



ICHTHYOSIS FOCUS

Vol. 13, No. 2

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

Spring 1994

F.I.R.S.T. BEGINS PLANNING FOR 1995 NATIONAL CONFERENCE

Planning is just now getting underway for preparing our 1995 National Conference. Within the next few weeks the Board of Directors will have selected a city for the conference, and soon after that the conference site and exact dates will be firmed up.

Plan, though, for a National Conference in June, 1995.

1993 ANNUAL REPORT

The State of the Foundation

The good news is, you, our members and supporters, made 1993 a record year—for the second year in a row. Not counting income from the national conference in Chicago (which was used to produce the conference), Foundation revenues increased by about 4% over 1992. At the same time, expenditures for 1993 (again, not counting national conference expenses) were down from 1992 levels by one percent. This holding of the line on spending is a significant accomplishment, since 1993 was the first year in the Foundation's history in which the budget supported the salary of a full-time executive director.

The bad news is, the Foundation fin-

ished the year in the red, showing a loss of \$1,153,311, or about 1½% of the year's revenues. Although the loss is quite small, it still represents a failure to achieve one of the year's primary goals: to finish the year in the black.

Although the Foundation's Fund Balance (the measure of F.I.R.S.T.'s net worth) declined slightly in 1993, at the end of the year we remain fiscally sound, posting a year-end fund balance of \$86,758—slightly more than one year's operating expenses. This is a very strong financial position by any measure.

You, our members and individual supporters, remain the most important
(Continues on Page 7)

NEWMAN'S OWN CORPORATION OFFERS \$180,000 PRIZE FOR CHARITY IN RECIPE CONTEST

The Nine Best Appetizer, Main-Dish & Dessert Recipes Using Newman's Own Products Will Win Their Creators \$180,000 for Their Favorite Charities

In its fourth annual recipe contest, the Newman's Own company is looking forward to giving some lucky (and talented) chef \$180,000 to donate to their favorite charity. Entrants may provide a recipe for either a main dish, an appetizer, or dessert that is made from one of the Newman's Own products.

Nine finalists will be selected, one from each of the company's eight product categories (plus one from a school class):

1. Salsa; 2. Diavolo Sauce; 3. One of the four pasta sauces; 4. Ranch Salad Dressing; 5. Light Italian Salad Dressing; 6. Olive Oil & Vinegar or Caesar Salad Dressing; 7. Lemonade; 8. Popcorn.

The nine finalists will be flown to New York with a companion, given \$1000 for expenses, then meet Paul Newman for a tasting of the recipes to be held at New York's famous Rainbow Room.

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The editor invites correspondence. Please offer us your comments, criticisms, observations and suggestions. Tell us what you wish to see and whom you wish to hear from in *Ichthyosis Focus*.

Please send your letters to us *c/o Ichthyosis Focus* at our office in Raleigh.

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

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

Please find enclosed a check for \$40.00. I would like to thank you for your dedications and hard work to make the public more aware of ichthyosis. Hopefully, this will also spread across Canada.

I really enjoy and look forward to receiving your newsletters. I feel I am more informed than some of the local dermatologists. I like to read the whole newsletter, but I am most interested in new treatments or creams that may be available.

Although I have ichthyosis vulgaris, I have never found a cream or ointment that really helps my hands, especially. They are very dry, wrinkled, and they crack open all the time. The rest of my skin I can control somewhat. I am from a family of five; my two brothers also have ichthyosis, and so does my son.

Recently I tried a 10% glycolic acid moisturizer on my hands and it felt smooth going on; after a few days use, though, my hands were red and sore and my skin was peeling off.

We've been to dermatologists over the years, but mostly I have gotten more information from your newsletters. The only thing I've been told is "you've got to live with it, and there's no miracle cure."

Thank you again for your informative newsletter.

Mary Ann Brentnell
Lindsay, Ontario, Canada

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

Hello! Just had to write and thank you for all the literature you sent on ichthyosis. I learned more from reading one day's post than I've learned in three years from the hospital. Thank you! Thanks also for your letter. Just to know that someone *understands* has honestly made so much difference. Sometimes I've felt

so alone, but your letter and the newsletters have helped me realize there are other children in the world like Peter.

Peter doesn't sweat, so he gets very hot. In the summer he usually stays indoors near the fan, but English summers are nowhere near as hot as yours and we usually get quite a lot of rain.

I have taken Peter to a herbalist who has helped with a lot of problems other than his skin. Peter has *never* wanted to eat and meal times have always been a battle. He could not chew, so all his food had to be blended; the smallest lump in his food would cause him to choke. A speech therapist said his mouth was "under sensitive," but did not know how to rectify the problem. The herbalist seems to have brought some feeling back into his mouth, and although he still doesn't chew he can now manage porridge and mashed potatoes and mince without it being blended. After three years of blending absolutely *everything*, you can imagine what a difference this has made. Also, Peter's nails were very, very brittle, yet the herbs have strengthened them. He's only been going to the herbalist for four months, so we still try various "concoctions" to try improving his skin. There have been no breakthroughs as yet, but I will keep you informed.

