



ICHTHYOSIS FOCUS

Vol. 15, No. 2

A Quarterly Journal for Friends of F.I.R.S.T.

Spring 1996

President's Letter

by Deborah B. Vilas

Dear Members,

Well, there is a FIRST time for everyone, even your president. In mid-February, the Board of Directors committed themselves to a fundraising campaign that included involving their friends, acquaintances and family. Each one of us agreed to compose a letter and send it to our Christmas or Chanukah list, those people to whom we send holiday cards every year. Admittedly, I was anxious. What would my friends think? Would I offend them by asking for money? And what about my friends who didn't have the money to begin with? I was sure that they would feel badly when I solicited them.

I was in for a big, pleasant surprise. Not only were people not offended by my request, but they seemed thankful that I had approached them! They were moved by my letter and the pic-



ture on the brochure that I included, and they were more than willing to help. Some friends of mine who were not wealthy sent in small donations. Others sent in larger ones. Each one meant something special to me. Not only was I helping to raise money for F.I.R.S.T., I was educating people about a very important cause. It taught me a valuable lesson. People like to make a difference in this world. Giving to an organization that affects someone in their lives makes their donation more real and meaningful to them.

And so, members, I now come to you. Won't you pick up a pen (or your computer mouse) and reach out to those who know you best? Give them a chance to assist you with a project that is close to your heart. If you call our office we'll send you brochures and envelopes to include in your mailing (800-545-3286). Fol-

(Continues on page 13)

NATIONAL ICHTHYOSIS AWARENESS WEEK

MAY 20 - 26

Don't forget that May 20 - 26 is National Ichthyosis Awareness Week. All are encouraged to join this effort with a fund raising and public awareness event in your local communities. Contact the F.I.R.S.T. office for information sheets, press packets, and other materials to help you get your event underway.

F.I.R.S.T. PART OF THE 1996 COMBINED FEDERAL CAMPAIGN (CFC)

F.I.R.S.T. has become eligible to participate in the 1996 Combined Federal Campaign (CFC). Federal employees will now be able to designate F.I.R.S.T. as a recipient of contributions made through CFC payroll deductions.

F.I.R.S.T.'s number in the 1996 CFC handbook is

0810

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CORRESPONDENCE CORNER

Dear friends at F.I.R.S.T.,

Congratulations on 15 years of hard work and service to those of us who need you so very much. As I write, our 21-month-old daughter, who has tri-chothiodystrophy with ichthyosis, is battling yet another illness. We seem to move from one sort of crisis to another, although overall things are better. Kelsey battles mostly gastrointestinal problems, and except for occasional problems, her ichthyosis is tolerable.

We were certainly sad to hear of Cynnie Bates stepping down as Region 4 coordinator. I spoke to her by phone several times and found her very supportive.

The real reason I'm writing today is to request some literature. I have been feeling for some time that if more people just were educated about ichthyosis it would help us along. I am so weary of people asking about Kelsey, then, as I try to explain the problem, I see their eyes glaze over. Deep within myself I think the response would be different if they were knowledgeable about this problem.

I am preparing several articles for my local newspaper and a request to Oprah to air a program about children with ichthyosis. You mentioned in your newsletter that you had public information material. I am interested in any of these items that you

think would help be out. I would also like another copy of *Release the Butterfly* for my family doctor.

Thanks for all your support and help!

Julie A. Creek
Williamsport, Indiana

Dear F.I.R.S.T.,

We cannot thank you enough for your newsletters, and the literature you sent on ichthyosis has been invaluable.

We have two daughters. Jamie is six years old and was born a collodian baby and was later diagnosed with lamellar ichthyosis. Emily is one, and her skin is fine. Our first child was a little boy we named Brenton. He was born with harlequin syndrome and sadly died at age 3 days.

We shifted to Dunedin two years ago and our new skin specialist here made us aware of F.I.R.S.T. It has opened a whole new world to us. At last some concrete information written in black and white that we can understand. Little is known of lamellar ichthyosis in New Zealand, and harlequin ichthyosis is almost unheard of.

After Brenton died we were told that we had a one-in-four chance of having another baby with harlequin. Otherwise the child would be quite normal. We were totally devastated when Brenton died, and it was after a lot of heartache that we de-

F.I.R.S.T. CAN BE REACHED ON-LINE VIA COMPUSERVE

Our CompuServe address: 74722,1571

You may also reach us over the INTERNET by
addressing Email this way: **74722.1571@compuserve.com**

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cided to have another baby. Our darling daughter Jamie was born not with harlequin but with lamellar ichthyosis. This greatly surprised our doctors. The explanation was that the gene must come in varying degrees of severity. [It is probable that Brenton was misdiagnosed. -ed]

Whatever the reason, Jamie is our little miracle, and we love her dearly. Over the years we have tried several different creams. At the moment, we use aqueous cream with 10% glycerine twice daily all over, and emulsifying ointment on her face, hands and feet. Her scalp is not easy to keep right, and I find combing with a very fine comb the best way to lift the scales. I've tried different shampoos. The DeLorenzo range is working well at the moment.

Jamie's hands and feet do get particularly dry and her face very red. Since starting school, Jamie has had problems with teasing from other children. This has upset her deeply, resulting in stomach aches and nightmares. My heart breaks for her. Children can be so cruel, and in some instances adults not much better.

We decided something had to be done so with the support of the school I am currently speaking to each class about Jamie's skin in the hope that if the kids understand then maybe a lot of the teasing will stop.

Despite all of that Jamie loves her school work and is doing very well. She also enjoys ballet and is now in her third year of dance and has just started piano lessons.

We have always supported and encouraged Jamie as much as we possibly can. She is a bright, kind, caring little girl who absolutely adores her wee sister.

Thank you F.I.R.S.T. for all you are doing. Although the United States is a long way from New Zealand, it is a wonderful feeling to know that you are there and that we are not alone.

Mandy Metzger
Dunedin, New Zealand

PEN PAL IN NEW ZEALAND

My name is Jamie Metzger. I am six years old and I live in Dunedin, New Zealand.

I have lamellar ichthyosis. My mum reads *Ichthyosis Focus* to me and it makes me feel better to know that there are other people with the same skin as me. In New Zealand it is very rare and there are only 20-25 people in the whole country that have it.

I have to put cream on my skin so that it doesn't get too dry. My face can sometimes be very red and some of the kids at school tease me about it and my dry, crackly hands. I makes me very sad.

