



ICHTHYOSIS FOCUS

Vol. 17, No. 2

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

Spring 1998

Enzyme Abnormality Found In CIE

by Betsy Bates Freed



Betsy Bates Freed, 40, is a medical writer for a company that publishes clinical newspapers for physicians, including one for dermatologists, *Skin and Allergy News*.

She and her husband, David, a screen writer and author, have two great kids:

Bobby, age 11, a Boy Scout and soccer player; and Rachel, age 9, a talented artist and softball slugger who has EHK. The

Frees live in Santa Barbara, California, where the pets, the vegetable garden, and the 1907 house they're restoring keep them all very busy.

An abnormal clumping of a certain key enzyme in the deep epidermal layers of the skin has been found in some, but not all, people with Congenital Ichthyosiform Erythroderma (CIE), a form of ichthyosis.

A team of California researchers led by Dr. Keith A. Choate of Stanford University published the discovery in the January issue of the *Journal of Investigative Dermatology*. Dr. Choate's co-investigators were Dr. Mary Williams of the University of California, San Francisco, a F.I.R.S.T. medical advisor, and Dr. Paul A. Khavari, also of Stanford.

Many individuals with lamellar ichthyosis lack the protein known as TGase1 (keratinocyte transglutamate).

In 4 of 5 study participants with CIE, TGase1 was present in the epidermis, but it was clustered in the cells' interiors. Normally, TGase1 is expressed along the outer margins of epidermal cells. As the outermost skin layers (the stratum corneum) are forming, it links together the proteins that form the dense shell surrounding each skin cell. "This dense shell is what makes our skin tough," said Dr. Williams in an interview.

Dr. Williams was intrigued by the fact that not every CIE patient displayed the unusual cluster of enzymes, even though all five patients had similar-appearing skin. Most likely, the phenomenon will be explained when the genetic basis of CIE is better understood.

"We now know there's more than one gene involved in CIE," said Dr. Williams, who noted that the mutations in different genes can produce identical symptoms or diseases.

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**National Family Conference 1998
Registration Deadline
May 18, 1998**

Call the National Office at 1-800-545-3286
for late registration information.

See pages 14-15 for program information.

**ICHTHYOSIS
FOCUS**

Vol. 17, No. 2
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Ichthyosis Focus
is published quarterly by the
Foundation for Ichthyosis &
Related Skin Types
(F.I.R.S.T.)

Anyone is free to reprint,
with credit to F.I.R.S.T.,
material contained in
Ichthyosis Focus.

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F.I.R.S.T. is a 501(c)(3)
charitable organization
supported by private
donations. All contributions to
F.I.R.S.T. are tax deductible to
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law.

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.

CORRESPONDENCE CORNER

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

Hi, my name is Rebecca Butler,
I am president of a church youth
group, and we'd like to give you a
donation to help to find a cure, or
help in the research. I have lamellar
ichthyosis and at all the conferences
they always have something that
helps. The new lotion, Neo-
Ceuticals, is good, but we hope
researchers find something better.
There's always room for
improvement right?

I know the donation will go to
good use and I would like to
personally thank all of you. You all
do a great job with *Ichthyosis Focus*,
and you made a great web site!!,
although you might want to try to set
up a chat room, where people can go
to chat about different problems, or
medications.

Yours Truly,
Becky Butler
Rochester, NY

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

Your last quarterly journal
(Winter 1998) was the best and most
informative of any issue you've put

out. Congratulations! - you're
making headway.

I find glycerin applied on my
skin while it is still moist has been
the most helpful to my skin problem.

Sincerely,
Joyce Lyon
Olin, IA

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

Our son was diagnosed at birth
with ichthyosis. We were told it is a
rare disease and haven't been able to
find out much information about it.
Our doctor has given us a copy of
your newsletter and we were really
excited to find out that there are
others who can maybe help us find
ways to deal with his condition. Our
son is two weeks old and the
particular type of ichthyosis has not
been diagnosed yet, but any help you
can give us would be wonderful.
Thank you!

Sincerely,
Deb & Jay Nordguard
Rothsay, MN

Our mission...

The Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.) is a 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.

Ichthyosis Focus is provided as a service to members of F.I.R.S.T. as a medium for the free exchange of information. Neither F.I.R.S.T., its Board of Directors, its Medical Advisory Board, nor the *Focus* Editor endorse any treatments or products reported on in *Ichthyosis Focus*. Views and opinions expressed in this publication do not necessarily reflect the views of F.I.R.S.T. or Foundation officials.

President's Letter

By Donna Rice

My children have a favored book called, That's Bad... No, That's Good!, which came to mind as I wrote this letter.

In January, Mark Levitan submitted his resignation as Executive Director of F.I.R.S.T. - That's Bad...

...No, That's Good, because Mark has agreed to stay on as advisor to the New Executive Director, consultant to the Board of Directors, and as a member of the Board's Finance Committee.

Elena Levitan, who has served as the Foundation's Program Director since September of '96 is also moving on, That's Bad...

...No, That's Good, as Elena has been appointed to the position of Executive Director of F.I.R.S.T.

I am very pleased not to have to say goodbye to Mark. I thank him for his service to F.I.R.S.T. this past year. He oversaw a difficult transition, with our move from North Carolina to Pennsylvania, and was still able to generate an increase in membership and a 24% increase in total assets. I am very pleased that Elena has accepted the position of Executive Director, where she will continue to oversee the daily activities of the Foundation, including quarterly production of the Focus, planning of our National Conference and helping to meet the diverse needs of our community of individuals and families affected by ichthyosis.