I would very much like to hear from other moms, so please put my name and address in your newsletter. Thanks again for your letter. Seeing little Caitie and reading the newsletters has given me so much encouragement and most of all hope for his future.

Carolyn Hames
7, Ridley Close
Blaby
Leicester LE8 4AW
England

(Letters Continue on Page 10)

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.

Deadline for submissions to the next issue of FOCUS: July 1, 1994

NOTES FROM THE E.D.'S DESK

by Nick Gattuccio

The steam is evidently fast abandoning the Clinton administration's efforts at health care reform. In some people's view, the status quo appears more bearable than the many uncertainties about untested reforms. Furthermore, a great many Americans are perfectly well satisfied with their present health insurance coverage. These are generally people whose employers provide satisfactory coverage at very low (or no) cost to them.

Added to these factors is a successful lobbying campaign by those with a vested interest in *not* seeing significant changes in the system. Talk of pharmaceutical price controls, health care spending caps, employer mandates, physician gatekeepers, and many other of the key provisions of several plans currently in the pipeline on Capitol Hill strike at the heart of time-honored commercial self-interests. This has helped make the health care reform debate an intensely partisan issue. That is, Democrats and Republicans are busying themselves striking out at one another's solutions. In fact, there is fair speculation that Republican hyperactivity about the "Whitewater" affair is largely a partisan political effort to undermine administration credibility in the midst of the health care reform debate.

It has been said that all politics are local. However, it might be truer to say that all politics are partisan. By this I mean that political views, in the final analysis, are anchored in vested self interests. This applies to us, too—that is, we little people; the man and woman in the street; the voters.

Those of us in that tiny minority, whose health care needs are often great, and for whom health care is a luxury (often less affordable

than a Mercedes Benz), have very important self interests at stake in the health care reform debate. Unfortunately, our experience is shared by few; and because it is shared by few, it is unlikely that partisans of powerful political blocks will expend much of their energy and political capital to support it.

So the steam is going out of the concept of health care reform as proposed by the Administration. Many feel that this is a good thing, and perhaps it is. Perhaps the compromises and changes brought to bear by many of those with vested commercial interests will save us, the little people, from a gigantic fiasco. But then again, maybe it won't.

As the debate becomes increasingly complicated, as new reform plans go before Congress and further self interests cast nets on the debate, we fear that the central issue will be lost. And the central issue is very simple: Affordable quality health care for all Americans, regardless of economic well being and the existence of pre-existing conditions.

As the American manufacturing sector continues to decline, and as employment in this country continues to shift to a lower-paying service-based economy, Americans will increasingly lose employer-based health coverage. Because the health care crisis presently affects only a minority of Americans is no reason to settle for the status quo, because the status quo is ignorant of a future in which increasing numbers of Americans will fall between increasingly widening "cracks in the system."

So the steam is going out of the health care reform debate, and we face the prospect of cosmetic reforms to placate the electorate. Consider it, or consider it done.

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Nicholas Gattuccio
Executive Director

Alliance of Genetic Support Groups Seeks Participants for a Survey About the Human Genome Project

The Alliance of Genetic Support Groups and the Child Development Center at Georgetown University have received an NIH grant to develop a Human Genome Education Model for consumers of genetic services and health professionals. To develop the model, they are seeking members of support groups for genetic disorders who would be willing to spend 25-30 minutes on the telephone responding to questions on ethical, legal and social issues related to the Human Genome Project.

Those interested in participating in this survey should contact Joan Weiss or Mary Ann Wilson at the Alliance office by **June 1, 1994**. They may be reached at 1-800-336-4363, or 301-652-5553.

Survey participants must be at least 18 years old and have someone in the family with a genetic disorder that was diagnosed more than one year ago, or have a known risk for a genetic disorder in the family.

NEWMAN'S OWN RECIPE CONTEST

(continues from page 1)

At this luncheon, Rainbow Room chefs will prepare each of the nine finalists' dishes, and the Grand Prize winner will be chosen by Mr. Newman.

The finalists and retailers named by the nine winners (see official rules in the May, 1994 issue of *Good Housekeeping*) will win a total of \$180,000 to donate to their favorite charities.

This contest is sponsored by Newman's Own, Inc. and *Good Housekeeping* Magazine. Anyone wishing to enter the contest should *obtain a copy of the May, 1994 issue of Good Housekeeping to review the full list of contest rules and get a contest entry form*. If you are unable to obtain a copy of this issue of *Good Housekeeping*, call the F.I.R.S.T. office and we can send you a photocopy of the contest rules and entry form.

Deadline for entries is August 1, 1994.

We encourage everyone to take a shot at this contest. In addition to being a fun way to dress up your own dinner table while experimenting with creations, there is always the chance that you could win, or at least be a finalist. *Someone's* going to win, after all. Heather and I are already working on it!

