



# ICHTHYOSIS FOCUS

Vol. 12, No. 2

A Quarterly Newsletter for Friends of FIRST

Spring 1993

## At Long Last: F.I.R.S.T. Has A FAX

Enormous thanks from all of us to Dr. Wilmer C. Betts (husband of F.I.R.S.T. board member, Georg' Ellen Betts) and his colleagues at the North Raleigh Psychiatric Clinic for donating to F.I.R.S.T. a fax machine—and a beauty! After only two weeks of use, already I can't imagine life without it. Fully automatic, it will accept fax transmissions 24 hours a day, seven days a week. It has already had an enormous impact in our handling of pressing business. We can't be more grateful.

Thank you sincerely, Dr. Betts.

### OUR FAX NUMBER:

**919-781-0679**

## SPECIAL 1992 ANNUAL REPORT ISSUE A REPORT ON THE STATE OF THE FOUNDATION

### THE PRESIDENT'S REPORT

by Frances McHugh  
President

1992 was perhaps the most important year since F.I.R.S.T. was founded thirteen years ago.

The Foundation experienced tremendous growth beginning in 1991, which accelerated in 1992, testing the limits of our organization. Measured by expenditures, the Foundation tripled in size in the period 1990-92.

Only two years ago this Foundation survived on about \$25,000 per year. In

*(Continues on Page 6)*



### REPORT FROM THE C.F.O.

by Georg'Ellen Betts  
Chief Financial Officer

The financial statements appearing in this annual report were prepared by and are the responsibility of the Foundation's management, which has designed a system of internal control to safeguard its assets, ensure that transactions are properly authorized, and provide reasonable assurance as to the integrity, objectivity, and reliability of financial information.

These statements are in conformity

*(Continues on Page 6)*

## UPDATE: CHICAGO '93

1993 National Conference Taking Shape; Keynote Speaker Slated

Registration Forms Have Gone Out To All Active Members

If You Haven't Yet Received Yours, Be Sure to Call Our 800 Number In Raleigh

Planning is well underway for the upcoming national conference slated for June 25th and 26th in Schaumburg, Illinois (just outside of Chicago). Conference registration forms were mailed to all active F.I.R.S.T. members in mid-April. *If you have not yet received your conference application form, please call us in Raleigh at our 800 number and we'll put one in the mail to you.*

We're pleased to announce a slate of distinguished speakers for the conference. Keynote speaker will be Dr. Peyton Weary, president-elect of the American Academy of Dermatology. Dr. Weary is a former member of F.I.R.S.T.'s Medical Advisory Board. Dr. Weary's wife will also join us. She wishes to speak to us

about life in the days before there was an organization like ours—when their own child was born with EHK.

Also joining us will be among the country's most distinguished researchers studying ichthyosis. Among these are Dr. Sherri Bale and Dr. Peter Steinert of the Skin Biology Lab at the National Institutes of Health, and Dr. Elaine Fuchs of the University of Chicago/Howard Hughes Medical Institute. Also participating will be Dr. Joann Villamarin, a pediatric psychologist who will coordinate some of our young-adult activities.

And there will be a great deal more. Don't miss this opportunity to meet a ballroom full of people who share your unique life experience!

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# Ichthyosis Focus

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Spring 1993

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Frances McHugh,

Focus Editor  
Nicholas Gattuccio

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supported by private  
donations.

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The editor invites cor-  
respondence of any kind.  
Please offer advice, criticism,  
and by all means help us with  
ideas for stories. Tell us what  
you want to hear about,  
whom you wish to hear from,  
and what kinds of information  
you would like to see in *Ich-  
thyosis Focus*.

Send your letters, sugges-  
tions, criticisms, ideas, and  
comments to the F.I.R.S.T.  
office in Raleigh. We'd like to  
offer the community an op-  
portunity to learn from your  
experiences, and we'd like to  
hear your opinions and views  
on subjects of importance to  
us all.

## C O R R E S P O N D E N C E C O R N E R

Cynn timer Bates of Lexington, Kentucky, wants us to know about "a great book to look for," entitled *How To Talk So Kids Will Listen and Listen So Kids Will Talk*, by Adele Faber and Elaine Mazlish, ©1980, Avon Books, New York. Cost is \$9.00, and "well worth it," says Cynn timer, who adds, "included are many practical examples and a realistic tone."

Mrs. Arnold Bushold of Latham, New York, wrote us a very nice letter recently. Along with some excellent recipes for the F.I.R.S.T. cookbook, she offered: "I received my *Focus* for Winter 1993. It's always so interesting to see the progress you people are making. The letters and updates of so many of the people who are taking care of family members are sometimes so sad, but they are very important to our family. My granddaughter, Megan Marie, 18 months old, has EHK. She had such a struggle her first six months, but when we got her into the hands of the right doctor for her nutrition, things got much better for Megan.... We have joined together as a family and all are doing their share to help and support our 'little Meggie', to get as much care and help necessary, to give her as much love and attention needed so that she can have a very normal life."

Mrs. Bushold has a few questions, too: "We have started with an Avon cream, Anew, for her face. Has anyone found this to be effective? We use Baker Cummins' P&S Liquid on her scalp, but behind the ears is a problem." Can anyone recommend something for this?

We heard recently from Alice M. Linder in Sunland, California, who received a sample through our mailing of the Dermal Therapy Lotion: "My fondest dream has come true—at age 75—to find DTR Dermal Therapy Lotion for my lamellar ichthyosis. For the past 56 years I have lived in California, but I was born and raised in South Dakota where the winters were especially hard on my legs from peeling, flaking and bleeding, and the summers causing me to overheat. Living in California since 1937 has been much better for my skin. Thanks to F.I.R.S.T. for sending me the sample of DTR a few weeks ago. I have proven to be an answer to my prayers.

From Vancouver, B.C., we heard from Carol Murray, who had some very nice things to say: "We really appreciate our copies of *Focus*; they are *always* helpful. The publication is intelligent, positive, and honest. Thanks so much."

