



ICHTHYOSIS FOCUS

Vol. 15, No. 1

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

Winter 1996

F.I.R.S.T. CELEBRATES 15TH ANNIVERSARY 1981 - 1996

January 2nd, 1996 marks the 15th anniversary of the founding of the National Ichthyosis Foundation, the former name of the Foundation for Ichthyosis & Related Skin Types. Founded in the San Francisco area and nurtured there until its move to Raleigh, North Carolina in 1989, F.I.R.S.T. has never swayed from its central mission — offering information, education and support services to its far-flung membership of persons affected with ichthyosis and their families.

THE BEGINNINGS

January 2nd, 1981, is the date on which the National Ichthyosis Foundation (NIF) was chartered as a nonprofit charitable organization. The Articles of Incorporation were formally adopted, and the NIF officially became an entity. January 2nd is F.I.R.S.T.'s Founders' Day.

In fact, though, the core of individuals who founded our organization were working hard to make it a reality far sooner. The first issue of Ichthyosis Focus (page one shown here) came out in the Summer of 1980. The Founders were meeting regularly, planning what they hoped would become a viable support network for patients and families affected with ichthyosis.

F.I.R.S.T.'s original founder

(continues on page 4)

NATIONAL
ICHTHYOSIS
AWARENESS WEEK
MAY 20 • 26, 1996
SEE PAGE 7

NEWSLETTER

Send all correspondence to:
Barbara Landwehr 151 Toyon Drive
Pam Brown 696 Orangewood Drive

Vallejo, California
Fremont, California

94590
94536

INTERESTING INFORMATION...

Ichthyosis is a rare condition which affects at least one in every 100,000 people. Categorically there are four major forms of Ichthyosis.

1. Lamellar Ichthyosis (Congenital Ichthyosiform Erythroderma, non-bullous)
Rate of occurrence: 1:100,000
2. Epidermolytic Ichthyosiform (Congenital Ichthyosiform Erythroderma, bullous form)
Rate of occurrence: 1:100,000
3. X-Linked Ichthyosis (Steroid Sulfatase (enzyme) Deficiency)
Rate of occurrence: 1:10,000 males only.
4. Ichthyosis Vulgaris (most common form)
Rate of occurrence: 1:250
Various other syndromes include, but are not limited to the following:
 1. Atypical Ichthyosiform Erythroderma with deafness and keratitis. Very Rare.
Rate of occurrence: 14 or 15 reported cases.
 2. Sjogren's Syndrome (Including Mental Retardation).
 3. Rud's Syndrome (Including Mental Retardation).
 4. Refsum's Syndrome (Similar to Epidermolytic Hyperkeratosis but not all over the body).
 5. Erythrodermatitis Variabilis (Including Fetus--Frequently stillborn).

We apologize if your problem is not listed. We would like to hear from you also.

OUR BEGINNING...

Pam and I were introduced to one another by Dr. Mary Williams one day at the University of California Medical Center in San Francisco. Dr. Williams asked me to share with Pam, as a mother, what has happened over the years with my daughter.

Our girls, Debra Landwehr---age 2, age 15, and Jaime Lyn Brown---age 2, have different forms of Ichthyosis, both of which are rare (1:100,000). Debra has Lamellar Ichthyosis and Jaime has Epidermolytic Hyperkeratosis.

We talked about the problems of having a child with Ichthyosis and discussed how great it would be to have a support group. We definitely recognized the tremendous need for such an organization. So I mentioned to Pam that Dr. Williams and I had already discussed it, but it hadn't gone any further.

Meanwhile, Dr. Williams had received a telephone interview and didn't know exactly what it was for. Then she received a letter from a woman in Brooklyn. This woman had written to Dr. Williams because she had read an article that was the result of the telephone interview. So a few more letters arrived.

We decided that now is the time to formalize our new organization. The National Ichthyosis Foundation held its first official meeting on August 13, 1980, and it was at that time that we wrote a letter to inform people that we exist. The second meeting was held on August 27, 1980, to write this Newsletter. So, here we are!
TO BE CONTINUED....

**ICHTHYOSIS
Focus**

Vol. 15, No. 1
Winter 1996

Copyright © 1996
by F.I.R.S.T.

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.

P.O. Box 20921
Raleigh, North Carolina
27619-0921

919-782-5728
800-545-3286
FAX: 919-781-0679

President of the Board
Deborah Vilas

Executive Director
& *Focus* Editor
Nicholas Gattuccio

Editorial Assistant
Betsy Wilford

**Board of Medical
Editors**

John DiGiovanna, M.D.
*National Institutes of
Health*

Carl Ehmann, M.D.
*Bowman Gray Research
Center*

Philip Fleckman, M.D.
University of Washington

Karen Holbrook, Ph.D.
University of Florida

Joseph McGuire, M.D.
Stanford University

Neil Prose, M.D.
Duke University

Mary Williams, M.D.
*University of California,
San Francisco*

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

CORRESPONDENCE CORNER

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

I have been so touched by some of the letters in your newsletter that it has prompted me to write you regarding my family and how we have (or haven't) dealt with ichthyosis vulgaris. I have one teenage son with this condition and two brothers also have it. My oldest brother and youngest sister have "normal" skin. My son also suffers from psoriasis, which in itself is very hard to treat.

Over the years we have tried many different products. In my younger years my mother used shortening or lard products to slather onto our skin. We went through jars of Vaseline, Nivea and Kerio-Lotion, and many types of shampoos. In my teens, I did get a prescription for a helpful product which was composed of urea and Eucerin.

I have also used Avon products, Mary Kay, NuSkin and Neutrogena. None of these have worked long term. Aqua Glycolic does not work for me, but Lac-Hydrin is helpful. We have a water softener and I always use a bath oil. I do find Skin-So-Soft bath oil also helpful.

I have also gone the natural health way — eliminating red meats, caffeine, sugar, white flour and all refined foods. I also took vitamin A capsules (with caution!). I used jojoba oil and calendula

cream. These did not work for me. I did this regimen for about six months with no noticeable improvement.

I try to make the best with what I have. This also applies to sports. I get involved in activities which don't make me too hot. I play baseball (at night, under the lights), golf in the early evening, and I bowl. In the winter, I downhill ski, cross-country ski, and I recently took up figure skating. My son does not get involved in as many sports as he used to. His psoriasis showed up when he was twelve and this has been a worse complication for him than his ichthyosis (I think).

My biggest problem with this disease probably has been the intimacy of someone touching my skin. The simple act of shaking hands is not something I look forward to. My hands are very dry, wrinkled, and they become cracked in these harsh Canadian winters.

