

# THE FA FAMILY NEWSLETTER

Newsletter Number 6

June, 1989

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

## FUNDRAISING EFFORTS EXCEED \$235,000!

Fanconi Anemia scientific research efforts have received major new assistance through efforts of families and friends of FA victims. As of May 31, 1989, this intense four-month campaign by FA families to raise funds has generated an incredible \$235,918.17 for basic and applied research.

Congratulations to you all! This shows what a small group of caring people - - united in desperate concern - - really can do!

Some thoughts and facts:

Even amidst illness, financial stresses and other pressing concerns, fully 32 families - more than one-quarter of us - already have contributed or raised funds. (See details, p. 2) We hear from more families each week. Others are just beginning their fundraising efforts. EVERY PENNY MAKES A DIFFERENCE.

Our collective campaign has now fully funded the most immediate project needs of three important scientists who submitted proposals to us. Arleen Auerbach, Ph.D. of Rockefeller University; Blanche Alter, M.D. of Mt. Sinai Hospital, New York; and N.T. Shahidi, M.D. of the University of Wisconsin. An accompanying story describes the research in progress. See p. 3

Several families chose to raise funds and give directly for a specific researcher known to and trusted by them. These efforts generated significant dollars that assisted our joint efforts. Many thanks!

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We have now helped to organize a non-profit corporation to pursue future efforts. **The Fanconi Anemia Research Fund, Inc.** (66 Club Road, Suite 300, Eugene, OR 97401; tele: 503-344-6307) has incorporated and begun operation. Among the members of the initial independent Board of Directors are Joyce Owen, Ph.D., molecular biologist and Bruce Strimling, M.D., a pediatrician with front line experience in treating FA. FA families in Pennsylvania and Italy have begun active discussions about forming corporate affiliates of the Fund in their jurisdictions.

We now know that our fundraising goal of \$100,000 was far too modest. New projects worthy of financial support have come to our attention. In addition, the needs of existing projects we have funded may well extend for a number of years. We should aim to raise \$500,000 by the end of this year. We believe this goal is realistic. It is obviously urgent.

Please take special pride in the low expense and incredibly high yield of our efforts. Many charitable solicitations spend more than half (and sometimes up to 90 per cent) of their receipts for

fundraising expenses. **Not this all-volunteer effort!** **Well over 95%** of all funds generated so far have gone to our designated research centers and the earmarked research fund! Costs of postage, printing and letters of thanks to every donor are a very small, but very important part of our costs. We doubt that any new charitable effort of this kind has **ever** given so much to its major purpose. You can tell this with pride to your donors. It's true!

One final thought: many people who never sought public funds, let alone publicity, for any family purpose decided - - fearfully - - to throw themselves into this effort. They gave up helplessness and personal privacy. Almost all now report a special new sense of "empowerment". They regained a sense of control over their destiny. They now know that they can fight back against FA in a meaningful way for their child or children. We feel all that, too. The spectacular initial results speak for themselves. Thanks, again, so much. **This is just a start!** (eds.)

## FA FAMILY FUNDRAISERS: PRELIMINARY RESULTS

While many family efforts have just begun, fundraisers conducted to date are impressive by any measure. Thirty-two families have made individual contributions or conducted a fundraising campaign. **EACH AND EVERY EFFORT WILL HELP US COMBAT THIS DREAD DISEASE.**

We do not have room to mention and obviously cannot do full justice to all of the hard work and imagination that produced such impressive results. Even families presently uncomfortable with having their names listed in this newsletter contributed substantially in funds raised for the work of one or more researchers.

Here is a sampling:

- Willingness to generate and endure news media coverage significantly helped the Bill and Jackie Lucarell effort in Girard, Ohio. They have been on local television and the subject of several newspaper articles. Children at Jimmy Lucarell's preschool sold Reese's peanut butter cups, and 40-45% of the profit (totalling \$2,000) went to FA research. The preschool also conducted two bake sales. The Lucarells sent a fundraising letter to friends and relatives. To date, their many efforts have netted \$16,300 for FA research. And the Lucarells have exciting plans for additional fundraisers. Their determination to work until a cure is found is inspirational.

