



ICHTHYOSIS FOCUS

Vol. 18, No. 1

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

Summer 1999

A F.I.R.S.T. Research Award

The Foundation for Ichthyosis and Related Skin Types is very proud to announce the award of our first research grant. The grant was awarded to Gabriele Richard, M.D. and will partially support her study of Netherton's Syndrome, a rare form of ichthyosis associated with hair abnormalities and other problems. The \$10,000 research grant was awarded in conjunction with the Dermatology Foundation. It was announced at their annual award presentation that was held during the annual American Academy of Dermatology meeting in March.

The Dermatology Foundation is a non-profit organization that raises

Dermatology Foundation, F.I.R.S.T. is able to take advantage of their large, established grant application and review process.

Our grants are targeted to support young investigators and new ideas in

the area of ichthyosis research. It is our aim to continue to award these grants on an annual basis, and we hope that the size and/or number of our awards will grow over time.

GRANT FUNDS NETHERTON'S

Gabriele Richard, M.D. is the recipient of F.I.R.S.T.'s research award. She is Assistant Professor of the Department of Dermatology and Cutaneous Biology and the Department of Medicine, Division of Human Genetics, at Thomas Jefferson University, in Philadelphia. Our grant will help support her investigation of the "Clinical and Genetic Studies of Netherton Syndrome, a Congenital Recessive Ichthyosis". This research is part of the continuing efforts of Dr. Richard and co-investigators, Drs. Bale and DiGiovanna to further define and understand the different forms of ichthyosis, in terms of their clinical features and genetic cause.



Dr. Gabriele Richard

Her goal is to "outline the spectrum of clinical manifestations of Netherton syndrome and to localize and identify the disease gene" responsible for this disorder. Her team will conduct detailed physical, dermatologic and genetic exams, and collect DNA from affected individuals and their families. Dr. Richard expects that her work will lead to a better understanding of Netherton Syndrome and its cause. It could also help to improve genetic counseling, and provide tools and essential insight to develop new therapeutic strategies. If you've been diagnosed with Netherton Syndrome, Ichthyosis Linearis Circumflexa, or Peeling Skin Syndrome, and are interested in learning more about this study, contact Dr. Richard at 215-503-1467.

See RESEARCH on page 3

Our heartfelt thanks to the family and friends of Edward Charles "Teddy" Hoffman. Their generous contributions in Teddy's memory have made this research award possible.

funds from dermatologists, researchers and related industry. It was founded in 1964 in order to advance patient care through research. By awarding our small grant in conjunction with the

ANNUAL REPORT SECTION BEGINS AFTER PAGE 6

ICHTHYOSIS Focus

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Request to reprint information contained in Ichthyosis Focus should be directed to the editor.

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The editor invites correspondence.

We welcome your comments, observations and suggestions. Please send your letters to us c/o Ichthyosis Focus at the address listed above.

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 Editors endorse any treatments or products reported 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.

Correspondence Corner

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

I've been meaning to join F.I.R.S.T. for a long while, but am just now getting around to it. I am twenty-two years old. I was born with Lamellar Ichthyosis, and until a year or so ago when I heard of your organization, I had never met or heard of someone else with ichthyosis. It truly was a struggle growing up with ichthyosis. Not having a support group or anyone who could identify with what I was going through. I was emotionally taxed.

It gives me great hope and strength knowing F.I.R.S.T. is out there. For all that you do, thank you!!

Sincerely,
Jennifer Kittlaus
Evanston, IL

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

I just found a really cool website on the internet (www.ichthyosis.com) that is devoted to people with ichthyosis. There is also a chat room where people can get together and share ideas on how to take care of their skin. It is really hard to find people who have ichthyosis. This chat room and message board are a great way to do so.

Thank You,
Anne Carmicino

Editor's Note: The website, www.ichthyosis.com, is privately owned, produced and maintained by Laura and Chris Phillips. Laura has Lamellar Ichthyosis and is a member of F.I.R.S.T.'s Board of Directors. F.I.R.S.T. intends to continue to improve our own site, www.libertynet.org/~ichthyo/ and Laura and Chris have kindly agreed to help us in our efforts.

Hi,

This evening while cleaning out my briefcase I came across and read the spring 1998 edition of *Ichthyosis Focus*.

It says there that you, the editor, invite correspondence.

Editor, I'm aware that other, later issues of *Ichthyosis Focus* have come out, because I remember throwing them away... lots of fluff and very little of substance has come to be the mark of the quarterly issues.

A little about me. I'm a 53 year-old man who has a mild case of Ichthyosis Vulgaris. ... although I have the most common of all forms of ichthyosis, there is rarely a mention of my malady in *Ichthyosis Focus*. Oh, there is Lamellar and X-linked and CIE and every other kind of ichthyosis mentioned many times, but the form which I have, and which out-numbers all the others combined, is virtually ignored.

But, indeed, I found it. There on page 13 of the spring issue, near the bottom, was the very name of the malady, which has followed my every move on the planet. It's actually there, in print! No facts or figures, mind you. Nothing of substance, or even a fluffy story, but by God, the name of it is right there. I want you to know that I noticed.

Sincerely,
David Morris

Editor's Note: We recognize that Ichthyosis Vulgaris is not always well represented in the discussions in our newsletter. We will make every effort to correct these shortcomings in the future. A group of researchers at the National Institute of Health and elsewhere are currently studying Ichthyosis Vulgaris. We will track their work and report their findings in the future. Families with three or more affected individuals who are interested in learning more about this research should contact Sheri Bale, Ph.D. at (301) 402-2679 (collect calls accepted).

Dear Friends,

Several months ago, I informed the Board of Directors of F.I.R.S.T. that I would not be able to continue in my present role as Executive Director. My decision to step down was a difficult one, accompanied by many mixed emotions. My time with F.I.R.S.T. has been incredibly rewarding and I will truly miss the many extraordinary individuals and families I've come to know. On the other hand, I am eagerly anticipating being able to spend more time with my two young children, Jonathan, age 4 1/2, and Julia, age 3. I'm also looking forward to being able to pursue several other personal interests.

Upon receiving my notice, the Board of Directors organized a Search Committee. This small, hard-working group interviewed many qualified applicants and unanimously recommended Ms. Jean Pickford of Lansdale, PA for the position. Jean has almost 10 years of experience with support and advocacy groups, most recently as Special Events Director at the American Heart Association's regional affiliate. She began her career with the National Tay-Sachs & Allied Disease Association of the Delaware Valley, where she served as Assistant to the Executive Director. I am very pleased to welcome Jean as F.I.R.S.T.'s new Executive Director and I'm looking forward to working with her this summer during this transition.

Jean will arrive in the National Office in early June, about the same time this issue goes to press. I know many of you have been waiting for this newsletter and I apologize for the long delay. My limited hours these last few months are primarily to blame. I'm confident that our new, full-time Executive Director will get our newsletter publication schedule back on track.