This is also a great opportunity to make an enormous impact on F.I.R.S.T. We wish everyone good luck!

My husband of twenty years, Victor and I and our four children live in Katy, Texas, a small rice farming community 30 miles west of Houston. Although

we're not farmers, we take advantage of the small town atmosphere and still have access to the city, just minutes away.

I "retired" as a speech-language pathologist in 1988, when our only child, Sarah, was nine. I often tell the story (even though it's not really true) that I quit work to have babies, because we promptly had three babies in four years. Now, I'm a 40-year-old "stay-at-home" Mom of two girls and two boys who range in age from one to 15 years.

Our third child, Haley Victoria, was born with lamellar ichthyosis in February of 1992 after a short, but complicated pregnancy. While we had anticipated problems due to the pre-

PERSONAL PROFILE

Donna Rice
RSN Region Six Coordinator



Donna Rice's children (clockwise from upper left): Sarah, Adam, Haley & Andrew.

mature delivery, we, like many other families, did not anticipate ichthyosis, nor had we even heard of the disease. Fortunately, we found F.I.R.S.T. when Haley was only four days old.

We count ourselves among the lucky, as we have support from our families, friends, physicians, and the community, but it's difficult to imagine going through these two years of Haley's life without the kind of support we've received from F.I.R.S.T. and the RSN. Our initial contact with the RSN was their congratulations on Haley's birth, and since that time it has included everything from discussions of creams and skin care to hearing my long winded tirades on the insensitivity of strangers. Our F.I.R.S.T. family helped us realize that we could raise Haley, and it has never abandoned us in our efforts to provide her with the highest quality of life possible.

F.I.R.S.T. SET TO PUBLISH LONG-AWAITED "PARENT'S HANDBOOK"

Over Three Years In the Making, A 60-Page Handbook On Everything
From Diapers to Grandparents and Bottles to Baths

Over three years in the making, our long-awaited "Parent's Handbook" for ichthyosis is set for publication later this Spring. The 60+ page book should be available to members by this Summer.

The book was written by three mothers of children with ichthyosis, all of whom are present or former members of the Foundation's Board of Directors. They are Betsy Bates-Freed of Los An-

geles, Cynn timer Bates of Lexington, Kentucky, and Heather Gattuccio of Raleigh. Over the past year their manuscript has undergone thorough review by members of F.I.R.S.T.'s Board of Medical Editors, and has been edited, designed and typeset by Foundation staff. The outcome is a first-class publication for parents of children with ichthyosis—an excellent reference manual.

The book covers a broad array of important topics. Just a short sampling of section headings gives a good picture of the book's scope and depth: Dealing With Doctors; Breast Feeding; The Finances of Major Medical Events; General Advice About the Skin; Baths; Creams, Lotions & Ointments; Overheating; Nutrition & Ichthyosis; Siblings & Their Special Needs; The Retinoids; Special Tips; and a great deal more.

We will keep you advised when the book is finally available. There will probably be a small charge for copies.

Following is an excerpt from the Parent's Handbook due out soon.

EXCERPT FROM THE PARENT HANDBOOK

From Chapter III: "Nutrition & Ichthyosis" (edited version for *Focus*)

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Because the skin is the largest organ of the body and because it has a very large surface area in contact with the environment, what happens to the skin has a significant impact on the whole body. The skin requires large amounts of iron, minerals and particularly protein to continue functioning. Increased loss of skin from the surface puts an enormous strain on one's entire system.

Children with hyperproliferative types of ichthyosis, such as widespread EHK and CIE, where there is rapid skin turnover, are most at risk for growth retardation. This is partially due to the rapid loss of nutrients from the surface of the skin. Some physicians suspect that the restrictive effect of the tight skin on the bone growth both before and after birth may also contribute. The nutritional demands are very high for these skin types and are even higher in children who are growing rapidly to begin with. In cases where epidermal cell turnover is very high, nutrients are used up rapidly and may even draw from other tissues of the body in order to maintain their hyperactivity.

Iron: Skin cells use a lot of iron and a child's rapid growth also demands large amounts of iron for blood production and tissue growth. Even normal epidermal and blood cells are among the fastest multiplying in the body, and when even more demand is put on the iron metabolism due to increased epidermal turnover, stress may result. Iron also plays a role in resistance to infection. Thus, iron deficiency anemia in children with ichthyosis may occur. Among other difficulties, iron deficiency may affect learning. Your pediatrician should check your child for iron deficiency if a problem is suspected. He or she may not be aware of the increased die-

tary requirements of children with ichthyosis.

Protein: Protein is needed in significant quantities for skin production. The body cannot make some of the building blocks of proteins (called amino acids), so these must come from food. Stores of essential amino acids, especially cystine and methionine, as well as iron, are vital to growth, the production of skin, and good quality hair. Excessive skin growth common to ichthyosis may draw down stores of amino acid building blocks to a point where normal growth cannot continue, and skin and hair quality may deteriorate. This in turn makes the skin more susceptible to infection by compromising the skin's barrier function.

