



# ICHTHYOSIS FOCUS

Vol. 13, No. 4

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

Fall 1994

## F.I.R.S.T. PUBLISHES SECOND TITLE IN ITS EDUCATION LIBRARY SERIES

### *ICHTHYOSIS: A Guide For Teachers*

Following up on the recent publication of the first title in our ongoing Education Library Series (*Release the Butterfly: A Handbook for Parents & Caregivers of Children with Ichthyosis*), F.I.R.S.T. this month released its companion volume, *Ichthyosis: A Guide for Teachers*.

Intended as a tool for parents whose children are undergoing the difficult transition from the home to school environment, the *Guide for Teachers* brings together in one volume the key information that teachers and other school officials should know about their students with ichthyosis.

Written by Deborah B. Vilas, herself a child life specialist, the book was adapted from her Masters thesis in special education. Included are sections that define ichthyosis and describe its primary and secondary symptoms; a summary of treatment regimens; sections on overheating and care for minor cuts and scrapes; and sections outlining central developmental challenges for students of various ages. Also included in the 40 page book is resources and further reading section.

Please see the back page of this issue of *Focus* for ordering information. Copies of both books are now available from F.I.R.S.T.

*A tool for parents  
whose children  
are undergoing  
the difficult  
transition from  
the home to  
school  
environment*

## PLANNING UNDERWAY FOR 1995 NATIONAL CONFERENCE IN SAN DIEGO

June 16th, 17th & 18th at the Bahia Hotel Resort

At its September 25th meeting, the Board of Directors officially approved the 1995 national conference budget, and planning is officially underway. This is by far the most ambitious conference ever undertaken — running an entire weekend — and we are already taking pains to make certain the conference lives up to all of our expectations.

Although little is yet set in stone (except time and place), I have already with several members of the medical

community, and rough outlines of the program are beginning to shape up.

Dr. Philip Fleckman, Director of the newly funded, NIH-sup-ported Patient Registry (see story on page 6) will conduct a special presentation for our group about this most important new development for ichthyosis research. Also in the works is a special workshop on retinoid therapy for treating ichthyosis.

As in Chicago, there will be an am-

*(Continues on Page 12)*

### IN THIS ISSUE . . .

President's Letter .....	2
The E.D.'s Desk .....	3
New Gene for Variant of EHK .....	4
Search Narrows for Darier Gene .....	5
Dr. Shulman Retires .....	6
NIH Funds National Ichthyosis Registry .....	7
Reflections on Camp Knutson .....	8
Correspondence .....	10
GrassRoots .....	12
News & Notes .....	13
<i>In Memorium</i> .....	13
RSN Announces 1995 Goals .....	14
RSN Roster .....	15
N.O.R.D. Report .....	15
Parent Book & Teacher Book Order Form ....	16

*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

**Focus Editor**  
Nicholas Gattuccio

**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.

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.

# PRESIDENT'S REPORT

by Deborah B. Vilas

Greetings to all on behalf of the Board of Directors. In my last letter to you, I told you a bit about myself. I would now like to give you a feeling for the Board as a whole, and to bring you up to date on some of the current actions that we have been taking.

Presently, we are blessed with a diverse Board membership. Our Board members' expertise spans a variety of professions, including health care, journalism, business, parenting, psychology, education, public relations, and marketing. This in itself is a great accomplishment for F.I.R.S.T. It is one that we have been working toward for some time.

Our most recent additions to the Board, Beth Peritz and Michael Dunleavy, bring with them backgrounds in law, social work, and development—areas that will help us tremendously as we strive to meet our goals for the coming years.

Nevertheless, the success of the Board does not lie solely in the collective skills of its membership. Equally important is the structure and operations of the Board.

Our Board is structured so that each member sits on at least two standing committees. F.I.R.S.T.'s standing committees presently consist of the following: Executive, Development, Finance, Personnel, Strategic Planning, Nominating, and Communications. These committees work on projects and ad-

dress issues put to them by the Board, and report their findings and actions back to the Board at our quarterly meetings. The wonderful thing about committees is that they are in action all of the time and can get a lot accomplished that a board, as a cumbersome whole, may be unable to do.

We conduct our Board meetings via teleconference, since our members live all over the country. At our most recent meeting, we acted on a range of motions proposed by Board committees. These included a motion on how to manage some of our assets; a unanimous decision to provide our executive director with health insurance; the nomination and election of two new board members; a vote to go forward with printing our forthcoming "Teacher's Manual."; and a vote to approve a budget for our upcoming 1995 national conference in San Diego.

It was an exhilarating and productive meeting. I am pleased to share its accomplishments with the membership at large. I have faith that the Board will continue to do good works for the Foundation and the people it serves. We are lucky to have such a talented, dedicated group of individuals looking after the interests of the Foundation.

With Warm Regards,  
Deborah B. Vilas

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

Contact Nick or Heather Gattuccio, or *Focus*, at  
CompuServe address: 74722,1571

*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: January 6, 1995

# NOTES FROM THE E.D.'S DESK

by Nick Gattuccio

As 1994 draws to a close we naturally begin to review the progress and accomplishments of the waning year. Because there was no national conference in 1994, we were able to devote our entire attention to Foundation operations, programs and services. And a great deal of that energy went into finishing up and publishing the first two titles in our ongoing Patient Education Library.

I know I speak for the Board of Directors when I say how proud we are of both our new publications—the *Handbook for Parents & Caregivers*, and our newest release, *Ichthyosis: A Guide for Teachers*. Both were the outcomes of extraordinary efforts of time and will and commitment to the central mission of the Foundation.

All of us, I'm sure, remember very well that first day that we heard the word, *ichthyosis*. It was a very foreign word, and most of what we learned from our physicians that first day we couldn't retain, because it was all so new, so foreign, and so unusual. When we then turned to our local libraries or other sources to find more information, there wasn't any. None at all.

Some of us then went to medical school libraries and learned how to do literature searches. There, we found difficult articles, where physicians and researchers wrote about specialized aspects of this family of disorders in very difficult, technical language which they only intended other doctors to read. Some of us got ourselves medical dictionaries and ploughed through them anyway, learning tiny slices of skin biology and chemistry and genetics as we went along. Others of us found this too difficult.

Ultimately—maybe soon, or maybe after a long delay—we stumbled upon F.I.R.S.T., and this helped a great deal. Here, at last, we could obtain at least *some* information about ichthyosis in a language we could understand,

and in terms that focused on the patient, not the tissue and molecules and genes. We could meet and hear from others who stood in shoes that fit like ours did. There was, at least, a community.

But still a gap remained.

Here at F.I.R.S.T. we knew there was still a gap. We saw rivers of useful, powerful information flow out of our members and course through the pages of *Focus*, and well up in sessions at regional and national conferences, but, like a river, it just kept flowing right on by. It rarely collected into a single pool. We knew this was a problem, and we felt it was time that we fix it. So we decided to dam up the river and begin collecting its waters into books.