- Therese and Terry Robertson sent their fundraising letter to over 600 friends and relatives. An astonishing 328 donors responded, contributing a total of \$11,431. We appreciate the affection of their friends and relatives and admire the exhausting work that a mailing of that size requires. Great job!
  - Hal and Bobbie Porter, who have written for this newsletter and who lost their son Phil to FA in 1984 continue their heroic and loyal battle against this killer disease. Their heart-warming letter produced \$3,823 for FA research. Contributions continue to arrive.
  - Three families raised between \$5,000 and \$6,000 for FA research. Norma and Giovanni Pagano, Diane and Matthew Senatore and Margaret and Brian Curtis are to be highly commended for these terrific results.
  - In addition to the Porters, three families raised between \$3,000 and \$5,000 for FA research. Our deepest thanks to Alice and Robert Nicholson, Marlene Stone and Robin Paulson, and Lorraine and Kevin O'Connor for these splendid results.
  - Sadly but gratefully we acknowledge the tragedies that generated two separate contributions to scientific research. The deaths of Meghan Auth and Sean Satterlee were commemorated by the generous gifts of loving friends and relatives.
  - Lorraine and Kevin O'Connor deserve special mention for their innovative fundraiser. They devoted all of their sales profits for one day from their health food store to FA research. Raffles and donations for a blood pressure test brought their total effort to \$3855.17.
- On the day of the fundraiser, two children, Tara Visconti, age 8 and her 10 year old brother Robbie, brought in a very large jar filled with penny rolls and some bills. Their grandmother said they were donating their very own savings (a penny collection and money received as gifts). Their heartwarming contribution was \$133.81.
- Three families raised between \$2,000 and \$3,000: Marie and John Wells, Durant and Ridgely Worthy and Sandy and Marc Weiner. This helps enormously!
  - Several families raised or contributed \$1,000 or more: Jim and Lisa Ramser, Lester and Phyllis Resh, Nancy and Reese Williams, Leonard and Jan Riley, Walter and Tina Smith,

and Nancy and Lester Jansen. We all appreciate your wonderful help!

- Four families conducted fundraisers which netted between \$500 and \$1,000. Our deepest thanks to Wayne Shattuck and Patty Cartwright, Vicki and Shawn Phillips, Byron and Denise Adamson and Robert and Elizabeth Mount.
- To our knowledge, six other families so far have participated in this campaign, raising up to \$500 for scientific research. We are deeply appreciative of the efforts of Dejuana Simon, the Engel family, Diane and Michael Bradley, Gayle Licari and Tony and Dale Keegan. If we have overlooked mentioning any effort, please excuse our mistake and contact us. **EVERYONE WHO DID ANYTHING HAS HELPED TO MAKE A REAL DIFFERENCE IN ALL OF OUR LIVES.**
- Your editors dropped everything for weeks on end and enlisted dozens of friends to stuff envelopes and process mailings. We had the great benefit of supportive articles in USA Today and Parade Magazine, and TV news specials both national and regional that promoted our effort. Local newspaper coverage was extremely effective. These, combined with a special mailing list of 6,000 political contributors, generated over \$150,000. We have identified new lists with potential donors and will continue our effort throughout the year, as we hope you will also.

## RESEARCH IN PROGRESS

The fundraising project has given or stimulated major financial support to three important efforts in basic and applied research on FA. Here is a brief progress report for each:

1. Arleen Auerbach, Ph.D. of The Rockefeller University has received \$83,410 in generated support from FA families for her genetic research. Dr. Auerbach, who is also assisted by an NIH research grant, is attempting to localize the FA gene(s) to a specific chromosome(s). The technique uses "linkage analysis" of DNA markers, a strategy that has already worked in another recessive genetic disease. Discovery of the marker for FA provides better tests for diagnosis and carrier detection. If the FA gene location is discovered, the gene itself might be located and cloned. This would greatly increase knowledge of FA, and hopefully lead to better therapies.