Children with excessive skin production need foods that are adequate or even "super-adequate" in their protein and iron content just to maintain "normal" growth. Some children with ichthyosis may be smaller than other siblings in the family, which may relate, at least in part, to their nutrition. Thus, a good diet and supplementary vitamins and minerals are important.

Infants with severe forms of ichthyosis may be born prematurely and are small for gestational age, and when nursing they may suck poorly due to restriction of the inflexible skin around the mouth. The breast, of course, is flexible to the mouth of the infant and is therefore preferred. Failing this, a premie nipple (one that is more flexible and doesn't require a strong suck to deliver) may be used with the holes slightly enlarged to better deliver milk. Again, breast milk is high in minerals, vitamins and protein. It is important for mothers to maintain good nutrition so infants will get the highest quality milk. Of course, if formula is used it should be one enriched with iron.

REPORT OF THE CHIEF FINANCIAL OFFICER

by Georg'Ellen F. Betts

The financial statements appearing in this annual report were prepared by and are the responsibility of the Foundation's management and Board, which has designed a system of internal controls to safeguard assets, guarantee the integrity of its fiduciary responsibility, and carry out its programs and services.

These statements are in conformity with generally accepted accounting principals

and are reviewed quarterly by independent accountants. Copies are filed with the North Carolina Department of Human Resources. Additional copies may be obtained by contacting the Foundation offices.

The Foundation's policy of requesting donations, in the form of memberships, only once a year provides the dollars for the newsletter and minimal operations of the office. All other programs are carried out by volunteers at home and are supported by available funds on a month-to-month basis. This practice makes it nearly impossible to meet other goals of support for research, advocacy services, or publication of educational material.

The future of the Foundation depends upon the loyalty, generosity and commitment of its members. Additionally, nationwide fund raising from the general public should be actively considered by the Board of Directors.

STATEMENT OF SUPPORT & REVENUE, EXPENSES & CHANGES IN FUND BALANCE For Year Ended December 31, 1993

Support & Revenue:	
Individual Donations	38,408.49
Corporate Support	22,697.12
Investment Income	4,730.51
Conference Income	7,734.00
Other	3,445.58
Total Support & Revenue	77,015.70
Expenses:	
Salary & Wages	26,994.92
Taxes (payroll)	2,109.33
Professional Services	2,771.50
Staff Training	485.00
Bank Charges	213.70
Office Rent	4,765.72
Office Supplies & Material	1,379.25
Equipment (buy/lease)	418.77
Accumulated Depreciation	1,733.93
Postage	4,713.66
Shipping	140.48
Phone	6,954.58
Printing	8,058.90
Dues & Meeting Fees	445.00
Subscriptions	192.00
License Fees	55.00
Administrative Expenses	4,943.97
Board Expenses	1,219.51
RSN Expenses	823.99
National Conference Exp.	9,749.80
Total Expenses	78,169.01
Excess Revenue Over Expenses (Deficit)	(1,153.31)
Fund Balance - Beginning of Year	87,911.00
Fund Balance - End of Year	<u>86,758.08</u>
Net Gain (Loss) in Fund Balance, 1992-93	(1,152.92)

BALANCE SHEET

For Year Ended December 31, 1993

ASSETS

Current Assets:	
Cash	7,902.16
Investments	74,014.08
Receivables	69.12
Prepaid Expenses	500.00
Total Current Assets	82,485.36
Fixed Assets:	
Computer Equipment	3,761.93
Furniture & Fixtures	10,379.24
Accumulated Depreciation	(6,538.21)
Total Fixed Assets	7,602.96
TOTAL ASSETS	90,088.32

LIABILITIES & EQUITY

Current Liabilities:	
Accounts Payable	2,695.76
Employee FICA Taxes	207.48
Medicare	48.50
Employee State Taxes	378.50
Total Current Liabilities	3,330.24
Fund Balance:	
Fund Balance - Unrestricted	85,325.00
Fund Balance - Prop/Equip.	2,586.39
Excess Revenue (Exp.)	(1,153.31)
Total Fund Balance	86,758.08
TOTAL LIABILITIES & FUND BALANCE	90,088.32

F.I.R.S.T. OUTLINES GOALS FOR 1994

In a "Work Plan & Goals Report" submitted to the Board of Directors in January of this year, Executive Director Nick Gattuccio outlined a list of strategic goals for the Foundation in 1994. If 1993 was a landmark year for the Foundation, then the goal for 1994 is to consolidate the gains and solidify our organization's financial footing.

Two goals will secure financial stability: conservative spending and ambitious fund raising. Our operating budget for 1994 is actually *smaller* than our budget for 1993, and attempts are underway to bring us in under budget. At the same time, the Foundation has initiated new fund raising strategies. We're working to develop our grassroots fund raising program. Last year we saw big gains on this front, and this year we're promoting grassroots efforts more strongly than ever. We're ambitiously soliciting private foundations for program grants, and we're developing joint distribution programs with our colleagues in the pharmaceutical industry. (Most of you received product samples on two occasions in 1993.) We're also attempting to build a planned giving program, encouraging bequests, life-insurance giving, and other creative forms of deferred (and tax advantageous) gifts.