I like school, though. The teachers are nice and I have a best friend called Ashleigh. I am learning to play the piano and I am into my third year of ballet. I would like to write to someone with the same skin as me and hope someone will reply soon.

Jamie Metzger
22 Blanc Ave
Fairfield / Dunedin
New Zealand

PEN PALS F.I.R.S.T.

We're starting a new feature in *Ichthyosis Focus* in which we try to match pen pals. If you would like to try hooking up with a pen pal, just write us a note and tell us a little about yourself (as Jamie has done here). We'll publish your note in upcoming issues of *Focus* along with your mailing address. Be sure to identify your note as a Pen Pal note, and **be sure to give us your permission to publish your address.**

Send your note to Focus, c/o F.I.R.S.T., P.O. Box 20921, Raleigh, NC 27619-0921.

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Our trip's final leg was a drive that started the morning before in Lexington, Kentucky. We pulled in to Raleigh, North Carolina at about ten the next morning in a 26-foot van, while Heather followed in the car. Caitlin Irene, then eighteen months old, took the long drive better than we had expected. She's a trooper. It was October 29th, 1992. And so it began.

We didn't hesitate when the opportunity to move across country to take the reins at F.I.R.S.T. presented itself late in the fall of 1992. We had been deeply involved for more than a year by then. Heather served on the Board, we shared RSN duties for Region 7 from our home in Portland, and I had begun doing *Ichthyosis Focus* from there. Somehow, picking up and moving 3,000 miles from friends and family to take a place at the center of the circle that is our tight-knit community seemed the natural thing to do. Now, it seems just as natural that we step aside this 15th anniversary year, as your Board steps up to lead F.I.R.S.T. into the future.

We've made a great many wonderful friends over the years. Recently, I calculated that between Heather and I, we've enjoyed more than 3,000 phone calls with this rare family of ours. It feels as though we've spoken with almost all of you out there, and we will miss this contact, sincerely. This contact, this fostering of a sense of community, and this breaking down of the walls of isolation that we all feel — this stands at the core of the mission and the goals of this Foundation.

From our point of view, this job has been about community all along. Because that's all F.I.R.S.T. really is, when you get right to it — an

EXECUTIVE DIRECTOR STEPS DOWN

After Nearly Four Years Serving Our Community,
Nick & Heather Move On



Caitlin Irene joins her father, executive director Nick Gattuccio (seated, left) at the National Institutes of Health, as representatives of the Coalition of Patient Advocates for Skin Disease Research meet with the new Director of the National Institute of Arthritis, Musculoskeletal & Skin Diseases, Dr. Stephen I. Katz (standing behind Nick), and Deputy Director, Dr. Stephen Hausman (standing far right).

organized community of individuals and families united by a rare genetic bond.

We're very proud of the work that we've done over the years. Our national conferences in Chicago in 1993, and in San Diego in 1995, were precious gatherings. The RSN is larger and stronger than ever. More of our members are involved in grassroots activity than at any time in the past, and the Foundation has perhaps the most diverse Board of Directors than at any time in our 15 year history. Our work with the National Registry for Ich-

thyosis & Related Disorders is a model of cooperation, resulting in a great many new members who would not have found F.I.R.S.T. otherwise. We've also forged important relationships with physicians and researchers throughout the country whose special interest coincide with our own. We're also reaching a great many new members of our far-flung family through our new electronic tendrils.

I speak for Heather as well as myself when I say how much we've enjoyed serving this remarkable community, and how much we'll miss it now that we're gone. Speaking as a parent of a child with ichthyosis, I can also say what a rare and remarkable opportunity this has been for us — to sit in the center of the circle. It has been a privilege to have the opportunity to deal not just with all of you, but with so many in the medical, research, and political communities whose activities have such a profound influence on all of our lives.

Help Wanted - Executive Director

The Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.) is seeking a proactive Executive Director to plan, coordinate and evaluate programs and activities. Areas of responsibility include: fund raising, quarterly newsletter, Regional Support Network and National Conference. Duties include managing budget, developing and directing volunteer staff; recommending policies and programs to fulfill our mission and goals; working with the Board of Directors and committees internally and associations and government agencies externally. Excellent writing, public relations and organizational skills are necessary. Financial management and budgeting experience is needed, along with a proven record of fund raising. Strong word processing and desktop publishing skills are required, along with a working knowledge of database concepts and capabilities. (Macintosh experience a definite plus.)

Please send your resume and a cover letter including compensation requirements to: M. Petersen, 452 Fifth Ave, 14th floor, c/o RNB, New York, NY 10018, or email FIRSTsrch@aol.com.



Heather Gattuccio with Caitlin Irene and Lorenzo, Washington, D.C., March 1996

People who have disabilities in our society, or *who are perceived to have disabilities*, are given very mixed messages when it comes to the issue of employment.

On the one hand, society wants all of us to be self-supporting and independent, and wants only the most unfortunate among us to have to depend on government subsidies for the basic necessities of life. On the other hand, people with disabilities, or people who are not really disabled by a condition that causes them to look different in some way (such as an ichthyotic skin condition), have had a tremendous uphill battle getting a job from those same members of society who don't want "those people" to be on "welfare." I have had the experience many times of applying for and not getting jobs for which I was over-qualified, and I have heard from several other people with EHK who have all had struggles with employment issues.

The good news is that there are now a couple of Federal laws that should protect us from the most overt kinds of discrimination. The bad news is that more subtle forms of discrimination are a lot harder to prove and a lot harder to fight. I am going to explain briefly how these laws work, and how they might be applicable to someone with ichthyosis.

The Americans With Disabilities Act of 1990 (ADA)

Under the ADA, a person may be regarded as having a disability if he or she (a) has a physical or mental impairment that substantially limits one or more of the major life activities; (b) has a record of such an impairment; or (c) is regarded as having such an impairment. To use myself as an example, I could be regarded as being covered by this law in two different ways. Under (a), because the blistering on my feet causes severe difficulty for me walking or standing, and also under (c), because the appearance of my skin is so different that other people might think I have a much greater problem than just a hard time walking. Another issue with ichthyosis that applies is the inability to withstand extreme temperatures — this affects a major life function and can reasonably be considered a disability. Even if you just look "different," or if people think you're sick, or might have been burned, or might be contagious, this is enough to trigger legal protection under the ADA.