"Michael, our 13-year-old son who has EHK has found that Hermal Bath Oil helps to a significant extent in removing brown skin from his legs and feet. Hurray for Hermal!"

"After years of experimenting with all kinds of treatments and shampoos," writes Jan Whitworth of Birmingham, Alabama, "I found a shampoo that really helped my son's dry scalp. It is called Biojoba, manufactured by Toico Labs in Los Angeles, and can be found in beauty supply stores. It's a little expensive—\$15.00 for a 16.9 oz. bottle—but it's worth it.

Also, my son has a problem with skin sloughing off down in his ears. It's hard keeping them cleaned out. Does anyone else have this problem and can they offer a solution?

From Silver Springs, Maryland, Jacqueline Koutsoukoa writes that "Melrose Cream is great! It can be mixed with Lac-Hydrin for a more beneficial effect. Please inform everyone that it can be obtained from the Furlow Company in Amarillo, Texas (806) 372-4691.

From Auckland, New Zealand we heard from Ann and Paul Dyson, who wrote: "We are the parents of Sam Dyson, and eight month old baby suffering from a severe case of Nether-ton's Syndrome, a rare form of ichthyosis. To the best of our knowledge he is the only diagnosed case of this condition in New Zealand and we are eager to find any information available on his condition and likely prognosis. We would like to contact other parents or individuals with the same or similar conditions."

Anyone willing to help out is encouraged to contact Ann and Paul Dyson at:

2/23 Cleary Road  
Panmure  
Auckland  
New Zealand

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➡ Deadline for submissions to the next issue of *FOCUS*: July 1, 1993 ➡

*Ichthyosis Focus* is provided as a service to members of F.I.R.S.T. as a medium for the free exchange of information. Neither F.I.R.S.T., its Board of Directors, its Medical Advisory Board, nor the *Focus* Editor endorse any treatments or products reported on in *Ichthyosis Focus*.

Views and opinions expressed in this publication do not necessarily reflect the views of F.I.R.S.T. or Foundation officials.



# FROM THE E.D.'S DESK

by Nick Gattuccio

We're pleased to offer the present 1992 Annual Report issue of *Focus*. We retained the Raleigh accounting firm of Williams Overman & Pierce to conduct the first full audit of Foundation assets and accounts in our short history. We did so for two reasons. First, our organization is experiencing such significant growth, and we are on the threshold of such important changes, that we felt we needed to establish a fiscal "ground zero," so to speak. We owed it to ourselves and to all of you to revise and update bookkeeping and accounting systems to cope with these changes and growth, and we thought it best to draw a clear picture of the present in order to effectively measure the future.

Second, we're exploring new sources of funding for this organization, many of which require us to submit for inspection a full audit. The audit was expensive, but it will enable us to explore a great many new funding opportunities. Among these are enrollment in the nationwide Combined Federal Campaign (I just received word that our application to CFC has been accepted), access to certain United Way opportunities, and, perhaps most important of all, access to grants from any number of private and corporate foundations. Seeking foundation grants is an area never explored by F.I.R.S.T., and it is long overdue. Just this week I filed two grant applications seeking program funding (in the amount of \$17,000) to underwrite publication of two new educational books we hope will appear late this year or early next.

March was a busy month. Early in March I traveled to Washington with my wife, Heather, and daughter, Caitlin, for F.I.R.S.T.'s yearly opportunity to testify before the congressional appropriations subcommittee which oversees funding for biomedical research via the National Institutes of Health—specifically, the Institute at NIH responsible for skin disease research, the National Institute of Arthritis, Musculoskeletal and Skin Disease, or NIAMS.

Heather testified before the subcommittee on behalf of F.I.R.S.T. and did a superb job. Our message was simple: It is considerably less costly to cure a disease than it is treating it for a lifetime. Unfortunately, though, this simple

message is a difficult one to convey this year. As we all know, health reform is a very big issue this year, and indications are that research appropriations may suffer as a result. The problem is compounded by budget deficit difficulties that we hear about almost daily in newspapers and television news reports.

The problem was driven home during my second trip to Washington later in March for rounds of meetings and activities in connection with a gathering of the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR), a coalition to which F.I.R.S.T. belongs. In meetings with congressional staff, NIAMS officials, and others placed close to the issues, the message was the same: 1994 is shaping up to be a bleak year for research appropriations. Indeed, when President Clinton's budget was finally released in April, appropriations for NIAMS showed a decrease. Some observers expect, however, that once Congress finishes acting on the budget, NIAMS appropriations may be restored to a level that at least matches the rate of inflation. At best, then, we can expect the status quo; at worst, serious shortfalls.

. . .

The entire issue of health care reform occupied a great deal of the attention of those gathered in Washington. Early observations indicate that we cannot be too vigilant. Although the Health Care Reform Task Force headed by Hillary Clinton has not yet released its reform package, early indications are that some form of managed care package will form a large part of any future national health care program.

The earliest formal model of a minimum benefits package is the so-called "Oregon Plan," which institutes a "rationed" health care benefits package. In theory, the Oregon Plan is based on the assumption that by limiting the *range* of treatments covered, they will be able to expand the *number* of people covered under the plan. The Oregon Plan lists 745 disorders and treatments and then draws a line at a point on the list. Everything above the line is covered, everything below it is not. So where does ichthyosis stand on the Oregon list? Number 740—six from the bottom, and forty lines below "corns and calluses"! See page 9 for more.