The Foundation has grown and we are reaching more people affected by ichthyosis and more physicians treating patients with ichthyosis. One of Elena's first responsibilities as Executive Director is to hire additional staff and secure professional office space to accommodate everyone. Elena and the foundation have been fortunate this past year to have the assistance, on a part-time basis, of Amy Bottoms, who among her other duties is responsible for the layout and graphics of the Focus. The Board of Directors has also approved the hiring of a part-time National Program Director for the Regional Support Network, a move designed to effectively meet the needs of all individuals interested in connecting with others, and we anticipate having that position filled prior to the summer conference.

The 1998 National Conference will be here before we know it and I hope everyone will be able to make it to the wonderful city of Philadelphia to meet Mark, Elena and Amy and all the other people who help make F.I.R.S.T. first! Come, and put faces with those names you see in the Focus and those voices on the phone. Meet other families living with ichthyosis and the physicians and researchers dedicated to finding new ways to treat ichthyosis and improve the quality of our lives.

See You There-

Donna

*Donna Rice clowning
with her children
Andrew, Haley and
Adam.*



Donna Rice
President
Katy, Texas
(12/98)

Michelle Petersen
Vice President
Metuchen, New Jersey
(12/99)

Laura J. Phillips
Chief Financial Officer
New York, New York
(12/99)

Elise Johnson
Secretary
Lynnewood, Washington
(12/00)



Michael F. Dunleavy
Blue Bell, Pennsylvania
(12/00)

Gloria Flippin Graham, M.D.
Atlantic Beach, North Carolina
(12/99)

Lewis Horowitz
New York, New York
(12/00)

Tiffany Karst
Shawnee, Kansas
(12/99)

Leonard Milstone, M.D.
Chairman
Medical Advisory Board
New Haven, Connecticut
(12/99)

Rita Tanis
Fairfield, Connecticut
(12/98)

Deb Vilas
New York, New York
(12/00)

Janet Weary
Charlottesville, Virginia
(12/98)

Mary L. Williams, M.D.
San Francisco, California
(12/00)

Third Annual Ichthyosis Awareness Week

October 4-10, 1998

Ichthyosis Awareness Week (IAW) is a full week dedicated to making the general public aware of ichthyosis and its impact on individuals and families. It was first instituted in 1996 and was held again last year. Many members took the opportunity to raise funds for F.I.R.S.T., while at the same time raising awareness in their communities. I am very fortunate to be able to publicly thank each of these families with a grassroots fundraising award, which will be presented at the 1998 Family Conference this summer.

F.I.R.S.T.'s Board of Directors has recently agreed to change Ichthyosis Awareness Week from May to October. This change is due to some concerns about IAW interfering with end of school activities and preparations for the summer conference. The hot weather in some of the southern and western states in May was also a factor in our decision. The third annual Ichthyosis Awareness Week is scheduled for October 4-10, 1998. I hope that this move will allow more members to become involved in this important event.

I have accepted the position of IAW coordinator for this year's event and will talk about a variety of activities at the summer conference, in future issues of the Focus, and in mailings to interested members. I hope to encourage more of you to get involved by providing assistance, helpful hints and support.

Those of you that have already planned an event for another date are, of course, encouraged to go ahead, as awareness of ichthyosis should be a year round event! I look forward to talking with each of you at the conference and providing you with additional information as the 1998 IAW nears.

Tiffany Karst
1998 IAW Coordinator

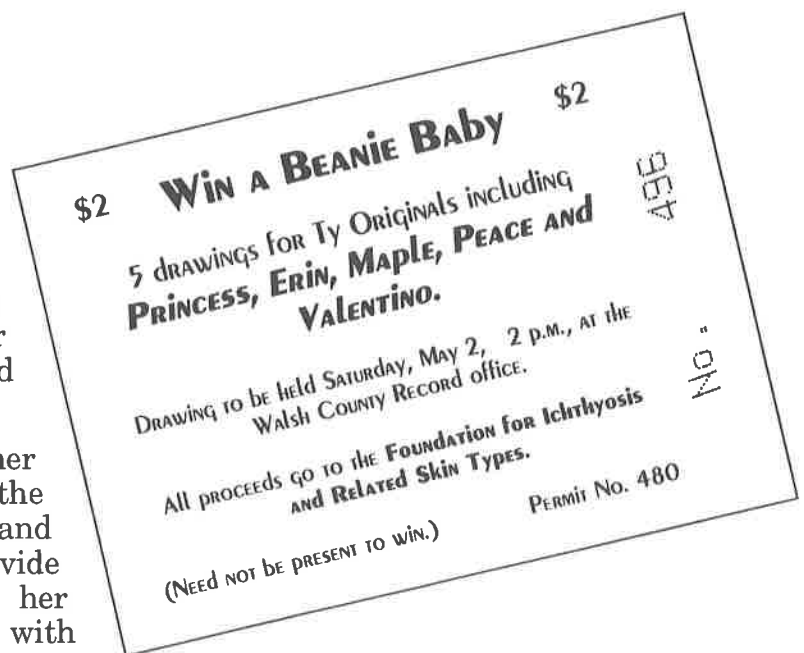
Ticket to Success

F.I.R.S.T. member Susan Suda writes for her county newspaper. She and her co-workers managed to get five of the rarer Beanie Babies to raffle for F.I.R.S.T., and the newspaper covered the cost of printing the tickets.