So that's the background to the release this fall of our two new books. We're proud of them. We feel they are valuable additions to the plate of programs and services offered by F.I.R.S.T. to its membership, and we sincerely hope members take advantage of these new offerings and use them as tools for improving opportunities for yourselves and your children.

Ultimately, we hope to produce an entire series of useful publications about ichthyosis and its care and treatment. We see this as one of the fundamental aspects of the Foundation's mission—patient education and information. But this is an open-ended commitment and will occur over the coming years, as the need arises and the resources present themselves.

\* \* \*

From everyone at F.I.R.S.T., please accept our best wishes for a happy holiday season, and for a healthy and prosperous new year. We thank all of you for your generous support in 1994, and look forward to your continuing commitment in the new year.

## F.I.R.S.T.'s BOARD OF DIRECTORS

Deborah Vilas  
President  
New York, New York  
(12/94)

Michelle Petersen  
Vice President  
Metuchen, New Jersey  
(12/96)

Lynne Alba  
Secretary  
Norristown, Pennsylvania  
(12/96)

Georg'Ellen Betts  
Chief Financial Officer  
Raleigh, North Carolina  
(12/94)

Betsy Bates-Freed  
Los Angeles, California  
(12/95)

Pamela Stockton  
Raleigh, North Carolina  
(12/95)

Virginia Frantz  
New York, New York  
(12/95)

Thomas Buehler  
Chicago, Illinois  
(12/96)

Janet Weary  
Charlottesville, VA  
(12/95)

Michael Dunleavy  
Blue Bell, PA  
(12/94)

Beth Peritz  
Ridgewood, NJ  
(12/94)

Leonard Milstone, MD  
Chairman  
Medical Advisory Board  
New Haven, Connecticut

...

Nicholas Gattuccio  
Executive Director

# RESEARCHERS LOCATE GENE FOR A VARIANT OF EHK

*In a blistering form of ichthyosis termed Ichthyosis Bullosa of Siemens (IBS), the culprit gene was mapped to the keratin 2e gene, making it genetically distinct from EHK*

J.A. Rothnagel, H. Traupe, S. Wojcik, M. Huber, D. Hohl, M.R. Pittelkow, H. Saeki, Y. Ishibashi, and D.R. Roop. "Mutations in the Rod Domain of Keratin 2e in Patients With Ichthyosis Bullosa of Siemens." *Nature Genetics*, v. 7 (Aug., 1994), pp. 485-490.

W.H.I. McLean, S.M. Morley, E.B. Lane, R.A.J. Eady, W.A. Griffiths, D.G. Paige, J.I. Harper, C. Higgins, and I.M. Leigh. "Ichthyosis Bullosa of Siemens—A Disease Involving Keratin 2e." *Journal of Investigative Dermatology*, v. 103(3) (Sep., 1994), pp. 277-281.

P.M. Steijlen, H. Kremer, F. Vakilzadeh, R. Happle, A.P.M. Lavrijsen, H-H. Ropers, and E.C.M. Mariman. "Genetic Linkage of the Keratin Type II Gene Cluster With Ichthyosis Bullosa of Siemens and With Autosomal Dominant Ichthyosis Exfoliativa." *Journal of Investigative Dermatology*, v. 103(3) (Sep., 1994), pp. 282-285.

H. Kremer, P. Zeeuwen, W.H.I. McLean, E.C.M. Mariman, E.B. Lane, P.C.M. van de Kerkhof, H-H. Ropers, and P.M. Steijlen. "Ichthyosis Bullosa of Siemens Is Caused by Mutations in the Keratin 2e Gene." *The Journal of Investigative Dermatology*, v. 103(3) (Sep., 1994), pp. 286-289.

Researchers at four labs — one in the U.S. and three in Great Britain — recently announced the discovery of yet another genetic defect accounting for a blistering form of ichthyosis. Termed ichthyosis bullosa of Siemens (IBS), the culprit gene was mapped to the keratin 2e gene on chromosome 17.

First reported in the August 1994 issue of *Nature Genetics* by Dr. Joseph Rothnagel at Baylor College of Medicine in Houston, and co-authored by an international team of colleagues including researchers in Germany, Switzerland and Japan, similar findings were reported by three other labs just weeks later in the September issue of the *The Journal of Investigative Dermatology* (see citations).

The new mutation lies in the vicinity of the keratin 1 (K1) gene, one of the genes in which a mutation causes symptoms of EHK. However, in the two years since researchers first mapped the sites of the genetic mutations for EHK to the K1/K10 keratin pair, they noticed that as many as 10% of EHK patients did not have a genetic mutation on either of these two known genes. This led to further investigations of these patients, leading ultimately to this latest discovery of a distinctly different mutation in the K2e gene.

## IBS Quite Similar To EHK

Although quite similar to EHK, the researchers consider IBS to be a separate disorder. It is not only genetically distinct from EHK, but has subtle clinical differences as well. In fact, the clinical description of IBS was first made in 1937 by the German physician H.W. Siemens.

Researchers believe that many patients presently diagnosed with EHK may in fact have IBS. However, it is important to note that the clinical differences between the two disorders are slight, and that care and treatment will not significantly differ between the

two. As stated by Rothnagel et al., "IBS and EHK are often not readily distinguishable from each other, given ... their similar clinical appearance."

Beyond the genetic distinction, the differences between IBS and EHK are noticeable only microscopically. Whereas with EHK blistering occurs due to cleavage near the basal cell layer (i.e., the bottom layer of the epidermis), with IBS the cell cleavage leading to blisters occurs a few cell layers higher up, in cells closer to the stratum corneum (the outermost layer of the epidermis). In actuality, both affected cell layers lie quite near one another—only one or two cell layers apart.

## Evidence Cited of Further Variant of IBS

If those with EHK are becoming confused by news of this new variant, hold your hats. The researchers from the Netherlands (P.M. Steijlen, et al.) suspect yet another variant, which is very similar to IBS, yet microscopically distinct. Termed ichthyosis exfoliativa (IE), it was first described in 1991.

Although the Steijlen group has yet to identify the precise location of the genetic mutation responsible for IE, they have significantly narrowed the search to the same region on chromosome 12 which carries the K1 and K2e genes, in which mutations account for EHK and IBS respectively.

## The More We Learn The Less We Know?

It is generally acknowledged in the ichthyosis research community that as more becomes known about the genetics of the many types of ichthyosis, greater complexity will emerge. Indeed, this is proving to be the case. The tidy picture we've had of a handful of definable types of ichthyosis (lamellar, CIE, EHK, etc.) is slowly disintegrating. In its place emerges a complicated picture of a great many closely related disorders resulting from any of several mutations in a variety of genes.