Our Patient Education Library program will become a reality in 1994 with the issue of the first two new titles (see article on page 5). The Board of Directors laid the groundwork for the

Library in the fall of 1993 by creating a restricted fund to hold monies for the production and publication of patient education materials. At its February, 1994 meeting the Board allocated \$7,500 of the Foundation's reserves to seed this Patient Education and Publications Fund. Grants are being sought to augment the Fund.

By year's end the Foundation's new computing center will be fully in place. This will include telecommunications capabilities and on-line patient information and referral services for members and physicians. We will have full publication production capabilities (this is now 75% in place), a new database management system, and integrated bookkeeping and financial management.

Planning the 1995 national conference will occupy a large share of the work plan for 1994. Site and dates will be announced within the coming months.

This is just a quick look at the eight-page (single spaced) work plan for 1994. The thrust is soundness and stability—building on existing strengths and cementing past gains. New programs largely augment existing ones, and all are tuned to the same goal: fulfilling the mission and supporting the membership of the Foundation.

We look forward to a fruitful and productive 1994, and we look forward to your continuing participation and support.

THE STATE OF THE FOUNDATION

(Continues from Page 1)

part of our continuing success. Members contributed \$38,408 in 1993, over half of the year's revenues (55%). By contrast, corporate support totaled just 29% of the year's revenues.

The year's accomplishments cannot be measured in dollars alone. Our national conference last June in Chicago was the largest and most successful ever. Our Regional Support Network has grown to embrace nearly 300 members, and the RSN produced two Regional Conferences during the year.

We completed and are set to publish in 1994 two significant new publications (see article on page 5). In 1993 we gained admittance to the Combined Federal Campaign for the first time ever, and we

initiated our first large-scale grant-writing program soliciting support from private foundations (which bore its first fruit this year).

Additionally, we've added five new members to our board of directors, significantly altering the profile of the board's professional experience and expertise. We've acquired a new computer, and are midway through a full-scale overhaul of our computing capabilities (soon to include on-line telecommunicating capabilities). We continue to upgrade our quarterly magazine, *Focus*, and we're planning new features and publications for the future.

We made great strides in 1993 solidifying our relationships with our friends

in the professional disciplines—research scientists and dermatologists, pharmaceutical representatives, and others in related fields. With the help of many members of F.I.R.S.T., great strides continue being made in elucidating the genetics of EHK. Scientists also developed the first prenatal test for EHK based on DNA sequence analysis.

1993 was a landmark year for this Foundation. We have effected the transition from an all-volunteer organization to one anchored by a professional staff. Foundation programs and services are expanding and evolving rapidly, greatly enhancing the Foundation's ability to serve you, its membership.

We look forward to 1994 being yet another breakthrough year. However, we understand that this will not come about by sitting idly on the status quo. We invite you to join us in the future.

Editor's Note: Over the past year we have received several inquiries about reports that treatment with the B-vitamin niacin has beneficial effects for patients with ichthyosis. Two sources for this information have emerged. First, *The Encyclopedia of Common Diseases*, written by the staff of *Prevention Magazine*, states that doctors in Egypt have had success treating ichthyotic patients with niacin. The report cites a 1962 article published by an Egyptian physician. Second, the 1990 (3rd) edition of the *Nutrition Almanac*, written by Lavon J. Dunne and published by McGraw-Hill, states (page 212) that "physicians in Egypt have discovered that niacin completely clears the disease [ichthyosis]...." This account cites no source, but it may be the same article cited by *Prevention Magazine*.

Because the connection between niacin and ichthyosis is not reported in the American medical literature, we asked two of our medical editor to evaluate and report on the questions raised.

A. Dr. John DiGiovanna, M.D.

Ichthyosis is an imprecise term used to describe many scaling skin conditions. Over the past decades we have been able to separate some of the subtypes of ichthyosis into useful clinical categories. Unfortunately, the clinical categories were less distinct at the time the article you cite [the 1962 article from Egypt] was written.

In many countries with large populations of poor individuals, severe vitamin deficiencies are common, as they were 30 years ago when the cited report was written. Niacin (a B vitamin) deficiency causes a disease called pellagra, which may include a scaly skin condition. This condition would clear completely with niacin replacement. Today, niacin deficiency is well understood and is rare in the U.S. Unfortunately, niacin supplementation is unlikely to benefit most patients with ichthyosis.

A. Dr. Carl Ehmann M.D.

Anecdotal information on the use of niacin for the treatment of ichthyosis has been published in *The Egyptian Pharmaceutical Bulletin* (vol. 44, no. 4; April, 1962); however, no well controlled studies using niacin for treating ichthyosis have been reported. Diet deficiency of niacin can lead to the progressive and potentially fatal disease of pellagra. While patients with pellagra may have skin lesions, they are very different than those seen in ichthyosis.