Dr. Auerbach hopes that this effort to find the affected chromosome will take no more than two years. Since the use of DNA probes is very labor intensive, our research support has directly speeded the effort.

2. Blanche Alter, M.D. of the Mount Sinai Medical Center, New York City has received \$35,000 in generated support in addition to an important grant from the National Organization for Rare Disorders. She seeks to answer the following questions through careful laboratory studies:
  - A) Can the development of aplastic anemia in FA victims be predicted?
  - B) Do the stem cells of FA patients respond to a variety of newly discovered "growth factors"? If the results are positive, various of these factors might be useful in treating aplastic anemia in FA victims.
  - C) Does the growth hormone often suggested for FA victims of short stature also stimulate blood production?
  - D) Are there adverse impacts, such as leukemia, of growth factors or growth hormones when used for FA victims? These studies together should provide a clearer picture of the specific defect or defects in the blood production system of FA patients. That, in turn, should lead to development of more helpful therapies for aplastic anemia.
3. Dr. N.T. Shahidi of the University of Wisconsin received \$36,000 from our fundraising effort (he previously received \$5,000 from Brad and Lea Ann Curry's fundraiser, for a total of \$41,000 from FA families and friends) to conduct a three part research study of FA:
  - A) Increasing evidence suggests that blood cell proliferation is controlled by certain "regulatory factors". Some of these factors inhibit blood cell production. Preliminary investigations suggest that FA patients in relapse produce abnormally high amounts of inhibitory factors. It is important to measure whether these factors relate to the severity of aplastic anemia in FA patients. As part of this study, Dr. Shahidi will investigate the relevance of toxic environmental factors on the marrow cells of FA victims.
  - B) "Growth factors" stimulate blood cell production. These factors interact with specific sites on the cells to stimulate cell production. Dr. Shahidi will compare the number of receptor sites for a certain growth factor in FA patients with those in normal individuals and in patients with acquired aplastic anemia to determine if there is a decrease in receptor sites in FA patients. If this is so, he will then study whether androgens or other steroids increase receptor sites for certain growth factors in FA patients.
  - C) Dr. Shahidi will further investigate theories as to why FA patients who initially respond to androgens later become non-responsive. There may be an identifiable "inhibitor" process that can be defined, isolated and ultimately counteracted.

We are pleased to include the latest progress report from our advisor, Arleen Auerbach, Ph. D.



## THE ROCKEFELLER UNIVERSITY

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

May 25, 1989

Dear FA Families:

I am happy to have this opportunity to thank Dave and Lynn Frohnmayer and all of the other FA parents who participated in the recent fundraising effort for Fanconi anemia research. The money we received will be of tremendous help to us in our effort to map the Fanconi anemia gene (see previous FA Family Newsletter, November 1988 for details of this project). The money will be used to continue the salary of one scientist who was supported by contributions to our laboratory in previous years, as well as to hire an additional person to work on the project. The money will also enable us to purchase all the consumable supplies needed to do our experiments with as much speed as possible. With all of our laboratory staff focusing on this project, we are very optimistic about finding a linkage with a DNA marker and thus finding the location of the FA gene. With some luck, the gene could be mapped in a year.

Our studies attempting to map the FA gene rely on our ability to get a blood sample from members of families that have more than one affected child with Fanconi anemia, or those in which the parents of an affected child are related to each other. These samples can provide us with DNA for immediate use in experiments, and can be used to establish permanent cell lines from which we can obtain additional DNA in the future. We would appreciate hearing from any families that fit these categories and would like to participate in this study.

We continue to collect information for the International Fanconi Anemia Registry and to pass this along to physicians who call with questions regarding the disease. Because of the rare occurrence of FA, we feel that it is important for there to be a centralized repository for this information. Families in the Registry are urged to keep us updated on any change in the health of their affected children.