# RESEARCHERS NARROW SEARCH FOR GENE THAT CAUSES DARIER DISEASE

**A**lthough the precise location remains to be determined, researchers have narrowed the search for the gene responsible for Darier disease to an extremely narrow region on chromosome 12.

Announced in the October, 1994, issue of the *Journal of Investigative Dermatology*, the findings are the result of an international effort that includes the collaboration of F.I.R.S.T. Medical Advisory Board members Ervin Epstein, Jr., M.D. and Lowell A. Goldsmith, M.D. (see citation).

These findings follow earlier reports that localized the Darier gene to this general region on chromosome 12. The present study narrowed the range to an area of roughly 5 million base pairs of DNA. This is a very small segment of DNA, according to Dr. Epstein, but still could hold up to 100 different genes.

By analyzing samples of genetic material from members of 10 families in which several related members over multiple generations were affected with Darier disease, researchers were able to locate with relative certainty the narrow band in which the gene can be expected to be found. However, understanding the precise inner workings of Darier disease must await identification of the exact gene and a description of its role in the structure

and function of the epidermis.

Although this region is located on the same chromosome that contains known genetic mutations that result in symptoms of EHK (that is, mutations in the keratin 10 gene, which is also on chromosome 12), the present study specifically *excludes* genes that code for the keratins, as well as other important components in the biology of the epidermis.

Because many of the essential building blocks of the biology of the epidermis are not yet fully understood, the researchers believe that identification of the genetic mutation in Darier disease will reveal important new information about the structure and function of the epidermis.

Darier disease is an autosomal dominant type of ichthyosis characterized by abnormally keratinizing epidermis. It was first described in 1889 by Jean Darier in Paris and James C. White in Boston, and is sometimes known as Darier-White disease. It is also known as keratosis follicularis.

Dr. Epstein and his collaborators are continuing their hunt for the Darier gene, and are interested in contacting Darier patients who may be willing to participate in their work. Dr. Epstein may be reached at his lab at 1-800-285-1267.

*Identification of the gene for Darier disease will add enormously to our understanding of the basic biology of the epidermis*

S. Ikeda, P. Wakem, A. Haake, N. Ewing, R. Polakowska, Y. Sarret, A. Trattner, M. David, M. Shohat, D.W. Schroeder, E.H. Epstein, Jr., and L.A. Goldsmith. "Localization of the Gene for Darier Disease to a 5-cM Interval on Chromosome 12q." *Journal of Investigative Dermatology*, v. 103(4) (Oct., 1994), pp. 478-481.

## OUTLINE OF KNOWN KERATIN GENE MUTATIONS

GENE	DISORDER	CHROMOSOME
K1 & K10	Epidermolytic hyperkeratosis (EHK); Ichthyosis exfoliativa (?)	K1 = chromosome 17 K10 = chromosome 12
K2e	Ichthyosis bullosa of Siemens Ichthyosis exfoliativa (?)	chromosome 12
K5 & K14	Epidermolysis bullosa	K5 = chromosome 17 K14 = chromosome 12
K9	Palmo-plantar keratoderma	chromosome 17
?	Darier Disease	chromosome 12

DR. LAWRENCE E. SHULMAN  
RETIRES AS DIRECTOR OF THE NATIONAL  
INSTITUTE OF ARTHRITIS,  
MUSCULOSKELETAL & SKIN DISEASES AT  
THE NATIONAL INSTITUTES OF HEALTH

*Director since the  
Institute's  
founding in April,  
1986, Dr.  
Shulman, guided  
Institute during  
formative years  
and set the tone  
for the Institute's  
sensitivity to the  
needs of patients*



**D**r. Lawrence E. Shulman, M.D., Ph.D., the first director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), is retiring from his position as of October 31st, 1994. He will remain Director Emeritus and continue at the National Institutes of Health (NIH) to carry out projects in prevention research, in which he has a keen interest. Dr. Shulman held this position since the Institute was first established in April, 1986.

It is under the auspices of NIAMS that the vast majority of research in skin diseases, including the ichthyoses, occurs. Some of this work takes place on the NIH campus itself in the form of intramural research projects, primarily those carried out in the Laboratory of Skin Biology. However, the vast majority of research takes place outside the Bethesda, Maryland campus through NIH/NIAMS-funded extramural research. Virtually all ichthyosis-related research findings reported on in the pages of *Focus* are supported in whole or in part by funding from the NIH.

Additionally, NIAMS supports building the foundations for research by fostering development of rare disease patient registries. NIAMS funds a registry for patients with epidermolysis bullosa, founded five years ago, and has recently announced funding of a patient registry for those with keratinizing disorder—the ichthyoses.

Over the years Dr. Shulman has shown a remarkable sensitivity to the needs of patients. He has actively fostered use of patient advocacy representative on NIAMS research review boards, and has actively sought the

views of patient representatives throughout his tenure as NIAMS Director.

Dr. Shulman's career at the NIH began in 1976 when he was appointed the first NIH Associate Director for Arthritis, Musculoskeletal and Skin Diseases for what was then the National Institute of Arthritis, Metabolism, and Digestive Diseases. In 1983 he was named Director of the Division of Arthritis, Musculoskeletal and Skin Diseases of the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases, where he served until the establishment of the NIAMS.

Throughout his career, Dr. Shulman has maintained his association with the Johns Hopkins Medical Institutions. He joined the Medical School faculty there, becoming the first Director of the Rheumatology Division, which he developed over the next 20 years before going to NIH.

An internationally recognized leader in rheumatology, Dr. Shulman has made many significant contributions to biomedical research, particularly in the areas of systemic lupus erythematosus, scleroderma, and other connective tissue diseases. Among his notable achievements is the discovery of eosinophilic fasciitis, also known as Shulman's disease.

Over the years perhaps no single individual has had a greater impact on the state of skin disease research than Dr. Shulman. We in the patient community have been fortunate to have had a leader who never lost sight of the patient. We congratulate Dr. Shulman for a long and distinguished career, for the great benefits that have come to skin disease research over the decades, and we wish him well in his new position as Director Emeritus.

# THE NATIONAL INSTITUTES OF HEALTH TO FUND "THE NATIONAL REGISTRY FOR ICHTHYOSIS & RELATED DISORDERS"

---

Dr. Philip Fleckman at the University of Washington in Seattle Will Head  
This Rare Disease Registry Devoted to Patients With Ichthyosis and  
Related Disorders of Keratinization

---

**T**he National Institute of Arthritis, Musculoskeletal & Skin Disease (NIAMS) at the National Institutes of Health last month announced that it will fund a rare disease registry for inherited disorders of keratinization. This is a broad class of genetic skin disorders, including most included in the family of related ichthyotic diseases. Not included, however, is ichthyosis vulgaris because it is not considered a rare disorder.

Dr. Philip Fleckman, on the faculty in the Division of Dermatology at the University of Washington Medical Center, and a member of F.I.R.S.T.'s Medical Advisory Board, won the five-year NIH contract to establish and operate the ichthyosis registry, to be located at the University of Washington in Seattle.