## FIRST Board of Directors

Frances McHugh  
President  
Delran, New Jersey  
(exp. 12/94)

Lynne Alba  
Vice President  
Norristown, Pennsylvania  
(exp. 12/93)

Georg'Ellen Betts  
Chief Financial Officer  
Raleigh, North Carolina  
(exp. 12/94)

Cynn timer Bates  
Lexington, Kentucky  
(exp. 12/93)

Deborah B. Vilas  
New York, New York  
(exp. 12/94)

Betsy Bates-Freed  
Los Angeles, California  
(exp. 12/95)

Virginia Frantz  
New York, New York  
(exp. 12/95)

Pamela Stockton  
Raleigh, North Carolina  
(exp. 12/95)

Virginia LaBrant  
Redington Beach, Florida  
(exp. 12/95)

Thomas Beuhler  
Chicago, Illinois  
(exp. 12/93)

Leonard Milstone, M.D.  
Chair, Medical Advisory Board  
New Haven, Connecticut

...

Nicholas Gattuccio  
Executive Director



# F.I.R.S.T. PERSON

F.I.R.S.T. MEMBERS TELL THEIR STORIES ABOUT  
LIVING WITH ICHTHYOSIS

## Day Care Blues

by Jennifer Tomasik

I have heard from parents about their day care disasters. I would like to tell you there is hope. Trying to find day care for a child without "special needs" is stressful enough (Is the center clean? Are the caretakers understanding? Are the meals well balanced? Can we afford it? ... and on and on...).

Now, on top of these questions, there are many more issues about the special care your child with ichthyosis needs. These are questions about applying lotions and administering medications; about taking care of boo-boos and blisters; about knowing when a problem is serious enough to merit calling you at work. And you need to be confident that your child will not be excluded from activities, that child care workers will allow your child to interact with the other children in the group.

I will tell you how I found a truly wonderful day care that loves my daughter *unconditionally*.

I have a 16-month-old daughter, Samantha, who has EHK. When she first started day care she was eleven months old. I visited several centers and chose the one that impressed me the most. Samantha and I went unannounced to visit for a couple of hours. The center allowed

us to visit in the classroom and have snack time with the other children. While Samantha was having snack time, I went to speak with the director and told her about Sam's skin disorder. I encouraged her to ask questions, and I asked her if she felt there would be any problems with Sam attending their facility. I started Samantha on half-days a couple of times a week to see how things would work.

At home I made a list I called "Sammy's Do's & Don'ts" and took it to be put in her "cubby" as a daily reminder to workers about her special needs. I also provided a 16 oz. bottle of Lubriderm Lotion and wrote on it in a black marker, "Beauty Cream." On the tube of Bac-troban I provided for blisters and tears in the skin, I wrote with the same marker, "Boo-Boo Cream."

Before Sam started I spoke with her teachers and asked if they would be uncomfortable taking care of her. I encouraged them to look at her and feel the texture of her skin so they could become familiar with her. I told them she has a severe thickening of the skin and that it was similar to having severe dry skin. I didn't go into the scientific explanation because that tends to make it more that it really is, and I also didn't want to hand

them a lot of technical words they wouldn't have understood anyway.

The main things they needed to know were that it isn't contagious, that she can do anything the other children can do, that if she is outside and it is hot she needs plenty of liquids, and that if she falls her boo-boos will look worse than they really are, and that she is a terrific baby!

Only when they change her diaper does Sam get special attention; then they "smoosh" her down with her Beauty Cream. When she runs low on any of her special products, they just put on her daily report that she needs Boo-Boo Cream or Beauty Lotion.

I feel that Samantha does not need to be treated differently because she has "different" skin. I also have this different skin, and as a child I was always singled out because my mother put too much emphasis on letting teachers, parents and students know all of the facts, when in fact it wasn't any of their business. I do not feel that everyone needs to know, because just telling people gives them the idea that something is very different about your child, and you want your child to have as much a chance at normalcy as other children have.

So far I have not had any confrontations with other parents about Samantha. When the time comes (and I know it will one day), I will tell them that she has dry skin. I will tell them what they need to know and I will tell them without going on the defensive.

I call the day care center once a day (okay, maybe twice), but only because I miss her and because I like to hear her in the background and be reassured that she's doing fine. The teachers love Samantha so much and I never worry that she's not getting the proper care. There have been many a time when I have dropped by unannounced, peeked in to see her playing with the other children (touching, holding hands, crawling all over one another) or being cuddled by one of the teachers, and I feel the tears in my eyes. My heart swells because I know she's no different than the other children. She has the same wants and needs as any other child.

I wish you all the best in finding day care, and if I can help you in any way please call me at (404) 587-1886.

*Jennifer Tomasik is FIRST's R.S.N. Coordinator for Region 3. She lives with her daughter Samantha and her husband in Roswell, Georgia.*

## CHANGES ON F.I.R.S.T.'S BOARD OF DIRECTORS

We welcome the addition of Thomas Beuhler of Chicago, Illinois, to the Foundation's board of directors. Tom has been active with our F.I.R.S.T. since shortly after his son was born with ichthyosis in 1991. Tom's addition to the board will provide significant new energy.

At the same time we regret to note the departure from the board of Andrea Thorn of Clinton, Mississippi. Andrea goes back many years with F.I.R.S.T., and has served ably as the board's secretary since 1991. We will sorely miss her experience, dedication, and commitment to the mission of this Foundation. We wish her good luck with her new commitments.



# GRASSROOTS

*It is time, we think, that we begin highlighting many of the tremendous efforts made by those of you in the ichthyosis community who take it upon yourselves to put forth the energy to organize and conduct your own F.I.R.S.T. fund raising events on the grassroots level. We'll use this section in each newsletter to do this, and to promote special ideas passed along to us by you. Without the generosity of our membership (not just money, but generosity of time and energy), this foundation would long ago have collapsed.*

Kudos to **Suzanne Getz** of Piscataway, New Jersey, who hosted in her home a **Discovery Toy Party**. The event raised \$155.00 for F.I.R.S.T. Suzanne writes, "Family and friends were very receptive. I was happy that they were purchasing high quality educational toys that encourage physical, social and emotional growth—and at the same time it was benefitting F.I.R.S.T.!"

We can't thank you enough, Suzanne. It's a splendid idea, offering a Discovery Toy demonstration, providing sensitive toys for the children while also offering F.I.R.S.T. a significant and unexpected boost.