Because of the lack of any well controlled clinical studies on the use of niacin in ichthyotic patients, and because toxicity can occur when it is given in large and chronic doses, niacin cannot be recommended for the treatment of ichthyosis.

Q. I am 31 years old and have lamellar ichthyosis. I was on Accutane from the time I was 18 until I was 24 years old. I finally went off of it due to bone spurs on my spine.

I was on Tegason for about a year and had to go off of it due to my nervous system. My question is: I've always heard that there was a medicine out or coming out that has fewer side effects than the other two, especially its

effect on cholesterol levels. Is this medicine called Neotigason (Acitretin), and if so, can you tell me more about it.

A. Dr. John DiGiovanna, M.D.

Acitretin (Neotigason) is a synthetic vitamin A derivative (a retinoid). It is closely related to etretinate (Tegison). If you take etretinate, your body converts it into acitretin. In fact, acitretin may be the active form of etretinate.

This means that acitretin and etretinate will probably have similar toxicities. If you take etretinate for a long period of time it can be stored in the body. Even many months after you stop taking etretinate, it can be detected in the blood. The advantage of acitretin is that it is not readily stored in the body.

The Food and Drug Administration will determine when enough information is known about acitretin to consider it safe and effective, and therefore make it available to patients.

If you have questions you would like to see answered in the Q & A section of Focus, please send them to the Focus Editor, P.O. Box 20921, Raleigh, NC 27619. All questioners remain anonymous. Questions may be edited for publication.

Special Thanks to Departing RSN Regional Coordinators

Joe and Marlene Huffman and Claudia and Mark MacNaughton

On behalf of the Foundation, I want to offer special thanks to two of our RSN Regional Coordinators who are stepping down after nearly three years of dedicated service to the organization. Region Eight and Region Five are both losing dedicated servants of the membership. Our sincere thanks to them and their families for the enormous help they've given our members in their regions.

Both worked tirelessly for years to help the Foundation and those in their regions, working tirelessly on the phones and coordinating successful regional conferences over the years. We wish them the best of luck in the future.

The Fine Art of Fundraising

by Tomas Buehler

I don't think there is anything more frightening than asking friends, family and even people you do not know for money. It does not matter what the cause or the charity is, it always feels as if you are infringing—doing something you should not be doing.

Sometimes this is how I feel, and my background is in sales, asking people for money and to make a commitment. Even so, I still get a knot in my stomach whenever I ask someone to help support F.I.R.S.T. with a donation. Am I asking too soon after my last fund-raiser? What if they do not have any money? What if they support another charity, will I then be expected to support that?

This is my advice to people who want to do a fund-raiser but don't know if they can come right out and ask someone face-to-face for money: start with a letter campaign, and get the support of immediate friends and family to help bolster your confidence. It seems that we can do more as a group than as individuals, and when

things are not at their brightest, it helps to have a support group.

Our first attempt at a fund-raiser was kicked off by my mother-in-law. She decided to write a letter explaining her grandson's ichthyosis and asked for support for F.I.R.S.T. Later, I joined in, and between us we raised \$1,245.00, far more than we expected.

That small success gave me the confidence to start contacting corporations in the Chicago area. What a dismal failure!

I soon realized that the corporations I contacted had no self-interest in our cause, and as a result my efforts were useless. The secret, I learned, is to get to the companies and organizations that know you and have knowledge of, or an interest in, ichthyosis. These are the people who will come to your aid.

So what are we doing now to raise money and awareness? Well, we approached the Charity Committee at my place of employment, and they have agreed to sponsor an event for F.I.R.S.T.

This will be a 24-hour volleyball marathon against one of our corporate clients. We will inform the local press and TV stations to cover the event, giving F.I.R.S.T. some publicity, while also enhancing the company's public image.

On top of this, we are going to do our letter campaign again. Our last mailing was to thirty people. This time we'll target one hundred people.

If you have ever considered doing a grassroots fund-raiser, but have no idea where or how to begin, think first about useful resources and allies in your community: your church, Boy Scouts, Girl Scouts, 4-H Clubs, Knights of Columbus, Lions Clubs, your employer, bowling centers and leagues, and even your child's school. This is only a short list of the kinds of organizations in your community that regularly support creative efforts at fund-raising for a worth cause.

Whatever your fund-raising idea, and regardless of who becomes involved, always be sure to include your local newspapers and TV stations. Local media is always on the lookout for appealing human interest stories. The staff at the F.I.R.S.T. office in Raleigh will be happy to help you prepare a press release.

And remember, every fund-raising success makes your next effort that much easier. Good luck!

KAREN & BAILEY JONES: A Can Is a Can Is a Can...

Who Said It Can't Be Easy?

Recycling Cans At Work Provides Big Gain for F.I.R.S.T.