This contract award culminates more than four years of effort on the part of many members of the F.I.R.S.T. community to encourage the NIH to fund a rare disease registry for the ichthyoses. In December, 1993, NIAMS announced its intention to invite applications for development of rare disease registries, and in February, 1994, it issued a formal "Request for Proposals" (RFP) from those interested in developing such a project.

The RFP announced by NIAMS did not specify which disorder or family of related disorders would be included in a funded project. In fact, the competition was open to any project which fell under the NIAMS umbrella (arthritis, musculoskeletal and skin diseases). Furthermore, NIAMS stipulated that it would fund only a limited number of projects.

By all accounts, competition was fierce. NIAMS is said to have received more than 30 highly suitable proposals. Altogether, five

rare disease registry projects were funded.

A great many people played key roles, and not just over the past 10 months since the RFP was announced. Efforts go back several years. First, of course, Dr. Fleckman is to be congratulated for developing a premier proposal for a national registry for ichthyosis and related disorders. He has committed uncountable hours over the past year to preparing a winning proposal; the ichthyosis community—researchers and patients alike—will benefit immeasurably for his successful effort.

But many others played key roles, too, largely in the background. Dr. Leonard Milstone, chair of F.I.R.S.T.'s Medical Advisory Board, has been a firm supporter of this project over the years, and his efforts earlier this year when the RFP was announced, as well as before that, while F.I.R.S.T. was encouraging Congress to support the idea, were pivotal.

Also crucial were the efforts of Susan Snyder, former F.I.R.S.T. executive director, who spearheaded the drive to persuade members of Congress of the enormous value of an ichthyosis patient registry. She is the person most directly responsible for encouraging members of Congress to include wording in 1993 appropriations legislation which supported, in principle, the establishment of a national registry for ichthyosis.

Although F.I.R.S.T. is not formally affiliated with the Registry, the Foundation stands fully behind the project and is ready to do all it can to ensure its success. As the Registry comes into operation (in early 1995), you will hear a great deal about it in the pages of *Focus*. Also, Dr. Fleckman will be with us at our national conference in San Diego to discuss the Registry in detail.

*This new  
National Registry  
for ichthyosis  
culminates more  
than four years of  
effort on the part  
of a great many  
members of the  
F.I.R.S.T.  
community.*

# REFLECTIONS ON CAMP KNUTSON

by Janet Weary

---

Fifty Young People With Skin Disorders Attend Week-Long Summer Camp Sponsored by the American Academy of Dermatology

---

*The author shares impressions of a unique and valued glimpse of special young people in a special place and time.*



Children are sharing summer memories, so it seems appropriate to share a few of my own (it is mid-September as I write). Some of those children went to camp, and thanks to Camp Knutson, so did some of our children with chronic skin problems. My husband and I were privileged to join their fun for a few days in August.

First of all, I learned a lot about Camp Knutson that I didn't know before. Though the idea of a special camp for children with skin problems was conceived by Dr. Mark Dahl, whose vacation home shares the same lake, the cost for our group was totally underwritten by contributions to the American Academy of Dermatology.

The camp itself is owned and run by the Lutheran Social Services. Its permanent staff of counselors, led by Rob Larson, dedicate its summer to providing a camp experience to many different groups of adults and children with special needs. Each group lends the camp its own personality, activities and relationships changing with each set of campers and their leaders. All these groups enjoy the camp for varying amounts of time, and by the time our children arrived, seventeen other groups had shared "Rob's and company's" tender care. Each group brings with it its own leaders, and in our case a rather large contingent of both youthful counselors and medical staff to provide dormitory and medical supervision.

The camp is situated on a small peninsula jutting into the lake, so it's surrounded by water. The dining and activities building,

dorms, an infirmary, and cottages for the staff sit among the camp's many shade trees, which also embrace a basketball area, volleyball court, swings, a wonderful cook-out area, and of course the beach and dock.

Each afternoon is swim time, but there are also boat rides, tubing and fishing, and it seemed that no one wanted to miss these activities, even on cloudy days.

You can guess that the staff was a hard-working group who provided supervision and care for children with a wide range of special needs. Among the group were young people with ichthyosis (17 of them), atopic dermatitis (13), psoriasis (7), epidermolysis bullosa (3), alopecia (3), and there was one each with six other rare disorders.

Lest some parents might hesitate to consider the camp experience for their child for fear of inadequate care, here are a few reassurances. No one has been seriously ill at either the '93 or '94 camps. Yes, there were

the usual headaches, stomach aches, skinned knees, and home sickness, but no rampant bacterial or viral infections, and no serious episodes of asthma among the atopic young people, no sunburns, and no skin care neglected. In fact, at least one child learned of some new and better ways to care for herself. One nine-year-old with serious epidermolysis bullosa not only came to camp alone, but also brought with him a 45-minute video showing how to remove and replace his dressings — a process taking close to two hours.

Each child has his or her own manila envelope which contained complete instructions

*"Lest some parents might hesitate to consider the camp experience for their child for fear of inadequate care, here are a few reassurances"*



for care, and all medications were kept available to the medical staff. In the dining room, for instance, any special dietary restrictions and oral medications were monitored and provided with each meal. In the dormitories, topical medications for personal care handled by the campers themselves could be overseen by their counselors. These young counselors managed their duties with dedication, but also with the grace to remember that having fun was the main purpose of the camp. The infirmary was always open (the doctors lived there), and any child who needed care could get it immediately — including hugs and hand holding, if that's what the prescription called for.

The Academy had rejected the idea of providing psychological counseling, feeling that freedom from being different and the opportunity for pure pleasure was what this week was all about. Early on the children dealt out their own questions and answers about their various conditions, and by the time we arrived the subject of their skin had become much less interesting than their shared camp experiences. What one could not help but notice was the mutual respect and support the children gave to one another.

Camp Knutson is three hours from the Minneapolis airport, so the arrival and departure logistics for fifty campers, some in wheelchairs, was a mammoth job. We sat in on the evening review of "operation airlift" and could not help but be impressed by the organized expertise of the staff. Every one had an assignment and knew when, where, and with whom to be. Three large vehicles, all the visiting staff, the medical personnel, and about twenty volunteers at the airport were involved in getting everyone on the right road home. A nearby

church was commandeered for food and recreation while waiting for all of the flights involved, and no child went to or from a airplane without his accompanying adult caregiver.