So what does this mean for you? Title I of the ADA prohibits discrimination against a *qualified individual with a disability*, in regard to job application procedures, hiring, advancement or discharge, employee compensation, job

MIXED MESSAGES

Employment & The Law for Persons With Ichthyosis

by Teri A. Adams, J.D.

training and other terms, condition and privileges of employment.

A "qualified individual with a disability" means that the individual has the stated qualifications for the job (ex-

perience, education level, etc.) and can perform the stated essential functions of the job, with or without a "reasonable accommodation." A *reasonable accommodation* is a purposely vague term, because the drafters of this law wanted people to have to think about what is "reasonable" in the context of a particular job, with a particular employer, and the particular circumstances. For example, if I'm working for a big money corporation, and I need an expensive reading machine because I'm blind, the courts would very likely say that since the corporation can afford a reading machine, and I'm the most qualified candidate for the computer programming job, the corporation has a legal obligation to buy it for me.

On the other hand, if I want a job as a sales clerk at the corner store and it isn't air conditioned, and I can't stand the heat, the courts would probably look to the income of the store, their ability to pay for an air conditioner and increased utility bills, and at how many employees work at the store, and consider all of these factors when deciding whether it was reasonable to make the owner of the store install air conditioning.

The point is, the intention was to create a law that has a measure of good old common sense in it, while at the same time trying to address the fact that (1) people with disabilities, or who are perceived to have disabilities, have been historically discriminated against in the area of employment; (2) that people with disabilities may need some accommodations to enable them to work at their full potential; and (3) that society has an interest in enabling qualified persons with disabilities to find employment and be able to support themselves just like everyone else.

The Message for F.I.R.S.T. Members

Since attending F.I.R.S.T.'s National Conference in San Diego last June, I have heard from several people who have EHK, and they all had "horror" stories about difficulties they had encountered around employment — everything from losing a job entirely, to being ostracized because one of their co-workers wasn't comfortable with the way they looked.

The reality is that the ADA isn't going to fix this problem overnight for us, or for other people with visible

(continues on page 7)

Summer's coming, and we all know what this means for our children with ichthyosis — insufferable overheating.

We get a lot of calls about cooling vests, and we thought it was about time to bring some of the information we have on hand together in one place for everyone to share.

We don't pretend to know about all that's out there, so we're hoping that by printing the following information, we'll learn about more heat-control products and strategies that all of your out there are using. Please share your val-

Cooling Vest Update

uable experience with us, so that we can pass your knowledge along to the rest of our members.

As always, we do not endorse or recommend any of these products. Check with the manufacturers to make certain you're getting a product that both fits right and works effectively. If you have problems with any of these products or companies, please pass that along to us, too.

We hope this information is helpful. And, again, let us know about other products or cooling strategies that you know of.

ILC Dover, Inc. Ice Pack Vest Model 15

ILC Dover is the company that manufactures space suits for NASA. Their main business, though, is making heat-regulation garments, primarily for use in industries where workers are exposed to high heat environments. ILC Dover is also the only company we know of that makes a cooling vest in a child's size.

The Model 15 slips over the head and is secured in front with velcro straps. Horizontal pockets in front and back (three in front and three in back in the adult size; two each front and back on the child size) hold gel packs. The gel packs need about 8-10 hours to fully freeze, and once inserted fully frozen they last about 4 hours (depending somewhat on how hot it is).

The vest is made of flame resistant blue cotton. The adult size, fully loaded, weighs three pounds; the child's size weighs just about two pounds fully loaded.

At our last check, the child's size Model 15 cost



ILC Dover Model 15. The adult model shown here

\$175.00, which includes one set of gel packs. A second set of gel packs (highly recommended that you have a back-up set in the freezer) costs \$46.00.

ILC Dover also makes a water-circulating, battery-powered cooling vest (the Model 19). This model is available only in adult sizes and costs about \$225.00, plus another \$110 for battery and charger.

Please be sure to confirm pricing and features with the manufacturer before you purchase! If you're considering purchasing one of these products, be sure to contact the company to obtain a catalog and current prices.

Your can reach ILC Dover at the following:

P.O. Box 266

Frederica, Delaware 19946

Phone: 302-335-3911, or 1-800-631-9567

Fax: 302-335-0762

Another Source to Check Out

There is a mail-order company that specializes in industrial safety equipment, including various body cooling systems. The company is named Lab Safety Supply. You can request a catalog by calling 1-800-356-2855. They are located at P.O. Box 1368, Janesville, WI 53547-1368.

ThermalWear Body Management System

Offering a different cooling technology altogether, the ThermalWear Body Management System, manufactured by Exothermal Technology Corporation, is based on a non-toxic chemical formulation that acts as a "heat sink" to draw heat away from a person's body.

The ThermalWear product is also an over-the-head vest-and-pocket cooling system. Unlike the ILC Dover vest, it does not rely on frozen gel packs. Instead, its vest pockets are inserted with "KoolPacks," which contain their patented "heat transfer formula." This is a chemical liquid that cools quickly when submerged in cold water, and retains its coolness quite long.

The manufacturer reports that the KoolPacks can be fully recharged in 15 minutes in ice water (or even a cooler or cold stream, if on a picnic). Once charged,



they will last up to 4-8 hours on your body.

The vest itself is made of DuPont Thermolite material, a blend of fine fibers and sheath/core binder fibers. The manufacturer maintains that Thermolite does not deteriorate with washing, drying or cleaning, and is soft and flexible. Nonetheless, the fabric is warranted for just 90 days, while the KoolPacks themselves are warranted for one year. The vest fully

loaded weighs about three pounds. Child sizes are not available.

You may contact Exothermal Technology Corporation at:

1720 Main Street, N.E.
Palm Bay, Florida 32905
Phone: 800-991-5665
Fax: 407-952-3964

Employment & The Law

(continues from page 5)

disabilities or differences. However, we now have a legal remedy for discrimination, and I urge you to pursue it. I also urge you to become familiar enough with the law and its provisions — in more detail than I can go into here — so that when a situation arises you can talk intelligently to the human resources person in your company, or to your supervisor, or to a lawyer if it comes to that.

If you feel that you have been treated in an outrageous and illegal fashion, then you probably have been. If you don't stand up for yourself and for your rights, then the offending employer is going to keep getting away with discriminating against employees who are different from him or her in some way.

If you have to get a lawyer, find one who is familiar with the ADA, preferably someone who specializes in dis-

ability rights law. And, know this: under the ADA, the plaintiff's (that's you) attorney's fees are paid for by the defendant (that's the employer), *if you win*. This is why a good disability rights/civil rights attorney will take your case, even if you tell him you don't have any money to pay him, because if you have a good solid case, the "bad guys" will pay him later.