For your information, production of the first book devoted to research on Fanconi anemia has finally been completed. This book, entitled Fanconi Anemia, Clinical, Cytogenetic and Experimental Aspects, T. M. Schroeder-Kurth, A. D. Auerbach, G. Obe (Editors), was published by Springer-Verlag, Heidelberg. Some of your physicians might be interested in knowing about this book.

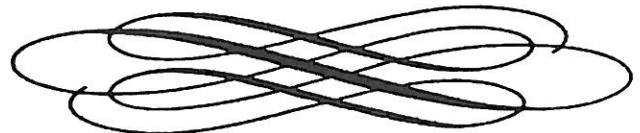
Best regards.

*Arleen D. Auerbach*  
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# ONE DOZEN QUICK TIPS ON FUNDRAISERS

We've learned many lessons about maximizing fundraising efforts. By making mistakes, we've also learned how to avoid future ones. Here's some of what we've heard and learned:

1. Direct mail solicitation is probably the most effective way to raise large amounts of money. Write to friends, relatives, co-workers, people with whom you share a common interest or activity, families on your Christmas card list, members of your church, etc. Any direct mail solicitation should **include a picture** of your child or children and your letter should focus on your specific situation. People respond best to real people - children in need - - not to abstract appeals. Several families persuaded local photography studios to take and duplicate photos free of charge. One local photo developer reduced his quoted price to us by 2/3 when he learned it was for our non-profit charitable purpose. Don't be afraid to ask for "in-kind" donations like this.
2. **Always include the name** to which checks should be made. If you wish our non-profit corporation to process contributions, the payee is **"Fanconi Anemia Research Fund, Inc."**
3. **Always include a return address**- preferably your own address - for donations. That way you can record the names of donors and send thank you's before forwarding contributions on to the research effort.
4. If possible, **include a self-addressed return envelope**. A custom-made rubber stamp for this purpose is inexpensive (under \$20.00). Because your editors mailed many thousands, we had return envelopes pre-printed professionally. Much of the printing cost was also donated by an in-kind response to our appeal.
5. Don't be afraid to ask friends, club members or social groups to help with the otherwise tedious tasks of typing, duplicating or stuffing envelopes. Many people *really* enjoy helping this way; some cannot contribute any other way. Once "invested" personally in your effort, your friends will involve *their* friends as contributors. (We know that several thousand dollars were contributed directly to our effort by such "networks"). *Never* do alone what 10 good-spirited volunteers can help you do!
6. Obtain the support of any local service club you can find. Previous newsletters have reported the success of the Montellas and others of our FA group. Call them for tips! Your chamber of commerce or local newspaper will have listings of volunteer groups. Almost all clubs are in search of worthwhile projects. A leukemia victim in rural Oregon was able to receive a marrow transplant because a group of Elks Clubs made his cause their own, and raised \$135,000 in six weeks!
7. It is extremely hard for most of us to subject ourselves to coverage by local newspapers and television news programs. Yet media coverage reaches people you would never think to solicit directly, and reinforces your direct appeal. Hundreds of people we do not know and will never meet donated thousands of dollars to our fundraiser - a most heartwarming response! Local media usually welcomes a human interest story. The hardest part is losing your anonymity and exposing a painful part of your life to the public. Those willing to make that effort are richly rewarded.
8. If you contact your local newspaper, don't go to the "news" desk unless you have news. **Seek out the editors and reporters of "features", "living", "lifestyles" or "community" sections** of the newspaper for coverage. We have the most powerful, most tragic, and - -potentially the most hopeful stories to tell. People read and identify with these feature articles.
9. If you agree to media coverage of your effort, *always* secure a commitment that the media story will include the **specific name and address of the fundraising entity** that receives contributions for FA research. If a TV station is covering your effort, ask that the name and address of your fundraiser be displayed on the screen, or that viewers be encouraged to call the station for information on making donations. Readers and viewers are frustrated when they learn of a need but are not given direction as to how they can help.
10. Be careful of high overhead / low recovery fundraising events. A stand-up reception with snack food and no host beverages is usually far better than an expensive and (to some people) intimidating sit-down dinner. **Be realistic** about costs, likely attendance and likely recovery on any event you schedule.
11. You may have great ideas about fundraising projects, mailings and other efforts. If the initial financial cost is hard for you to manage, contact your editors immediately. We can suggest or find resources to reimburse reasonable costs.
12. Don't forget that the most inexpensive currency you can spend in our effort can be the most priceless. It's called **"thanks"**. Thank your donors, your helpers and your friends. They want things to be better; that's part of why they help. We will ask them to help again and again. Let them know we deeply appreciate their efforts.