On Saturday evening, after everyone was gone, Rob and his permanent staff gathered at Dr. Dahl's cottage to



relax and review the week. Camp counselors are a special breed, I thought as I listened to their talk, and this group was a very special one indeed. They were on a high as they exchanged stories of the triumphs of the children over their difficulties. You would have been, too, had you seen a child with epidermolysis bullosa manage to go tubing safely in spite of a tracheotomy and dressings, or seen another leave her wheelchair to dance with her companions; or if you had seen two nine-year-old children with atopic



dermatitis —one from this country and one from England — discover that they not only share their skin disease, but also twin grins and a friendship so strong that an ocean surely cannot end it; or a Panamanian girl with extensive EHK find her own special counselor who spoke fluent Spanish; or the group of three siblings with lamellar ichthyosis, all within the age group so all could come together; or the girl, also with lamellar ichthyosis, who was just a little over the age limit, who found her role as a cabin counselor?

In February in New Orleans, in conjunction with the annual meeting of the American Academy of Dermatology, we will host a fun-raiser to benefit Camp Knutson. The event will allow us to display our photos of camp activities and show a wonderful video of the camp. Although the amount we can raise at such an event is limited by the time and space available, it still gives us the opportunity to do three important things: publicize the camp and help it grow; publicly acknowledge the financial contributions of individuals, state dermatology societies and corporate supporters, and acknowledge the time and work contributed by the many volunteers; and, finally, to remind the world that with a little extra effort from those who can provide it, children with chronic skin disease can grow and flourish and fulfill their potential every bit as much as those not burdened with these difficulties. Camp Knutson can be part of that effort — some of the fun part.

---

*Janet Weary, who lives in Charlottesville, Virginia, is a member of the Board of Directors of F.I.R.S.T. She visited Camp Knutson this past summer with her husband, Dr. Peyton Weary, who is currently President of the American Academy of Dermatology.*

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

The Editor:

I have a comment regarding Ken Strehle's letter in the summer *Focus* about water softeners. Yes, this does help. My father and son have recessive X-linked ichthyosis and both have benefitted from softened water. I believe the water's mineral content determines its hardness/softness.

We plan to have our plumbing modified so that only the hot water is softened, for conservation reasons, and because we do not like to drink softened water. My father also discovered softened water while traveling, and the water softener has helped his skin more than anything else.

Mary McIlvaine  
Racine, Wisconsin

Dear Editor:

I also have ichthyosis vulgaris. There is no question in my mind as to the benefits of soft water. We live in an area that has very hard water. I noticed when I was in my late teens and had an occasion to shower in soft water that my skin was less dry and cracked than when using hard water. We have had a water softener since 1961 and we would never be without one.

I have been meaning to write you regarding the letter from Walter Ciszek regarding his mixture of six parts aloe vera vitamin E moisturizing lotion mixed with one part glycerine. I was unable to locate the brand of aloe vera vitamin E lotion he mentioned, so I tried another mixed with glycerine and the results were outstanding. Within a few weeks I was able, for the first time in my life, to get by with only one application of lotion each night after showering. Rarely do I have the need to apply any lotion in the morning except to my face and hands after shaving or when I wash my hands during the day. This mixture is far superior to many more expensive lotions which I have stopped using.

Frank J. Mosunic  
Morgan Hill, California

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

I have two grandsons with lamellar ichthyosis. For many years I was able to purchase moisture mitts for them from Verco Enterprises in Mt. Clemens, Michigan. The last time I sent in an order it was returned to me saying they no longer

make the mitts. If anyone knows if these mitts can still be purchased and where, I would appreciate that information. I enjoy the newsletter and over time I have picked up many helpful

ideas about things to use to make the boys more comfortable.

I am enclosing the order form for the Parent Handbook, and I am delighted to know there soon will be a handbook for teachers [see back page for details]. It would be impossible to place a value on the work F.I.R.S.T. is doing or the information made available to people who have some form of ichthyosis.

My congratulations to Ms. Deb Vilas on becoming Board President. Keep up the good work.

Edna Cotton  
Helena, Montana

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

I am a sixteen-year-old girl with ichthyosis vulgaris. I am looking for pen pals any age, boy or girl, as long as they are willing to write frequently. I play trumpet and softball.

Amy Winkel  
1523 S. Washington St.  
Kokomo, IN 46902

P.S. During the summer my legs (where my ichthyosis is) itch and my scratching sometimes causes bleeding. Does anyone know why or how to get rid of the itching?

I was diagnosed with Pityriasis Rubra Pilaris in May, 1994, and have been struggling with this disease since then. I would like to correspond with others with this disease to discuss how it affects them, and perhaps discuss coping strategies.

Tony Pack  
2417 Tantelon Pl.  
Winston-Salem, NC  
27127  
(910) 785-4389

Dear Editor,

I find the health care reform program by Clinton to be a political boondoggle. What is being attempted by the Administration is providing 50% more health care for less money than is now being paid for existing health care. We spend on trillion dollars on health care, so under the terms of the new program we will spend one and a half trillion dollars for health care. If you now have a doctor that you trust, you will find that he will have a 50% increase in work load. The politicians' ideas on health care reform consist of violating all of the rules which have been established over the years and this is supposed to provide people with more health care. It will really result in a disaster.

If you want to solve the problem, you first need to break the problem down into parts and attack each part separately. One part is low cost health insurance. To obtain this, the government must write the policy. This should be for universal coverage, and everyone could select customized coverage in their policy. For example, if you were a senior, you would not want maternity coverage, so you would remove this and receive

a rebate on premiums. If you wanted catastrophic coverage which cuts in at, say, \$1,000, you could get it. Once you have selected your policy you would send it out to the insurance companies and have them bid. The public could then pick out the company they want to carry their policy. The insurance company would not be allowed to change the policy. Removing the high pressure salesmen and the fine print and legalese from the insurance industry will lower the cost of health insurance.

Charles K. Maxey  
Deming, New Mexico

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

First of all, thank you for your attention to our phone call asking for F.I.R.S.T. publications. We were very happy to receive them so quickly.

I have three children, and my second, Diego, now eight years old, was born with "ichthyosis bullosa" [EHK]. We do not know anyone with this disorder. Here in Brazil, things are very difficult and we don't have any associations for people with skin diseases. That's why we feel stronger having the help of F.I.R.S.T.

Since Diego was born, my husband and I and our whole family fight to give him a better quality of life. Although things are hard and the medical expenses enormous, we are optimistic and believe in a strong future for our son. Diego is a very special child. His pains do not impede him, and he is an excellent student.

When he was born, I was in despair. I wanted to isolate us from the rest of the world. In my heart was the only place for pain and bitterness. I felt that it was unfair and went through many nights searching for a cause for such cruelty. In the beginning it was hard for Diego, for he was in the hospital fighting for his life. Each time that he returned home I felt happy, and when I looked in his little eyes I felt a positive energy. He and his fight gave

me peace and hope. It was with love and help from him that I finally got free from the bitterness and discovered that he did not belong just to me and that I had no right to keep him isolated from the rest of the world.

