not want us to be sad today. Ronnie and I think we can honor Alex's memory by smiling and laughing, enjoying each new day and the warmth of family and friends, taking time to smell the flowers and trying, as Alex would have, to bring the gifts of music and magic to the world through acts of kindness, compassion, love and friendship.

And Alex would tell us all to keep rooting for the Celtics.

Dear Friends,

This has been a very sad time for our family. Ronnie and I look around and realize that so many families have suffered the loss of a beloved child as we have. I think that along with the medical updates and the hopeful news that our newsletters bring, we must address the grief and loss that many of us are working through. It might be helpful if we could share any meditations, poems or prayers that you may have found comforting to read, as well as any other words or suggestions that helped you walk through difficult times. Book titles with a brief summary would also be excellent to share.

We welcome your thoughts. The following are words from a play about a young woman named Hannah Senesh who perished during the Holocaust. Someone gave it to us and it speaks beautifully to us of our cherished Alex.

There are stars whose radiance is visible on earth though they have long been extinct. There are people whose brilliance continues to light the world though they are no longer among the living. And when the night is especially dark, these lights burn the brightest. They help to light the way.

Dedicated to the memory of Alex Norris

With love,

The Norris Family

Thank you for your beautiful suggestion, Fredi and Ronnie. Families are invited to send thoughts they find helpful or comforting to our office for inclusion in our newsletters.

FUND RAISING

Creative Fundraisers Bring Enjoyment—and Research Dollars!

Donna Barnes' fundraising letter last January raised community awareness of Fanconi anemia and her son Jessie's battle. Caring friends wanted to do more. This spring, women from Donna's church organized a rigatoni dinner. Everything except the meat was donated. Two hundred forty people attended and the event raised $2,000 for Fanconi anemia research! Donna remarked that everyone had a wonderful time.

Dottie Day brought Chris Williamson and Tret Fure from Oregon to Vermont for a benefit concert. The event required a lot of work and planning, but was quite successful. Dottie raised approximately $1,000 for research, and many people learned about Fanconi anemia for the first time. The positive feeling generated by this event made it all worthwhile.

Pam Baxter regularly thinks of new, creative ways to raise research funds. This spring she wrote and sold a coloring book, using this disease as the theme of her publication. She raised over $500 in this effort!

This is a small sampling of the many original fundraising ideas generated by families in our support group. We are all grateful for these heartwarming efforts!

Grandmother's Special Memorial

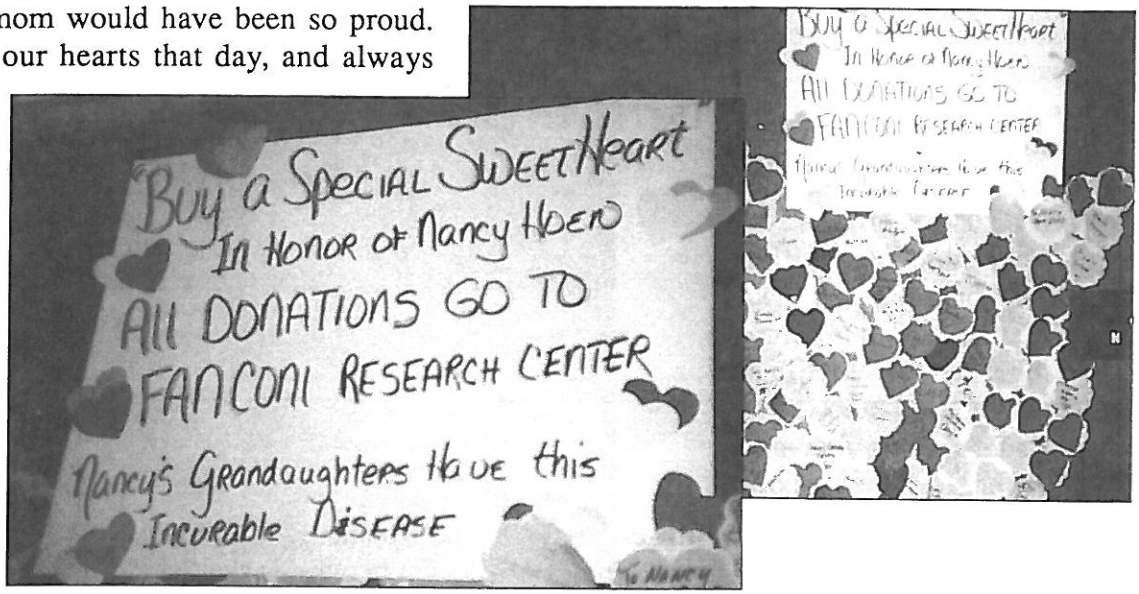
Therese Robertson wrote us about the touching contributions her mother, Nancy Hoen, and friends made in honor of Mrs. Hoen's FA grandchildren, Melissa and Jamie Robertson:

"In the past years, my mother raised money at her VFW chapter for FA and other charities. She and her friends sold shamrocks on St. Patrick's Day, colorful leaves in the fall and hearts on Valentine's Day.