With co-workers at the Willamette Industries plant in Johnsonburg, Pennsylvania, F.I.R.S.T. member Karen Jones maintains a collection box for aluminum soft drink cans. That's all there is to it. So far this year Karen has sent us over \$200 collected this way. Last year F.I.R.S.T. received several hundred dollars from the program. The Willamette Industries program divides the receipts with local school programs.

Says Karen of her daughter Bailey: "Bailey is a straight 'A' student in the 2nd grade. She loves to read, draw, color, sing and write stories. Her other interests include roller skating, bike riding, swinging, and Barbie dolls! She is looking forward to attending another F.I.R.S.T. conference someday soon so she can meet other people with ichthyosis. Unfortunately, she was too young to remember the last one we went to (although the rest of us got a lot out of it)."

Our thanks to Karen and Bailey for their continuing work!



Karen Jones and her daughter, Bailey—
Christmas, 1993

N.O.R.D. REPORT

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

Health Insurance: Profits vs. Coverage

According to the Department of Commerce, operating profit margins for insurance companies for the first nine months of 1993 rose to 4.09% from 3.85% for the same period a year earlier. Large companies with strong managed care networks benefited most. Overall, economists expect a 9% increase over 1992 for the entire insurance sector.

Insurance companies take nearly 25% of total health care spending, according to the Department of Commerce, while in other industrialized countries this number is 11% or less.

Most growth in the U.S. health insurance sector went to HMOs, as enrollment grew to 41.4 million in 1992 from 29.3 million in 1987. Pressure to profits came in the form of rising hospital expenses, which are expected to rise 12.5% this year; rising physicians' expenses, which will grow by 11%; and rising nursing home expenditures, which will rise 12.5%. On the other side of the coin, the number of people enrolled in fee-for-service insurance plans fell to 49% in 1993 from 71% in 1988.

With sharply rising health care costs, increasing profits in the health insurance industry might be difficult to explain. The "Foster Higgens Report," detailed in a February 15th article in the *Wall Street Journal*, explains them in

terms changing insurance premiums and coverage packages.

On the one hand, employees had to pay 9% more for health insurance benefits in 1992, while the employer's share of payroll devoted to health insurance dropped during the same period.

Insurance premiums rose 5.9% per employee in 1993, while for larger firms that figure was 9.1% per employee. According to Foster Higgens, smaller employers appear to be paying less because they provide a narrower benefits package, higher deductibles, and less frequently provide dental and prescription drug coverage and dependent benefits.

Combining both large and small firms, cost per employee averaged \$3,781 in 1993, and increase of 8% over 1992. However, employer costs for prescription drug benefits alone jumped 15% last year, which is twice the rate of overall growth in health plan expenses.

Why U.S. Drug Prices Are Higher Than In Other Countries

NORD's President, Abbey Meyers, testified recently before the House Subcommittee on Health and the Environment about U.S. pharmaceutical pricing inequities. She noted that consumers do not benefit from current price pressures because when manufacturers grant discounts on their prices to large bulk buyers

(for example, hospitals, HMOs, etc.), they tend to offset these discounts with higher prices to retailers—your local drug store. As a result, prices at the pharmacy counter are rising faster than inflation.

She also noted that another reason why Americans pay higher prices than people in other countries for the same prescription medication is that the U.S. is the only industrialized country that does not control the prices of drugs. In order to support research and development (not to mention marketing), drug companies must recoup profits in their only large unregulated market—the U.S. As a result, the U.S. is subsidizing the world's research and development of new drugs.

Executives of American pharmaceutical firms Glaxo, Merck, and Genentech testified at the same hearing and said essentially the same thing. Americans are paying higher prices for pharmaceuticals so that companies can use the money for research and development. This is good in principle, but it's not fair that American consumers alone pick up the tab. Said Ms. Meyers, "It's time to tell the rest of the world that the party is over."

Just how much more expensive are drugs in America?

Subcommittee Chairman, Rep. Henry Waxman, received a General Accounting Office (GAO) study on February 2, 1994, comparing U.S. prices for 77 frequently prescribed drugs with prices in England. The GAO found that 66 of the 77 cost less in England, and that 47 of these cost less than half what they do in the U.S. Of these 77 drugs, the average costs 60% more in the U.S. than in Britain. Concluded Congressman Waxman, "Beyond any doubt, the U.S. is subsidizing low drug prices for the rest of the world."

Correspondence Corner (Continues from Page 2)

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

I am 37 and have CIE. I remember the days when I was young in Texas and my treatment was A&D ointment to the skin and nightly applications of Noxzema to the scalp. I have since learned that I get the best results from Eucerin cream (I remember when it was 99 cents a pound jar; now it is \$11.00 to \$13.50 in Atlanta). My present dermatologist con-

tinues to work with me to find other creams. Sometimes I feel like a guinea pig, but treatment has come a long way.

I am thankful that my parents always tried to find the best treatment for me. To this day they send me samples of different things, whether creams, lotions, or even vitamins. My mother first saw the article about F.I.R.S.T. in Ann Landers, and since then you have been a source of information and encouragement.