My husband is a very loving and understanding partner. He never "sees" my skin, only the person in it. My son still has problems dealing with his skin, but we are all working on his attitude.

I do get somewhat depressed about my skin at times, but mostly I am able to deal with it. It's really not too bad, but it's how I "let" society see me.

I probably could go on and on about

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

Our CompuServe address: 74722,1571

You may also reach us over the INTERNET by

addressing Email this way: 74722.1571@compuserve.com

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.

living with this skin condition while growing up, but I've made it through those hard years and am looking forward to the "retirement" years coming up.

Thank you for letting me write you about dealing with ichthyosis. It has helped me to write these feelings down. I was particularly upset about my son, as his skin has really flared up lately. We also belong to the National Psoriasis Foundation. I am wondering if other people with ichthyosis have other skin conditions too?

Thanks for a great newsletter!

Mary Anne Brentnell

Lindsay, Ontario, Canada

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

My daughter, Trudie, was born with ichthyosis and I tried to educate doctors and the general public. She's 32 years old, now, and during her elementary school years children were very cruel and wouldn't hold her hands during recess. One day she said to one youngster, "You might have something worse than I do but you haven't found out about it yet."

She, too, is an educator, and will tell people why her hands look like a puzzle. So, know that our family truly applauds your organization.

Dolores Heikkla

Jackson, Michigan

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

I am now using the (newish) Dial moisturizing antibacterial liquid soap in the pink bottle. I use it on a soft nylon scrubbing puff.

The effect so far is this: my EHK is most severe over flexural areas (elbows, knees, ankles, wrists, hands), and is terribly dry in the winter. I normally use Lac-Hydrin lotion and supplement with Eucerin and Lubriderm after I shower, but often I feel none of these things are actually helping the dryness. The soap seems to 1) help the dryness, 2) help the Lac-Hydrin with the exfoliation, 3) cut down on bacterial growth. The keratinization in the flexural areas is now at least 50% reduced, and on other areas, my skin appears vir-

tually normal, whereas before it was flaky and uncomfortable.

It took a while for this soap to make a difference, and I would recommend that anyone give it at least two months to see the maximum benefit. I also (this is important) take one one-hour soaking bath a week, and use that opportunity to do a major scrubbing to optimize the effects of the Lac-Hydrin. For a day or so after this, I just use Lubriderm, since my skin tends to feel somewhat tender, then I go back to the Lac-Hydrin until the next bath.

Pass the word: I would have to say that this soap has had the most major effect on my skin of anything I've tried since I began using Lac-Hydrin about ten years ago. I don't know what's in it, but it also makes nice suds and has no yucky smell.

Hope this helps someone.

Terry Melton

State College, Pennsylvania

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

Our daughter is adopted and has been with us since she was first out of a hospital setting, and she is the joy of our lives — bright, funny, witty and loving. Our entire community has embraced her with open arms and she has much love.

We tried for several years to adopt another child with lamellar ichthyosis, but could not find one in need of a home. Although we are getting older, we would still consider adoption. We are not actively searching, but I am telling you this in the event that someone should contact you for help in finding an adoptive home.

Robin Scudder

Brattleboro, Vermont

Hello,

It's good to see that we have a presence on the Net. I would like to hear from other members who have access to the internet. My internet address is dariers@halcyon.com

Paul Stappenbeck

Seattle, Washington

(continues on page 12)

BOARD OF DIRECTORS



Deborah Vilas

President

New York, New York

(12/97)

Michelle Petersen

Vice President

Metuchen, New Jersey

(12/96)

Janet Weary

Secretary

Charlottesville, Virginia

(12/98)

Phyllis Sanders

Chief Financial Officer

Raleigh, North Carolina

(12/98)

Lynne Alba

Norristown, Pennsylvania

(12/96)

Michael Dunleavy

Blue Bell, Pennsylvania

(12/97)

Beth Peritz

Baltimore, Maryland

(12/97)

Donna Rice

Katy, Texas

(12/98)

Rich Graham

Colchester, Vermont

(12/96)



Leonard Milstone,

MD

Chairman

Medical Advisory Board

New Haven, Connecticut

Nicholas Gattuccio

Executive Director

(that is, the person who originally drove the idea for creating the National Ichthyosis Foundation) was Barbara Landwher, whose daughter Dietra was affected with lamellar ichthyosis. Living in the Bay Area near San Francisco, California, she enlisted the support of research dermatologists and specialists in ichthyosis, Drs. Mary Williams and Peter Elias, both of whom served on the NIF's original Board of Directors.

By 1983 the leadership torch had been passed to Charles Eichhorn, an attorney in Oakland who served through the mid-1980s variously as the NIF's Board President and volunteer Executive Director. The Medical Advisory Board continued to grow under the leadership, first, of Mary Williams, M.D., and then Dr. Lowell Goldsmith.

THE N.I.F. MOVES EAST & BECOMES F.I.R.S.T.

By 1988 the core of energy in the Bay Area began to wane. Charles Eichhorn wanted to give more energy to his law practice, volunteer energy had begun spreading around the country, and it was clearly time for new leadership to take the reins. Shortly before, Ellen Rowe had come onto the Board of Directors, and she increasingly assumed leadership positions, leading ultimately to her election as Board President in 1989.

It was decided at this time that it made more sense moving the organization to its new leadership than the other way around, so the California leaders packed up the NIF and shipped it off to Ellen Rowe in Raleigh, North Carolina. Ellen leased an office in North Raleigh (the one we're in to this day), rented a post office box, hooked up the phones, set up the files, and we were in business in North Carolina.

At about the same time, Dr. Williams suggested that a great many keratinizing disorders (or disorders in which faulty keratinization plays a role) which were closely related to ichthyosis were lost in the shuffle of rare, "orphan" diseases, and that the National Ichthyosis Foundation might consider broadening its mandate and its service base by including this broad spectrum of disorders. In agreement with this idea, the Board formally changed the organization's name to the Foundation for Ichthyosis & Related Skin Types, Inc., or F.I.R.S.T.

Ellen Rowe served as Board President and unofficial director until the fall of 1992, with the help of paid office help — something new for our growing organization. By the fall of 1992, however, even this was not enough. F.I.R.S.T. had grown too much, and our programs and ser-

Fifteenth Anniversary

(continues from page 1)

vices had become too demanding to be administered by a volunteer Board supported by an administrative assistant. So the Board decided that it was time to take the critical

step of investing in a paid Executive Director, in whom they could vest responsibility for day-to-day operations of the Foundation.