If you would like to do something

like this in your area, just call us in Raleigh and we'll help you organize something in your area.

Another extraordinary effort has been undertaken for over two years by **Harry & Lynne Alba**, of Norristown, Pennsylvania. In association with **Genuardi's Supermarket** in Norristown, the Alba's and their friends collect cash register receipts, which they then redeem from Genuardi's for cash. The supermarket kicks back a percentage of cash register totals to worthwhile causes, and for over two years F.I.R.S.T. has been among the beneficiaries of this gener-

ous program. F.I.R.S.T. receives between \$600 and \$900 per year through this program.

Efforts like this one work because someone—in this case Harry & Lynne Alba—take the initiative and give a portion of their energy to make it happen. It works, too, because of the community-minded spirit of grocers like Mr. Genuardi. People like these *are* out there!

Local efforts such as these are instrumental to ensuring the long-term stability of this organization. Although the board of directors and staff of the Foundation bear the brunt of the responsibility for ensuring sound financial footing, we must realize that over 75% of our operating budget comes from you in the form of annual dues and donations. In short, without you there is no organization.

This is why we are so appreciative of your generosity. But this generosity can come in many forms. While some give money, others give their time and energy too. As we see, support has many faces.

In coming issues of *Focus*, we will highlight other successful grassroots fund raising efforts.

## A SPECIAL PLACE FOR KIDS

### THE AMERICAN ACADEMY OF DERMATOLOGY SPONSORS SUMMER CAMP FOR CHILDREN WITH SKIN DISORDERS

This summer, from July 24th to July 31st, 60 boys and girls between the ages of 10 and 13 will attend a special camp for children with severe skin disorders. A special project of AAD president, Mark Dahl, M.D., the camp will offer children an opportunity to spend a week among other young children who have similar skin conditions. And the object is to have fun!

To be held at Camp Knutson on the Whitefish chain of lakes north of Brainerd, Minnesota (about three hours from Minneapolis), the camp will be professionally staffed, with experienced and trained counselors, volunteer dermatologists, a camp nurse, a dermatologic nurse, and a visiting psychologist. Each camper's medical needs will be individually monitored. There also will be a group of young adults with skin disorders who will act as counselors and friends to offer support and advice to the younger campers.

And here's the best news:  
The AAD is subsidizing the  
\$250.00 fee.



For more information and/or additional brochures and applications, contact Ruth Sikes at the AAD at (708) 330-0230.

**CAMP KNUTSON**  
CROSSLAKE MINNESOTA

A Special Place For Special Kids

Of course, transportation costs are not included, although some scholarships will be available. Transportation from the Minneapolis airport to the camp will be provided by the Academy. For more information and applications, contact **Ruth Sikes at the AAD at (708) 330-0230.**

SPONSORED BY THE AMERICAN ACADEMY OF DERMATOLOGY

ASSOCIATES FOR SKIN DISEASE RESEARCH  
American Academy of Dermatology  
940 N. Meacham Road  
Schaumburg, IL 60195-4014



# FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES

## 1992 ANNUAL REPORT

### PRESIDENT'S MESSAGE

(Continued from Page 1)

1992 that figure was up to just under \$70,000. Growth of this magnitude creates difficulties, but your board of directors has committed itself to managing these difficulties and making this Foundation a most productive and useful support and education resource for those with ichthyosis.

That is our mission, after all, and our reason for being here in the first place. We exist to serve our ichthyosis community—to offer you support, information, and to do all in our power to assist with research efforts dedicated to understanding and ultimately curing this family of diseases called ichthyosis.

I want to thank each and every one of you for your continued financial support of our Foundation—*your* Foundation. We on the board of directors are only the caretakers of your Foundation, after all. Without you, we would not exist at all.

We look forward to the coming years with optimism. Significant breakthroughs are coming from research labs around the country, and all of you are increasingly showing how much you care about your community. Please join me in looking forward to a bright and prosperous future for all of us.

*The Foundation for Ichthyosis & Related Skin Types, Inc. (F.I.R.S.T.) is a 501(c)(3) nonprofit corporation incorporated in the state of California. The Foundation is organized pursuant to provisions of the California Nonprofit Public Benefit Corporation Law.*

*Principle offices of the corporation are located at 3824 Barrett Drive, Suite 205, Raleigh, NC 27609, where records and documents of the corporation are held. All records and documents are available to inspection during normal business hours.*

*F.I.R.S.T. is governed by a volunteer board of directors (listed on page 3); the Foundation maintains as agent for the service of process in the state of California Mr. Charles Eichorn, Esq., of Alameda, California.*

### REPORT OF THE CHIEF FINANCIAL OFFICER

(Continued from Page 1)

with generally accepted accounting principles and have been audited by the Foundation's independent certified public accountants, Williams Overman Pierce & Company, Raleigh, North Carolina. The auditor's report expresses an informed judgment as to the fair presentation of the Foundation's reported operating results, financial position, and cash flows; and recommendations by them have been implemented by the management. A copy of the auditor's report has been filed with

the North Carolina Department of Human Resources, Division of Facility Services. Additional copies may be obtained by contacting the Foundation's executive director or chief financial officer.

The Foundation believes that its system of internal control is an effective one and adequate to accomplish its goal of developing long term financing for continued operation of its programs and for establishing an endowment fund to support research on the ichthyoses.

WILLIAMS OVERMAN  
PIERCE & COMPANY  
certified public accountants

#### INDEPENDENT AUDITORS' REPORT

Board of Directors  
The Foundation for Ichthyosis  
and Related Skin Types  
Raleigh, North Carolina

We have audited the accompanying balance sheet of The Foundation for Ichthyosis and Related Skin Types as of December 31, 1992, and the related statements of support and revenue, expenses, and changes in fund balances and changes in financial position for the year then ended. These financial statements are the responsibility of the Organization's management. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with generally accepted auditing standards. These standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of The Foundation for Ichthyosis and Related Skin Types, as of December 31, 1992, and the results of its operations and changes in financial position for the year then ended in conformity with generally accepted accounting principles.