## UNRELATED BONE MARROW DONOR PROGRAM GROWS

The National Marrow Donor Registry and Program have been in active operation for 18 months seeking unrelated donors of bone marrow. The effort is crucial, since only about thirty percent of victims of aplastic anemia, leukemia and other killer diseases have a suitable HLA matching family donor for a transplant.

Dave Frohmayer of our group has served on the Board of Directors of the National Registry since its beginning. In a White House ceremony on March 14, 1989, the Registry celebrated the 100th transplant for which the Registry had secured an unrelated donor. The dramatic beginnings of the Registry are described in the moving article, "A Christmas Miracle" in the December, 1988 **Readers Digest**.

The Registry has enrolled 34,000 volunteer donors. **This is far short** of the 100,000 donors needed to serve an estimated 80% of the need. **Tell your friends who want to help that they can help people in need by enrolling as a donor.** Details on volunteering can be secured by writing the National Registry at 2829 University Ave. S.E., Suite 542, Minneapolis, MN 55414-3254, or by phoning, toll-free, to 1-800-654-1247.

We caution that the use of unrelated donors for FA is still a very experimental option. Any decision should be discussed carefully with your treating physician and experts at a transplant center.

## UNITED KINGDOM GROUP ORGANIZES

David Westmoreland of Nottingham, England is organizing a Fanconi anemia support group for families in the United Kingdom. The group held its first meeting on January 20, 1989 at the Hammersmith Hospital in London. A Medical Advisory Committee was formed, and agreed to provide the group with current information on treatment and research.

The group developed a strategy for informing new families about the support group, and decided to meet on a yearly basis to share information. Individuals present felt there was a need for a patient information booklet on Fanconi anemia. Professor A. John Barrett agreed to approach the Leukemia Research Fund to see if they could publish such a booklet.

We welcome with enthusiasm the formation of the United Kingdom support group. We will report on their progress in future newsletters.

### Appreciation

A generous donation from Vicki Athens has paid for photocopying and mailing expenses of this newsletter. Past and future newsletter support has been provided by voluntary contributions from 28 of our FA families.

You have our deep gratitude for this generous support. Eds.

Meghan Elizabeth Auth was born on July 27, 1980 to James C. Auth and Deborah White. She died on February 1, 1989, following a viral infection.

Meghan's grandfather, James Galvin, retired early as a teacher so he could help Debbie with Meghan's care. Mr. Galvin described his granddaughter as a very sweet, loveable, happy child. She was "loved by all who knew her; her classmates gravitated towards her".

In spite of the many medical procedures she had to endure, Meghan was cheerful and never complained. Mr. Galvin remarked that "She handles life a lot better than her loved ones!"

Following Meghan's death, her classmates took up a collection and planted a tree in the schoolyard as a living memorial to her. A lovely plaque incorporating her picture hangs in the school hall. This special child, so sweet and full of life, touched many lives, and is greatly missed.

**Editors' note:** We know a number of FA families who suffered the loss of a child in the last few months. We share in your grief, but respect your privacy. If you want to share memorial information, please contact us.