I've only discussed the basics here. If you have any questions, please write to me care of F.I.R.S.T. and I will try to answer your questions in my next column. I would also like to know of any other disability rights law issues in which you might be interested.

You are invited to send your questions and comments to Teri A. Adams, c/o F.I.R.S.T.
P.O. Box 20921
Raleigh, NC 27619-0921.

TWO SPECIAL CAMPS FOR SPECIAL KIDS

For young people between the ages of 10 and 13, the American Academy of Dermatology once again this year is sponsoring Camp Discovery at Camp Knutson in Crosslake, Minnesota.

Formerly called simply Camp Knutson, this wonderful Academy program is now in its third year. This special week for kids with chronic skin disorders will take place from July 13th to 20th.

Enjoy a week of swimming, boating, fishing, and arts and crafts. The camp will be staffed with dermatologists and nurses, so all of campers' needs will be expertly met. And, like those attending the camp, all of the camp counselors will also be young people with skin conditions. So everyone belongs, and everyone shares in the discovery of what it's like to be included.

To attend Camp Discovery, young people must be referred by a dermatologist, and there is an application form that the dermatologist must fill out. There is no cost for campers, and some travel scholarships are available. To obtain an application and get further information, please call Debra Kroncke at the American Academy of Dermatology (847-330-0230). And please act quickly, as available slots are filling fast.



Camp Discovery '96

at
Camp Knutson
Crosslake, Minnesota
July 13-20, 1996

Camp Horizon, a camp for children with chronic skin diseases, will be held again this summer from August 18th to 24th. Children from the ages 8 to 13 are welcome to attend. The camp is designed to provide a fun-filled week of activities for children who might otherwise not be able to attend summer camp.

Located in the heart of central Pennsylvania farm country, the camp has 35 acres of open fields, a fishing and boating pond, a pool, outdoor pavilions, a large mess hall, insulated cabins, and a well-equipped infirmary. A dermatologist, pediatrician and dermatology nurse are present at all times to handle emergencies and routine skin care.



Activities during the week include fishing, paddle boating, nature awareness, arts and crafts, games, and just plain fun. Life-long

friends are made almost instantly in a safe, non-threatening, nonjudgemental atmosphere that fosters acceptance regardless of what's seen on the outside. Local fund raising efforts have made all of this available without having to charge any tuition to campers.

Interested families are encouraged to call the Department of Dermatology at the Geisinger Medical Center in Danville, Pennsylvania, at 717-271-8050.



*Foundation for Ichthyosis
& Related Skin Types
(F.I.R.S.T.)*

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**Annual Report
for the Fiscal Year 1995**

The Year 1995 marked a turning point for The Foundation for Ichthyosis & Related Skin Types. Not only did we experience growth, but we also matured significantly as a not-for-profit organization dedicated to serving the needs of the ichthyosis community. A new wealth of professionalism on the Board of Directors (an attorney, an accountant, and a corporate executive) has contributed to an organization that in 1995 served more people with a greater range of programs and service offerings than at any time in F.I.R.S.T.'s history.

The year's highlight was our biennial National Family Conference this past June in San Diego, California. A record turnout gathered for the most ambitious program ever. Nearly four hundred members from six countries, a dozen health care professionals, and nearly the entire Board of Directors helped make the San Diego National Family Conference a new benchmark in the level and quality of conference program offerings.

But the real story in 1995 centers on our services to the breadth of our membership. On this front, we distributed nearly 800 copies of our new educational books — *Release The Butterfly: A Handbook for Parent & Caregivers of Children With Ichthyosis*, and our other new title, *Ichthyosis: A Teacher's Guide*. Additionally, we just made available a Spanish language version of the latter text: *Ichthyosis: Una Guia Para Maestros*.

Our Regional Support Network continues to grow, now counting over 300 active members. Region 4, headed by Cynnie Bates and Jill Wood, this past August hosted a Regional Conference in Indianapolis. Our quarterly journal, *Ichthyosis Focus*, also continues to grow in circulation, and to mature as a vehicle through which our community interacts.

As F.I.R.S.T. enters its 15th anniversary year, and as we approach the new millennium, your Board of Directors has renewed its commitment to ever expanding the scope of program and service offerings, and to developing the necessary resources for making the Foundation's future more stable and productive than ever before.

Deborah B. Vilas
Board President

FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES
(F.I.R.S.T.)
STATEMENTS OF FINANCIAL POSITION
September 30, 1995

ASSETS

Cash and cash equivalents	\$ 27 102
Investments - certificates of deposit	45 000
Furniture and office equipment	3 933
Deposits	<u>500</u>
	<u>\$ 76 535</u>

LIABILITIES & NET ASSETS

Accounts Payable:	
Supplies and expenses	\$ 4 733
Employee withholdings	<u>624</u>
Total liabilities	<u>5 357</u>
Net Assets:	
Unrestricted net assets	<u>71 178</u>
Total net assets	<u>71 178</u>
	<u>\$ 76 535</u>

Extracted from audited financial statements of the fiscal year 1995 conducted by the accounting firm of
Williams Overman Pierce, Raleigh, North Carolina

**FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES
(F.I.R.S.T.)**

**STATEMENT OF ACTIVITY AND CHANGES IN NET ASSETS
Nine Months Ended September 30, 1995**

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>TOTAL</u>
Revenues:			
Contributions	\$ 29 818	\$ 1 808	\$ 31 626
Grants	3 310		3 310
Registrations and fees	20 380		20 380
Interest	<u>4 008</u>		<u>4 008</u>
	57 516	<u>1 808</u>	<u>59 324</u>
Net assets released from restrictions	<u>1 808</u>	<u>(1 808)</u>	<u> </u>
Total unrestricted revenue & other support	<u>59 324</u>	<u> </u>	<u>59 324</u>
Expenses:			
Public and member information services	20 099		20 099
Regional and peer support services	8 720		8 720
Educational meetings and conferences	31 142		31 142
Public policy advocacy	2 089		2 089
Fund raising	4 262		4 262
General & administrative	<u>10 084</u>		<u>10 084</u>
Total expense	<u>76 396</u>	<u> </u>	<u>76 396</u>
Decrease in net assets	(17 072)		(17 072)
Net assets at beginning of period	<u>88 250</u>	<u> </u>	<u>88 250</u>
Net assets at end of period	<u>\$ 71 178</u>	<u> </u>	<u>\$ 71 178</u>

Extracted from audited financial statements of the fiscal year 1995 conducted by the accounting firm of
Williams Overman Pierce, Raleigh, North Carolina

Where The Money Goes

Members might fairly ask what we spend your dues and contribution on each year — more than \$75,000.