The strength and determination of our members in overcoming your own personal obstacles and advocating for the needs of your children has been an inspiration to me. Being able to work with, and for, all of you has truly been an honor. You've taught me about the best in people and I've learned a great deal about myself along the way.

Thank you,

Elena



GRANT TO FUND RESEARCH

RESEARCH from page 1

Upon learning of Dr. Richard's selection by the Dermatology Foundation, Dr. Leonard Milstone, Chair of F.I.R.S.T.'s Medical Advisory Board, said, "The Medical Advisory Board is delighted with the choice of Dr. Richard to receive the FIRST research grant. She has had excellent training in identifying specific genes that cause ichthyosis. Hopefully the grant will encourage her to expand her interest in ichthyosis from her new home base in Philadelphia."

Dr. Richard came to Philadelphia last fall from the Washington, D.C. area, where she pursued her research career at the Genetic Studies Section of the Laboratory of Skin Biology, NIAMS (part of the National Institutes of Health). She is a German citizen, and completed her internship and residency in Dermatology there after graduating from the Erfurt Medical Academy in 1983. Recently, she successfully concluded a two-year fellowship in Ph.D.-Medical Genetics.

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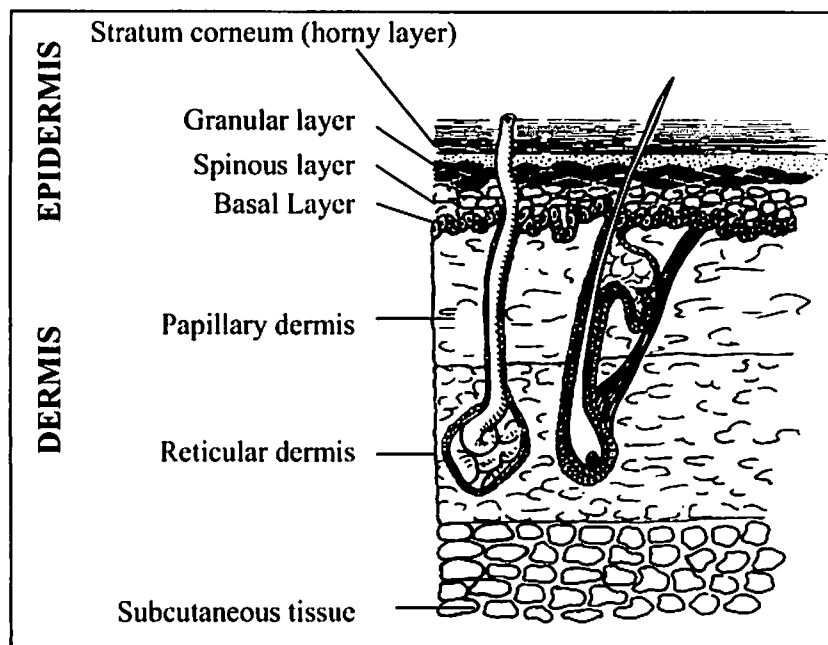


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A Discussion of Skin Anatomy

The skin is composed of three primary, distinct layers: subcutaneous tissue, the dermis and the epidermis. The deepest layer is the subcutaneous tissue. This is the fatty layer that supports the skin, underlying tissues and organs and helps to insulate the body. Above subcutaneous tissue is the dermis. The dermis is remarkable for giving our skin its softness, elasticity, and strength. Within the dermis, the uppermost tier is called the papillary dermis, and the lower tier is called the reticular dermis. The dermis is composed primarily of connective tissue, a rich blood and nerve supply, and is the location of the origin of some skin appendages such as sebaceous oil glands, eccrine (sweat) glands, and hair follicles.

The outer layer of skin is the epidermis. Within the epidermis are four discrete layers consisting of cells in varying stages of growth and differentiation. Examples of these cells include keratinocytes, melanocytes and Langerhans' cells. Keratinocytes originate in the epidermal basal layer and, through division and displacement, move up through the spinous layer, granular layer, and the outermost layer called the stratum corneum or the horny layer. These cells are consistently shed as new cells continue their upward movement from the basal layer. This maturation process of epidermal cells requires several proteins, including an enzyme called transglutaminase I (TGM I). Many patients with lamellar ichthyosis do not have TGM I, so the skin cells are not shed normally, leading to the marked thickening of skin. Another protein of maturation is called filaggrin. Individuals with Ichthyosis Vulgaris often show less of the filaggrin protein in the epidermis, but the primary cause of Ichthyosis Vulgaris is still unknown and does not seem to involve the filaggrin gene.



The lipids or fats that make up the membranes of skin cells are also important. When the balance of those lipids in cells is upset, the normal pattern of skin cell maturation is disrupted. For example, individuals with recessive X-linked Ichthyosis are missing an enzyme called sterol sulfatase. In the absence of this enzyme, a lot of cholesterol sulfate accumulates in the outer areas of epidermis and cannot be turned into cholesterol. In another ichthyotic condition, Sjogren-Larsson syndrome, an enzyme that works on lipids, fatty aldehyde oxidase, is missing and the imbalance results in skin thickening.

Other proteins of epidermal cells hold the cells together. The most abundant protein is keratin, which gives the cells their integrity. When abnormal keratin is produced, the epidermal cells can fall apart, leading to blistering. Individuals with Bullous Congenital Ichthyosiform Erythroderma (Epidermolytic Hyperkeratosis) have mutations in keratins 1, 10 or 2e. As a result the upper cells of the epidermis fall apart and one shows blistering on the skin. The marked thickening of skin in the ichthyotic condition likely occurs to compensate for the tendency of the skin to blister and protects from the damage of trauma. There are many other epidermal proteins that hold epidermal cells together and cause the skin cells to mature and grow normally. As we learn more about skin fats and proteins, we hope to understand better the causes of ichthyosis.

This article was written by Dr. Amy Paller, and based on a discussion of skin anatomy which appeared in an article titled "Fracture Blisters: A Review of the Literature" in the December 1997 issue of Dermatology Nursing, Vol. 9, No. 6.

National Registry for Ichthyosis and Related Disorders Needs You to Enroll Today!!

By Geoff Hamill, R.N., Registry Coordinator

Hello! to everyone I had a chance to see at last summer's conference! It was a wonderful experience, and afforded me the privilege of volunteering at Camp Discovery in Danville, PA in August. I'd like to talk with you about enrolling in the Registry. We need your help!

The registry is funded by the National Institutes of Health to promote research into diagnosis and treatment of the ichthyoses. Our director, Dr. Philip Fleckman, my assistant, Kim Pineda, and I are trying to enroll everyone in the United States who has ichthyosis, with the exception of Ichthyosis Vulgaris. We collect specific information about how your condition has affected you throughout your life. We provide a way for registered individuals who are interested in new research to be notified about these projects. We DO NOT release contact information about any enrollees to researchers, but we DO pass along to you the information about the project, and how to contact an investigator if you have an interest in participating. There is NO OBLIGATION to participate in any project. Even if you aren't interested in participating in projects, your enrollment in the Registry can help in creating a very valuable resource to those researchers who are interested in studying and treating people with ichthyosis and related disorders.