## NEW YORK AREA GROUP MEETS

On November 28, 1988, the first meeting of FA family members in the New York City area was held at the Mt. Sinai Medical Center in Manhattan. Organized by Dr. Blanche Alter from Mt. Sinai and Arleen Auerbach, Ph.D. of The Rockefeller University, the meeting was designed to serve a variety of purposes.

The nine families present were given time to become acquainted in an informal setting. Also in attendance were doctors and medical researchers from both institutions who were interested in learning of families' concerns.

Each family gave a brief history of its involvement with FA. Dr. Alter reported on the latest developments in bone marrow transplantation and treatment of FA. Dr. Auerbach discussed her effort to identify the gene responsible for FA. Specific areas of individual concern were addressed.

Doctors Alter and Auerbach and their colleagues deserve a heartfelt vote of thanks for organizing this first ever meeting. Their time and efforts are deeply appreciated.

## NEW YORK AREA SUPPORT GROUP MEETS AGAIN

Arleen Auerbach, Ph.D., and Blanche Alter, M.D., hosted the second meeting of the NY area support group on April 16, 1989 at The Rockefeller University. Ten families attended.

Introductions included a brief description of the current health status of affected children. While there were many similarities in symptoms and treatments in progress, each individual's experiences were quite unique. Some had been contending with FA for years, while others were newly diagnosed. Some of the children were leading relatively "normal" lives and some had reached the point of needing to have a bone marrow transplant. There was agreement that support for and promotion of the newly formed National Bone Marrow Donor Registry is urgently needed.

Many symptoms are associated with FA. Treatment must be tailored to each individual. Dr. Alter provided insight into the rationale behind the various treatments being used. She reported that Memorial Sloan-Kettering had suspended bone marrow transplants for FA because of limited success. Dr. Gluckman in Paris uses a protocol which

produces far better results and may be used at Memorial Sloan-Kettering shortly.

Dr. Auerbach described her work in locating the gene responsible for FA. Recognition was given to FA families who have conducted fund-raising efforts to speed research.

The group agreed to continue meeting once every three or four months. Dr. Auerbach asked families to let her know of specific concerns, and offered to invite health care experts to meet with the group to answer questions.

## CANADIAN FUNDRAISER SUCCESSFUL EVENT

On September 25, 1988, Charlie and Moira MacLellan gave a fund-raiser which netted \$6,665 to benefit the Sick Children's Hospital in Toronto. Moira writes that "Charlie wanted to have a party for our tenth wedding anniversary, so instead we decided to try and do a little fundraising." Called the John and Danny MacLellan Benefit, "It was like a big party, with music, dancing, food and drinks". Willie O'Hagan, singer and entertainer and a country band led by Willis Jarvis provided entertainment. "We had door prizes and spot prizes, donated by people who cared; generally, I think people had a great time." Many suggested that this should be a yearly event.

## COMMENTS FROM FAMILIES PARTICIPATING IN FUNDRAISING

Lorraine and Kevin O'Connor: "Everyone was so kind, generous and helpful. Our fundraiser proved to be a very positive experience during a very difficult time. We sincerely hope the enclosed will be of some good help to the researchers."

Hal and Bobbie Porter: "I know that, for Bobbie and me, this experience has been helpful and rewarding. It has caused us to renew some contacts with friends and has made us more aware of their importance."

Jackie and Bill Lucarell: "Bill tells me to please express his gratitude and admiration for you and Dave. You have given him the will to fight back. Our sincere and heartfelt thanks."

Vicki Phillips: "It was very heartwarming to hear from strangers who read the story and don't know you from Adam. Their words of encouragement brought me to tears. I had a check for \$7 that meant more to me than if it were \$107."

Jackie and Bill Lucarell: "We're not going to stop until 'all our children' are cured."



**Audrey**

**Emily**

**Natalie**

We would like to thank the Frohmayer family for giving us the opportunity to write this article for the FA newsletter. We value every piece of information regarding this disease, and the newsletter provides this. Dave and Lynn have dedicated most of their present life to FA and should be commended for all of their painstaking efforts. The Frohmayers have certainly gained our utmost respect.