She announced the raffle in one of her regular columns, "On the Beat". In the column, she wrote about F.I.R.S.T., and how the Foundation had helped provide information to her family when her daughter, Hannah (age 2), was born with lamellar ichthyosis. In an effort to create even greater awareness about ichthyosis, she volunteered to speak to community groups, resulting in a recent engagement with the local Optimist Club.

The tickets are \$2.00 each and she has reported selling more than 750 with a full month to go! The drawing will be held in early May. We'll report the results in our next issue.

Thank you Susan, for your fundraising event, and for your continued efforts to increase awareness of ichthyosis.



Other Fundraising Ideas

Bingo ♦ Bowl-A-Thon ♦ Car Wash ♦
Can Drive ♦ Garage Sale ♦ Giftwrap
Services ♦ Golf Tournament ♦ Putt-
Putt for Charity ♦ Talent Show ♦
Theatre Night

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



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Ardmore, PA 19003
610-789-3995
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Annual Report for the Fiscal Year 1997

A Letter From the Chief Financial Officer;

As you will see in the accompanying financial statements, fiscal 1997 was a strong year for the Foundation for Ichthyosis and Related Skin Types. The Foundation's total assets increased 24%, breaking the \$100,000 mark for the first time. This significant increase in the Foundation's asset base resulted primarily from increases in contributions. Whatever our revenue source - our generous individual contributors, corporate gifts, locally organized fundraising campaigns - F.I.R.S.T.'s diverse group of steadfast patrons renewed their support for the organization.

Operationally, F.I.R.S.T. continued providing program support for the ichthyosis community in 1997. Our *Ichthyosis Focus* newsletter continued to develop both in size and quality, at the hands of our contributors and editors. F.I.R.S.T.'s website made it's debut, and also will continue to evolve, into a more comprehensive and interactive site. The Regional Support Network (RSN) carried on its work, and will soon be headed by a paid part-time RSN Director. The Board has also committed resources to finding new ways to make its programs available to all individuals and families affected by ichthyosis, even if they are unable to become contributing members of F.I.R.S.T.

Overall, F.I.R.S.T. heads into 1998 poised for additional growth, both in maturing program services and in new areas. Beginning in fiscal 1998, the Board of Directors is designating certain revenues for funding research related to the ichthyoses. This represents one aspect of a multi-faceted effort on the part of the Board to expand F.I.R.S.T.'s mission to include supporting and actively advocating additional research into causes, treatments and ultimately a cure for ichthyosis.

As you read through the Financial Statements, please note our new mission statement in Footnote A. F.I.R.S.T. has come a long way since its inception 17 years ago. And while we still have a long way to go in achieving the ambitious goals we continue to set for the Foundation, everyone involved in supporting F.I.R.S.T. should celebrate the countless moments throughout every year when F.I.R.S.T. makes a difference-- a new parent's first contact with someone who really understands; educating teachers and young classmates; a community for families; a contact point for treatment information-- F.I.R.S.T. makes a difference in our lives!

Laura Phillips
CFO, Board of Directors

Copies of the financial statements are available upon request from the Foundation's national office.

INDEPENDENT AUDITORS' REPORT

To the Board of Directors
Foundation for Ichthyosis
and Related Skin Types
Havertown, Pennsylvania

We have audited the accompanying statement of financial position of Foundation for Ichthyosis and Related Skin Types as of September 30, 1997, 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, 1997, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.

November 25, 1997

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FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES
STATEMENT OF FINANCIAL POSITION

September 30, 1997

(with financial information for September 30, 1996)

<u>ASSETS</u>	<u>1997</u>	<u>1996</u>
CURRENT ASSETS		
Cash	\$85,208	\$49,951
Investments	<u>15,000</u>	<u>30,000</u>
	100,208	79,951
FURNITURE & EQUIPMENT	<u>1,529</u>	<u>1,892</u>
TOTAL ASSETS	<u>\$101,737</u>	<u>\$81,843</u>
 <u>LIABILITIES & NET ASSETS</u>		
CURRENT LIABILITIES		
Accounts payable	<u>\$1,250</u>	<u>\$1,061</u>
 <u>NET ASSETS</u>		
UNRESTRICTED		
Operating	89,793	75,988
Board designated for research	<u>3,650</u>	<u>-</u>
	93,443	75,988
TEMPORARILY RESTRICTED	<u>7,044</u>	<u>4,794</u>
TOTAL NET ASSETS	<u>100,487</u>	<u>80,782</u>
TOTAL LIABILITIES & NET ASSETS	<u>\$101,737</u>	<u>\$81,843</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, 1997

(with summarized financial information for the year ended September 30, 1996)

	1997			1996
	Unrestricted	Temporarily Restricted	Total	Total
SUPPORT & REVENUES				
Contributions	\$86,403	\$7,250	\$93,653	\$76,738
Investment income	3,349	-	3,349	3,666
In-kind contributions	-	-	-	6,000
Other	<u>910</u>	<u>-</u>	<u>910</u>	<u>1,874</u>
	90,662	7,250	97,912	88,278
NET ASSETS RELEASED FROM RESTRICTIONS	<u>5,000</u>	<u>(5,000)</u>	<u>-</u>	<u>-</u>
TOTAL SUPPORT & REVENUES	<u>95,662</u>	<u>2,250</u>	<u>97,912</u>	<u>88,278</u>
EXPENSES				
Program services	55,778	-	55,778	53,689
Management & general	17,098	-	17,098	18,317
Fundraising	<u>5,331</u>	<u>-</u>	<u>5,331</u>	<u>6,668</u>
TOTAL EXPENSES	<u>78,207</u>	<u>-</u>	<u>78,207</u>	<u>78,674</u>
CHANGE IN NET ASSETS	17,455	2,250	19,705	9,604
NET ASSETS - BEGINNING OF YEAR	<u>75,988</u>	<u>4,794</u>	<u>80,782</u>	<u>71,178</u>
NET ASSETS - END OF YEAR	<u>\$93,443</u>	<u>\$7,044</u>	<u>\$100,487</u>	<u>\$80,782</u>