The good news is, we spent only approximately 18% of our revenues on fund raising and general & administrative costs. The lion's share, approximately 80%, is spent on programs and services, as it should be. Another 2% is spent on public policy advocacy on behalf of those affected with ichthyosis.

In 1995, the largest cost was for our National Family Conference in San Diego. We spent a little over \$30,000 producing that conference, and recovered about \$26,000 in attendance fees and other conference revenue. The rest supports our ongoing efforts to fulfill our mission. *Ichthyosis Focus* costs about \$10,000 a year to produce and distribute, and another \$6,000 in staff time. We commit about \$3,000 per year to supporting the activities of the RSN. We distribute educational material and general information about ichthyosis and about F.I.R.S.T. to our members and to the general public, and this costs us more than \$10,000 per year in direct and indirect costs.

Although ichthyosis is rare, and although we are a small organization, our ambitious mission and goals cost large sums of money to sustain. Most years we support these costs with our income from our members and our supporters in the corporate world. In 1995, however, we did not. We suffered an operating loss of approximately \$17,000, primarily as a result of significant declines in corporate grants. In 1996 and beyond we're renewing our commitment to not just expanding our programs and growing as a service organization, but to sufficiently funding our efforts as well.

A Note on the 1995 Audit

The Board of Directors in September, 1995, directed that F.I.R.S.T.'s accounting year be changed to end each year on September 30th. For that reason, the 1995 audit reflects a nine-month year from January 1st through September 30th, 1995.

At the same time, F.I.R.S.T. also elected to adopt Statement of Financial Accounting Standards (SFAS) Numbers 116 and 117 ("Accounting for Contributions Received and Contributions Made" and "Financial Statements of Not-for-Profit Organizations," respectively), which primarily resulted in changes in our financial statement presentation.

Phyllis Sanders
Board CFO

The financial information contained in this Annual Report is extracted from the Audited Financial Statements of the Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.) for the fiscal year 1995, conducted by the Foundation's accounting firm of Williams Overman Pierce, Raleigh, North Carolina. Copies of the complete financial statements, with notes and auditor's opinion, are available upon request from the Foundation's national office in Raleigh.

President's Letter

(Continues from page 1)

lowing this letter, you'll find a sample letter that I wrote to people I know. I wrote four letters that were each slightly different, depending on my audience. This letter was sent out to acquaintances, as opposed to close friends or family. Feel free to use this letter and to tailor it to your own needs.

We are looking forward to making National Ichthyosis Awareness Week a huge success, and your fund raising efforts will make all the difference. This is your chance to make a difference.

Warmest Regards,
Deb

Deborah B. Vilas
7 East 88th Street
New York, NY 10128

Dear Friend,

I would like to acquaint you with an organization with which I have become deeply involved during the last four years. I may have mentioned it to you, but I want to tell you a bit more about F.I.R.S.T., the Foundation for Ichthyosis & Related Skin Types.

You are already familiar with the fact that I seem to have a perpetual glow or suntan even in the dead of winter. You may also know that my rosy complexion is part of a genetic skin disorder that I've had from birth. In mild cases like mine, it may appear as no more than dry skin or a reddish, rough complexion. In the more severe forms, it is debilitating, both physically and psychologically. In the worst cases, it is fatal. There is no known cure.

Growing up with different skin was painful and isolating for me. Discovering F.I.R.S.T. as an adult made me keenly aware of how much it would have helped me if I had known about the organization as a child. One of my life's goals is to do as much as I can through the Foundation to ensure that other kids don't grow up feeling as alone and ashamed as I did.

F.I.R.S.T.'s mission is right on target with my own personal goals. It serves to help those suffering from ichthyosis by providing information, support and educational material, as well as connecting people with ichthyosis with others who share their experience. This condition is so rare that most dermatologists have never seen a case in their office, much less diagnosed or treated a patient. Without the network that F.I.R.S.T. provides, there would be almost no way for people to obtain information or consistent care.

Now to my request. During the past four years, I have been serving as a board member of F.I.R.S.T. The past year and a half I have been its president. I have continued to help with the development of programs to provide a broader level of support to our membership. The Foundation now has its first full-time executive director charged with expanding the scope and reach of the services. This costs money.

This year our budget will approach \$79,000. With that, we pay our director and maintain a full-time office in Raleigh, North Carolina. We also publish a quarterly newsletter, provide informational pamphlets and a booklet for use in schools to educate students and teachers, distribute a booklet to help parents deal with the special needs of their children with ichthyosis, hold a biennial national conference for our membership, and lead a Regional Support Network staffed with volunteers that reaches across the nation to provide personal support to children and adults with ichthyosis. We have a Medical Advisory Board that keeps us abreast of what is going on in research and treatment efforts. Its members also give their time and expertise to help dermatologists provide a higher quality of care to patients.

We need help to keep this effort going. I have enclosed a small brochure to give you more information on ichthyosis, in the hope that you will contribute to the work of F.I.R.S.T. Please mail donations directly to the Foundation in Raleigh. I know that you and I are bombarded by appeals for charitable donations. My only request is that you consider F.I.R.S.T. and its grassroots—and growing—efforts to improve the quality of life for an overlooked group of children.

Sincerely yours,

Deb

R National **REGISTRY** for **I** **ICHTHYOSIS** and Related Disorders

Registry Director: Philip Fleckman, M.D.
Registry Coordinator: Geoff Hamill, R.N.

University of Washington
Dermatology/Box 356524
Seattle, WA 98195-6524

1-800-595-1265

The National Institutes of Health (through its National Institute of Arthritis, Musculoskeletal and Skin Disease—or NIAMS) is sponsoring a National Registry for Ichthyosis & Related Disorders. The goal of the Registry is to develop a clinical database of individuals affected with the ichthyoses and other rare skin disorders (that is, a roster that compiles information about people with these disorders).

The Registry's purpose is to create a list of affected individuals for the purpose of stimulating research about these disorders. This should have a profound impact on research in the ichthyoses and related disorders, since the greatest obstacle facing researchers doing studies on rare diseases is locating affected individuals willing to help them out.