As discussed in Note 3 to the financial statements, the Foundation changed its method of accounting from the modified cash basis to the accrual basis as required by generally accepted accounting principles.

*Williams Overman Pierce & Company*

Raleigh, North Carolina  
March 12, 1993

Members  
American Institute of  
Certified Public Accountants  
North Carolina Association of  
Certified Public Accountants

THE FOUNDATION FOR ICHTHYOSIS  
AND RELATED SKIN TYPES  
STATEMENT OF SUPPORT AND REVENUE, EXPENSES,  
AND CHANGES IN FUND BALANCES  
Year Ended December 31, 1992

THE FOUNDATION FOR ICHTHYOSIS  
AND RELATED SKIN TYPES  
BALANCE SHEET  
December 31, 1992

Support and Revenue:		\$
Donations	62,392	
Interest and dividends	4,507	
Other	35	
	<u>66,934</u>	
Total support and revenue		
Expenses:		
Salaries	20,665	
Payroll taxes	1,412	
Conferences and meetings	1,027	
Administrative	598	
Administrative travel	1,946	
Telephone	8,957	
Office rent	4,718	
Equipment maintenance	950	
Technical assistance	2,900	
Printing	7,215	
Postage	4,909	
Depreciation	616	
RSN	2,840	
Dues and fees	669	
Supplies	1,501	
Food and lodging	3,644	
Moving expenses	2,459	
Bank charges	191	
Professional fees	300	
Miscellaneous	1,640	
Total expenses	<u>69,157</u>	
Excess of expenses over support and revenue	( 2,223 )	
Cumulative effect of change in accounting principle	( 1,440 )	
	( 3,663 )	
Fund balances - beginning of year	<u>91,574</u>	
Fund balances - end of year		\$ <u>87,911</u>

ASSETS

Current Assets:		\$
Cash and cash equivalents	22,417	
Certificates of deposit	60,000	
Marketable securities	5,248	
Prepaid expenses	500	
	<u>88,165</u>	
Total current assets		
Furniture and equipment	7,390	
Less: Accumulated depreciation	<u>4,804</u>	
	<u>2,586</u>	
		\$ <u>90,751</u>

LIABILITIES AND FUND BALANCES

Current Liabilities:		\$
Accounts payable:		
Payroll taxes withheld	144	
Other	<u>2,696</u>	
Total current liabilities	<u>2,840</u>	
Fund Balances:		
Unrestricted	85,325	
Plant fund	<u>2,586</u>	
	<u>87,911</u>	
		\$ <u>90,751</u>



# Q & A

by Melodie Buxman, M.D.

**Q.** I have severe atopic dermatitis and ichthyosis vulgaris. I have heard there is a treatment using thymus derivatives, and I would like more information about this. I have severe itching, rashes which sometimes weep, and hives. I have tried antihistamines, cortisone ointments, and wet dressings with little relief.

**A.** The treatments you have had are entirely appropriate, and most atopics would respond well. Your dermatitis appears to be very severe. There are some additional considerations if your rashes are unresponsive: low-grade staphylococcal skin infections sometimes cause atopic dermatitis to go out of control; a short course of antibiotics may be of benefit. Some atopics are contact sensitive to certain raw foods—that is, those affected this way develop hives followed by worsening of their atop dermatitis if they touch these foods. Allergies to foods taken internally may worsen atopic dermatitis. This is uncommon, but an allergist may be able to demonstrate a strong allergy to a particular food, elimination of which can improve some cases of severe atopic dermatitis. Studies on the drug Thymopetin, which you are inquiring about, have ceased for atopic dermatitis, since a comprehensive 10-center study on this drug has failed to yield statistically significant results. Some atopics do respond very well to this drug, and it will be marketed in the future for treatment of AIDS. It will then be available to the general public.

Some other items of interest for severe atopic dermatitis: Gamma interferon will soon be available. Cyclosporine, which is given to organ transplant patients to prevent organ rejection, has been shown to be of benefit in some cases. For more information about these drugs, you might consider writing to The Eczema Association, 1221 S.W. Yamhill, Suite 303, Portland, Oregon 97205.

**Q.** I wonder if you have a solution to a problem of mine. I have ichthyosis vulgaris, and my occupation requires me to meet people and shake hands frequently. My hands are dry, wrinkled and tend to be sore in the winter. Also, does menopause play any role in dryness of the skin?

**A.** Generally, ichthyosis vulgaris alone is not associated with the hand problems you describe; many folks who have this type of ichthyosis also have some degree of atopic dermatitis, a condition in which the skin cells have difficulty retaining water, and become "wrinkled," with accentuated skin lines. These intensify with rubbing and scratching due to itching, and open, sore or even infected areas may develop.

To minimize this, avoid prolonged contact with hot water, and moisturize your hands several times a day. You may need to obtain a good lubricating cortisone cream from your doctor for problem areas. Once your hands are in reasonable shape, a 10-12% glycolic or lactic acid moisturizer (available by prescription) seems to help keep the skin flexible and prevent future outbreaks.

After menopause, the skin gradually decreases production of the natural oils which protect against water loss and lubricate its surface. Chronic sun damage also has the effect of thinning and wrinkling the skin, and increasing dryness.

**Q.** Do you know of any long-term affects of the drug Tigason? My brother has been on Tigason for about 10 years straight and on Neotigason for the past two years. Is this drug a better alternative? I would like to take this drug but found with the Tigasons that the skin all came off my hands and feet, leaving them raw and blistered.