Over 250 people are enrolled in the Registry, and another 141 are in the process. I know there are members of F.I.R.S.T. who have not yet registered, and I want to encourage you to give us a call. It's pretty easy, and it's something only YOU can do! If you have enrolled, then call a friend and encourage them to participate, because we cannot do it without you!

For any questions, or for enrollment forms and information, PLEASE call, write, or e-mail me today! (See box above.) I look forward to hearing from you, and I'll make your enrollment as convenient for you as possible - I promise!

Camp Discovery

Camps For Children With Chronic Skin Disorders

Over 130 children from all over the United States, Canada and Bermuda with various chronic skin disorders attended camp last summer at two special weeklong camps in Minnesota and Pennsylvania. The camps, sponsored by the American Academy of Dermatology's Camp Discovery program have a large staff of dermatologists and dermatology nurses to care for the medical needs of the campers. Many of the counselors have skin diseases themselves and serve as role models for the campers.

Camp Discovery at Camp Knutson hosted 50 children in mid-July. The camp is located on scenic Whitefish Lake in Minnesota. It offers a wide range of activities such as swimming, boating, fishing, water skiing and canoeing, along with traditional camp activities such as arts and crafts and games. Last year was highlighted by a visit from a member of the Minnesota Timberwolves basketball team.

Camp Discovery at Camp Horizon had 80 children attend its fourth season last August. The campsite, in the heart of central Pennsylvania farm country, has an outdoor pool, insulated cabins, a large mess hall, activity pavilions, an infirmary and fishing pond. Camp fires, a carnival, crafts, fishing, paddle boating, archery, team building, animal awareness and a chance to camp out in tents were just part of the fun.

Both camps allow children with ichthyosis and other chronic skin diseases to have a great time in a safe secure environment that is sensitive to their medical and emotional needs. Friends for life are quickly made in an atmosphere that supports each child's self-worth, regardless of how they look on the outside. Aggressive fund raising efforts have provided enough money to offer both camps free of charge.

This summer's camps will be held on the following dates: Camp Discovery at Camp Knutson on July 10-17, 1999, and Camp Discovery at Camp Horizon on July 14 or 15-21, 1999. More information on Camp Discovery may be obtained by contacting Howard Pride, M.D. at 717-271-8050 or the American Academy of Dermatology at 847-330-0230.

National
REGISTRY for
ICHTHYOSIS
and Related Disorders

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

1-800-595-1265

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

E-mail: ichreg@u.washington.edu

URL: <http://weber.u.washington.edu/~geoff/ichthyosis.registry/>



Laura Ashton, Becky Butler, Nicole McMillian, and Bailey Jones



ICHTHYOSIS AWARENESS WEEK & FUND RAISING NEWS

Each year we receive wonderful letters and e-mails describing the unique ways FIRST members have of educating their communities and raising funds to support our services. This past year close to 20 families held awareness events throughout the country, raising more than \$12,000 for FIRST, but just as important, raising awareness of ichthyosis and the people it affects, in record numbers.

Tracie Pretak and Tiffany Karst have become pros with their annual fund raising events and each year they get bigger and better. Tracie and her family started with a spiritual concert in their local church several years ago and it has grown into a concert tour, complete with a musical drama, solo by daughter, Bailey and professional video. A feature article in the newspaper and a live radio interview followed this. Tracie has also perfected her Release the Butterfly fund raiser (see back cover for more information).

Tiffany and her family have held a garage sale each spring for the past 5 years. It has grown over the years to a three-day event that raises over \$2700. Each year, Tiffany meets shoppers with ichthyosis that were not previously aware of F.I.R.S.T.

Another pro, Randy LaBarbera, has been raising awareness for F.I.R.S.T. for many years and recently sent in a donation from his local Gateway Woman's Club. And, boy does Patti Steinitz know how to get the message out! A newspaper feature article about her daughter, Hunter, which ran two years ago, led to heartwarming spot on the evening news this year. It was judged to be one of the best of the year and was chosen for an encore airing a few months later.

Bill and Diana Grady were very pleased with the newspaper article about their daughter, Shawna, as well as the support from friends, family and the community for their Bowl-a-Thon. Awareness of ichthyosis took the form of an article in the school newsletter for Tammy Beers' daughter, Samantha, and distribution of F.I.R.S.T. brochures at Concord Hospital in New Hampshire for Dona Hoar. Barbara Molica took the time to write a letter to the Montel Williams Show to seek his support for public awareness, and Liza Santamina laced up her running shoes to participate in the Human Race.

Raffles were popular for Patti Metzger in New York, and for Kathy Smith and Donna Rice in Texas, while Debra Bowie's sorority denied themselves lunch and donated the proceeds to F.I.R.S.T. Lesa Dees'



Randy LaBarbera with Ruth Daniels, Treasurer, and Carolyn Warbritton, President, of the Gateway Woman's Club of Jacksonville, Florida.

Hairdressers' Association made a contribution, as did the employees of Ernst Paper Products in California and the staff of two Shoppers Drug Mart stores in Ontario, Canada.

In the Philadelphia area, home to our national headquarters, member Frank Meli arranged a contribution from UNICO, an Italian-American Benevolent Association, and Lisa Short helped secure donations as our coordinator for the Bloomingdale's Shopping Benefit.

Sound like a lot of work? There is no doubt about that! However, it is also a lot of fun and most members report the lasting benefits of educating their communities and meeting new people that are affected by ichthyosis, but unaware of F.I.R.S.T. We congratulate all for a job well done and encourage each of you to call the National office if you would like to become involved in a grassroots fund raising or awareness event.



Local Cub Scout Troop having fun at the Grady Bowl-A-Thon.



FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES

Annual Report for the Fiscal Year 1998

Dear Friends,

In the following pages you will find the annual report for fiscal year 1998. This document demonstrates the sources of our revenue, shows how our funds are spent, and outlines the financial growth and health of the Foundation. As you will undoubtedly notice, the majority of our funds come from YOU, individuals and families affected by ichthyosis. I believe the true strength of F.I.R.S.T. is a direct result of this support. This foundation was started by a group of concerned parents, affected adults and dermatologists. It has grown over



F.I.R.S.T.'s National Conference in June.

the years due to the commitment and energy of this original group and all of the new families who have become involved during our 17-year history. The original mission, to create an organization to provide information and support to individuals and families with ichthyosis, has evolved as our services have widened, but the reason for our existence remains clear: YOU!

Your financial support, your volunteer activities, and your consistent commitment to the mission of F.I.R.S.T. enable us to provide the services that are both essential and important to you. In the past few years that support has allowed us to reach more families through attendance at our National Conference, participation in our support network, and through

our newsletter, *Ichthyosis Focus*. This base of member support, augmented by corporate and community donations, has enabled us to significantly expand our services. This year, we were able to release our new educational video "*Butterflies, the Children of Ichthyosis*", update and reproduce our brochure, and begin designating funds exclusively for research support.