F.I.R.S.T. EMBRACES THE 1990s

The transition from an organization run by a volunteer Board, to one where the Board delegates day-to-day control to a salaried director, is a very big, sometimes difficult transition. Our first executive director, then in a part-time position, was Susan Snyder. Susan made great strides toward effecting the transition, as well as accomplishing a great deal in the area of legislative advocacy—particularly regarding the Registry. However, her tenure was short, and in the summer of 1992 F.I.R.S.T. faced another leadership crisis of the kind seen in 1983 and 1989. This is not uncommon for a voluntary health organization.

At this time Frances McHugh was elected Board President, and following a summer of intense debate, the Board decided to go forward with the plan to hire a full-time, salaried executive director. Ultimately, the Board hired Nick Gattuccio. Rather than move the organization across country once again, as had been done in 1989 when Ellen Rowe took over, Nick and his family moved to Raleigh to take the position, beginning in November, 1992.

The Board's commitment to supporting a full-time executive director (and, ultimately, a professional staff) began a new era for the organization. Revenues *more than doubled* in 1992, and have risen at more than twice the national average ever since.

More important than revenues, though, is that a staff has both the time and the professional commitment to develop and maintain programs and services in a way that a volunteer board never could. Furthermore, a full-time director is able to maintain full-time contact with all of our important family relations—our friends in science, medicine, government and industry.

THE FUTURE IS BRIGHT

As we prepare to enter the new millennium, be assured that your Board of Directors is committed not only to growth, but also to genuinely increasing the range and quality of the programs and services which the Foundation offers its members. We are becoming better known, and we're becoming better at serving our Ichthyosis Family.

August saw another of F.I.R.S.T.'s

Regional meetings — this one in Indianapolis with Region 4.

Region 4 RSN Coordinator Cynnne Bates organized the meeting, and area representatives Mark & Jill Wood, who live in Indianapolis, handled the local end of organizing the regional conference. It's a huge job, and our thanks go out to Cynnne, Jill and Mark for their hard work and deep commitment to the Region 4 Ichthyosis Family.

R.S.N. REGION 4

REGIONAL CONFERENCE ALBUM

Special thanks also go to three dedicated physicians who generously gave their time to come to Indiana-

polis to join our Region 4 families — Susan Mallory, M.D., from St. Louis; Anne Lucky, M.D., from Cincinnati; and Patricia Treadwell, M.D., who lives in Indianapolis.

Following is a gallery of portraits from the conference. (Sorry, but photo captions were not included.)



Your Board of Directors last month declared May 20-26, 1996 to be National Ichthyosis Awareness Week. The goal is to build a network of Ichthyosis Awareness events during that week so we can create a massive, nationwide information, education and fund raising event to increase aware-

ness of ichthyosis and F.I.R.S.T. This event is set to coincide with the Foundation's 15th Anniversary.

It has long been felt that one of the greatest obstacles facing our Ichthyosis Family is the obscurity of ichthyosis — the fact that no one ever seems to have heard of it. This

NATIONAL ICHTHYOSIS AWARENESS WEEK MAY 20 • 26, 1996

We Need Your Help To Create A Nationwide Event to Increase Awareness of Ichthyosis & F.I.R.S.T.

year 2000, ichthyosis will no longer be an obscure and alien word, and that the general public, school districts, health care professionals, politicians, and everyone else we deal with will not respond with glazed eyes and confused looks when they hear us say, *ichthyosis*.

creates difficulties for us in our daily lives (at school, in the workplace, and even in the grocery store), and it creates difficulties for the Foundation when it seeks out grants or other funding, or seeks other means to develop public awareness.

So we're setting out to change all of this. Our goal is that, by the

We're encouraging everyone to think about giving

F.I.R.S.T. one weekend of this, our 15th Anniversary year. On the weekend of May 25-26, 1996, which culminates our National Ichthyosis Awareness Week, we need everyone's help as we create a network of activity that stretches from coast-to-coast, border-to-border, to increase the public's awareness of ichthyosis in a nationwide festival of events that raise funds for us, too.

What can you do?

You can have an enormous impact in your local community by hosting a local Ichthyosis Awareness Event. We hope to have at least one event in every state in the U.S. This is an ambitious goal, but we can reach it with your help. Your RSN Regional Coordinators and members of your Board of Directors will be helping out.

The important thing is realizing how easy it is to host an Awareness

BE A PART OF F.I.R.S.T.'S NATIONAL ICHTHYOSIS AWARENESS WEEK

Event — it can be as simple as a neighborhood yard or garage sale, or as ambitious as a marathon event. Here are just a few possibilities:

Yard/Garage Sale. The easiest way to help. With neighbors, family, or other F.I.R.S.T. members in your area, you can organize a weekend sale. In the weeks leading up to the Awareness Event, you can reach out to friends and co-workers, family and neighbors for donations of "junk" from attic or basement to contribute to the sale.

Game Night. Those of you in areas with baseball teams — and it doesn't have to be the big leagues, either — can arrange game nights. Professional baseball teams are only too glad to help arrange group ticket buys at deep discounts, which you can then turn around and sell as a

charitable contribution to co-workers, neighbors, family and friends.

Sports Marathon. One of our former Board members, Tom Buehler, last year organized a 12-hour volleyball game between his company and a client company. The event was great fun for all who played, it garnered great local press coverage, and it raised over a thousand dollars for F.I.R.S.T.

These are just three of many ways you can help promote National Ichthyosis Awareness week in May. Please give us a call in Raleigh to discuss other ideas you might have.

How can F.I.R.S.T. help?

We'll be there to support all of your efforts. We'll have press release and public information material, lots of T-shirts (San Diego conference shirts), plenty of F.I.R.S.T. brochures and educational material, logistical support and advice. We'll also be publishing names and photos of all participants. Call Nick in Raleigh to talk about your participation.

Estate Planning & The Mary M. Cleary Legacy Circle

In 1990, Mrs. Mary Margaret Cleary made a bequest to F.I.R.S.T. in the form of a gas well, which has formed the economic cornerstone of F.I.R.S.T.'s growth and development over the past five years.

We had just become F.I.R.S.T. (after being the National Ichthyosis Foundation for ten years), and we were both young and weak financially. Mrs. Cleary's gift gave us the capital we needed to become financially sound.

Mrs. Cleary had no idea how many lives her gift would touch when she planned her estate. But her gift became a seed that grew and flowered into a rich garden of new services and programs for our Ichthyosis Family.

One small estate planning effort can create an immeasurable legacy in your name.

Why Plan?