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, 1997

(with financial information for the year ended September 30, 1996)

	<u>1997</u>	<u>1996</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
CHANGE IN NET ASSETS	\$19,705	\$9,604
ADJUSTMENTS TO RECONCILE CHANGES IN NET ASSETS TO NET CASH PROVIDED BY OPERATING ACTIVITIES		
Depreciation	1,337	2,040
Loss on asset disposal	90	-
(Increase) decrease in assets		
Prepaid expenses	-	500
Increase (decrease) in liabilities		
Accounts payable	189	(3,671)
Other liabilities	-	(624)
	<u>21,321</u>	<u>7,849</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
PROCEEDS FROM REDEMPTION OF CERTIFICATE OF DEPOSIT	15,000	15,000
PURCHASE OF FURNITURE AND EQUIPMENT	(1,064)	-
	<u>13,936</u>	<u>15,000</u>
NET CASH PROVIDED BY INVESTING ACTIVITIES		
NET INCREASE IN CASH	35,257	22,849
CASH - BEGINNING OF YEAR	<u>49,951</u>	<u>27,102</u>
CASH - END OF YEAR	<u>\$85,208</u>	<u>\$49,951</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, 1997

(with summarized financial information for the year ended September 30, 1996)

	1997			1996	
	Program Services	Management and General	Fundraising	Total Expenses	Total Expenses
Salaries and benefits	\$29,389	\$ 9,199	\$2,665	\$41,253	\$36,326
Board meetings	2,032	630	200	2,862	3,773
Conference travel	1,250	-	-	1,250	2,772
Depreciation	949	294	94	1,337	2,040
Dues and subscriptions	745	372	-	1,117	950
Educational video	5,000	-	-	5,000	4,000
Moving	-	2,507	-	2,507	-
Office	1,138	352	112	1,602	2,012
Postage and shipping	2,700	300	449	3,449	5,044
Printing and publications	6,382	259	1,737	8,378	8,330
Professional fees	-	2,400	-	2,400	1,915
Regional support network	292	-	-	292	-
Rent	-	-	-	-	5,700
Staff travel	1,866	187	-	2,053	-
Supplies and materials	751	233	74	1,058	1,572
Telephone	3,284	365	-	3,649	4,240
TOTAL FUNCTIONAL EXPENSES	<u>\$55,778</u>	<u>\$17,098</u>	<u>\$5,331</u>	<u>\$78,207</u>	
1996 TOTALS	<u>\$53,689</u>	<u>\$18,317</u>	<u>\$6,668</u>		<u>\$78,674</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, 1997

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, 1996 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 International 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.

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 \$0 in 1997 and \$6,000 in 1996. Office space for 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. Furniture and Equipment

Furniture and equipment consist of the following:

Office equipment/furniture	\$4,615
Computer equipment	<u>3,762</u>
	8,377
Less: Accumulated depreciation	<u>6,848</u>
	<u>\$1,529</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.

H. Temporarily Restricted Funds

At September 30, 1997 temporarily restricted net assets of \$7,044 represent support for a video project to be completed after September 30, 1997.

KEEP YOUR COOL

Summer's approaching, with its increased risk of overheating. Some of our members, especially active young children, have found that specialized cooling equipment can help them beat the heat and enjoy the outdoors for longer periods of time.

The companies listed below manufacture either cooling vests which contain special packs which are cooled and inserted into pockets and/or water circulating, battery powered vests.

Life Enhancement Technologies
2682 Middlefield Rd. Bldg L
Redwood City, CA 94063
415-568-5900

ILC Dover, Inc.
One Moonwalker Rd.
Frederica, DE 19946
302-335-3911

Steele Inc.
26112 Iowa Ave., NE
PO Box 7304
Kingston, WA 98346
360-297-4555

Exothermal Technology Corp.
1720 Main Street NE
Palm Bay, FL 32905
407-952-1200

Micro Climate Systems, Inc.
965 E. Saginaw Rd.
Sanford, MI 48657
800-397-3004

Dura*kold
1117 Cornell Parkway
Oklahoma City, OK 73108
405-943-8811

As always, we do not endorse or recommend any of these products. (Check with the manufacturers to be certain that you're getting a product that both fits right and works effectively.) Several companies also make other cooling apparel such as headgear and seat cushions.

Other Handy Products...

The "Squeeze Breeze" is a small spray bottle with a battery activated fan made by Innovative Design Enterprises, Inc. Also made by Innovative Design is the "Misty Mate" that is like the "fanny-pak" which contains a cylinder that dispenses a cooling mist. For more information call them at 708-628-9592.

The "Chill Out" is a head/neck-band that contains water absorbing crystals that cool and expand when soaked in cold water. More information about "Chill Out" can be obtained from the maker of the product, Rainbow Designs at PO Box 1317, Citrus Heights, CA 95611-1317 or call them at 916-725-1034.