As you review the annual report, applaud the efforts of the founders of F.I.R.S.T., those members conducting "grassroots" fundraising events and yourselves. We began because of you and continue to grow because of you. Please accept my sincere thanks and silent applause.

Sincerely,

Donna Rice

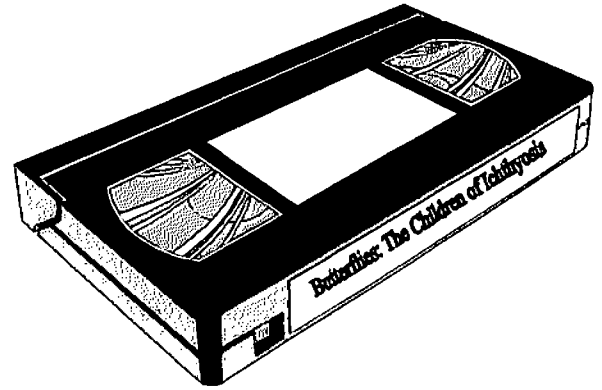
Donna Rice
President, Board of Directors



F.I.R.S.T.'s Medical Advisory Board meeting in March.

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

1998 was a very busy year for F.I.R.S.T., particularly since it was a year in which we hosted our bi-annual National Conference. Considering the extent of activities undertaken, it is noteworthy that the Foundation closed out fiscal year 1998 with a modest 4% increase in net assets. The substantial increase in revenues and expenses from the previous year totals are primarily due to the increased activity that occurs in a conference year.



One of the Foundation's most significant financial accomplishments during 1998 is the adoption of a new investment policy. By appropriately investing money while it's idle, the Foundation can increase its asset base and reduce some of the pressure on fund raising needs. The Foundation's investment policy specifies an appropriate asset allocation, defines acceptable quality investment selections (for example, fixed income instruments must be investment grade), and outlines periodic reporting requirements. While a charitable organization needs to carefully balance its fiduciary duties to both generate investment income on idle funds and minimize risk, even a very modest incremental increase in investment returns can make an enormous difference in the long-term financial health of an organization.



The Children's Program at the National Conference.

On the September 30, 1998 fiscal year end, the new investment policy was in the process of being implemented. At that time, almost all of the Foundation's liquid assets were in various interest- and non-interest bearing cash accounts, because the old accounts were being closed out and the new investment accounts were not yet open.

The continued financial support of our members and other friends of the organization, coupled with the implementation of a sound investment policy, position the Foundation to move into the next millennium with the financial strength to accomplish our goals.

Sincerely,

A handwritten signature in black ink, appearing to read "Laura Phillips".

Laura Phillips
CFO, Board of Directors



Coalition of Patient Advocates for Skin Disease Research meeting with representatives of the National Institute for Arthritis Musculoskeletal & Skin Diseases (NIAMS) in March.

F.I.R.S.T.'s Board of Directors



F.I.R.S.T.'s Board of Directors at the Board Retreat in November: (standing from left) Michael Dunleavy (PA), Rita Tanis (CT), former Board member Francis McHugh (NJ), Debra Vilas (NY), Laura Phillips, CFO (NY), Janet Weary (VA), Elise Johnson, Secretary (WA), Tiffany Karst (KS), Michelle Petersen, VP (NY), Gloria Graham, M.D. (NC), (seated, left) Donna Rice, President (TX), (not pictured) Lewis Horowitz (NY), Leonard Milstone, M.D. (CT), and Mary Williams, M.D. (CA). Also seated are Board Advisor Mark Levitan (PA) and Executive Director Elena Levitan (PA).

INDEPENDENT AUDITORS' REPORT

To the Board of Directors
Foundation for Ichthyosis
& Related Skin Types
Ardmore, Pennsylvania

We have audited the accompanying statement of financial position of Foundation for Ichthyosis and Related Skin Types as of September 30, 1998, and the related statements of activities, cash flows and functional expenses 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. Those 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 Foundation for Ichthyosis and Related Skin Types at September 30, 1998, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.

Cogen Sklar, LLP
Bala Cynwyd, Pennsylvania
October 27, 1998

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES
STATEMENT OF FINANCIAL POSITION
SEPTEMBER 30, 1998
(WITH FINANCIAL INFORMATION FOR SEPTEMBER 30, 1997)

	<u>1998</u>	<u>1997</u>
ASSETS		
CURRENT ASSETS		
Cash	\$101,260	\$ 85,208
Deposits	475	-
Inventory	2,186	-
Investments	-	15,000
	<u>103,921</u>	<u>100,208</u>
FURNITURE AND EQUIPMENT	<u>2,099</u>	<u>1,529</u>
TOTAL ASSETS	<u><u>\$106,020</u></u>	<u><u>\$101,737</u></u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	<u>\$ 1,107</u>	<u>\$ 1,250</u>
NET ASSETS		
UNRESTRICTED		
Operating	91,356	89,793
Board designated for research	9,807	3,650
	<u>101,163</u>	<u>93,443</u>
TEMPORARILY RESTRICTED	<u>3,750</u>	<u>7,044</u>
TOTAL NET ASSETS	<u>104,913</u>	<u>100,487</u>
TOTAL LIABILITIES AND NET ASSETS	<u><u>\$106,020</u></u>	<u><u>\$101,737</u></u>

The accompanying notes are an integral part of these financial statements.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES
STATEMENT OF ACTIVITIES
YEAR ENDED SEPTEMBER 30, 1998
 (WITH SUMMARIZED FINANCIAL INFORMATION FOR THE YEAR ENDED SEPTEMBER 30, 1997)

	1998			1997 Total
	Unrestricted	Temporarily Restricted	Total	
SUPPORT & REVENUES				
Contributions	\$110,247	\$3,750	\$113,997	\$ 93,653
Investment income	3,921	-	3,921	3,349
In-kind contributions	1,160	-	1,160	-
Other	535	-	535	910
	115,863	3,750	119,613	97,912
NET ASSETS RELEASED FROM RESTRICTIONS	7,044	(7,044)	-	-
TOTAL SUPPORT & REVENUES	122,907	(3,294)	119,613	97,912
EXPENSES				
Program services	95,644	-	95,644	55,778
Management and general	14,401	-	14,401	17,098
Fundraising	5,142	-	5,142	5,331
	115,187	-	115,187	78,207
TOTAL EXPENSES	115,187	-	115,187	78,207
CHANGE IN NET ASSETS	7,720	(3,294)	4,426	19,705
NET ASSETS - BEGINNING OF YEAR	93,443	7,044	100,487	80,782
NET ASSETS - END OF YEAR	\$101,163	\$3,750	\$104,913	\$100,487

The accompanying notes are an integral part of these financial statements.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES
STATEMENT OF CASH FLOWS
YEAR ENDED SEPTEMBER 30, 1998
(WITH FINANCIAL INFORMATION FOR THE YEAR ENDED SEPTEMBER 30, 1997)