1. It creates a lasting memorial. Estate planning ensures that the mark you leave is consistent with your values and beliefs. You have the opportunity to create a lasting memorial — something that affects the future.

2. It give you control, both now and later. A will allows you to control the disposition of your assets when you are gone. A trust extends that control into the future by determining when your assets should be distributed, and to whom.

3. It minimizes estate taxes and expenses. Estate planning can save thousands of dollars in estate taxes and administrative expenses. These

savings may be used increase gifts to loved ones or to charities.

4. It can increase your retirement income. If you arrange your assets in an instrument such as a charitable trust, you can net income tax deductions now while increasing your retirement income.

How Do I Look Into This?

First, assess your goals and wishes for the future. What lasting impact do *you* wish to make?

Second, speak with your own financial advisors — your family, your attorney, your accountant, and any others whose views you value.

If you decide to go forward, you can (*although you do not have to*) call on us at F.I.R.S.T. to discuss your plans.

Estate Planning Tools

There are a great many meaningful ways to manage your assets today in order to influence them when you're gone. Your attorney and accountant can tell you more about the following estate planning tools.

1. A Will is the simplest and most basic form of an Estate Plan. Without a valid will, the state decides how your assets are distributed, so in any size estate a will is necessary. In larger estates, additional tools may be desirable.

2. A Trust offers even more control than a will, allowing you to control the time and circumstances of your assets' distribution. A trust may be revocable or irrevocable.

3. A Revocable Living Trust al-

lows you to name a trustee to implement the provisions of the trust without court supervision. The assets in trust remain in your taxable estate, although it may take advantage of your unified tax credit and marital deduction.

4. A Charitable Remainder Trust allows you to place your assets in a trust now and still receive a charitable deduction for tax purposes. You, as the income beneficiary, receive the income generated by these assets in trust for your lifetime and that of your spouse. Upon your passing, the trust is distributed to the charity you have named. Not only do you receive an income tax deduction immediately, but the value of the trust is excluded from your estate when you die.

5. An irrevocable life insurance policy is another example of an irrevocable trust. The trustee of this trust owns a life insurance policy on you. This removes the proceeds of the policy from your taxable estate, while making the proceeds available to pay estate taxes. Proceeds not needed for this purpose may be distributed as directed by the terms of the trust, which may include your loved ones and/or your favorite charity.

The Mary M. Cleary Legacy Circle

You can help yourself *and* your heirs, and at the same time create a lasting and meaningful legacy to further the mission and goals of F.I.R.S.T. We'll be happy to speak with you about the Cleary Legacy Circle and your gift of a lifetime.

Q. I have been diagnosed with CIE. I also have a geographic and fissured tongue. I wonder if there is any relationship between my tongue and my ichthyosis. Nobody else in my family has either CIE or a fissured tongue.

A. Geographic and fissured tongue is a condition where the surface of the tongue has irregularly shaped, changing

patches. Most of the time it is a change in appearance only, and becomes neither tender nor painful. It has been associated with a few skin conditions, such as psoriasis. It is not known to be associated with CIE. However, since it is not rare, it may occur by chance in anyone.

Q. Through literature put out by F.I.R.S.T., I have learned why I have difficulty perspiring and keeping my body cool when the weather gets hot. However, I do not fully understand why I also have difficulty keeping warm. I am quite often shivering when others are not. Can you explain this to me?

A. "Just thinking about shivering makes me cold!"

There are many reasons why some people tend to feel cold while others in the same place feel comfortable or hot (and vice versa). It may have to do with metabolism or activity level. One of the functions of the skin is to regulate body temperature. If we are hot, our body can redistribute blood flow to the skin, where it can give off body heat to the surrounding environment. While this is happening, the skin may turn red, because of the increase in blood flow. Similarly, people with ichthyosis who have red skin may lose body heat, and therefore feel cold.

Q. My ichthyosis involves occasional occurrences of yeast infections—under my arms, in my groin area, and even in my belly button! Is a combination of cortisone and lotrimin the best treatment? Beyond topical treatment, is there anything I can do to prevent yeast infections before they begin? I can connect these infections with occasions when I was overheated, but I also wonder, are they connected with my men-

Q & A

Guest columnist for this edition of Q&A is Dr. John DiGiovanna, Chief of the Clinical Section in the NIAMS at the National Institutes of Health in Bethesda, Maryland. Dr. DiGiovanna serves on F.I.R.S.T.'s Board of Medical Editors. Many of you met and spoke with Dr. DiGiovanna at our last national meeting in San Diego.

strual cycle? Also, can diet affect yeast infections?

A. Yeast infections (most often with a yeast called Candida) are common. Yeast is normally in the environment, and can live to some degree on your skin, as well as in the mouth, colon, and genitourinary tract. Your body is in a constant battle to defend against it, just as the yeast is constantly trying to

grow as fast as it can. When local conditions favor the yeast, it grows better. Bacteria that normally grow on your skin compete with the yeast. Sometimes, if you take antibiotics and change the bacteria, it allows the yeast an advantage and a yeast infection can result. If you take antibiotics often, that could explain frequent recurrent yeast infections.

Candida likes warm, moist areas, so it has an advantage in areas where the skin stays moist (like skin folds), or where the skin is not acting as a good barrier (scaly areas). Keeping these areas dry can help prevent infections.

Diabetics are also prone to yeast infections. When their diet (and the diabetes) is out of control, yeast infections can occur more often. When someone has recurrent yeast infections, a check for diabetes is sometimes warranted. Often, it helps to treat the areas where the yeast can hide, such as the colon or vagina. Since yeast infections can be complicated, no one treatment is always the best.

Q. I have lamellar ichthyosis. Growing up, I got several scalp infections which resulted in hair loss. I am currently bald, but I still hope that one day my hair will grow back. Am I hoping for something that will not happen? If not, is there anything I can use to help my hair grow?

A. Hair loss can occur for many different reasons. Lamellar ichthyosis can cause hair loss, but it is usually not so severe as to cause someone to be bald. If you have a scalp examination, your dermatologist should be able to tell you the chances are for regrowth, and what treatments, if any, would be likely to help.

Send your questions to the F.I.R.S.T. office at P.O. Box 20921, Raleigh, NC 27619-0921.

N.O.R.D. REPORT

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

Insurance Company Problems

The American Medical Association is trying to document cases of insurance companies denying or stalling authorization for medical care. This includes failure to refer patients to specialists, which has become increasingly common with the move toward managed health care programs. NORD's Chairman, Jess Thoene, MD, is also collecting information on these cases.