As Diego was growing up I learned to live each emotion one at a time, be it sadness or joy. Today I know that we still have a long journey, but I feel grateful to God, who gave me such a mission, such a good family, and especially Diego. As he grows up, I believe even more in his future, and in the joys that we'll share with him. And I've learned a truth: It is impossible to run away or to hide from ichthyosis. When it comes, we assume it, without shame or fear. Our child is our pride and we love him without feelings of rejection or guilt.

I am sending a donation to F.I.R.S.T. and will continue to do so annually as our economic situation permits. I thank you for the help you give to us. Sincerely,

Maria das Gracias B. Tanaka  
São Paulo, Brazil

Dear F.I.R.S.T.

Must thank you for the newsletter. I enjoy reading them. I am a woman of 77 years, and I've worked with my terrible skin for all these years. I've had everything in life but children, and we took in foster children for 32 years. We raised many, including handicapped. We have been married for 50 years come September, and we have eight grandchildren from our foster daughters. I would say I've had a good life in spite of my dry skin.

I make up my own skin cream. I use 2 lbs. of vaseline and 3 full bottles of baby oil and heat them together in a big pan—*slowly!* Then I cool it and pour it back into the vaseline jars. It's worked for me—feels better than expensive lotions.

I just wish I could tell you something that would cure this skin, so the

young ones would not have to worry with it all their lives. It's best to make them comfortable and let them go on with their lives and not dwell on it.

Geraldine Wood  
Manhattan Beach, California

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

I have been an active member of F.I.R.S.T. since it was the National Ichthyosis Foundation. I'm 25 and I have lamellar ichthyosis—pretty severely in my estimate. I have very little faith in dermatologists and doctors in general. I experienced side effects when I took Accutane for 3 months in 1983 and Tegison for about 9 months in 1987. Both medications produced great results, but then the side effects hit. I had nosebleeds and staph infection, and I started losing my hair after taking Tegison off and on for six months. Since then I have sworn off oral medications for good. Right now I use topical treatments (urea & PPG in hydrophilic ointment, 12% Lac-Hydrin on harder scale, and occasionally Keralyt). Basically, that's what I've been using for a decade. I wrap my arms and feet about two to three times a week in Glad Wrap to soften scales. This is the biggest hassle, simply because I need someone's help.

I have found that having ichthyosis has hindered me socially. Basically, I let it. I have improved since childhood. I graduated from college two years ago with a B.A. in English. Now I work at the university's library part-time, and I read for the blind as my second job.

I would really like to correspond with people with ichthyosis. I want to know about how aging affects ichthyosis. I also just want to make friends. However, I would also like to know about topical treatments which might be helpful.

Asima Mahdi  
Irmo, South Carolina

# GRASSROOTS

## GANDER MOUNTAIN CO. & NEW RESOURCES CORPORATION GEAR UP FOR 12-HOUR MARATHON VOLLEYBALL TOURNAMENT TO BENEFIT F.I.R.S.T.

Board member Tom Buehler sends us the following note from Lake Geneva, Wisconsin, where his employer, New Resources Corporation, has challenged a client company, Gander Mountain, to a 24-hour fund-raising volleyball game as a benefit for F.I.R.S.T. The event will have taken place by the time you read this (but not before we go to press). Read all about the outcome of the marathon fund-raiser in the next issue of *Focus*.

Take a Gander at who the Mountain and New Resources put F.I.R.S.T. for charities.

On November 5th, 1994, Gander Mountain and New Resources Corporation put F.I.R.S.T. first. The two companies will hold a 12-hour volleyball marathon to raise money for F.I.R.S.T. The fund-raiser will be held at the YMCA in Lake Geneva, Wisconsin from 9:00 am to 9:00 pm.

The goal of the fund-raiser is to

raise \$5,000 to help underwrite the publication of F.I.R.S.T.'s new patient education book: *Ichthyosis: A Guide For Teachers*. This book will be available from F.I.R.S.T. by the time you read this (see back page of this issue of *Focus* for details and order form).

Employees of Gander Mountain and New Resources Corp. who will play this marathon each sought out sponsors to commit donations based on the hours each employee plays. The Lake Geneva YMCA has provided facilities for the tournament at no cost. Our heartfelt thanks go out to them.

If anyone out there has questions about how to go about developing a grassroots fund-raiser like this, I invite you to call me (Tom Buehler) to discuss it. You can reach me at 815-337-3450.

Grassroots efforts such as these have a significant impact on the financial stability of F.I.R.S.T. We encourage everyone to get involved.

### 1995 National Conference (continued from Page 1)

bitious program for our young people. There will be child care for the very young ones, of course, but for adolescents and teens we'll have a special round of workshops, discussion groups, and presentations devoted especially to their needs.

#### This Is The Conference of The Family

This national conference has for its theme *The Family*. Consistent with the theme, we're designing the conference program with the entire family in mind. There will be program offerings of interest to each member — mom's group, dad's group, youth groups, a focus on siblings, and more.

In addition, we've scheduled out 1995 Family Conference at an ideal vacation destination, and we'll provide ample time and opportunity for everyone to enjoy San Diego — the Pacific Ocean, the San Diego Zoo, Marine World, Mexico excursions, baseball, museums ... *the works!*

Registration forms will be included in the next issue of *Ichthyosis Focus* (due out the first week of February). That and following issues of *Focus* will offer increasingly detailed summaries of the upcoming Family Conference program.

*I look forward to seeing you all in San Diego!*

### DETAILS, DETAILS . . .

<b>When</b>	June 16, 17 & 18, 1995 (Fri, Sat & Sun)
<b>Where</b>	The Bahia Hotel & Resort 998 West Mission Bay Drive San Diego, CA 92109 619-488-0551
<b>Room Rate</b>	\$68.00 per night (family rate)  Family rate means two adults and all children under 18 stay for the flat \$68.00 rate. For more than two adults (18 and over) in a room, add \$15.00 per person.  This rate is guaranteed for 3 nights prior to, and 3 nights following the scheduled conference dates, for a total of 9 nights. Note that this special rate on the extended days is on a <i>space available basis</i> , so be sure to book your rooms well in advance  You may book rooms at any time by calling the Bahia Hotel at 619-488-0551
<b>Registration</b>	Fees will be announced and registration forms made available in the NEXT ISSUE OF <i>ICHTHYOSIS FOCUS</i>
<b>Air Fares</b>	F.I.R.S.T. will announce soon an agreement with a travel agent for the conference, through which special air fare arrangements will be available.

# NEWS & NOTES

## Informed Consent: An Informational Brochure

A reminder that the Alliance of Genetic Support Groups publishes an excellent brochure that provides information that every prospective research participant should know about informed consent laws in the U.S. Entitled *Informed Consent: Participating in Genetic Research Studies*, the brochure contains important background information about genetic research and lists questions consumers might want to ask researchers before entering into a research study.

A copy of this brochure may be obtained by sending your request with a self-addressed stamped envelope to the Alliance of Genetic Support Groups, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815. You may call the Alliance with questions at 1-800-336-4363. Photocopied facsimiles of the brochure may be obtained from F.I.R.S.T.

by writing to the Raleigh office.