	<u>1998</u>	<u>1997</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 4,426	\$19,705
Adjustments to reconcile changing in net assets to net cash provided by operating activities		
Depreciation	821	1,337
Loss on asset disposal	-	90
(Increase) decrease in assets		
Deposits	(475)	-
Inventory	(2,186)	-
Increase (decrease) in liabilities		
Accounting payable	<u>(143)</u>	<u>189</u>
Net cash provided by investing activities	<u>2,443</u>	<u>21,321</u>
 CASH FLOWS FROM INVESTING ACTIVITIES		
Proceeds from redemption of certificate of deposit	15,000	15,000
Purchase of furniture and equipment	<u>(1,391)</u>	<u>(1,064)</u>
Net cash provided by investing activities	<u>13,609</u>	<u>13,936</u>
 NET INCREASE IN CASH	 16,052	 35,257
 CASH - BEGINNING OF YEAR	 <u>85,208</u>	 <u>49,951</u>
 CASH - END OF YEAR	 <u><u>\$101,260</u></u>	 <u><u>\$85,208</u></u>

The accompanying notes are an integral part of these financial statements.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED SEPTEMBER 30, 1998

(WITH SUMMARIZED FINANCIAL INFORMATION FOR THE YEAR ENDED SEPTEMBER 30, 1997)

	1998			1997
	Program Services	Management and General	Fundraising	Total Expenses
Salaries and benefits	\$39,535	\$ 9,165	\$2,432	\$ 51,132
National conference	27,112	-	-	27,112
Printing and publications	9,109	169	1,765	11,043
Board meetings	2,185	511	142	2,838
Conference travel	803	-	-	803
Depreciation	632	148	41	821
Dues and subscriptions	504	252	-	756
Educational video	2,178	-	-	2,178
Moving	-	-	-	2,507
Office	1,194	279	78	1,551
Postage and shipping	4,636	244	633	5,513
Professional fees	-	2,675	-	2,675
Regional support network	-	-	-	292
Rent	2,327	259	-	2,586
Staff travel	301	33	-	334
Supplies and materials	788	184	51	1,023
Telephone	4,340	482	-	4,822
TOTAL FUNCTIONAL EXPENSES	<u>\$95,644</u>	<u>\$14,401</u>	<u>\$5,142</u>	<u>\$115,187</u>
1997 TOTALS	<u>\$55,778</u>	<u>\$17,098</u>	<u>\$5,331</u>	<u>\$78,207</u>

The accompanying notes are an integral part of these financial statements.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES
NOTES TO FINANCIAL STATEMENTS
SEPTEMBER 30, 1998

A. Organization and Operations

The Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.) is a nonprofit voluntary organization dedicated to helping families with the genetic skin diseases collectively called the ichthyoses. F.I.R.S.T. provides support, information, education and advocacy for individuals and families affected by ichthyosis. F.I.R.S.T. supports research into causes, treatment and a cure for ichthyosis.

B. Summary of Significant Accounting Policies

Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence and/or nature of any donor restrictions. Support that is restricted by the donor is reported as an increase in unrestricted net assets if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a restriction expires (that is, when a stipulated time restriction ends or the purpose restriction is accomplished), temporarily restricted net assets are reclassified to unrestricted net assets and reported in the Statements of Activities as net assets released from restrictions. There were no permanently restricted net assets.

The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the amounts reported in the financial statements and accompanying notes. Actual results could differ from those estimates.

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with generally accepted accounting principles. Accordingly, such information should be read in conjunction with the organization's financial statements for the year ended September 30, 1997 from which the summarized information was derived.

C. Statement of Functional Expenses

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

D. Income Taxes

The organization is incorporated in the state of California and is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. The organization is registered as required with the Pennsylvania Bureau of Charitable Organizations.

E. Investments

Investments consist of certificates of deposit with original maturities of longer than three months.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES
NOTES TO FINANCIAL STATEMENTS
SEPTEMBER 30, 1998

F. In-kind Contributions

The organization recognizes donated goods and services when the fair value of the donation is determinable. The organization recorded in-kind contributions of \$1,160 in 1998. Office space for part of the past year has been donated to the organization, however no in-kind contribution has been recorded because the fair value of this contribution is not determinable.

G. Inventory

Inventory consists of various supplies and educational materials and is stated at the lower of cost (determined by the first-in, first-out method) or market.

H. Furniture and Equipment

Furniture and equipment consist of the following:

Office equipment/furniture	\$6,006
Computer equipment	<u>3,762</u>
	9,768
Less: Accumulated depreciation	<u>7,669</u>
	<u>\$2,099</u>

Assets are stated at cost. The cost of furniture and equipment is depreciated over the estimated useful lives of the related assets on a straight-line basis.

I. Commitments

The organization moved into commercial office space in May of 1998. For the year ended September 30, 1998, total rental expenses under the leases amounted to \$2,387. The future minimum payments under this lease are \$3,313 in 1999.

The organization has committed to funding a \$10,000 research grant which will be awarded in June 1999. Temporarily restricted net assets of \$3,750 and a portion of board designated research funds of \$9,807 represent support for this research grant.

1998 Contributions List

\$100 - \$249

Dr. & Mrs. Harvey Adams
Tom & Jennifer Alba
George & Marilyn Allison
Joan Alnor
Merritt F. Andrews
David & Cynthia Ashton
Robert & Donna Averill
Lisa M. Bachand
David & Betsy Bates Freed
Joseph Beeler
Reba C. Benson
Robert Bialer
Gary Bierwagen
Jeff & Jamie Biller
W.B. & Jane Blackford
Darlene Blackwell
Patricia Blackwell
Frances Blankis
Barbara Bloom
Cecile Bogan
Robert & Debra Bowic
John Bratton, Jr.
Susan Buckley
Thomas & Dianne Buchler
Brad & Becky Burris
John Burton
*Calvary Baptist Church - in
honor of Caleb Johnson*
Marybeth Capaldo
Joseph Cardinal
Charles E. Carter
Rebecca Ceconi
Chambers Hill Lions Club
Barbara W. Close
Robert & Jean Cohen
Brian & Joyce Conneely
Jean Cox
Melanie Cronau
Raymond Davidson
Dermal Therapy Research
Luc De Batselier
Lesa Dees
Grace Detloff
Lucinda Dudley
Irene Dyck

Charles Eichhorn
Employees of Ernst Paper
 Produsts
Fax Paper Pigments
Vera Finzel
Philip Fleckman, M.D.
Rebecca Frankwicz
Tomi & Duane Friddle
James & Kathleen Gaffney
Capt. Joseph Galluccio
Genuardi's Family
 Supermarkets
Felice Geppert
Suzanne & Larry Getz
Shari Gilevich
Lowell Goldsmith, M.D.
Mr. & Mrs. Robert Grafrath
William Graham
Susan Granados
Ruth Gurwell
William & Linda Hatfield
Ray & Margaret Haywood
Marianne P. Heck
Ms. Frances A. Hiner
Gary & Barb Hodge
Alice & Michael Hricak
Dr. & Mrs. Harold Hudson
Paul & Janice Hudson
Catherine D. Hutchinson
Tim Jack
Margaret & Erling E.
 Jacobsen
Brian F. Jones
Lori Jones
Robert & Patricia Jones
Leonard & Jeanett Jurasek
Carey Kell
Jack E. King
Arnold Kovin
Justine LaFemina
Gary Lauters
Alan & Jennifer Leblang
Gaetano & Mary Licursi
Leonard & Denise Licursi
Lawrence Lieblich, M.D.
Gail Lord