If you have had these kinds of difficulties, please share your information with:

Jess Thoene, M.D.
Univ. of Michigan School of Med.
300 NIB RM 1182 SE
Ann Arbor, MI 48109

OR:

Carol O'Brian
Health Law Division
American Medical Assoc.
15 North State Street
Chicago, IL 60610

The Impact of Managed Care on Orphan Diseases

(excerpted from "Orphan Disease Update," Fall 1995)

"Managed Care" is an idea that evolved out of think tanks. For the most part, managed care appears to accomplish its objectives by reducing costs and delivering adequate health care to the majority of people. However, the majority of people are basically healthy or have common

health conditions, and therein lies the caveat.

In general, the health conditions that affect the majority of people have well known and accepted standards of care. Deviations from these standards are minor choices, such as which antibiotic to prescribe or

This means that rare disease patients with managed care insurance policies are often denied access to the only specialists who are capable of diagnosing or treating their uncommon health conditions

which brand of pacemaker to insert. Rare disorders, however, are difficult to diagnose, often requiring referral to a broad range of specialists.

Managed care insurance plans pride themselves on keeping costs low, and usually a "gatekeeper" (a generalist physician who first evaluates a patient) has to pre-approve each referral to a specialist. Thus, permission to see specialists may be denied, lengthening the trauma of misdiagnosis and inappropriate treatment.

Frequently, the only physicians who are familiar with rare diseases are located at university teaching hospitals. The cost of care at these hospitals is much higher than at community hospitals because universities must cover the cost of training medical students. Consequently, man-

aged care insurers do not ordinarily sign contracts with teaching hospitals because they are too expensive. This means that rare disease patients with managed care insurance policies are often denied access to the only specialists who are capable of diagnosing or treating their uncommon health condition.

Hospitals attached to medical schools have historically specialized in rare diseases. In the past, patients who could not be adequately treated at community hospitals were ordinarily referred to academic hospitals, where professors also perform research. Young interns and residents were challenged by these unusual cases, even if they could not expect to see the disease again throughout their careers.

Today's tendency to prevent patients with rare disorders from being referred to university-affiliated

hospitals has several consequences: (1) People with orphan diseases who have managed care insurance are often denied access to specialists, or they have to fight very hard to achieve reimbursement from their insurers; (2) Young doctors are not being properly trained in the recognition of rare disorders and their treatment; and (3) University-affiliated hospitals are having severe economic problems.

Many politicians say this is a consequence of "competition" and "free market" forces. However, most patients do not have the freedom to choose the type of insurance policy they want. In most cases, workers get the insurance policy their employer chooses, and their employer may choose the lowest cost "managed
(continues on page 13)

As we celebrate our Foundation's 15th Anniversary, I cannot help but look to our future and wonder what shape it will take. As our history shows, we are

an organization of both growth and change—all, I believe, for the better. With growth, however, comes the challenge of remaining accessible to our membership.

F.I.R.S.T. has always had a family feel to it. This is palpable at our conferences, and in our phone conversations and correspondence. This family connection sustains both our members and our governing body as well. It is so much easier to put effort into something to which our hearts connect.

We are at a point, however, at which we must ask ourselves some important questions. Can we pursue our mission to its fullest potential while remaining as small as we are? Can we reach the goals submitted by our Strategic Planning Committee without compromising some of the services we have always provided?

We are, first and foremost, a support organization. We exist to help people with ichthyosis get the services and information they need, and to educate the medical profession and the public at large. This is part of our mission statement, and it is what we have been working tirelessly at for fifteen years.

But now we have come to a crossroads. The day-to-

PRESIDENT'S LETTER



well as a more competitive director's salary. But we cannot sustain this kind of growth nor meet these staff goals without bringing in substantial funds. It is this increased focus on fund raising that challenges us. In order to expand our services, we need to expand our staff. In order to do this, we must put an enormous effort into fund raising. During this time of change, we need to enlist the support of our membership more than ever.

We do not want to lose that feeling of family, and I don't believe we will. The answer lies in *extending* the family. We hope that each member will see her- or himself as an integral part of our growing family. If you have ideas for fund raising, time for fund raising, or connections with people who have the skills and time for fund raising, please send them our way. If you have the inclination, but no inkling how to go about it, call our office and we'll put you on the right track. And, most of all, please stay with us as we travel down new paths. Renew your membership. Volunteer some time on a project. We have a vision of the future, and you're all part of that vision. Happy anniversary and warmest regards,

Deborah B. Vilas

In New York City this past September, four members of the Board of Directors, the Board's past president, Frances McHugh, and the executive director, all met in the home of our current Board president, Deb Vilas, to kick off the critical job of developing a long-term strategic plan for the Foundation.

A strategic plan is a blueprint. It is important that an organization's leadership periodically stop to reassess what the organization does, and how it serves its members, and how it goes about fulfilling its mission. These are the key issues addressed in

BOARD LAUNCHES STRATEGIC PLANNING

the planning process.

The team leader on the Strategic Planning Committee is Michael Dunleavy. Michael is new to the Board, and brings with him fresh perspective and considerable planning experience. Adding historical perspective to the Committee is past president and long-time Board member Frances McHugh and executive director Nick Gattuccio.

Other members of the Planning Committee are Deborah Vilas, our

current Board President, and Michelle Petersen, Board Vice-President.

Among the central purposes in having a long-term strategic plan is laying out clearly where the Board intends the organization's priorities to be in the coming years. This is helpful for the executive director and staff as they make short-term work plans and develop programs and services for the membership.

It will be well into 1996 before a formal strategic plan is submitted to the Board for approval, or adoption. Already, though, some ambi-

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

CLINICAL TRIALS SET FOR NEW CREAM TO TREAT ICHTHYOSIS

The trial will continue for about 15 months. During three of the 15 months participants will receive

Many F.I.R.S.T. members participated in earlier portions of the clinical trials to help Collegy obtain FDA approval for this new cream (called Glylorin). Now, dermatologists are conducting the final phase of clinical trials (Phase III), and they are seeking out patients with lamellar ichthyosis (LI) and those with nonbullous congenital ichthyosiform erythroderma (CIE) who are willing to participate.

"blinded" treatment—that is, you will not know whether you are receiving the active cream or a placebo. Thereafter, all participants will receive only the active cream. No one under three years old may participate.

All doctor's visits, procedures and medications will be provided free of charge, and at the end of the trial participants will receive a stipend for participation.