Pamela Brown
Atlanta, Georgia

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

Enclosed is a check for \$35.00 for a family membership in your organization. I was so glad to find you!

My 20-month-old son has EHK. Ever since he was diagnosed I have been trying to find someone who knows what this disorder is like. Last Friday I discovered an address and an 800 number for F.I.R.S.T. I called that day. I talked to a really helpful man (I forgot to ask his name, but was later told it was probably Nick). He asked me questions that really

Newsletter on Special Education Law

There is a newsletter available from Chapel Hill, North Carolina entitled *The Parent's Newsletter on Special Education Law*. It is for parents of children with disabilities who want information on federal laws that apply to their child's education. The newsletter is published six times a year and is edited by Edward J. Bedford, an attorney and the parent of a child with a disability.

For more information, contact the *The Parent's Newsletter on Special Education Law*, P.O. Box 4571, Chapel Hill, NC 27515.

Books, Books, Books...

After the Tears: Parents Talk About Raising a Child with a Disability, by Robin Simons (Harcourt Brace Jovanovich, 1987). An excellent resource guide which covers the full range of domestic and professional issues confronting parents with special needs.

Family-Centered Care for Children

With Special Health Care Needs (3rd edition), by T. Shelton, J. Stepanek, E. Jeppson, and B. Johnson. The bible of the "family-centered" health care movement, this edition explains the nine elements of care that collectively constitute a philosophy about how systems, policies, and practices need to change to become more family-centered. Cost is \$12.00; available from the Association for the Care of Children's Health (ACCH), 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814.

Parenting a Child with Special Needs: A Guide to Reading and Resources. Describes and discusses the many issues associated with parenting a child with a disability and lists valuable readings and organizational resources to assist the family. Available from the National Information Center for Children and Youth with Disabilities (NICHCY); call 1-800-695-0285.

Herald Pharmacal Amends Offer on Aqua Glycolic

Officials of Herald Pharmacal have asked us to inform F.I.R.S.T. members that they will raise their special member price for Aqua Glycolic Lotion. Members accustomed to the \$48.00 case price (12 8-oz. bottles) will now pay \$102 when ordering directly from Herald. The new price is set to go into effect on August 1st, 1994.

Although the price increase is quite steep, we're reminded that even this price represents tremendous savings off the normal retail price, which is \$192 for 12 8-oz. bottles.

Herald officials invite your questions or comments. They may be reached at 1-800-253-9499.

showed he knew what EHK was. I was so tickled. Three days later I received my first newsletters in the mail.

I poured over them and then I called Cynnie Bates, my regional coordinator. She immediately gave me the phone number for the mother of a seven-year-old with EHK. I talked to her for about two hours on the phone that night. Thanks Jill!

I am anxious to attend a regional conference this summer and to talk with others who have EHK.

Thanks for being there! I hope I can soon help other mothers of kids with EHK the way Jill and other people at F.I.R.S.T. helped me.

Deidra Long
Mt. Gilead, Ohio

We love hearing from our members, so please write with your comments and observations about ichthyosis, about F.I.R.S.T., your health care experiences, or anything at all. Address your letters to the Focus Editor, F.I.R.S.T., P.O. Box 20921, Raleigh, NC 27619.

LETTER FROM A F.I.R.S.T. MEMBER WHO'S COME UP WITH HIS OWN "SOLUTION"

Dear Fellow Members:

In my search for control of, and relief from, my symptoms, I have tried common preparations, costly ones, cooking oil and plastic wrap, with varying degrees of success, disappointment, and even revulsion.

For the past year, I have enjoyed remarkable freedom from thickening, stiffening, and cracking by using a conventional lotion base with a generous addition of lanolin. Principal components are water, mineral oil, stearic acid, propylene glycol, lanolin, urea, and menthol.

If your skin tolerates these components, you may find, as I did, that this preparation reproduces superior results with fewer aesthetic drawbacks, like stinging and gumminess. I have had it manufactured to my specifications, and I will be very pleased to make samples available to members who request it. You are welcome to phone or write any time.

Rick Bibbs: 512-834-8199 (home); 512-837-2000, ext. 28 (office); 12912 Powderhorn, Austin, TX 78727.

MEMORIALS

We remember our members & friends of members recently passed away

Sidney H. Hastings
Deltona, Florida

Norman L. Koenig
Brook Park, Ohio

Bernard F. Lange
Brook Park, Ohio

John Corcorau
Rochester, New York

Larry Smith
Rochester, New York



FOCUS is printed on recycled paper.

Regional Support Network

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

REGION ONE

NY, PA, VT, NH, NJ, CT, RI, MA, ME
Lianne Busby
8001 Miller Road
Avoca, NY 14809
(607) 566-8403

REGION TWO

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Robin Joyce
Route 1, Box 189-F
Sandy Ridge, NC 27046
(919) 871-3277

REGION THREE

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

REGION FOUR

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REGION FIVE

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REGION SIX

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Raleigh, NC 27619
(800) 545-3286
(919) 782-5728

Y E S !

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

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