Jennie Maresca
Ronald & Alex Marks
Joseph Martin
George & Frances McHugh
Diane & Roger Measel
Teresa & Bunker Medbery
Diane K. Mencia
James & Alice-Marie Miller
Mrs. David Morris
Frank Mosunic
Richard & Joan Murphy
Donna Nack
*NeoStrataCompany - In honor
of Lisa Short*
Gail & Guy Nielsen
Herdis Olson
Thomas & Trice Ovbey
Donna Heilweil & Michael D.
 Pinnisi
Ann R. Pokalsky Glowacky
Judith Prichard
Jay & Joanne Purcell
Mrs. Joanne Read
Catherine & Jack Rice
Carl & Lois Richter
Richard Rival
John Rivara
William B. Rizzo, M.D.
Susan Robertson
Linda Rogers
Kathryn Rogers
David & Linda Schell
Aimee Schmidt & Zakkary
 Sharp
Joyce Schram
Eric Schweighoffer
Mr. & Mrs. French Sconyers
David C. Scott
Alan Shalita, M.D.
Lisa & Christopher Short
Edward & Claire Short, Jr.
Steven M. Sobkowski
Marian M. Stanton
Marvin Stark
Patti & Mark Steinitz
Barbara Straw

Henry & Martha Suski
 Norma C. Treat
 Janice & Sam Unruh, Jr.
 Steve & Teresa Van
 Heukelom
 Dr. George Vargos & Sr.
 Emma King
 Deborah B. Vilas
 Juan & Judith Villamarin
 Eileen N. Wagner
 Martha L. Waters
 Billy Webb
 Mark & Holly Weber
 Mrs. Arthur G. Williams
 Paul & Carol Williams
 Robert & Tommie Wood
 Brian Woods
 Marilyn Zinn
 Eric Zugerman

\$250 - \$499

*In memory of Miss Marjorie
 Rose Turner*
 Floyd & Agnes Evans
 Karoline Freed-Biggs
 William F. Geismann
 Gloria Graham, M.D.
 Mr. & Mrs. James Haluska
 Walter & Eleanor Hertzog

Vern Kelley
 Anne & Ted Kingery
 Randy LaBarbera
 Jennifer & Robert Laurin
 Arthur Lavery
 Elena & Ken Levitan
 Thomas McClune
 Laurence Miller, M.D.
 Neutrogena Dermatologics
 Oclassen Pharmaceuticals
 William D. Patrick
 Tracie J. Pretak
 David & Anna Purcell
 Melissa L. Ridenour
 Liza Santamina
 Merle & Mary Smith
 Charles & Jackie Treat
 Mary Williams, M.D.

\$500-\$999

*In memory of Charles
 "Teddy" Hoffman*
 Dr. & Mrs. Wilmer Betts
 Margaret H. Blair
 Bristol-Myers Squibb
 Jessie Doyle Deely
 Michael F. & Nancy
 Dunleavy
 Ernst Paper Products

Galderma
 Gateway Women's Club
 Lewis J. Horowitz
 Joe & Chris LaBarbera
 Mark Levitan
 Gwenda K. Parker
 Michelle R. Petersen
 Laura Phillips
 Philadelphia Chapter, UNICO
 National, Inc.

\$1000-\$4999

Lynne & Harry Alba
 Henry J. Bukaty
 The Crawford Sales Co.
 Charlotte E. Gregory
 Helen Kozinski
 Leonard & Ellen Milstone
 Marcia Ohlwiler
 James & Elza Phillips
 Donna & Victor Rice
 Eugene Van Scott, M.D.
 Peyton & Janet Weary
 Ruey J. Yu, Ph.D., O.M.D.

\$5,000+

Glaxo Dermatology



Special Thanks to...

Lynne Alba	Francis McHugh
Debra Bowie	Patti Metzger
Barbara Butler	Tracie Pretak
Lesa Dees	& Bailey Jones
Employees of Ernst Paper Products	Liza Santamina
Tiffany Karst	Lisa Short
Shelly Licursi	Patti Steinitz
Lynn McDougall	Kathy & David Smith
	Susan Suda

...their families and friends, and everyone who worked so hard in 1998 on F.I.R.S.T.'s behalf!

GLORIA F. GRAHAM, M.D. HONORED BY DERMATOLOGY FOUNDATION



Gloria F. Graham, M.D., a widely respected dermatologist and member of F.I.R.S.T.'s Board of Directors has been chosen as the 1998 recipient of the Dermatology Foundation's Practitioner of the Year Award.

The Practitioner of the Year Award was created by the Dermatology Foundation's Trustees in 1976 as a means of honoring dermatologists who epitomize the best clinical service to the individual patient.

In addition to an extremely active and dedicated private practice, Dr. Graham has been on the faculty at the University of North Carolina School of Medicine since 1971, is Clinical attending Professor at the Bowman Gray School of Medicine, and was Clinical Attending Staff at the Duke University Medical Center from 1978-1993.

NIH COUNCIL OF PUBLIC REPRESENTATIVES APPOINTED

Dr. Harold Varmus has announced the appointment of members to the new NIH Council of Public Representatives (COPR). The role of the COPR is to advise the NIH Director about the public's concerns regarding NIH research, and to act as a liaison to the patient community.

One of the nominees, Vicki Kalabokes is the CEO of the National Alopecia Areata Foundation and Co-Chair of the Coalition of Patient Advocates for Skin Disease Research, of which F.I.R.S.T. is an active member.

Over 200 people were nominated and Vicki was one of only twenty individuals selected for this important post. F.I.R.S.T. was one of many supporters of her nomination.

Congratulations Vicki!

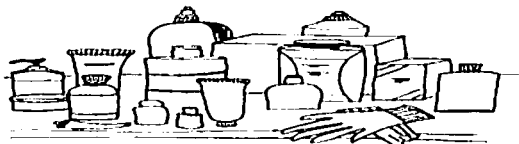
EUROPEAN SUPPORT GROUP CELEBRATES 2ND YEAR

One of our sister organizations in Europe, the London-based Ichthyosis Support Group, has recently celebrated its two-year anniversary in a big way. Its first National Day was held on Saturday, March 20th at Great Ormond Street Hospital in London, England. Fifty-two families from the UK, Ireland, Malta and Spain gathered to meet and share information. There were medical presentations and exhibitors from the pharmaceutical industry. Over seventy children with ichthyosis got to meet each other in a structured program with games and entertainment. BBC Children in Need provided the funding for this daylong program.