Below is a list of research dermatologists who are conducting these trials. If you have LI or CIE, and if you may be interested in participating in the study, please call the dermatologist at the nearest trial site. If you have questions about the trials, you may call the director of Clinical Trials at Collegy Pharmaceuticals in Novato, California, at 415-382-6770.

Nancy Esterly, MD
Medical College of Wisconsin
Milwaukee, WI
414-257-6899

Sewon Kang, MD
Univ. of Michigan Med. Center
Ann Arbor, MI
313-936-4070

Amy Paller, MD
Children's Memorial Hospital
Chicago, IL
(Speak to Marge at 312-880-4698)

Mark Ling, MD, Ph.D.
Emory University
Atlanta, GA
(Speak to Joyce Weinheimer at 404-778-3728)

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

Moise Levy, MD
James Nigro, MD
Texas Children's Hospital
Houston, TX
713-770-3718

Gary Peck, MD
Washington Hospital
Washington, D.C.
(Speak with Hildegard Jorgenson at 202-877-7734)

Matthew Stiller, MD
Massachusetts General Hosp.
Boston, MA
617-726-5066

Philip Fleckman, MD
University of Washington
Seattle, WA
206-543-5290

Anne W. Lucky, MD
Dermatology Research Assoc.
Cincinnati, OH
513-232-3376

Neil Prose, MD
Duke University Med. Center
Durham, NC
919-684-5146

Virginia Sybert, MD
Children's Hospital & Med. Ctr.
Seattle, WA
206-526-2158

Ruby Ghadially, MD
UC San Francisco
415-750-2091

Leonard Milstone, MD
Yale University
New Haven, CT
(Call Cynthia Selfridge at Collegy for information: 415-382-6770)

Miriam Keltz Pomeranz, MD
New York University Med. Ctr.
New York, NY
212-263-5244

Patricia Treadwell, MD
Wisher Memorial Hosp.
Indianapolis, IN
317-630-7396

Jon Hanifin, MD
Oregon Health Sciences Univ.
Portland, OR
503-494-5603

Hermon Solomon, MD
Dermatology Clinic PA
Wichita, KS
316-685-4395

Sophie Worobec, MD
Univ. of Rochester
Rochester, NY
716-274-4557

tious goals are emerging from the planning process.

The Planning Committee has placed fund raising at the top of the priorities chart. Although formal goals have not yet been adopted, there will be a push for a significant fund raising effort over the coming five years — to take us into the next century — with a goal of developing a \$2 million endowment during the five-year period.

Along with this, the Committee is hoping to recommend a significant membership drive, with a goal of



Strategic Planning Committee Meets in New York last September: (left to right) Nick Gattuccio, Michael Dunleavy, Michelle Petersen, Deborah Vilas, and Frances McHugh.

5,000 new members in this same five-year period.

The Planning Committee has

taken for its next challenge developing strategies for achieving these ambitious goals. This next step in the planning process will begin this February, when the Planning Committee meets once again in Washington, D.C., in conjunction with the annual meeting of the American Academy of Dermatology.

It is hoped that a long-term strategic plan can be completed and approved by the Board by this Spring, and reported on to the membership shortly after.

21

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

I have been a member for years, and I enjoy getting your newsletter, but I haven't heard much about some things that really help people who have ichthyosis. I've had it for 78 years, and it isn't any easier to accept now than when I was a kid. I just hate it and I know other people feel the same. I would like to hear of a breakthrough, *something* that really helps in our struggle against living with rough, red skin. Talk don't do it. I'd like action!

I've *never* been able to find a doctor who could tell me what kind of ichthyosis I have. They guess. Some doctors have never seen it or know the first thing about it. They ask me how I take care of it. Can you believe that? Even some of the hospitals have no knowledge of it, or how to take care of it. One doctor told me a mother was using Crisco on it. Poor thing!

It would be good to inform hospitals (all of them) with flyers or letters explaining what the condition is.

I'm looking forward to the newsletter about your meeting in San Diego. Our car broke down and we had to miss it, darn! So get the good news out, we're waiting.

Geraldine Wood

Manhattan Beach, California

Dear *Ichthyosis Focus* readers,

I am writing to share my experience with the Registry [the National Registry for Ichthyosis & Related Disorders]. At the F.I.R.S.T. national conference this summer, I was lucky enough to speak with Dr. Phil Fleckman. After looking at my skin, he questioned whether I really had ichthyosis vulgaris, which I had through all my life, and recommended that I have a blood test to confirm the diagnosis. I had the test done through my local dermatologist (paid for by the Registry), and found that I actually have recessive X-linked ichthyosis! I believe I received my original diagnosis from my family doctor when I was a kid in the 1950s. I would also like to mention that I was treated very respectfully by Geoff Hamill, the Registry Coordinator. Enrolling in the Registry took very little time.

I also want to mention that I have been using Aqua Glycolic Lotion from Herald Pharmacal for the past three years and it has completely cleared up my skin.

Rich Graham

Colchester, Vermont

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

I just received my first newsletter from F.I.R.S.T. Our daughter was born seven years ago, I have often wished there were an organization like this to give me information.

Correspondence (continues from page 8)

My daughter was born a collodion baby. Originally she was diagnosed with lamellar

ichthyosis; a few years later, though, her diagnosis was changed to ichthyosis vulgaris. During the years I have tried so many different creams and lotions. I currently use Aveeno lotion on her body and Norwegian Hand Cream on her face. I have had so many problems with her ears. She scratches them until the canals get infected. I also have to have her ears syringed frequently to prevent accumulations of build-up in her ears. Our new dermatologist recommended using P&S Liquid Pheno scalp treatment system, which I put on before bedtime and in the morning I shampoo her hair with P&S shampoo. Then I proceed to use a very fine comb to pick up the loosened scales and flaky skin of her scalp. It works remarkably well. I do this three times a week.

My daughter does remarkably well. Nobody really questions her at school or at play about her skin. Her friends don't seem to notice anything different about her skin. They know it is there, but it is just part of her. She does not see her skin as a handicap; she simply knows she has to take special care of her skin. As long as she does that, her skin looks fairly good.

If anybody has suggestions or comments, please write me. I would love to hear from other parents who have children with ichthyosis.

Irene Dyck

9740 71st Ave

Grand Prairie, Alberta, Canada T8V 6P9

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

My name is Henry Kittrell and I am 77 years old and have X-linked ichthyosis. This past year I have been using Alpha Hydroxy and Heel Care Lotion from Dermal Therapy Research. I apply a small amount of Heel Care on the lower parts of my legs, and a thin layer of the Alpha Hydroxy on the rest of my body. I do this after blotting dry after my shower each morning. Every night I apply a small amount of Vaseline Intensive Care.