## Member Seeks Discussion About How Ichthyosis Affects Older Adults

We received a letter from Mary Ann Brame of Dallas, Texas, who would like to hear a discussion of how older adults manage their ichthyosis. "What have I got to look forward to," she asks. We at F.I.R.S.T. think this is an excellent idea, and we would like to publish in future issues of *Focus* an ongoing discussion among members on this matter. We'll print the discussion in the letters section of the newsletter. We encourage all of you to send us letters describing your experiences to us here in Raleigh. *Be sure to let us know if you want us to print your letter without your name.*

Pen Pals ...

Tatiana Hamor, age 14, would like to correspond

with others who have epidermolytic hyperkeratosis (EHK). You can write Tatiana at:

Box 6211  
Tampa, FL  
33608-0211

## Some Risk With CVC Prenatal Test

The Centers for Disease Control (CDC) released a 1988-1992 study which found that chorionic villus sampling (CVS)—a

prenatal test that detects genetic defects early in pregnancy, increases an infant's risk of missing fingers and toes by a factor of six.

Whereas the normal frequency of this birth defect is .0058 (fifty-eight thousandths) of one percent, after CVS the risk rises to .035 (thirty-five hundredths) of one percent. Previous studies have shown that CVS raises the chance of miscarriage by one percent.

The CDC made no recommendations regarding CVS, but it said expectant mothers should know about the risks. The CDC can be reached at 404-639-3311.

**Children's Home Society of Minnesota seeks families interested in the international adoption of children with special medical and developmental needs. Several children with ichthyosis wait in Asia.**

For more information, contact:



Sara Dorow, Program Coordinator  
Children's Home Society of Minnesota  
2230 Como Avenue  
St. Paul, MN 55108  
(612) 646-6393 \* fax (612) 646-0436

## IN MEMORIUM

Contributions have been made to F.I.R.S.T. in the name of the following persons

**George S. Ebbert**

**Leonard A. Duffy**

All of us at F.I.R.S.T. offer our heartfelt sympathy to friends and family

## HERALD ANNOUNCES NEW PRODUCT

### OFFER FOR F.I.R.S.T. MEMBERS

Herald Pharmacal, makers of Aqua Glycolic Lotion, have announced that F.I.R.S.T. members are now eligible to purchase Aqua Glycolic Shampoo at a special reduced case price of \$54.00 (case of 12 8-oz. containers).

This special offer is in addition to their ongoing special of \$102.00 for F.I.R.S.T. members for cases (12 8-oz. containers) of Aqua Glycolic Hand & Body Lotion. Aqua Glycolic products are based on glycolic acid formulations.

To order, call Herald Pharmacal at 1-800-253-9499. Be sure to identify yourself as a F.I.R.S.T. member. *You must be a current member to be eligible.*

# REGIONAL SUPPORT NETWORK ANNOUNCES GOALS FOR 1995

by Heather Gattuccio  
RSN National Coordinator

As F.I.R.S.T.'s Regional Support Network enters its fourth year, we continue striving to offer our community the support it needs. As the RSN has grown in numbers and strength, we've come to realize that the word "support" in our program title has a variety of definitions, and we respect them all.

Parents of a new baby born with ichthyosis often need ongoing support in the beginning. They seek practical information about how to care for their baby as well as an empathetic ear to listen to their questions and concerns. A veteran parent, however, may wish to discuss an issue that has recently developed in their older child's life, such as a difficult teacher or overheating problems in after-school sports. For

school aged children, support may mean a pen pal or phone pal with whom to exchange support in the form of friendship. Children often find it empowering to know they are not alone in dealing with their different skin and all those annoying lotions. Finally, we know that teenagers and adults with ichthyosis often wish to communicate with one another to share practical information and life experiences. In the RSN, "support" often simply means to listen.

There are significant benefits to joining the RSN. By writing to, talking with and meeting others who deal with ichthyosis on a daily bases, we reduce our sense of isolation; we come together with others who have "been there." Many who connect with other parents and individuals with ichthyosis often express

relief at knowing they aren't alone, and at getting answers to practical questions that professionals often can't answer.

The RSN helps families and individuals become their own experts so they can take charge of their own experiences and feelings.

Presently, the RSN is divided into eight regions. Each region is run by a volunteer regional coordinator who is assisted by a regional representative plus a network of families and individuals experienced with ichthyosis. Because the RSN is a strictly vol-

unteer program, it is only as strong as the people working within it.

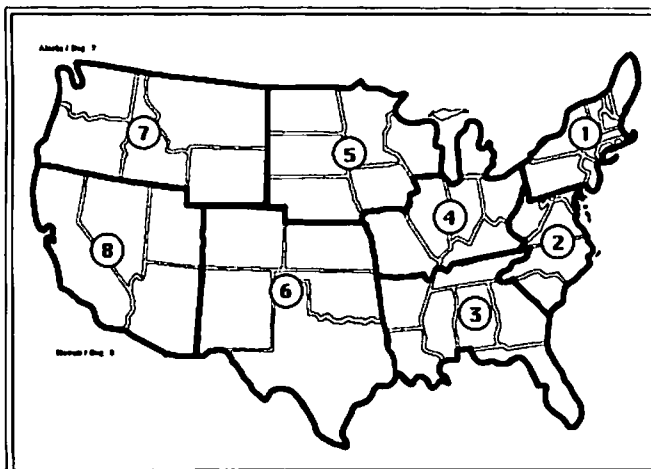
We are now in need of new people to serve as regional coordinators and representatives.

At the same time, we're hoping to find con-

tact families and/or individuals in all fifty states. While you may not feel that you are in need of the RSN's support services at this time, you *may* be in a position to offer it to someone else.

So please consider serving others in your region or state by sharing with them your understanding, positive attitude and empathetic ear. Most of us understand all too well the pain, confusion, isolation and frustration that ichthyosis can present, particularly when it is new to us.

If you are interested in becoming a regional coordinator, regional representative, or state contact, please call or write to Heather Gattuccio at the Raleigh office to obtain an application. *We invite you to join us today*



## Primary Responsibilities of Regional Coordinators

1. Serve as person of first contact for newly referred, offering support, information and encouragement;
2. Network with region and help interested people get in touch with one another;
3. Write a quarterly letter to your region (we duplicate and mail from Raleigh);
4. Attend quarterly telephone conference calls with other regional coordinators.

## Primary Responsibilities of Regional Representative

1. Assist regional coordinator with correspondence and contact responsibilities;
2. Participate in quarterly conference calls when regional coordinators is unable to attend.