**A.** I assume your brother is an adult, and is followed closely by his physician, with blood counts, blood chemistry screens (to

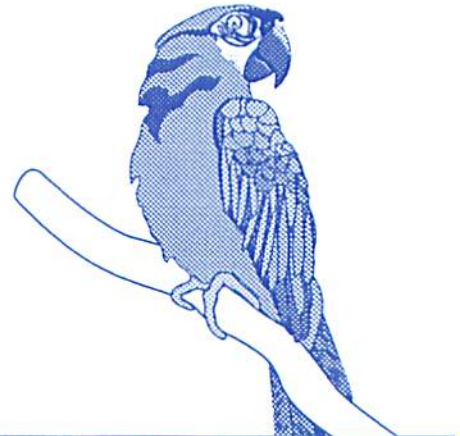
rule out any liver damage or elevated cholesterol and triglycerides). Provided he has tolerated the drug well, the major concern would be development of bone spurs, particularly along the spinal column, limiting side-to-side motion of the back and head, and causing discomfort. Since this can progress fairly rapidly, it might be wise to get an X-ray of his spine to be sure.

You did not mention your age. I would be concerned about using either of these drugs in a woman of childbearing age. Tigason (Tegison in the U.S.) is stored in the body and can be detected in the blood as long as two years after it is stopped. This drug is very damaging to a fetus, should one become pregnant while taking it. I assume by "Neotigason" you are referring to acetrein, the form of Tigason made by the body, and in fact the active part of Tigason. The interesting thing about acetrein is that it may not be stored in the same way as Tigason, and therefore, theoretically, could be safer. It has the same side effects, however.

Tigason has a marked effect on the palms and soles, and is very effective for hyperkeratotic problems in these locations. However, severe peeling reactions such as you report have occurred, and sometimes lowering the dose helps, or discontinuing until healing occurs, and restarting at a lower dose may help. Some individuals still may not be able to tolerate the side effects.

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Melodie M. Buxman, M.D., a dermatologist on the FIRST's Medical Advisory Board, will be happy to answer your medical questions about ichthyosis and secondary problems. Please send your questions to Dr. Buxman, care of the F.I.R.S.T. (anonymously, if you wish) at FOCUS: P.O. Box 20921, Raleigh, NC 27619-0921.





# N.O.R.D. REPORT

The National Organization for Rare Disorders (NORD) is an umbrella organization representing the interests of groups like F.I.R.S.T. in the difficult arenas of political lobbying and health-care advocacy. "N.O.R.D. Report" is an ongoing digest of highlights from NORD's newsletter, NORD ON-LINE.

## Pharmaceuticals Under the Clinton Administration

Senator David Pryor is expected to have considerable power under the Clinton Administration. This Democrat from Arkansas is Chairman of the Senate Special Committee on Aging, and he has been a major critic of the pharmaceutical industry for many years.

Most Washington insiders suspect that Clinton's pharmaceutical policy will follow David Pryor's lead: Tie research and development (R&D) tax credits to a company's pricing policies, while forcing companies to spend less on sales and marketing, and more on new drug development.

Senator Pryor intends to pass legislation tying annual drug price increases to the rate of inflation. Companies that raise prices higher than inflation would lose their tax credits. The Pharmaceutical Manufacturers Association (PMA) is spending \$6 million on an advertising campaign to convince the public that high prices are needed to cover the huge costs of R&D.

"The only real solution to the [drug price] crisis," said Pryor in an October

speech to the Senate, "lies in strong mechanisms that reduce the cost of pharmaceuticals for all Americans. We have to be certain that the American taxpayer pays a fair price for those drugs that are developed with financial support from federal government laboratories and institutions, such as the National Institutes of Health."

## Epidermal Nevus Syndrome: Research Underway

The Congenital Nevocytic Nevus Registry has been established by Dr. Alfred W. Kopf for the long-term study of such lesions. This study will provide information on the natural history of congenital nevi, including the incidence of malignant melanoma. For information on entry into the registry, please contact: Alfred W. Kopf, M.D., Dept. of Dermatology, NYU School of Medicine, 562 First Avenue, New York, NY 10016; (212) 340-5260.

*[Epidermal Nevus Syndrome is a rare disorder recognized among the group of "related" ichthyotic skin disorders. Some members of F.I.R.S.T. have this disorder in their families.]*

# NOTES ON THE "OREGON PLAN"

The following is excerpted from the State of Oregon Publication, "Prioritization of Health Services: A Report to the Governor and Legislature," prepared by the Oregon Health Services Commission, 1993. This approximately 800-page document summarizes what has come to be known as the "Oregon Plan" for health care reform—a health care rationing plan ordered on a minimum (or "standard") benefits package. Copies of the report may be obtained from the Oregon Health Services Commission for \$20.

Included as Appendix "E" is Oregon's notorious "Integrated List Of Health Services," which lists 745 diseases (or disease groups), ranked from 1 through 745. The following examples of rankings are excerpted from the most recent reordering of the list, that dated April 19, 1993. Because the Oregon Plan is not yet in effect (it awaits funding), the cutoff line below which services will not be covered is not yet fixed. However, Oregon's Governor Barbara Roberts has offered a recommendation to the state legislature that this line should be set at number 606.

Following is a sampling taken from the "Oregon List" of some disorders with their numerical rankings.

<u>RANK</u>	<u>DISEASE</u>
1	Severe/moderate head injury
24	Hodgkin's Disease
89	Sterilization/Vasectomy
104	Cystic Fibrosis
156	Asthma
262	Tourette's Disorder
371	Epidermolysis Bullosa
457	Eating Disorders
506	Psoriasis & Similar Disorders
579	Sexual Dysfunction
606	Peripheral Nerve Disorder
---	(CUTOFF LINE)
661	Obesity
695	Diaper or Napkin Rash
700	Corns and Calluses
723	Benign Polyps of vocal cords
740	Ichthyosis
745	Spastic Dysphonia (END OF LIST)

## F.I.R.S.T. HELPS OUT IN EGYPT

We received recently an appeal from Drs. Sherri Bale and John DiGiovanna at NIH. They had just returned from field studies in Cairo, Egypt, where they located a large population of families with lamellar ichthyosis. Because local custom sanctions intermarriage between first cousins, this recessive form of ichthyosis appears in affected families with a high frequency. The problem is, these people have nothing at all to treat their symptoms with. Imagine, if you will, using no lotions or treatments at all on yourself or your child with lamellar ichthyosis.