The Registry should solve this problem by creating a central resource containing diagnostic information about the individuals who have enrolled. Researchers can then easily locate affected individuals, as well as obtain information about the frequency and involvement of their disorders. In addition, even if you choose never to participate directly in research studies, the information you provide the Registry should prove valuable in better understanding these disorders.

The Registry will NOT give identifying information out to researchers. Instead, those enrolled in the Registry will be contacted *by the Registry* and informed of any appropriate research projects. At that time, you can decide for yourself if you wish to contact the researcher involved.

Please contact the Registry Coordinator, Geoff Hamill, to ask more questions and to obtain enrollment forms.

LEA JORGENSEN RECEIVES GIRL SCOUT GOLD AWARD

by Sharon & Jeffrey Jorgenson

Lea Jorgenson was born a colloidion baby, with lamellar ichthyosis. She has seen doctors all her life. Lea needs to watch herself in the summer heat of South Dakota, so she doesn't overheat. But she doesn't let this stop her in life. She is very active in both school and Girl Scouting activities.



Just recently, Lea became the first girl in Waubay, South Dakota's history to receive the highest award possible in Girl Scouting. She received the Gold Award.

To receive this award, you must complete a community service project, which requires efficient organizational skills, time management and leadership skills. Her project was to compile a history of Waubay through interviews with local residents.

She also has taught CCD classes at her church, was a tutor in school for grade school students, helped in the library as an assistant, and

has worked at a local veterinarian's office.

Lea is a junior at Waubay High School. She has been in plays, in oral interpretation, and is also very active in Future Farmers of America (FFA).

In FFA, she has been raising some heifer calves to become part of her father's dairy herd. She is presently serving as Waubay's FFA secretary.

Lea doesn't let her skin stop her in life. She puts on her cream every day and keeps on going. Her classmates and the community have seen her grow from a little girl into a confident young lady.

When Lea graduates from high school in 1997, she plans on going on to college and becoming a veterinarian. With the way she attacks a challenge, I believe she will make it.

Please send us your children's success stories so we can publish them in Focus. We feel that the best examples we can offer our children are stories of peers whose lives tell of their determination to challenge the obstacles.

Lowell Goldsmith, M.D. Appointed Dean of the University of Rochester School of Medicine & Dentistry

Dr. Lowell Goldsmith, a former Chairman and member of F.I.R.S.T.'s Medical Advisory Board, was honored with an appointment to the position of Dean of the University of Rochester School of Medicine and Dentistry. We join Dr. Goldsmith's colleagues in offering our sincere congratulations.

In addition to serving as Chairman of F.I.R.S.T.'s Medical Advisory Board in the mid-1980s (and as a member of the Advisory Board since F.I.R.S.T.'s founding), Dr. Goldsmith has also served

as President of the Society of Investigative Dermatology, and serves on the Board of Directors of the American Academy of Dermatology. Until his appointment as Dean this past January, Dr. Goldsmith served as the James H. Sterner Professor and Chairman of the Department of Dermatology at the University of Rochester School of Medicine, and as Dermatologist-in-Chief at the Strong Memorial Hospital in Rochester, New York.

The bad news is, because of his added responsibilities, Dr. Goldsmith felt it was necessary to resign his position on our Medical Advisory Board. We accept his resignation with regret, and offer him grateful thanks for his many years of service to F.I.R.S.T., and wish him good luck in his new position.

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.

Quote of the Day

"Only three cents of every health care dollar is spent on medical research. Without more support, new discoveries will just have to wait."

—C. Everett Koop, M.D.
Former U.S. Surgeon General

Senator Jeffords Introduces Amendment to Raise "Lifetime Limits" on Health Insurance

Lifetime insurance caps (like pre-existing condition exclusions and portability restrictions) are a mechanism that limits access to health insurance by the seriously or chronically ill. These caps (which typically limit lifetime health insurance coverage to \$1 million or \$2 million) have the effect of driving those most in need of health coverage out of the market.

At a Capitol Hill press conference last month, Senator Jim Jeffords (R-VT) stated: "What I propose to do about this problem is to offer an amendment to S.1028 [the Kassebaum-Kennedy Health Insurance Reform Act of 1996] ... to address the current discrimination that is occurring in the private market with regard to limiting the amount of coverage an insurance policy will pay."

The Jeffords amendment to the Kassebaum-Kennedy Health Insurance Reform Bill will raise lifetime caps to \$10 million. Interestingly, if the insurance industry

standard of a one million dollar cap set in 1970 were indexed for medical inflation, it would be worth over \$10 million today.

Efforts to Outlaw Genetic Discrimination Doomed to Fail

Over the past year, several legislators have introduced legislation that would prohibit insurance companies and/or employers from discriminating against present or potential policy holders and/or employees on the basis of genetic information.

Senator Tom Harkin tried to amend the Kassebaum-Kennedy Health Insurance Reform Act in committee to prohibit insurance discrimination, but the effort failed. Senator Mark Hatfield introduced the Genetic Privacy Act of 1995, co-sponsored by Senator Connie Mack, while, Representative Cliff Stearns introduced the same legislation on the House side. Additionally, Rep.

Louise Slaughter introduced in the House the Genetic Information Non-discrimination in Health Insurance Act, while Senator Diane Feinstein has announced intentions to submit similar legislation in the Senate.

Unfortunately, none of these bills are expected to pass, because the influential insurance lobby opposes the concept of nondiscrimination.

Drug Prices Rising Again

During the health care reform debate last year, President Clinton embarrassed pharmaceutical companies by showing they had raised prices two or three times faster than inflation during the preceding decade. Consequently, the companies "voluntarily" agreed to hold their price hikes in line with the Consumer Price Index (CPI) annual rate of inflation. Now that the pressure on drug pricing is off, however, the companies appear to be returning to prior pricing practices. Wholesale prices of the top 500 prescription drugs rose 4.1% in the third quarter of 1995, compared with the CPI inflation rate of 2.5%. The companies say they need to hike their prices in the retail market because they must give deep discounts to hospitals and managed care health plans.