Our family situation is probably very similar to many of yours. Our oldest daughter Natalie has FA. She was born with arm abnormalities which led us to the diagnosis of this dreaded disease. During the last four years we have been on an emotional roller coaster as many of you have. We quickly learned about fear: fear of the unknown and the very real fear of losing an innocent and priceless child.

Our priorities seemed to change overnight as we dedicated ourselves to Natalie and this unknown disease. We gathered as much information and literature as we possibly could. We had help learning about FA from our group of doctors which we felt very fortunate to have met. With input from Natalie's geneticists, hematologist, pediatrician and Lynn we have felt more comfortable in combating the ever present questions of why, what if, and how come? We also feel the more we know about FA could only benefit Natalie and ourselves.

Our everyday task of being a normal family changed as did our priorities. With our desire to help Natalie any way we could we sought a perfect HLA match for a potential bone marrow transplant by having more children. Our second daughter, Audrey, was born January 4, 1987. She is a beautiful, healthy girl who is a very important asset to our family. Unfortunately, she is not an HLA match for Natalie. We didn't give up hope. On January 14, 1988 our third daughter was born and was truly an answer to our prayers. Emily is a perfect match. Both pregnancies were monitored very closely with prenatal testing to detect FA.

Emily instantly became the difference between hope and reality. As a perfect match she has given us and Natalie a very real chance to fight the war.

We still have a tremendous amount of fear, yet there is still hope. Hope that we can prolong a bone marrow transplant, hope that Natalie's counts will maintain constant levels, hope that medicines will stimulate blood counts, and hope that gene therapy will one day be a household word.

Yes, it seems that some prayers have been answered with the birth of Emily, but we are concerned about another situation. We can't help but wonder why some of you insist on standing idle while others are *making* time to raise money. We understand that it takes a very valuable and precious commodity to generate a fund raiser: **TIME**. Time is a constant all FA families share but how much time do we really have? Sure research is being done, but time is an important factor. Without money to support extra research, cures could be prolonged and who, reading this article, can afford to wait?

We have raised over \$30,000 and some of you have even raised more than this. If we could generate an overall effort from *everyone* to give a little time and produce a little money, you would be surprised with the results. If we can do it, you can do it. We have confidence in all of you. Be a leader, take care of your precious investments. Don't wait for someone else or something else to dictate your situation.

Good luck to all of you. If any of you has the need to talk about anything such as help with fundraisers, needs questions answered or needs support, please don't hesitate to call.

Our hearts and ears are open.

Brad and Lea Ann Curry

51 Oakridge Drive

Lanesville, IN 47136

812-952-3075







### Tom Kucera

On May 20, 1986 Tom was finally born. His birth was preceded by a two-week period of sonograms, medical speculation, wondering and worrying over what might be wrong with our baby.

My pregnancy was uneventful, with no ill health or complications. In mid May our obstetrician ordered a sonogram to confirm the date of birth. It was then found that Tom had enlarged ventricles which indicated hydrocephalus. It was also determined that other birth defects probably existed, but we couldn't be sure of what type or how many until birth.

The two weeks leading up to Tom's birth were perhaps the most difficult. We were advised to make arrangements as to which regional tertiary care center we would prefer Tom be flown to, as our local hospitals did not have adequate neonatal facilities to handle such medically fragile children. We chose Children's Hospital and Medical Center of Seattle because of family and friends in that area.

Tom was born at 12:31 p.m. and flown a few hours later to Seattle. Tim will probably never forget those early minutes in the Infant Intensive Care when our new son was immediately put through a battery of apparently cruel tests and exams designed to pinpoint as many of Tom's birth defects as possible. I was only able to see Tom for a matter of minutes before he was whisked off by air ambulance.