After hearing of this we turned to friends in the pharmaceutical industry. We asked what they could do for these families, and the response was gratifying. Chesebrough Ponds is sending 20 cases of topical products; Baker Cummins and Swiss American Products are also coming through with donations. Our sincere thanks to all for their help in this human tragedy. Special thanks to William Schmitt of Chesebrough Ponds, Erica Seiferling of Baker Cummins, and Whitney Delcourt of Swiss American.



# NEWS & NOTES

## Financing Health Care for Children With Special Needs

New England SERVE is one of the National Centers for Children with Special Health Care Needs funded by the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services.

Among their many publications, New England SERVE has available a booklet entitled *Paying the Bills: Tips for Families on Financing Health Care for Children with Special Needs*, a booklet developed by parent authors to share information and strategies for getting information and strategies for getting payment for children's health care. Single copies of this booklet are available at no charge.

Send a self-addressed 9" x 12" mailing envelope with \$1.05 in postage affixed to New England Serve, 101 Tremont Street, Suite 812, Boston, MA 02108.

## Children May Benefit from New SSI Rule

Children who have disabilities may receive higher Supplemental Security Income (SSI) benefits as a result of the new method Social Security now uses to compute the effect of their parents' income on their monthly payments. The new rule, effective November 1, 1992, eliminates two of the three formulas previously used to determine how that income will affect a child's eligibility for SSI and the amount of the monthly benefit payment.

Two groups of children (or family members) are encouraged to contact Social Security to see if the new rule affects their eligibility: (1) children whose applications for SSI benefits were filed before November 1992 and who were denied benefits based on their parents' income; and (2) children for whom no application was filed because it was believed their parents' income would make them ineligible. The new rule applies only when one or both parents are working.

Children who already are receiving SSI benefits could be eligible for higher payments under the new rule. Social Security will recalculate the amount and send the additional money. Current beneficiaries do not need to request that this action be taken.

## Baby Go To Sleep!

Here's a solution for sleepless nights

and solace for infants in an NICU: a cassette tape entitled *Baby Go To Sleep*.

Available from Audio-Therapy Innovations, at P.O. Box 550, Colorado Springs, CO 80901 (800) 678-7748, the audiocassette is "designed to be played in NICUs, has a calming effect on babies and their parents, especially in the intensive care setting. This tape is recommended to nurses in NICUs as well as in pediatric departments, day care centers, and the home—anywhere the sleepless cries of babies and young children need quieting. It induces sleep in children from newborn to age six using gently, deliberately sung lullabies and nursery rhymes."

## Personal Keep-Cool Misting System

Specialty mail-order store Hammacher Schlemmer offers a product that may be of interest to some—a personal misting system. In their words it sprays "an ultra-fine mist around you which quickly cools the surrounding air as it evaporates. Its one-pint water reservoir rests snugly around your waist while a flexible 36-inch long misting tube clips to your hat, glasses or collar. Water is kept in the mister's reservoir under moderate natural pressure and is released in a fine mist at the touch of the control clip. It

## IN MEMORIAM

We received in March a letter from a long-time member and supporter, **Herdis Olson** of Jackson, Wyoming, who sent F.I.R.S.T. a very generous donation of \$200 *in memory of her mother, Marie Pedersen, who died in February in Copenhagen, Denmark.*

Our sincere sympathy goes out to friends and family, and our gratitude to Herdis on behalf of the Foundation.

will spray up to 40 minutes continually, or up to four hours with intermittent use."

We do not vouch for the product, of course, but we thought you might like to hear about it. Cost is \$39.95 (ouch!), and you can have it in black or hot pink. Order number is 46438H, and may be obtained by calling 800-543-3366.

## News & Notes Is Open Forum

Please feel free to send us information that you run across which may be of interest to others in our community. We are particularly interested in books you may have read, and in news stories you think may be useful.

Send your items for News & Notes to Nick Gattuccio at the F.I.R.S.T. office, P.O. Box 20921, Raleigh, NC 27619.

## RECIPES...RECIPES...

*Please don't forget...we're collecting recipes for a F.I.R.S.T. cook book we hope will appear in 1994. Following is an example of one we've received so far.*

From Heather Robertson in New Zealand we have a tasty sounding traditional dessert:

### PAVLOVA

#### Ingredients

3 egg whites  
Pinch of salt  
1 cup sugar  
1 tablespoon corn flour  
1 teaspoon lemon juice

Beat the egg whites and salt until stiff. Add sugar, gradually beating

well between each addition. Make sure the sugar is completely dissolved. Fold in the corn flour and lemon juice. Pile the stiff mixture onto a flat tray and make a pile in the center that is about six inches round.

Preheat oven to 400°. Place the Pavlova in the oven and turn down to 250°. Cook for one hour. After cooking, turn the oven off and leave the Pavlova in the oven for at least one more hour. *Don't open the oven door or the Pavlova will collapse!*

When cool, cover with whipped cream and sliced fruit (kiwi fruit for authentic New Zealand version).

*Send your recipes to the F.I.R.S.T. office, attention Heather Gattuccio.*



# A SPECIAL MESSAGE TO MY FRIENDS

by Wendy Vaughn

*Editor's note: We received a letter recently from Wendy Vaughn in which she spoke eloquently about living as a teenager and student with ichthyosis. She tells us that she and her mother will be attending the national conference in Chicago in June, and had a special request about the conference: "I think that some of us, even the children, should stand up and speak to everyone about their lives ... I most definitely would like to, and I'd go first!"*

*Wendy enclosed three poems telling us, "here are a few poems that a couple of my friends wrote which I think express my true feelings and give advice for all those with ichthyosis." The poems are*



*printed here.*

*Wendy has a special message that she wishes to share:*

To see things in the world as others do is an important self-made goal. To look at the

world through different eyes can make a broken man whole.