Late Breaking News on Health Insurance Reform & Patient Privacy

On April 2nd, the House bill for health insurance reform (the House version of the Kassebaum-Kennedy bill, S.1028, in the Senate) passed the House 267-151, sending it on to the Senate (which is expected to take it up on April 18th). The bill would prevent insurance companies from denying coverage to persons on the basis of genetic information. The bill also includes provisions ensuring portability of health insurance, reforms the issue of pre-existing condition exclusions, establishes medical savings accounts, provides for medical liability reforms, anti-trust reforms, as well as other health insurance reform provisions. *We encourage all members to write their Senators to encourage support for Senate Bill S.1028.*

REGIONAL SUPPORT NETWORK (RSN)

RSN NATIONAL OFFICE PROGRAM DIRECTOR

Donna Rice
2902 W. Elm Circle
Katy, TX 77493
713-391-4407

REGION ONE

NY, PA, VT, NH, NJ, CT, RI,
MA, ME

Shelly Licursi
311 White Birch Drive
Cinnaminson, NJ 08077
609-786-8766

REGION TWO

DE, MD, WV, VA, NC, SC
Robin Joyce
Route 1, Box 189-F
Sandy Ridge, NC 27046
(910) 871-3277

REGION THREE

TN, GA, FL, AL, MS, LA, AR
Debra Bowie
3694 Shady Hollow Lane
Memphis, TN 38116
901-346-0513

REGION FOUR

KY, OH, IN, IL, MO, MI
open

REGION FIVE

WI, MN, IA, ND, SD, NE
Carolyn Gramlich
535 West Sandhurst, #111
Roseville, MN 55113
612-489-1448

REGION SIX

TX, OK, NM, CO, KS
Donna Rice
2902 West Elm Circle
Katy, TX 77493
(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
Chris Beeler
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Tucson, AZ 85719
(602) 887-7188

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Barbara Rockwell
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Tiffany Karst
913-268-3692

Kentucky

Cynnne Bates
606-276-0142

Massachusetts

Susan Overstreet
413-259-1267

Mississippi

J. Charlene Wiggins
601-769-2454

New York

Cathy Lopez
718-842-7269

South Carolina

Nancy Bryant
803-881-2036

Wisconsin

Theresa Tremmel
414-538-4922

I first became aware of F.I.R.S.T. (then called the National Ichthyosis Foundation) in 1983, when I was "officially" diagnosed with epidermolytic hyperkeratosis (EHK). I have been a member, in one form or another, ever since then. Knowing other people who are dealing with the same issues I am is a great comfort.

I went to my first National Conference in 1985. It was enlightening to actually meet so many people who looked like me. To be able to discuss the problems of ichthyosis with someone who knew what I was talking about was wonderful. I have learned a lot about EHK and other forms of ichthyosis through the Foundation.

I have two sisters, a brother, and two nephews. I am the only one in my family with ichthyosis. I was born in Newmarket, England, and I came to the U.S. in 1963. A job transfer brought me to Roseville, Minnesota, in

RSN PROFILE

CAROLYN GRAMLICH

REGION 5 COORDINATOR



Donna and Carolyn Gramlich
on a trip to Seattle,
Washington, in 1994.

1994. I've been doing mostly clerical and computer work for the past 12 years. For eleven years I worked for a needlepoint store handpainting and designing needlepoint canvases.

My primary reason for wanting to be our RSN Region Five Coordinator is to help people who are dealing with ichthyosis connect with one another. Just knowing that someone understands what you are going through can be a tremendous help. Before I knew about F.I.R.S.T., I had dermatologists tell me that they were treating other patients with ichthyosis. But I never had the opportunity to meet these other people until the Foundation came into existence.

F.I.R.S.T. members are instrumental in helping each other handle ichthyosis. It's good to hear that other people have encountered the difficulties that you do, and to learn that there is light at the end of the tunnel.

NEWS & NOTES

Bibliographies of Professional Literature
Pediatric Projects, Inc., a nonprofit in Tarzana, California, offers bibliographies of professional literature on the psychosocial aspects of children & youth in health care. They maintain a long list of specific bibliography topics for which they can provide comprehensive bibliographies of professional literature. You can contact the Pediatric Project at 1-800-947-0947 to obtain a list of bibliographies (email: medpubl@kaiwan.com).

Companies Offer Matching Gift Programs

Many companies offer matching gift programs that allow their employees to double the impact of their personal contributions. Many F.I.R.S.T. members take advantage of these programs. We encourage all of our members to inquire whether your employer offers a matching gift program. If so, your company will match your annual contribution to F.I.R.S.T. All it usually takes is obtaining a simple form from your employer that you fill out and send in with your contribution.

We then provide your employer with documentation they require from us. That's all there is to it. So please take a moment to find out if your employer offers a program like this so you can double your impact on F.I.R.S.T. with the stroke of a pen.

Young F.I.R.S.T. Fund Raisers In New York

With encouragement from or board president, Deb Vilas, the 3rd & 4th grade Sunday School class at the Unitarian Church of All Souls in New York City proudly announces they are doing a "Dollar Harvest" in April to raise funds for F.I.R.S.T.

Must Reading

We would like to recommend a useful new book entitled *Examining Your Doctor*, by Timothy McCall (Carol Press). This is a book about "being a smart, aggressive, competent patient," in the words of the Boston Globe. The book offers a no-nonsense guide to evaluating and selecting a physician — a process than many people find very difficult, and even intimidating.

IN MEMORIAM

We were saddened to learn of the death of young Adam Michael Baltazar, son of Eileen Baltazar of Clarendon Hill, Illinois. Adam died in February at two months. Our sincere condolences to out to family and friends of the Baltazar family. F.I.R.S.T. has received memorial contributions in Adam's name from the following friends and family.

June & John Gill
May Theresa
John McCombe
Jackie O'Brien
Rodney Fuller
Gary & Lisa Gabriel
Nancy Orlando

Meet Riley, a Jack Russell Terrier with Lamellar Ichthyosis

Robert Dunstan and Kelly Credille are research veterinarians at Michigan State University. Robert called me a while back with a curious question. "Do you think," he asked me, "that kids with ichthyosis would be interested in a dog with ichthyosis?" I didn't know what to answer. Like him, I wasn't even sure the whole idea wasn't a little bit tasteless. So I decided to ask an expert — my 5½ year old daughter, Caitie.

"Absolutely!" she answered.

Doctors Dunstan and Credille have dogs with lamellar ichthyosis (they're pretty sure it's lamellar; they will do genetic analysis soon), and with bullous ichthyosis of Siemans. They hope that animal models with rare skin disorders will be helpful to research dermatologists. "Hopefully," Dunstan tells me, "what we learn from Riley can help both puppies and children with ichthyosis."

Dunstan reports that Riley hates his baths, which he gets twice a week. He is also treated with etretinate (a retinoid, also called Tegison). More pictures are promised, and we'll keep you posted on this interesting and valuable project.