For more information about the Ichthyosis Support Group, contact Pamela Catlyn, 16 Cambridge Court, Cambridge Avenue, Kilburn, London NW6 5AB UK. F.I.R.S.T. has contact information for several other groups worldwide, and individuals who are interested in developing informal networks in their countries. Contact us for additional information.



Ichthyosis Support Group leaders Helen Bryant, Maggie Aldwin and Mandy Aldwin outside F.I.R.S.T.'s National office.



What's New, What's Hot, What Works!!!

Jill Larson from Rockford, Illinois writes:

I have had ichthyosis since birth and am now twenty-eight years old. I have tried prescription and non-prescription strength urea/lactic acid creams and lotions and found that they improved the roughness and scales, but my fair skin was always red! I have a real interest in natural remedies and have taken Lechiten and Flaxseed oil or flaxveal internally in hopes of supplementing essential fatty acids important in healthy skin. I have noticed some relief and improvement with these supplements. I also have taken a break from the "strong" lotions and creams and now coat my skin with Aloe Vera Gel when it is still damp and spray "Na-PCA" solution by Twin Lab (this is a sodium salt which is the natural moisturizing factor found in human skin) on my face and hands. Nature's Gate herbal moisturizing lotion is another of my favorite "layers" of protection. I find these products available at my local health food store. I've noticed these products have not caused stinging or soreness/redness and have helped my skin feel more comfortable.

Shanthi Singaram from Madison, Wisconsin writes:

I have a seven year old daughter with Lamellar Ichthyosis. Right now, I use Neutrogena Hand Cream for face, Neutrogena and Ultra Mide 25 for body, and Epilyt for scalp. Her most difficult places are scalp and feet. Epilyt seeps into her eyes and makes her already light sensitive eyes more irritated. I need help for scalp and feet. Suggestions will be greatly appreciated.

Sherry Guevremont, of Winter Haven, FL is seeking information on manufacturers and/or distributors of

vinyl occlusion suits. Her son, age 24, has always used such a suit but they are no longer available through his distributor.

In our Winter 1998 issue, FIRST member Tom Stuelphnagel described his use of a lightweight Tyvek suit that was recommended to him by a farming friend. Tom's source is an industrial products catalog called Gempler's (1-800-382-8473, www.gemplers.com). Consolidated Plastics Catalog (1-800-362-1000) also has a variety of Tyvek and PVC clothing at reasonable prices. Both catalogs offer a variety of gloves, foot covers, sleeves and hats, and Gempler's carries an assortment of cooling products as well. Nylon occlusive garments are available from Sleep Sauna (800-229-5210). Please contact the National Office if you are aware of any additional product sources.

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A-DERMA was proud to participate in the F.I.R.S.T. National Conference in Philadelphia and has recently given you the opportunity to try our products. If you have not yet received A-DERMA samples by mail, for more information or to order directly call 1-800-713-1063. Ask about our new membership program.

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Pierre Fabre

Acknowledgment: In the summer 1998 issue of Ichthyosis Focus, Vol. 17, No. 3 we reprinted a poem entitled "When God Seeks the Right Mother," author unknown. Members of F.I.R.S.T. informed us that the popular poem correctly titled "The Special Mother" was written by Erma Bombeck and was printed in her book Motherhood, the Second Oldest Profession




Product Listing

This listing contains basic information about a sampling of different skin care products. Some are tried and true and some are new. Some have been around awhile, but are new to us. The list is not intended to be exhaustive or all-inclusive. If we've missed one or more of your personal favorites, please let us know. We will print updated product information periodically. Size/price information may vary by region and is subject to change by the manufacturer. As always, we do not endorse or recommend any of these products. We encourage you to consult your dermatologist for treatment advice.

CREAMS & LOTIONS

Product Name	Product Line Description	Size / Price	Manufacturer & Customer Service	Availability
A-DERMA Gentle Treatment Cream Exomega Cream	Oatmilk formulation for dry, irritated, upset skin	3.4 oz./\$7.95 3.4 oz./\$9.95	Pierre Fabre, Inc. (800) 713-1063	Prices listed for purchase direct from manufacturer (plus shipping). Also at selected retail stores. Line includes cleansing products.
Alpha Hydrox Line	Large line of moisturizers & treatments, some with glycolic acid (AHA)	varies by product	Neoteric Cosmetics (800) 55 ALPHA	Retail stores nationwide. Call customer service for coupons/promotions.
Amlactin	12% Lactic Acid (AHA) Lotion	225g./\$10.00 400g./\$18.00	Upsher-Smith Lab. (800) 654-2299	Retail drug stores (ask at counter).
Aqua Glycolic Hand & Body Lotion Face Cream	14% Glycolic Acid(AHA) 10% Glycolic Acid(AHA)	8 oz./\$8.50 2 oz./\$8.50	Allergan (800) 347-4500 for orders (800) 253-9499 info & samples	Select Retail Stores. Listed prices are wholesale prices available to F.I.R.S.T. members who order by the case (12). Body wash was recently discontinued.
Aquaphor Original Ointment	Thick, mild petroleum based ointment	14 oz./\$17.00	Beiersdorf (800) 233-2340	Retail stores nationwide.
Atrac-tain Lotion Cream	2%Lactic Acid/ 5%Urea 5%Lactic Acid/10%Urea	8 oz./\$11.22 5 oz./\$11.28	Coloplast (800) 533-0464	Ask your pharmacy or call customer service for location in your area. Other sizes available.
Avalon Clear Oatmeal Hand & Body Cream Anti-Itch Body Spray	Anti-itch clear oatmeal therapy	8 oz./\$7.95 8 oz./\$6.95	Cooper Labs (888) 2 SOOTHE	Prices listed for direct purchase (plus shipping). Call for special offer information. Line also includes cleansing products.
Aveeno Oatmeal	Large line of Colloidal Oatmeal Products	varies by product	Johnson & Johnson (800) 526-3967	Retail stores nationwide.
California Legs AHA Renewal Lotion	Lactic Acid Lotion	170ml./ \$20.00 for a case of 6	Belvedere Int'l (905) 568-0700 x343	Send check for \$20.20 (US) to Patti Turnbull, Belvedere Int'l, 5675 Keaton Crescent, Mississauga, ONT L5R 3G3 CANADA.
Complex 15 Face Cream Cream Lotion	General Moisturizer, with glycerin	2.5 oz./\$6.75 4 oz./\$10.45 8 oz./\$9.10	Schering Plough (800) 842-4090	Retail stores nationwide.