This past winter is the first one I can recall that I could wear short sleeves all year. The rest of my body was also smooth and soft.

I want to thank Dermal Therapy Research for sending me the sample and also for the special price they offer to F.I.R.S.T. members. For more information or to order, call 800-668-8000

Henry Kittrell

London, Ontario, Canada

Apologies to Jasmyn Bowie & Laura Ashton



In the last issue of *Ichthyosis Focus*, in our coverage of the San Diego National Conference, we included the photo that you see here. Unfortunately, a mix-up led to us messing up the caption. Our friend Laura Ashton was identified as "Xssss Xxxx."

We felt terrible about this, and we want to make certain that all of you meet Jasmyn and Laura and learn their names correctly. We're very sorry for our mistake, and look forward to seeing them and everyone else back at our next national meeting in 1997.

N.O.R.D. REPORT

(continues from page 9)

care" insurance policy.

Undoubtedly, there are some good managed care insurance companies who recognize the unique needs of patients with uncommon diseases, and they do refer people to the university hospitals where expert physicians are familiar with orphan diseases. But without minimum federal standards that all insurers must adhere to, there is no guarantee that patients will have access to experts on a dependable and continuous basis.

The American health insurance system is drastically changing the complexion of medical care, and patients with disorders that are outside the norm are suffering. University medical centers are becoming an accidental casualty of the deteriorating system. Worst of all, biomedical research suffers as a result.

When patients and families realize that they have lost their freedom to see the specialists of their choosing, those who have the option to change insurance carriers will be fortunate. Gradually, however, the sickest people may choose traditional fee-for-service insurance while healthy people opt for HMOs. When this happens, people in good health will no longer be subsidizing the costs for the ill. Some economists feel that this shifting of consumers is the proper role of the free market. However, many do not understand that they, too, are vulnerable to serious and expensive illnesses.

The aim of these changes in our health care system is to tame the inflationary cycle of medical costs. We all agree that this is economically necessary; however, the burden of these changes seems to be falling disproportionately on people with orphan diseases who are being locked out of the health care system.

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

1-800-595-1265

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

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

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

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

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

A Blow To Pre-Existing Condition Exclusions

In the state of Washington, there is now a three-month enrollment window during which insurance companies must take all who apply for health insurance coverage. Insurers may impose a three-month waiting period for pre-existing conditions for which medical treatment has been given, but they can't deny insurance or exclude or limit coverage because of the pre-existing condition. According to Washington State Insurance Commissioner Deborah Senn, "This rule will eliminate use of exclusions based on pre-existing conditions, including genetic conditions."

BookTalk:

Examining Your Doctor, by Timothy McCall. A book that, according to the Boston Globe, is "about being a smart, aggressive, competent patient." From the Carol Press — talk to your librarian or your local bookstore.

NEWS & NOTES

F.I.R.S.T. Cookbook: Chapter 2

Debra Butler of Rochester, New York, is in the process of reviving the F.I.R.S.T. Family Cookbook. Many of you may have met Debra and her daughter Becky at the San Diego conference this summer. Debra asks all F.I.R.S.T. members (and their friends and families) to send her their favorite recipes. Please send them to Debra at 647 Latta Road, Rochester, NY 14612.

FOCUS Note

We apologize for the long delay between the last issue of *Ichthyosis Focus* and this one (the last issue was Vol. 14, no. 3, Summer 1995 — our special national conference edition). Nick was on an extended sick leave for much of the fall. We are sorry for any inconvenience.

In Memoriam

Laurene Carper

by Henry J. Bukaty

Louise Rexford Wilson

by Josephine B. Mechling

Richard Kozinski

by E.P. & Chris Beeler

St. Michael's Church, Canton, OH

Brian & Barb McNicholas

James & Irene Hammontree

Thomas & Faye Hudec

Kenneth & Alice Dobson

Brian & Jacquelyn Huntley

John & Judith Marzilli

Ruthanne Brumbaugh

Robert & Marilyn Grabowsky

Eileen Hill

Dolores Petros

Tina Sanson

Margaret Kovach

Celia, Charles & Butch Giganti

Jan Tierney

Jack & June Underwood

Carol Spring

Mildred Huntley Johnson

John & Rosanne Campanella

Potter-Claiborn-Gleelhood, Inc.

Employees of Benfield Mfg. Co.

Cynn timer Bates Steps Down As Region 4 Coordinator

Following four years of committed service to F.I.R.S.T.'s Regional Support Network, Cynn timer Bates is stepping down as Region 4 Coordinator. An original founder of the RSN in the early 1990s, Cynn timer has spent uncountable hours talking to folks, writing letters, and planning regional conferences for our friends in the Midwest. Cynn timer has offered literally volumes of information to so many of us in the ichthyosis family.

Luckily, Cynn timer will remain available on a smaller scale as state contact for Kentucky.

RSN NOTES

Cynn timer would be the first to say she couldn't have done her work in Region 4 without the help of Regional Reps Mark & Jill Wood of Indianapolis. The Woods, too, are passing the torch after many years of dedication and hard work. Sincere thanks to Mark & Jill for their hard work and commitment.

Region 4 Coordinator Position Available

We encourage all of you in Re-

gion 4 (KY, OH, IN, IL, MO, and MI) to consider serving as Regional Coordinator, or as backup in the role of Regional Representative.

If you are comfortable networking with peers in the ichthyosis community and like providing support and information, please contact the Raleigh office to request an application. Regional Coordinators are supported by the national organization with regular conference call meetings and steady interaction with the Program Coordinator and other Regional Coordinators.