Mom became ill at Christmas. In late January, her VFW lady friends started a project selling hearts to honor Nancy Hoen and her two granddaughters with FA. The hearts sold for a dollar each and the goal was $300.

A week before Valentine's Day, the friends had already collected $150 and assembled a huge heart-shaped wall display. My mother was very proud when she saw a photo of it. Mom passed away on February 7, but during her memorial luncheon at the VFW Hall they sold more hearts and collected a final total of $335!

I know my mom would have been so proud. She was in all our hearts that day, and always will be."



Family Fundraising Efforts

From January 1, 1994 through June 20, 1994, fifty-three families participated in raising funds for Fanconi anemia research. These efforts generated $123,424 towards our push for a cure! Many thanks to all of you who have worked so hard for this cause. You all share credit for the progress we continue to make in understanding and treating this disorder.

We have recently learned how very far our research dollars can go. We have repeatedly provided small, start-up grants to laboratories. Our "seed money" has assisted some researchers in their efforts to obtain substantial federal support. The amount you personally have raised or contributed to our research fund has been multiplied many times over! Your hard work is directly contributing to scientific discovery, and that progress will affect the lives of many we care about so deeply. Please, continue your efforts!

The amounts reported below were deposited in our account by June 20, 1994. Later deposits will be reported in the next newsletter. Our deepest thanks to each and every one of these families!

Over $30,000

Lynn & Dave Frohnmayer

$15,000 - 30,000

Ron & Fredi Norris

$10,000 - 15,000

Deane Marchbein & Stuart Cohen

$5,000 - 10,000

Mark & Linda Baumiller
Chick Deeks
John & Karilyn Kelson
Jim & Carol Siniawski

$3,000 - 5,000

Alice Nicholson
Martin & Linda Sankey
Mark & Susan Trager

$2,000 - 3,000

Denise Canard
Aaron & Jean Randolph
Terry & Therese Robertson
Jeff & Debbie Slater

$1,000 - 2,000

Donna Barnes
Elaine Beyer
Phyllis Cafaro
Bill & Pat Danks
Dottie Day
Neil & Iris Frank
Bill & Jackie Lucarell
Jack & Pam McCarty
Steve & Alison McClay
Leonard & Jan Riley

$500 - 1,000

Andrew & Vicki Athens
Pam Baxter
Donna DellaRatta
Jose & Amparo Guadix
Tim & Jennifer Kiesel
Marlene Stone
Marc & Sandy Weiner
Nancy & Reese Williams

Up to $500

Darryl & Diana Blecher
Carol Ceresa
June Delvalle
Jerry Dennerline
Pat & Mary DiMarino
Ed & Janice Duffy
Peter & Ann Eckstadt
Mike Gallo
James Galvin
Dave & Paula Guidara
Sharon Van't Hof
Leardon Keleher
Michael & Pam McCoury
John & Barbara Miller
Louis & Virginia Napoles
Dennis & Susan Nichols,
Courtney & Kristen Nichols
Kevin & Lorraine O'Connor
Diane Piatek
Richard & Janice Thomas

With deep sadness, we report that contributions were received in loving memory of Christopher Canard, Caleb Marchbein-Cohen, Hugh Deeks, James DellaRatta, Michael Elzinga, Alexandra Greenberg, Christopher McCoury, Nancy Nicholson, Alex Norris, Jason Randolph, Avi Weiner and Donna Williams.

We Honor Our Grantors and Corporate Contributors July 1993 - June 1994

Meyer Memorial Trust
Tiger Foundation of New York
Amgen, Inc.
The Edwin & June Cone Fund of the Oregon Community Foundation
The Streisand Foundation
The Barker Foundation
Collins Medical Trust
The Chiles Foundation
F.E. Stewart
The Cafaro Company
Hitachi Foundation
Hitachi Corporation
Ortho Biotech
Georgia Pacific Corporation
Joseph Alexander Foundation
Samuel S. Johnson Foundation
The Trailblazers
American Greetings Corporation
R. B. Pamplin, Jr.