I have lamellar ichthyosis and what a struggle it has been for me. I'm almost 18, and I've had to deal with my skin defect for a long time. What I want to tell all the beautiful and wonderful children out there is that although life goes on and you get older, it may get tougher but it will truly make you a stronger person.

I am that example!

## MOTHER OF SPECIAL NEEDS CHILD ADDRESSES GRADUATE STUDENTS

by Deborah B. Vilas

On Monday, March 29th, Cathy Lopez (far left in photo) appeared on a panel speaking to a class of graduate students at the Bank Street College of Education in New York. The panel consisted of parents of chronically ill children, and Cathy spoke about her experience as the mother of a ten-year-old son (Nestor) with lamellar ichthyosis.

Cathy was extremely articulate and spoke very openly about the myriad challenges facing her as a mother of a newborn with a rare disorder. She shared the story of



his birth and subsequent development, the effects it had on her family, and how it has impacted on her life in general. She shared pictures of Nestor and handed out F.I.R.S.T. pamphlets to all of the students.

Cathy is a nurse working in a school for children with special needs, a career change that occurred after the birth of her son.

## THREE POEMS FOR WENDY VAUGHN

A closed book is shy  
It's one who never cries  
And if it does so  
You'll never know  
Because a closed book is shy.

A shy person is a closed book.  
All the beauty is lost inside.  
So just take another look.  
Don't let them hide—  
Because a closed book is shy.

Help this book overcome his shyness.  
Show him to the world,  
don't let his story sit untold  
Because an open book is beautiful.

. . .

I've heard you laugh and I've heard you cry  
I've even seen a few tears in your eye.  
I've listened to you yell and sit and complain,  
But I'm always here in your time of pain.

Do you need someone or want to be alone?  
Well, if you need me, just pick up the phone.  
I love you too much to see you so down.  
So if you need someone, I can always be found.

A few words of wisdom is all I can give,  
they may not make you happy, but you'll live.  
All I have to say is cheer up and don't frown.  
You shouldn't let everyone get you so down.

You can change your life if you see the need.  
All you need is God to help you succeed.  
Those are my words of wisdom that you should  
remember  
And I'll be here when you need me always and  
forever.

. . .

To run is not an easy task, improvement harder yet—  
But if you truly want it, you'll reach the goals you set.  
For when you feel it in your heart, believe it can be done.  
And never give up on your dreams; you can be number  
one.

It will be hard, guaranteed, but the challenge is the thrill.  
If there were no challenge, there'd be no dreams to fulfill.  
The work may seem impossible, the aches too much to  
bear—  
But this very feeling is yet our greatest dare!

It takes some motivation and a lot of pain at first,  
But as you take each step, you begin to quench that  
thirst—  
That thirsting for advancement, for being a success.  
For knowing it is possible for you to be the best.

Don't deprive yourself of a chance by never even trying.  
It isn't fair to cheat yourself and believe it will suffice.  
Find love of what you do and continue to achieve,  
And remember, most importantly, BELIEVE! BELIEVE!  
BELIEVE!





*FOCUS is printed on recycled paper.*

## Regional Support Network

The Regional Support Network is in place to facilitate communication between members of the ichthyosis community. Parents can exchange practical tips and child-care information. Adults can support one another by sharing experiences in job hunting, self-treatment, medical issues, social coping strategies, and other issues. If you wish to join the support group in your area, please contact the representative for your region. *If you wish to join your area's Network, call your Regional Coordinator or F.I.R.S.T.'s toll-free number to receive the "pink" registration form.*

### REGION ONE

NY, PA, VT, NH, NJ, CT, RI, MA, ME  
Deb Vilas  
7 East 88th Street, #4-B  
New York, NY 10128  
(212) 427-5904

### REGION TWO

DE, MD, WV, VA, NC, SC  
Robin Joyce  
Route 1, Box 189-F  
Sandy Ridge, NC 27046  
(919) 871-3277

### REGION THREE

TN, GA, FL, AL, MS, LA, AR  
Jennifer Tomasik  
880 Lake Overlook  
Roswell, GA 30076  
(404) 587-1886

### REGION FOUR

KY, OH, IN, IL, MO, MI  
Cynn timer Bates  
133 Elam Park  
Lexington, KY 40503  
(606) 276-0142

### REGION FIVE

WI, IA, MN, ND, SD, NB  
Joe & Marlene Huffman  
1326 DeSoto Avenue  
Glencoe, MN 55336  
(612) 864-4508

### REGION SIX

TX, OK, NM, CO, KS  
Donna Rice  
2902 West Elm Circle  
Katy, TX 77439  
(713) 391-4407

### REGION SEVEN

WA, OR, ID, MT, WY, AK  
Sheri Gelivich  
1344 S.E. Rex  
Portland, OR 97202  
(503) 236-3203

### REGION EIGHT

CA, NV, UT, AZ, HI  
Mark & Claudia MacNaughtan  
610 East 800 North  
Genola, UT 84655  
(801) 754-3064

### NETHERTON'S SUPPORT GROUP

Cathy Sipper  
P.O. Box 127  
Rutledge, AL 36071  
(205) 335-6827

*Regional Support Network National Coordinator: Heather Gattuccio (919) 846-7027*

F.I.R.S.T. is a 501(c)(3) charitable organization supported entirely by tax-deductible private donations.

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All contributions of \$100 or more are acknowledged in *FOCUS*

# Y E S !

## *I Want To Help F.I.R.S.T. Help Others In The Fight Against Ichthyosis*

- Single \$25 / year  
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 Sponsor \$100 / year  
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Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_  
Zip: \_\_\_\_\_ Phone: \_\_\_\_\_

**Mail to: F.I.R.S.T. / P.O. Box 20921, Raleigh, N.C. 27619**