H.E.D. Foundation Helps Get Cool Vests To Those Who Need Them

Much of the technology used in today's cooling equipment was developed as a result of NASA's space program, and the need to regulate astronauts' body temperature. The Hypohydrotic Ectodermal Dysplasia (H.E.D.) Foundation is a non-profit organization which helps to provide cool vests to children (19 and under) who need them. H.E.D.'s founder, Sara Moody, works with NASA and Micro Climate Systems, Inc. to provide these vests as they become available. Awards are often, but not always, made in specific parts of the country in conjunction with the manufacturer and NASA officials. If you are interested in being considered for this program, please call F.I.R.S.T.'s National office at 1-800-545-3286.

The magazine show 20/20 is currently taping a story about Sara Moody and the H.E.D. Foundation. F.I.R.S.T. member, Joshua Bates (age 10) was recently awarded a cool vest through this program. He and his family have participated in the filming. The segment is expected to air sometime this spring.



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

... a regular feature about skin care problems and solutions.

Mrs. Maisie McMullen of Ontario, Canada writes:

My 35 year old son and my 10 year old grandson have x-linked ichthyosis. We have found a cream here in Canada that costs less than \$5.00 a tube called "California Legs Alpha Hydroxy Renewal Lotion". It is just amazing what has happened after using it for only two weeks.

They showered and applied cream everyday for 3 days. On the third day they used a hand mitt for the bath or back brush to remove the scales, and continued to do this daily. After one week, there was much improvement. After two weeks the skin in both my son and grandson looks like normal skin, and they are continuing to use it!

The office has received a number of calls and letters about NeoCeuticals Problem Dry Skin Treatment. Cindy Bremmer from St. Helens, Oregon writes about her experience with this relatively new product line:

I have fairly severe lamellar ichthyosis and even though I had a favorite cream it was a daily battle to treat my ichthyosis. Now with the PDS creams it is a joy to take care of my skin. It feels soft for the first time ever and the creams are gentle and healing even though they work tough. My ears and scalp used to have thick scales and are now almost scale free. It is amazing to see and feel my entire torso. I just shower briefly and apply the PDS creams. (I'm actually using the creams on my scalp instead of the scalp solution and getting great results, so people may want to experiment a little. I apply one of the creams to a dry scalp twice a week). This is the closest thing to normal skin I've ever had.

Joseph F. White of Parsippany, New Jersey called to tell us about St. Ives Swiss Formula Collagen-Elastin formula. He reports that he has used it every morning for over five years and has seen an improvement in his skin. He also likes its non-greasy feel and low cost.

Judith Herschaft has Ichthyosis Vulgaris, and has also developed allergies to some of the ingredients in the skin care products and shampoos:

Some of the chemicals that I am allergic to- Ammonium Lauryl Sulfate, Sodium Laureth Sulfate, Sodium Lauryl Sulfate, Propylene Glycol and Salicylic acid- are in many of the products used by those of us with ichthyosis. When I use these products my face begins to burn, gets bright red, swells up and my eyes close.

Aveno Lotion is non-irritating. Recently, a representative of Ferndale Labs in Michigan sent me some SBR-Lipocream. I use it on my face, hands and arms. It is extremely soothing. The formula is 70% oil dispersed in water. It is excellent.

Can anyone suggest some other alternatives for shampoo and body cream? I am desperate to find a solution.

**10% Lactic Acid (Alpha Hydroxy)
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Hundreds of FIRST members tell us this non-prescription moisturizer & exfoliant smoothes skin better than prescription products. New odor free formula only ~~\$15~~\$99 for a 16-oz bottle.



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F.I.R.S.T. neither recommends, nor endorses, products or services advertised in *Ichthyosis Focus*.

F.I.R.S.T.'S NATIONAL CONFERENCE 1998 PHILADELPHIA

Advanced Schedule. Meeting times may vary slightly in the final program, which will be distributed prior to the conference to all registrants. Individual sessions and time slots may also change.

FRIDAY, JUNE 19TH

- 4:00 - 6:00 p.m. Registration
6:30 - 9:30 p.m. Reception
Light snacks, cash bar, and plenty of time to mingle.

SATURDAY, JUNE 20TH

- 8:30 - 9:15 a.m. Breakfast
Continental breakfast and late registration
- 9:15 - 10:30 a.m. General Session
♦ *Opening remarks*
♦ **National Registry for Ichthyosis and Related Disorders** - Philip Fleckman, M.D.
♦ **Camp Discovery** - Howard Pride, M.D.
- 10:45 - 12:00 p.m. Breakout Session
Session A: **Basic Genetics of Ichthyosis** - Sherri J. Bale, Ph.D.
Session B: **Registry Enrollment Workshop** - Geoff Hamill, R.N.
Session C: **Infection: Causes and Control** - Amy Paller, M.D.
Session D: **Women's Discussion Group**
- 12:15 - 2:00 p.m. Lunch & Family Break - *with Awards Presentations*
- 2:00 - 3:15 p.m. General Session
Treatment of Ichthyosis, Panel Discussion and Q & A - Moderated by Amy Paller, M.D. with Eugene Van Scott, M.D., John DiGiovanna, M.D., and Steve Handler, M.D.
- 3:45 - 5:00 p.m. Breakout Session
Session A: **Focus on Topical Treatments** - Eugene Van Scott, M.D.
Session B: **Dad's Discussion Group**
Session C: **Camp Discovery** - Howard Pride, M.D.
- 6:00 - 9:00 p.m. Dinner - *followed by line and country dancing with Jack & Doreen Ingle*