FOR YOUR INFORMATION

Attention Physicians: Upcoming Conference on Genes in Primary Care

The Cambridge Hospital, in conjunction with the Harvard Medical School and the Massachusetts Institute of Technology, will host a 3 day Continuing Medical Education course entitled "Genes in Primary Care—What You Really Need to Know." This course, specially designed to acquaint internists and family physicians with the language and concepts of today's genetic revolution, will be held in Cambridge, Massachusetts on October 3-5, 1994 at The Cambridge Hospital.

Organizers of this course include world-renowned MIT molecular biologist David Houseman, MD and primary care physician Hilary Worthen, MD. Francis Collins, MD, PhD, Director of the National Center for Human Genome Research will deliver a special address.

The exciting curriculum is specially designed to create a hands on learning environment ranging from laboratory experiences to sessions on therapies, patient and family counseling, support groups and understanding molecularly based medical literature. Your editors strongly urge families to inform their physicians of this impressively organized seminar.

For further information, contact course organizer Alison Harris at

The Cambridge Hospital
(617) 498-1584 (telephone)
(617) 498-1814 (FAX).

1-800 Family Support Line Presents New Fundraising Challenge

by Linda DeSpain

The shock of FA diagnosis, feelings of isolation, not knowing where to turn for medical advice, and financial stress (or any combination of the above) can make long distance calls to our office seem like yet another hurdle and expense.

A toll-free support line could help all new families in particular move through their first months. In addition to new families, any family for whom long distance calling is a serious financial barrier could use this toll-free line to retain access to FA education, connections to leading treatment providers and new therapeutic trials.

The FARF Board of Directors recommends that we establish an incoming 1-800 FA Family Support Line, and that we take the challenge as a special fundraising project.

The goal is easy to reach—just $5,000 per year. The mission is undeniably vital.

Any family or community group who wishes to support other FA families by raising funds dedicated to the 800 line, please call Lynn, Leslie or Linda at 503-687-4658 and share your plans!

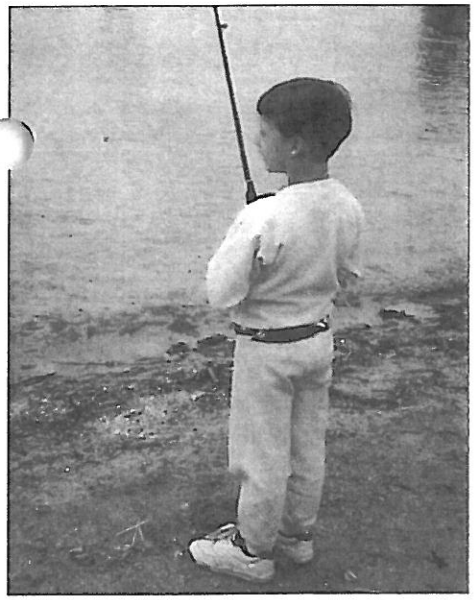
Dealing with Insurance Companies

The ongoing cost of treating FA patients is beyond the means of all but the most wealthy. Health insurance coverage is crucial for all of us. But insurance carriers often delay or deny approval of claims for treatments and procedures such as HLA or DNA tissue-typing, donor searches, marrow transplants, new drug therapies and other needed services.

You can fight back successfully. Darryl Blecher, an insurance expert and FA family member, has written a short pamphlet for our FA families. The pamphlet explains new insurance marketing principles, medical eligibility, and a number of action plans to help you and your doctor write the appropriate letters to obtain pretreatment coverage or to appeal denial of coverage.

Darryl has numerous useful tips on what to communicate to the insurance company's Medical Director, how to enlist your doctor's help, whether to threaten litigation or other action and how to appeal through an attorney, your state's insurance commissioner or by a lawsuit with media coverage.

To obtain this pamphlet, call or write the FA Research Fund and ask for Darryl Bletcher's pamphlet, "Communicating with Insurance Carriers". Many thanks, Darryl, for your help and expertise.



Scott McClay waits hopefully.

FA Families Unite

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crafts, athletics for every age group, a camping trip and caring counsellors. Adults enjoyed conversations, intensive and skillfully guided discussion groups, a series of scientific updates, a karaoke talent show and time alone for refreshment and personal renewal. The evaluations were universally strong.