REGIONAL SUPPORT NETWORK (RSN)

RSN NATIONAL OFFICE PROGRAM DIRECTOR

Heather Gattuccio
4279 The Oaks Drive
Raleigh, NC 27606
919-859-2712

REGION ONE

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

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

REGION TWO

DE, MD, WV, VA, NC, SC

Robin Joyce
Route 1, Box 189-F
Sandy Ridge, NC 27046
(910) 871-3277

REGION THREE

TN, GA, FL, AL, MS, LA, AR

Debra Bowie
3694 Shady Hollow Lane
Memphis, TN 38116
901-346-0513

REGION FOUR

KY, OH, IN, IL, MO, MI

Heather Gattuccio
4279 The Oaks Drive
Raleigh, NC 27606
919-859-2712

REGION FIVE

WI, MN, IA, ND, SD, NE

Carolyn Gramlich
535 West Sandhurst, #111
Roseville, MN 55113
612-483-7700

REGION SIX

TX, OK, NM, CO, KS

Donna Rice
2902 West Elm Circle
Katy, TX 77493
(713) 391-4407

REGION SEVEN

WA, OR, ID, MT, WY, AK

Sheri Gelivich
1344 S.E. Rex
Portland, OR 97202
(503) 236-3203

REGION EIGHT

CA, NV, UT, AZ, HI

Chris Beeler
1002 E. Gifford Drive
Tucson, AZ 85719
(602) 887-7188

Canadian Contact

Barbara Rockwell
3080 Ballydown Crescent
Mississauga, Ont L5C 2C8
(905) 896-9620

STATE CONTACTS

Kansas

Tiffany Karst
913-268-3692

Kentucky

Cynn timer Bates
606-276-0142

Massachusetts

Susan Overstreet
413-259-1267

Mississippi

J. Charlene Wiggins
601-769-2454

New York

Cathy Lopez
718-842-7269

South Carolina

Nancy Bryant
803-881-2036

Wisconsin

Theresa Tremmel
414-538-4922

My husband Paul and I met in high school and have been

married for 19 years. I was born and raised in Southern New Jersey, but Paul was born on Long Island, New York, and moved to New Jersey when he was 10 years old. We live in Cinnaminson with our two sons, Kevin, 12 years old, and Ryan, who is 10. Prior to Kevin's birth I had been employed by New Jersey Bell as a sales representative, but I am now a "stay-at-home" mom. I volunteer a good deal of my time at our boys' school.

We had never heard of ichthyosis, but when our second son, Ryan, was born, we were quickly introduced. Ryan has epidermolytic hyperkeratosis (EHK). As most parents can attest, the birth and first year can be difficult, confusing and frustrating. Our families were very supportive. My parents went to medical libraries trying to get information about ichthyosis, but there was very little written and even the doctors couldn't tell us much about it.

We heard there was a support group in California, and

AN RSN PROFILE: SHELLY LICURSI REGION ONE COORDINATOR



Shelly Licursi with sons Ryan, Kevin (behind), and husband Paul

my mother was able to get in touch with Charles Eichhorn, one of the founders of

F.I.R.S.T. Through the group (then the National Ichthyosis Foundation), we were able to contact people who had EHK, or who had a child with EHK.

We learned a lot. My mother, Frances McHugh, became very active in the organization, going to Washington, serving on the Board, and ultimately becoming president. We have always been very thankful for the people who took the time to write and share their knowledge and experiences

with us.

F.I.R.S.T. and the RSN are a wonderful source of support for anyone facing ichthyosis. I think it is so empowering to find people who have been through what you are going through and who can tell you it will be okay, that things will work out, and who can give you practical information about creams and skin care. Ryan is a happy, active ten-year-old, and he and his brother Kevin are the joy of our lives.



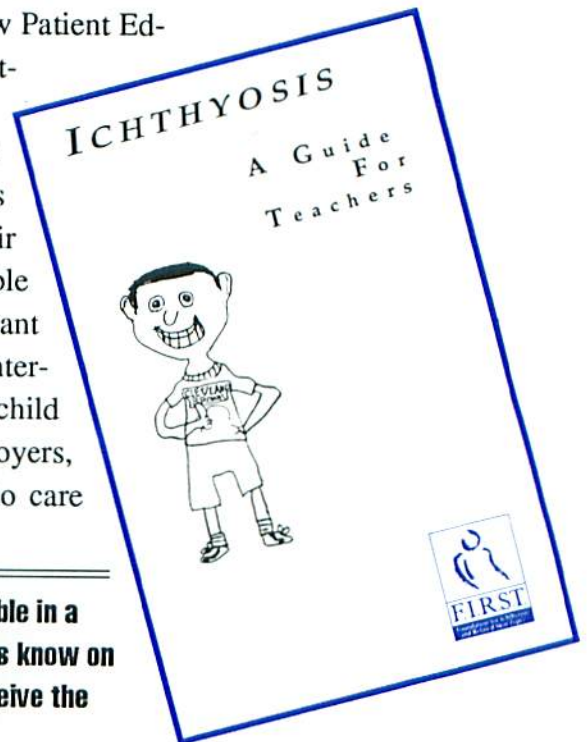
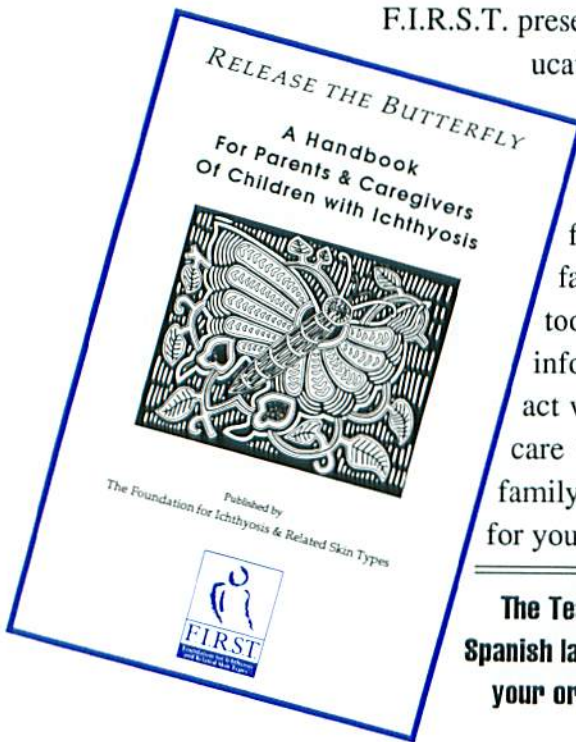
FOCUS is printed on recycled paper.

TWO TITLES IN F.I.R.S.T.'s PATIENT EDUCATION LIBRARY

F.I.R.S.T. presents two books in our new Patient Education Library. The out-

come of nearly three years of effort, both are intended as useful tools for members and their families. Each is valuable tool for conveying important information to others who interact with you or your child—child care workers, teachers, employers, family members, or others who care for your child.

The Teacher's Guide is Now Available in a Spanish language edition. Please let us know on your order form if you wish to receive the Spanish language version.



ORDER FORM

Name _____
Address _____
City/State/Zip _____
Phone _____

Release The Butterfly @
\$5.00 ea. _____

A Teacher's Guide @
\$5.00 ea. _____

\$1.50 postage each: _____

Make Checks Payable to
F.I.R.S.T.
MAIL TO:

F.I.R.S.T./Parent Handbook
P.O. Box 20921
Raleigh, NC 27619

TOTAL: _____