F.I.R.S.T.'s 1995 HONOR ROLL

A Roll Call of F.I.R.S.T.'s Most Devoted Supporters

\$2,000 - \$5,000

Dr. Eugene & Mary Van Scott
Friends of Frances Bernstiel

\$1,000 - \$1,999

Thomas & Diane Buehler
Henry J. Bukaty
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Denise & Schuyler Eastin
Tiffany & Brian Karst
Dr. Ruey J. Yu

\$500 - \$999

Carl Colliluori
In memory of Jane Colliluori
Mr. & Mrs. Shaun Kelly
Gwenda K. Porter
Tracie J. Pretak
James & Else Phillips
Sammy & Mary Williams
Ed Florig
Janet Showers Patterson

\$200 - \$499

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Lori Bryant
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Karoline Freed-Biggs
Captain Joseph Galluccio
Agneta Ganemo
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Paul Kelley

Arnold Kovin

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Laura & John Lindstrom
Jack & Nancy Martin
Donna Melle
Lynne Newell
Jean & Warren O'Brien
Herdis Olson
William D. Patrick
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Parker & Debra Piercey
David & Anna Purcell
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Donna & Victor Rice
Liza Santamina
Michelle & Rick Sherrill
Philip & Dorothy Stahl
Patti & Mark Steinitz
Simon & Magdalena Tarlovsky
Juanita Tumlinson
Jan E. Volpi
Margaret Vernet
Peyton & Janet Weary

\$100 - \$199

Chris & John Aanderud
Dr. & Mrs. Harvey Adams
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Vitalina Carranza
Charles E. Carter
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Kathryn E. Clark
Eleanor Colliluori
Brian & Joyce Conneely

Luc DeBatselier

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Peter Elias, M.D.
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Donald & Rose Gore
Carolyn Gramlich
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Robert Henderson
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Margaret Kovach
Mr. & Mrs. Richard Kozinski
Justine LaFemina

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 Susan Purcell

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 Kathleen & Jean Florig Sweeney
 Caroly Switgall
 Rita K. Tanis
 Gerald Taylor
 Madonna Taylor
 Frances Thom
 Norma C. Treat
 Aida Villa

Martha L. Waters
 Billy Webb
 Mark & Holly Weber
 Mary & Walter Wiewell III
 Mary Williams, M.D.
 Paul & Carol Williams
 Alice F. H. Workman
 Marilyn Zinn

**CORPORATE & INSTITUTIONAL
 CONTRIBUTORS**

\$500 - \$2,500

Dermal Therapy Research
 Fraternal Order of the Eagles
 Austintown, Ohio

\$100 - \$499

Stiefel Laboratories
 Vernon Furlow Co.
 Nature's Provisions
 Baker-Cummins Pharmaceuticals
 Herald Pharmacal

Cellegy Pharmaceuticals is developing a new topical cream for the treatment of ichthyosis.

These trials are investigational and are intended to determine the cream's effectiveness. Many F.I.R.S.T. members have taken part in clinical trials to help Cellegy obtain FDA approval for this new cream (called Glylorin). Now, dermatologists are conducting the final phase of clinical trials (Phase III), and they are seeking patients with mild lamellar ichthyosis (LI), and persons with nonbullous congenital ichthyosiform erythroderma (CIE) who are willing to participate in these trials.

All doctor's visits, procedures and medications will be provided free of charge, and at the end of the trial par-

**CLINICAL TRIALS SET FOR NEW
 CREAM TO TREAT ICHTHYOSIS**

ticipants will receive a stipend for participation. The trial will continue for about 15 months. During three

of the 15 months participants will receive "blinded" treatment—that is, you will not know whether you are receiving the active cream or a placebo. Thereafter, all participants will receive only the active cream. No one under eighteen months of age may participate.

Below is a list of research dermatologists conducting these trials. If you have LI or CIE, and if you are interested in learning more about the trials, please call the trial site nearest you. If you have questions, you may call Cynthia Selfridge, Director of Clinical Trials at Cellegy Pharmaceuticals in Novato, California, at 415-382-6770.

Nancy Esterly, MD
 Milwaukee, WI
 Contact Lisa Adali: 414-454-5312

Ervin Epstein, MD
 Oakland, CA
 510-444-8282

Philip Fleckman, MD
 Seattle, WA
 206-543-5290, or contact Daisy at
 206-548-5588

Ruby Ghadially, MD
 San Francisco, CA
 415-750-2091, or contact Elizabeth
 Harrington at 415-476-9350, or
 415-476-0808

Jon Hanifin, MD
 Portland, OR
 Contact Sue Tofta: 503-494-5603

Sewon Kang, MD
 Ann Arbor, MI
 Contact Amy Kim: 313-936-4070 or
 313-764-3376

Moise Levy, MD & James Nigro, MD
 Houston, TX
 Contact Donna: 713-770-3718

Anne W. Lucky, MD
 Cincinnati, OH
 Contact Diana Crowthers:
 513-791-6161

Leonard Milstone, MD
 New Haven, CT
 203-932-5711, ext. 4252

Amy Paller, MD
 Chicago, IL
 Contact Marge: 312-880-4698 or
 312-880-3574

Gary Peck, MD
 Washington, D.C.
 Contact Hildegard Jorgenson at
 202-877-7734

Neil Prose, MD
 Durham, NC
 Contact Shirley: 919-419-5918

Miriam Keltz Pomeranz, MD
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 Contact Clare or Lorne: 212-263-5244

Harmon Solomon, MD
 Wichita, KS
 Contact Diana Wirths: 316-685-4395

Mark Ling, MD, Ph.D.
 Atlanta, GA
 Contact Joyce Weinheimer:
 404-778-3084

Matthew Stiller, MD
 Boston, MA
 Contact Agnes or Michele:
 617-726-5066, or
 617-726-1660

Patricia Treadwell, MD
 Indianapolis, IN
 Contact Marta Sears: 317-274-3970

Sophie Worobec, MD
 Rochester, NY
 Contact MaryLou: 716-274-4570

Sheila Friedlander, MD
 San Diego, CA
 Contact Debbie: 619-974-6795

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F.I.R.S.T. Board President, Deborah Vilas, with her friend and photographer Ellen Turk, have produced this collage post card composed of children photographed at the 1995 National Family Conference in San Diego last June. With printing and production work donated, F.I.R.S.T. is now offering to members these special commemorative cards.

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