Dermal Therapy				
Alpha Hydroxy Lotion	10%Lactic Acid/10%Urea	16 oz./\$15.99	Dermal Therapy	Direct from manufacturer (free shipping on orders over \$20.00).
Hand, Elbow, Knee	6%Lactic Acid /15%Urea	3.5 oz./\$7.99	(800) 668-8000	
Heel Care	6%Lactic Acid/25%Urea	2 oz./\$7.99		
Eplyt	Contains propylene glycol and glycerin	4 oz./\$11.25	Steifel (888) 784-3335	Retail stores nationwide.
Eucerin Original				
Original Lotion	Mineral Oil Based	16 oz./\$15.00	Bieisdorf	Retail stores nationwide
Original Cream	General Moisturizers	16 oz./\$17.00	(800) 233-2340	Other sizes available.
Plus Lotion	+5% Lactic Acid (AHA)	12 oz./\$14.00		
Plus Cream	+2.5% Lactic Acid	4 oz./\$11.00		
Plus Face Cream	+4% Lactic Acid	4 oz./\$11.00		
Elta				
Moisturizer Crème	Mineral Oil based mild,		Swiss American	Retail stores nationwide. Other sizes available.
Lite Lotion	general moisturizer	16 oz./\$4.99 16 oz./\$10.99	(800) 633-8872	
Lac-Hydrin				
5% Cream	5%Lactic Acid (AHA)	8 oz./\$10.50	Westwood Squibb	Pharmacies nationwide.
12% Cream	12%Lactic Acid (AHA)	n/a	(800) 494-7258	12% is by Prescription Only.
12% Lotion	12%Lactic Acid (AHA)	n/a		Other sizes available.
Lacticare	Contains Lactic Acid	7.5 oz./\$9.45 11.5oz./\$12.28	Steifel (888) 784-3335	Retail stores nationwide.
PDS NeoCeuticals				
Regular Strength	Problem Dry Skin	7 oz./\$20.00	NeoStrata Company	Price listed is for direct purchase by F.I.R.S.T. members. Additional shipping charge of 2% of order with a \$5.00 minimum charge.
Extra Strength	products containing Alpha	7 oz./\$20.00	(888) 437-9598	
Scalp Solution	and Poly Hydroxyacids	0.34oz./\$8.00		
Anti-Itch Ear Solution		2.2oz./\$10.00		
Sarna				
Sarnol-HC	Cooling anti-itch lotion	7.5 oz./\$8.91	Steifel Labs	Retail stores nationwide.
	Sarnol-HC contains	2 oz./\$12.24	(888) 784-3335	
	hydrocortisone			
Theraplex				
Clearlotion	Non-greasy, Petroleum	8 oz./\$7.00	Medicis	Prices listed are available to F.I.R.S.T. members when ordering direct. Retail prices are higher. Free shipping with purchase of two or more items.
Emollient	Based Moisturizers	4.3 oz./\$8.00	(800) 716-4606	
Hydrolotion		8 oz./\$6.00		
Ulactin	2%Lactic Acid/10%Urea	8 oz./\$12.00 16 oz./\$14.00	Allerderm (800) 365-6868	Available at Drug Stores (ask at counter) or direct from company (plus shipping). Discount \$1/ea. when ordering 3 or more direct.

		<p>Karl Samuel Heinz Born: August 25, 1998 To: Karl & Mona Heinz</p>	<p>Aryeh Hexter Born: July 10, 1998 To: Doniel & Yehudis Hexter</p>	<p>Aricella "Aria" Marie DelGrande Born: December 17, 1998 To: Mark & Angela DelGrande</p>	
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2 THE INGREDIENT

All formulas contain a 50% protein polysaccharide oatmeal complex which is readily soluble in water.



Hand & Body Cream



Anti-Itch Bath Soak

Sensitive Skin Body Wash

Anti-Itch Body Spray

Sensitive Skin Cleansing Bar

3 THE FORMULAS

Easy to use formulas increase patient compliance.

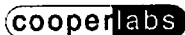
- Avalon Anti-Itch Bath Soak
- Avalon Sensitive Skin Body Wash
- Avalon Anti-Itch Body Spray
- Avalon Sensitive Skin Cleansing Bar
- Avalon Hand & Body Cream

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May You Always Feel Love

May you find serenity and tranquillity in a world you may not understand.

May the pain you have known and the conflict you have experienced give you the strength to walk through life facing each new situation with courage and optimism.

Always know that there are those whose love and understanding will always be there even when you feel most alone.

May you discover enough goodness in others to believe in a world of peace.

May a kind word, a reassuring touch, a warm smile be yours everyday of your life, and may you give the gifts as well as receive them.

Remember the sunshine when the storm seems unending.

Teach love to those who know hate, and let that love embrace you as you go into the world.

May the teaching of those you admire become part of you, so that you may call upon them, remember those whose lives you

have touched and who have touched yours, and are always a part of you even if the encounters were less than you would have wished.

It is the content of the encounter that is more important than its form.

May you not become too concerned with material matters, but instead place immeasurable value on the goodness in your heart.

Find time in each day to see the beauty and love around you.

Realize that each person has limitless abilities, but each of us is different in our own way, what you feel you lack in one regard may be more than compensated for in another.

Learn to view everything as a worthwhile experience.

May you find enough strength to determine your own worth by yourself, and not be dependent on other's judgments of your accomplishments,

"AND MAY YOU ALWAYS FEEL LOVED!"

Dedra & Brett Haynes submitted this poem in memory of their son, Eric, who had Keratitis-Ichthyosis-Deafness (KID) Syndrome and passed away last winter at the age of seventeen.

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Anti-Itch Ear Solution

Extra Strength Cream
Scalp Solution

Contains NeoStrata's Exclusive [bg1]NeoHydroxy™ Complex of

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HYDROLOTION is an ideal everyday moisturizer that has all of the heavyweight protection of petrolatum in a light, greaseless formulation.



THERAPLEX now offers a discount to all F.I.R.S.T. members!

THERAPLEX Moisturizers	Reg. Price	F.I.R.S.T. Price
CLEARLOTION	\$11	\$7
EMOLLIENT	\$13	\$8
HYDROLOTION	\$11	\$6

ORDER DIRECT & SAVE!

Call the THERAPLEX Hotline

1.800.716.4606

News & Notes

F.I.R.S.T. Member Expanding Annual "Butterfly Fundraiser"

Tracie Pretak (PA) has developed an easy and profitable fundraiser and is looking for members throughout the country to help it grow.

Each spring Tracie enlists the help of local businesses, who receive a supply of colorful paper butterflies and F.I.R.S.T. brochures. For each \$1.00 donation, the establishment displays a butterfly with the donor's name.

If you'd like to help and think you can generate interest among some small businesses in your area, contact Tracie at 814-929-5970.

National Library of Medicine Consumer Website

A new consumer friendly website, MEDLINEplus, provides public access to the most up-to-date health

information via the internet. Features include links to information about clinical trials, health-related organizations, and links to MEDLINE, the National Library of Medicine's database of peer-reviewed medical information. You can access MEDLINEplus through the National Library of Medicine website at <http://www.nlm.nih.gov>.
From Alliance Alert, December 1998, a publication of the Alliance of Genetic Support Groups

Officer Training Program on Persons with Disabilities

Patti Steinitz, our Harlequin Support Group Coordinator, is working to develop a police officer's training program on persons with disabilities. Anyone with a unique experience they'd like to share is invited to contact Patti at 412-231-1201 (PA).

Please help us to minimize our printing costs. Call us at 1-800-545-3286 if you do not wish to receive future issues of Ichthyosis Focus.

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