Upon arrival and examination at Childrens' we were informed that Tom's birth defects included: hydrocephalus, a partially formed closed right ear, a tracheoesophageal fistula (esophagus not connected to the stomach), duodenal atresia (duodenum of the upper intestine was totally closed), absent radius (long bone) and thumb on both arms, one kidney absent and the second only partially developed, micropenis and various other internal anomalies. A number of surgeries on our 4 pound boy would follow in the next few days.

Using the related birth defects as indicators the geneticists ruled out a number of syndromes before informing us in mid June that Tom had Fanconi anemia. By then our vigil at Childrens' was extending into the second month and we were simply hoping that Tom would live from one day into the next. But, he has come through all hospitalizations and surgical procedures with flying colors.

All told, Tom has gone through 6 months of hospitalization and over 20 surgeries. He is a very spunky and alert child, who one would never guess has endured such trauma, except for his demonstrative fear of hospitals. Tom is developmentally delayed in some gross motor areas due to his arms and his long hospitalizations, but this is no big deal to us so long as he is alive.

As a Fanconi, Tom's future holds the certainty of continued medical intervention, and we regretfully accept that fact. But for each week that passes we feel thankful and lucky that Tom is still with us. I feel we have come to appreciate the events of his life more than an average parent might.

Tom is now walking, talking, and all those other mischievous antics two year olds perform. He goes to school three days a week and enjoys every minute of it.

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## NEW NAMES TO ADD TO FA SUPPORT GROUP

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216-545-1110
11. Cathy & Joseph Lucarelli  
2671 N.W. 124th Ave.  
Coral Springs, FL 33065  
305-345-7128
12. Lorraine & Kevin O'Conner  
141 Raymond St.  
Rockville Center, NY 11570  
516-763-1105
13. Fred & Kathy Pharris  
Route 1, Box 489  
Beaver Dam  
KY 42320  
502-274-7418
14. George & Kathy Reardon  
1885 N. Oakcrest Ave.  
Decatur, IL 62526  
217-429-7766 (H) 217-424-5200 (W)
15. Robert & Linda Scullin  
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Sunbury, PA 17801  
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16. Susan & Mark Trager  
24 Oak Ridge Dr.  
Voorhes, NJ 08043  
609-770-8262
17. Irene Trahan  
130 Maggie Drive  
Abbeville, LA 70510  
318-898-1129
18. David & Christine Westmoreland  
4 Pateley Road  
Woodthorpe  
Nottingham, England NC3 - 5QF  
Tele: 0602-269634

## CHANGES IN NAME, ADDRESS OR PHONE NUMBER

1. Carol Ceresa - address:  
9 Mt. Rainier Drive  
San Rafael, CA 94903
2. Lynnette Chandler - address:  
727 Paseo Camarillo # 167  
Camarillo, CA 93010-0896
3. Jeanne & Tim Kucera - address:  
1525 Britf Rd.  
Mt. Vernon, WA 98273-9504  
206-424-3052
4. Dr. Giovanni & Norma Pagano  
add phone #  
Istituto Nazionale Tumori  
Fondazione "G. Pascale"  
v. M. Semmola, 12  
I-80131 Naples, Italy  
011-3981347721
5. Hal & Bobbie Porter - new phone #  
602-837-1632
6. Thurston & Juanita Rice have moved:  
Does anyone know their present address?
7. Cecelia Satterlee - change of name to:  
Cecelia Meloling
8. John & Marie Wells - address  
1100 Lynnewood Blvd  
Klamath Falls, OR 97601
9. Deborah & Len White - address  
503 Bradshaw  
Dixon, IL 61021
10. Bill & Kathi Wingo  
Delete from list of FA Support Group



"There's still a lot we don't know." G. W. COLE

from the:  
Rotarian Magazine, December, 1988

## EDITORS' NOTE

This newsletter about Fanconi Anemia addresses families, friends and health care professionals involved with the diagnosis, treatment, prevention and ultimate cure of the disease. The editors are not physicians. Any medical concerns should **always** be discussed with appropriate scientific experts and treating physicians.

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