SUNDAY, JUNE 21TH

- 8:30 - 9:15 a.m. Breakfast
Continental breakfast
- 9:30 - 10:45 a.m. General Session
♦ **Genetics: Past, Present, and Future** - Sheri Bale, Ph.D.
♦ **Closing Remarks**
- 11:00 - 12:15 a.m. Breakout Sessions
Session A: **The ABC's of Retinoids** - John DiGiovanna, M.D.
Session B: **Talking with Your Doctor** - Geoff Hamill, R.N.
Session C: **Mom's Discussion Group**
Session D: **Gene Therapy** - Leonard Milstone, M.D.

F.I.R.S.T.'s 1998 NATIONAL CONFERENCE

JUNE 19, 20 & 21

Hilton at Cherry Hill

2349 West Marlton Pike

Cherry Hill, NJ 08002

(10 minutes from downtown Philadelphia)

Guaranteed Registration Deadline

May 18, 1998

Call the National Office at 1-800-545-3286 for last minute registration forms and procedures.

Late registration (after May 18th) may be possible if there is still space available, but our special conference rate is only guaranteed until the registration deadline. Call the national office for additional information.

CHILDREN'S PROGRAM

Our children's program will be in session during scheduled meeting times. We will have the assistance of a number of volunteers with nursing and childcare backgrounds, and have reserved a large space with several partitions for different groups and activities.

The program will include different activities for children of all ages. Woody Wolfe, Jr. will entertain the kids with a sing-along in the morning, and a magic show in the afternoon. We're planning an optional miniature golf outing at an adjacent park for the older ones (weather permitting). There will be plenty of snacks and beverages on hand.

Please note that our children's program is only in session during meeting times on Saturday morning, Saturday afternoon, and Sunday morning. Childcare is not available during lunch and family break periods or after sessions close at the end of the day.

AIRLINE RESERVATIONS

US Airways has the most flights into and out of Philadelphia International Airport. As the official carrier for F.I.R.S.T.'s National Conference they are offering a 5% discount on their lowest applicable published fares on roundtrip travel from June 14, 1998 to June 26, 1998. To obtain these discounts, you must call US Airways' Meeting and Convention Reservation Office at (800) 334-8644 and refer to Gold File Number 34630417. There are also discounts on First Class and Business Class fares. Certain rules and restrictions apply. Call US Airways for details.

**RESERVE EARLY, AT LEAST
60 DAYS PRIOR TO DEPARTURE DATE, TO
RECEIVE THE MAXIMUM DISCOUNT.**

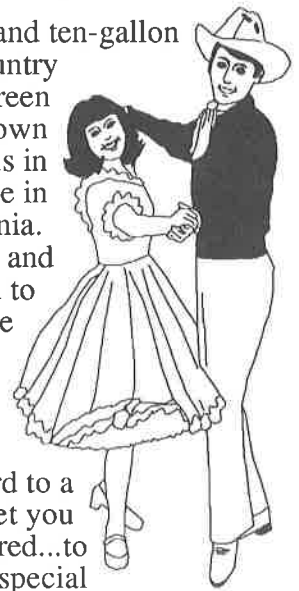
SATURDAY NIGHT...

Pack your boots, string ties and ten-gallon hats* for a night of country dancing with Jack and Doreen Ingle! They are well-known callers and will be joining us in Philadelphia from their home in Churchville, Virginia.

In a recent letter, Jack and Doreen wrote, "We are glad to know that families will be involved. We enjoy working with families and have something for all ages (and experienced levels) to enjoy.

We are looking forward to a fun evening. We want to let you know that we feel very honored...to be with this group for a very special time of dancing."

* Western gear is, of course, optional. Blue jeans and sneakers or comfortable shoes will do just fine. *



HOTEL ACCOMODATIONS

Hilton at Cherry Hill

For hotel information and reservations, call toll free at 1-800-HILTONS or the reservation desk in Cherry Hill at 609-665-6666. Identify yourself as a F.I.R.S.T. member to receive our special conference hotel rate.

The F.I.R.S.T. National Conference rate of \$80.00 is only guaranteed for rooms booked a minimum of one month in advance of the conference date - by May 18th, 1998.

If you have questions, or if you experience difficulties booking your room, please call F.I.R.S.T.'s National Office in Ardmore, PA at 1-800-545-3286.

A Commitment to Research

At its annual retreat last November, the Board of Directors determined that F.I.R.S.T. can and should fund a small research grant. Speaking for the Board, then-President Michael Dunleavy said "the Foundation has always encouraged ichthyosis research. We are pleased that the organization is now strong enough to begin funding investigations into the causes of ichthyosis or into improved treatments for patients with ichthyosis. We hope that the award can be made annually." A research committee was established. The committee will be chaired by Leonard Milstone, M.D., who also serves as chairman of F.I.R.S.T.'s Medical Advisory Board.

The initial award, in the amount of \$10,000, will be made in July 1999. The grant will be administered through the Dermatology Foundation after a nationwide competition. Deadline for application is October 1, 1998.

This award should permit initial testing of innovative ideas or provide partial support for a young investigator interested in ichthyosis research. The size of the grant is modest and the Board recognizes that it will not likely lead to a breakthrough discovery. Nonetheless, small awards, such as the F.I.R.S.T. research grant, are expected to generate wider awareness and enthusiasm for ichthyosis research among the general public as well as the research community.