## Primary Responsibilities of State Contacts

1. Correspond with interested parties in your state by mail and/or phone.

# 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.

## Medical Privacy

The October, 1994 issue of *Consumer Reports* contains an outstanding and somewhat frightening overview of medical privacy issues. The fact is, our medical records are *not* private. They are not only accessible to third parties, but information about each of us is often sold by pharmacists and physicians to databases, drug companies and others. If a medical fact is in a person's medical records, it will likely be traded, sold or given to a company that should not have access to it. No federal privacy laws presently exist to prevent this from happening.

## HMO Profits Increase; Spending on Patients Decreases

A Washington Post article (by David Hilzenrath) points out that profits and administrative expenses at HMOs

are increasing drastically, while spending on patient health care is decreasing.

According to Hilzenrath, HMO profit margins increased more than 33% last year. During the same period, spending on patient health care fell to just over .82¢ for every dollar collected. Meanwhile, administrative expenses rose 10.5%.

## Life Insurance

People with non-life threatening rare disorders are sometimes charged inflated rates for life insurance policies, or are denied life insurance altogether. If you or someone you know has been denied life insurance, or has been charged an inflated rate even though their disorder will not shorten their life, you may send a brief description of the situation to

Susan Charlton, Esq.

Anderson, Kill, Olick & Oshinsky  
Suite 7500  
2000 Pennsylvania Ave., N.W.  
Washington, DC 20006

## History of Gene Therapy

Larry Thompson, former editor of the Health Section of the *Washington Post*, has written an excellent book that tracks the history of human gene therapy from conception through protocols currently in progress. Entitled *Correcting the Code: Inventing the Genetic Cure for the Human Body* (Simon & Schuster, 1994), the book is on one level a biography of W. French Anderson, whose decades of work led to the first gene therapy experiments on Severe Combined Immune Deficiency (SCID). At the same time, however, the book chronicles the remarkable political, ethical and competitive nature of medical research in general, and the personalities of many whose careers hang on winning the race to a discovery.

This is an excellent book for anyone wishing a layman's introduction to this fascinating new frontier in medical science, as well as a look into the world of medical research.

## Regional Support Network

### REGION ONE

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

### REGION TWO

DE, MD, WV, VA, NC, SC  
Robin Joyce  
Route 1, Box 189-F  
Sandy Ridge, NC 27046  
(919) 871-3277

### REGION THREE

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

### REGION FOUR

KY, OH, IN, IL, MO, MI  
Cynn timer Bates  
133 Elam Park  
Lexington, KY 40503  
(606) 276-0142

### REGION FIVE

WI, IA, MN, ND, SD, NB  
open

### 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 SUPPORT GROUP

Barbara Rockwell  
3080 Ballydown Crescent  
Mississauga, Ontario L5C 2C8  
Canada  
(416) 896-9620

### NETHERTON'S SUPPORT GROUP

Cathy Sipper  
Rt. 1, Box 300  
Laverne, AL 36049  
(205) 335-6827

### NATIONAL COORDINATOR

Heather Gattuccio  
3726 Bellevue Road  
Raleigh, NC 27609  
(919) 781-6671

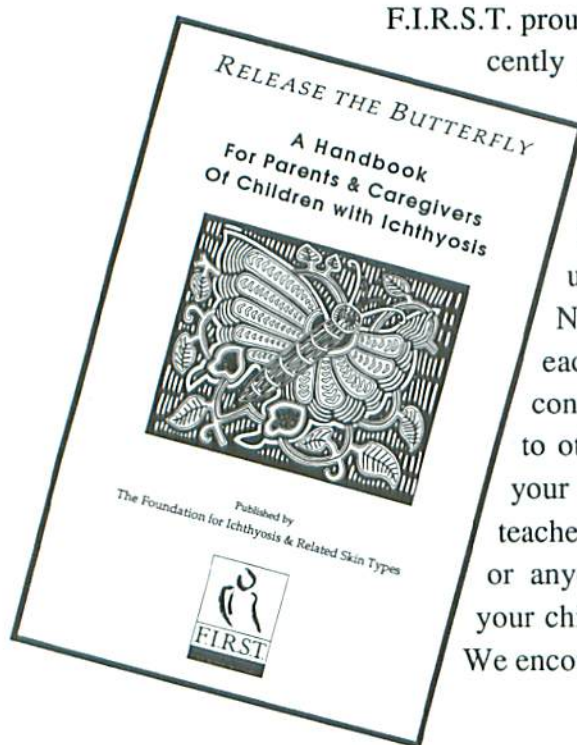
F.I.R.S.T.  
P.O. BOX 20921  
Raleigh, N.C. 27619-0921

Non-Profit Org.  
U.S. Postage  
PAID  
Raleigh, NC  
Permit No. 2209



FOCUS is printed on recycled paper.

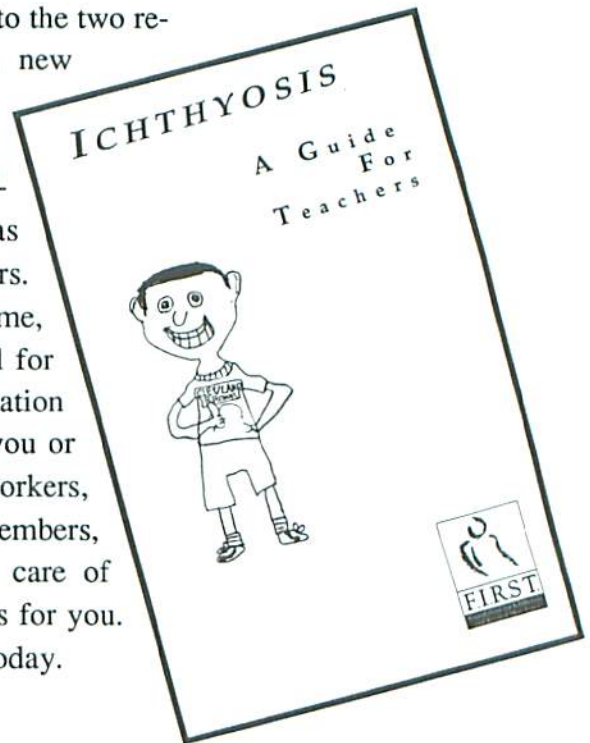
## F.I.R.S.T.'s TWO NEW TITLES IN ITS PATIENT EDUCATION LIBRARY



F.I.R.S.T. proudly introduces members to the two recently published books in its new

Patient Education Library. The outcome of nearly three years of effort, both are intended as useful tools for members.

Not only useful in the home, each can be a valuable tool for conveying important information to others who interact with you or your child—child care workers, teachers, employers, family members, or anyone else for whom the care of your child is as important as it is for you. We encourage you to order both today.



### ORDER FORM

Name \_\_\_\_\_

*Release The Butterfly* @  
\$5.00 ea. \_\_\_\_\_

Address \_\_\_\_\_

*A Teacher's Guide* @  
\$5.00 ea. \_\_\_\_\_

City/State/Zip \_\_\_\_\_

Phone \_\_\_\_\_

\$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: \_\_\_\_\_