Based upon the enthusiastic response of every family, and an incredibly generous offer from Larry Gould (see *special flyer*), we have agreed to schedule next year's family meeting at Lake Sebago once again. Most of our scientific and medical presentations will occur over the weekend of May 19-21, 1995, to accommodate those with school or work commitments. Those who can stay longer will enjoy the unique and wonderful Camp Sunshine experience, including parent discussion groups and fabulous children's programs. We really hope you will plan to attend our next Family Meeting at Camp Sunshine!

Want to Join the Information Superhighway?

by Joyce Owen, President

We have been wondering how many of our member families have access to computers. How many of you have a modem, or are thinking about getting one? Do you belong to a service like America Online or Compuserve? Do you have access to e-mail? We are thinking about setting up an FA Family Bulletin Board or electronic Mailing List if there is sufficient interest.

Here's a brief description:

- **FA Family Bulletin Board:**

For this option you would not need access to e-mail or other Internet services. You could call in any time (long distance call). You could "download" (copy onto your own computer) any files, such as stories, news releases, lists of names and addresses, or other information that interests you. You could post questions, comments, or information for other people. You could send private mail to others. Answers to your questions could be sent to you privately or posted on the Bulletin Board. Access to the Board could be restricted to FA families, physicians, and scientists.

- **FA Electronic Mailing List:**

For this option you would need to have an e-mail address through an online service or through your business. Membership in America Online is about $10 per month; there may be less expensive services. With this option, you would e-mail us your questions and comments, and we would prepare a "digest" of all your collected questions and comments plus our own answers and information. We would e-mail this digest to everyone on the Mailing List, probably every week or two, depending on the volume of information.

These are just two possibilities. Perhaps you can suggest others. Let us know if you are interested! You may call or write to the office, or send me e-mail:

jowen@oregon.uoregon.edu.

Your News Needed

The single biggest criticism of this Newsletter is that it does not contain enough news from our families. Older patients would like to hear from their contemporaries, and parents want to hear how other parents are coping. Everyone likes to read about the accomplishments, successes and challenges of our children. But to print those stories, we have to receive them from you! So send us your pictures and your news!

FARF now eligible for 1994 Combined Federal Campaign Donations

FA families, relatives or friends who are employees of the federal government may now donate to our cause by payroll deduction.

On June 8, 1994, the U.S. Office of Personnel Management approved our application for inclusion in the 1994 Combined Federal Campaign National List (CFC).

This approval opens new doors for fund raising campaigns in our communities where the federal government is a major employer. The CFC is not related to United Way, although it works in much the same way. Personal phone calls or letters to co-workers, luncheon talks, and special children's events are a few successful approaches families can use to help raise awareness of FA and financial commitment among those who may care most deeply.

Let's make the most of this opportunity!

Canadian Fund Formed

Good news comes from our wonderful neighbors to the North. Canadian families have now organized the Canadian Fanconi Anemia Research Fund, which allows contributions to be tax deductible. This development provides a real incentive for Canadian families, their friends and relatives to raise funds for FA research.

We congratulate Peter & Tami Dunstan-Adams who worked hard to comply with all the legal technicalities. We add our special thanks to Larry & Mary Heath and Charles & Moira MacLellan, whose early efforts to organize the Fund helped pave the way for this major accomplishment. Those wishing to assist the Dunstan-Adams family in this effort can contact them at:

330 Van Horne St.
Penticton, B.C. V2A 4K5
Canada
(604) 493-2910 (H)
(604) 492-4000 (W)

Pen Pal Wanted

Pen pal wanted for a 15 year old girl with Fanconi anemia.

Please contact the FA Research Fund office if you would be interested in writing to her.

EDITORS' NOTE AND DISCLAIMER

Statements and opinions expressed in this Newsletter are those of the authors and not necessarily those of the editors or sponsoring Fund. Information provided in this Newsletter about medications, treatments or products should not be construed as medical instruction or scientific endorsement. Always consult your physician before taking any action based on this information.

FA family newsletter

Fanconi Anemia Research Fund, Inc.
1902 Jefferson St., #2
Eugene, OR 97405
(503) 687-4658
FAX (503) 687-0548

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Medical Advisor for Newsletter
N.T. Shahidi, MD

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Dave and Lynn Frohnmayer

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Tanya Harvey

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