The Board is very pleased to be able to award this grant so soon after the program's inception. Proceeds from the Charles Edward "Teddy" Hoffman memorial fund and generous gifts from Dr. and Mrs. Peyton Weary and Mrs. Charlotte Gregory have made it possible to do so. The Board has also committed to setting aside a portion of our membership renewals and other general contributions to support the program.

REGIONAL SUPPORT NETWORK (RSN)

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803-559-9369

Wisconsin
Theresa Tremmel
414-538-4922

Children's Success Story



Hi! My name is Shannon Tormey. I'm 17 years old and I was born with Lamellar Ichthyosis. Having this type of ichthyosis has played a major role in my life. I have learned to be the best that I can be. I never settle for lower. Yes, many people have stared at me, especially when I was younger. Some people still do. However, my parents taught me to ask them if they want to know what's wrong with my skin. Most of the times they say sorry and then walk away! There are some that are genuinely interested, and listen to

me. Yes, it does bother me at times, but you can't live your entire life worrying about what others think of you. If you were to live your life that way you'd never succeed in anything. "Go for what you want to do, and don't let others get in your way," is what my Mom, Dad and brothers have told me.

Because they helped me along the way, I am now a very happy student at Notre Dame High School in Lawrenceville, NJ, enjoying my junior year. I have many friends at school and I love going out with them. There is always somebody who wants to be smart; you have to look beyond them. Have a great time with the people who are fun for you to be with. In my free time I love to talk on the phone, go to the park with my friends, shop, and play basketball. Hopefully, I'll be playing basketball at college. If I don't get to play at the college level, I do plan to be helping people in doing civic work.

Parents, please listen to me. I urge you to not let your child sit in pain. Teach them to make friends. Let them go out and see what's going on! It may be very hard to let your child do this. They will get hurt, but I'm here to tell you that with a supportive family, like the one God gave me, your child can do anything they want to do. Just be there when times get tough. Teach them how to turn stares into a learning experience (i.e., as mentioned above, ask the person if they have any questions). Your child will develop the ability to interact with other people if they use this technique. Do not be shy about the subject. In my life I have always asked questions. Let your child know that it is great to ask questions.

In my life, I have a special mission, and that is to teach people to look on the inside of one's heart rather than to look on the outside of one's life. It is so very difficult to teach a person to do this. Hopefully, in my lifetime, "we" will be able to do this, to live in a "blind" world.

Children with this skin disorder, please let me know if there is something that you have a questions about. I "will" understand where you are coming from and I might just have an answer for you! So please write to me and give me your thoughts about dealing with Lamellar Ichthyosis. I would love to hear from you. Tell me about your experiences in life.

Sincerely,
Shannon Tormey

R *National* **REGISTRY** for **I** **CHTHYOSIS** *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
E-mail: ichreg@u.washington.edu
URL: <http://weber.u.washington.edu/~geoff/ichthyosis.registry/>

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 improve methods of diagnosis and treatment of the ichthyoses. We do this by creating a list of affected individuals. This should have a profound impact on research in the ichthyoses and related disorders, since one of the greatest obstacles 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.

N.O.R.D. announces "Medical Equipment Exchange" program.

The National Organization for Rare Disorders (N.O.R.D.) has recently introduced a new medical equipment exchange on the Internet. The exchange will make previously used medical equipment available and affordable by helping to link buyers and sellers. To learn more or participate in the program go to N.O.R.D.'s home page: <http://www.NORD-RDB.com/~orphan> or contact Candace Effron at PO Box 8923, New Fairfield, CT 06812-8923.

Oral Retinoid Replaced

Patients currently taking Tegison (etretinate) are already aware that the drug has been replaced. Effective March 31, 1998, the manufacturer Roche has been shipping Soriatane (acetrein) in its place. Soriatane, another oral retinoid, is said to offer the same benefits as Tegison, with more convenient dosing and faster clearance from the body. Consult your dermatologist for information about the risks and benefits of oral retinoid therapy.

Camp Discovery 1998

The American Academy of Dermatology will again be sponsoring two special camps which are offered free of charge for children with chronic skin diseases:

Camp Knutson
Minnesota
July 11-18
ages 10-13

Camp Horizon
Pennsylvania
August 16-22
ages 8-13

For more information on attending the camps, or to

volunteer as a junior counselor or counselor, call Howard Pride, M.D. at (717) 271-8050 or Debbie Kroncke at (847) 330-0230.

A new camp is expected to be held in the Los Angeles area, August 27-30. Contact Jenny Kim, M.D. at 310-825-5420 for more information.



Chris Overstreet tosses horseshoes at carnival night.

NEWS & NOTES

Testimony Update

As we went to press with the last issue of *Ichthyosis Focus*, Shelly Licursi and her son, Ryan testified

before the House of Representatives; Committee on Appropriations; Subcommittee on Labor, Health and Human Services, Education and Related Agencies. Shelly is a volunteer coordinator for Region 1 of F.I.R.S.T.'s Regional Support Network. Ryan is a 13 year-old student with EHK.

They testified, on behalf of F.I.R.S.T., to the need for greater funding for skin disease research.

Shelly and Ryan had an opportunity to chat with Subcommittee Chairman, John Porter, and other congressmen and their aides during breaks in the session. They were also pleasantly surprised by the location. The meeting room was smaller and somewhat more informal than they had imagined.



Ryan Licursi with Congressman Porter.

Glaxo Dermatology announces Eugene Van Scott Research Fellowship

On February 28, 1998, Glaxo Dermatology announced the creation and endowment of the *Eugene Van Scott Research Fellowship* to support continuing research into the treatment and care of skin disorders. The fellowship, presented through the Dermatology Foundation, honors Dr. Eugene Van Scott, who has been a member of F.I.R.S.T.'s Medical Advisory Board since the Foundation's early days in the 1980's. Dr. Van Scott's career spans more than 30 years and comprises many advances and discoveries, including the use of alpha-hydroxy acids in dry skin disorders.

The first investigator to receive the *Eugene Van Scott Research Fellowship* award is Martine Michel, Ph.D. of the University of Washington. The award was announced at the American Academy of Dermatology conference in Orlando, FL and will be used to fund her research in "Calpain I Protein Phosphatase 2A: Two Enzymes of Normal Epithelial Differentiation That are Potentially Involved in Harlequin Ichthyosis."

BOOK REVIEW

"Does It Run In The Family?"
by Doris Zallen, Ph.D.

"Does It Run In The Family?", Dr. Doris Zallen's new book is an excellent resource for families with genetic disorders.

As more and more genetic tests become available, new and troubling questions are being raised, such as: How do the tests work? What will the tests reveal? What are they incapable of revealing? Why do they not provide clear-cut answers? What questions should you ask the doctor or counselor? What impact will the health care system, insurance industry and government policies have on your options? And how do you discuss your alternatives with relatives?

Understanding the new DNA tests and the issues surrounding them is crucial to families with inherited medical conditions. Dr. Zallen explains these complicated medical issues through stories of real families and the choices they made about genetic testing.

"Does It Run In The Family? - A Consumer's Guide to DNA Testing" is available at your library or from: Rutgers University Press, Livingston Campus, PO Box 5062, New Brunswick, N.J. 08903-5062. Telephone: 1-800-446-9323.

This review originally appeared in Orphan Disease Update, Volume XIV Edition 3, published by National Organization for Rare Disorders (N.O.R.D.), PO Box 8923, New Fairfield, CT 06812-8923.

In Memorium

We are deeply saddened to learn, in recent months, of the deaths of three young children with ichthyosis. Our heartfelt sympathies to:

Jayne and Dean Roderiques, parents of Brett Alexander Roderiques, who was born with Harlequin Ichthyosis.

The family of 3 year-old Kelsey Brinn Creek, especially her parents, Thomas and Julie, and brother Bryce Alexander. Kelsey battled P.I.B.I.D.S., a very rare syndrome which involves ichthyosis.

David and Pamela Hines, whose month-old son, Christopher David Hines, died of complications of Netherton's Syndrome.



The Joy of Life

*Do you remember the first time you walked across the floor?
Or the time when you ran to Daddy to kiss him by the door?
How about the time you ate cherry jello and your face got funny red?*

*Or the afternoon you screamed - "I want out of this old bed!"?
Do you remember vacations of water on the beach?
Do you remember the taste of a ripe and juicy peach?
It grieves us all, Dear Kelsey, that you never knew these things.*

*I choose this day to think about, to ponder, to recall,
the happiness you found in life... in spite of it all!*

*The joy of a cow bell ringing all day long,
The singing of your Daddy's crazy little songs.
The twinkle of a wind chime, the crunch of wadded trash,
The squeak of a window as I'm pulling down the sash.
The obnoxious purple dinosaur that you made us grow to love,
And that loud irritating noise when the dryer goes BUZZZ!*

*You knew of love, of Dad and Mom, of big brother fast at play,
You looked for chances to giggle and laugh every single day.
There are many lessons that we can learn from your too short life,
I'll follow your lead, dear Kelsey, I'll lay down the strife!
I'll think about the joys you knew, as you traveled through each day,
I'll thank God for His mercy and look for laughter on life's way.*

This poem was written by Julie Creek, in tribute to her daughter, Kelsey.

F.I.R.S.T.
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CHECK IT OUT

N.O.R.D.: This site offers a full range of N.O.R.D.'s services, including the newsletter, Orphan Update, the Rare Diseases Database, the Organizational Database, and Orphan Drug Designation Database.

<http://www.NORD-RDB.com/~orphan>

AAD: The site provides information about the American Academy of Dermatology, patient information on finding a dermatologist near you.

<http://www.aad.org>

ALLIANCE OF GENETIC SUPPORT GROUPS: A resource for consumers and professionals who are looking for genetic support and genetic services.

<http://www.geneticalliance.org>

NATIONAL LIBRARY OF MEDICINE/NATIONAL INSTITUTES OF HEALTH PUBMED: A search service with access to 9 million citations in MEDLINE and links to participating on-line journals and other related databases.

<http://www.ncbi.nlm.nih.gov/PUBMED/>

OFFICE OF RARE DISEASES: Information about more than 6000 rare diseases, current research and clinical trials, and support groups.

<http://rarediseases.info.nih.gov/ord/index01.html>

MARCH OF DIMES BIRTH DEFECTS FOUNDATION: Source for information about how to have a healthy baby and what to do if there is a problem. Also includes a list of the most prevalent types of birth defects.

<http://www.modimes.org>

FAMILY VILLAGE: Contains information and resources for people with a range of disabilities. Includes chat rooms for various disabilities.

<http://www.familyvillage.wisc.edu/>