

# ICHTHYOSIS FOCUS

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Published Six Times a Year by volunteers of F.I.R.S.T., P.O. Box 410453, San Francisco, CA 94103 (formerly The National Ichthyosis Foundation). Telephone (415) 591-1653. F.I.R.S.T. is a non-profit California corporation for the benefit and education of its members and the public regarding medical, psychological and social aspects of the ichthyoses, a family of genetic skin disorders. Letters, suggestions and contributions are welcome. Valerie Lutters, Editor.

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\*\*\*\*\* FROM THE EDITOR'S DESK \*\*\*\*\*  
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We have a giant-sized issue of Focus this spring, with more news of our past conference, an update from the political front, news about a break through in research into X-Linked ichthyosis, our first renew-your-membership drive, plus some of our regular features.

I'm particularly pleased that with at least two of these articles, we are bringing you news not only about things that have already happened, but about things that are presently happening, things over which you can still have some influence. For example, there's political planning presently going on in Washington that affects skin research and ultimately, hopefully, ichthyosis and you. You can have a positive effect on the way your senators and representatives approach funding for skin research if you write to those legislators and let them know how you, a voter, feel about these issues. For more particulars, see Mr. Eichhorn's article on page 5.

Readers can also have a direct effect on skin research if they, or a member of their family, have X-Linked Ichthyosis. Dr. Larry Shapiro of UCLA has reached some important insights into this disorder, and he is looking for volunteers to help with his research. All he needs is a blood sample -- from you! For more information on Dr. Shapiro's work, and who among you can help him, see his article on page 2.

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Correction! In the February issue of Focus we announced our new name, along with our new address. Well, the zip code we gave you was incorrect, so if you wrote down our new address (and we hope you did), please ZAP THE ZIP and replace it with this correct zip -- 94141. Our complete, correct, address is:

F.I.R.S.T.  
The Foundation for Ichthyosis and Related Skin Types, Inc.  
P.O. Box 410453  
San Francisco, CA  
94141

We apologize for any inconvenience this error may have caused you.

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Spring is either here or just around the corner. And from now on we hope that those crocuses, warmer days, and other signs of spring will remind you to renew your membership with F.I.R.S.T. From now on, May is Renew Your Membership Month, the time when we hope all of you will send in your \$15 and renew your membership with F.I.R.S.T. for another year. As always, we will continue to offer our services, including the newsletter, to anyone in the ichthyosis community, regardless of ability to pay. We have not yet refused membership to anyone on the basis of funds and we hope we never have to. And, because this is the first year we have instituted "May is Renew Your Membership Month," we know that some of you just sent in your \$15 within the last few months; certainly you are not being asked to repay your dues again so quickly. But all the rest of you -- those of you who know you sent in your dues sometime but you're not sure when, those of you who feel you're probably due sometime,..... we hope you'll fill in the form on page 6 and return it to us quickly along with your yearly dues. And, of course, your contributions are always welcome and needed at any time.

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We're pleased to offer a small photo page so you can put a few faces with the names you read about here in Focus. And one of those photos is virtually a photo of photos -- President Susan De Haan putting the finishing touches on the display that F.I.R.S.T. exhibited at the American Academy of Dermatology in New Orleans. That display was a collage of photographs showing not only examples of ichthyosis, but showing people with ichthyosis -- children, adults, people with brothers and sisters, parents and children -- the people behind the skin. We felt it was a very effective display, and we had it because you contributed photographs from your albums and shared them with us after we asked for them last spring.

We thank all of you who sent in those photos, but we could still use a lot more. We particularly need photos of people with Lamellar Ichthyosis. Won't you help us put the human face of ichthyosis in our exhibits? And remember, every picture must have information on the back (use a felt-tipped pen, please) telling us who the person is, his or her age and sex, and the kind of ichthyosis shown. We also need a written and signed basic Photo Release giving us permission to use the picture. On a separate sheet of paper, please prepare a Photo Release saying you give F.I.R.S.T. permission to use the photograph(s) for educational, research or promotional purposes. We can't use any picture without both identifying information and a basic Photo Release.

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Focus readers may want to glance at the March 16, 1987 issue of Newsweek magazine. The issue has a cover story about birth defects, and although ichthyosis is not specifically mentioned, the magazine does point specifically to the dangers of taking Accutane while pregnant or when becoming pregnant is at all possible. The magazine quotes one doctor, an embryologist at Massachusetts General Hospital, as being concerned not only about the dangers of synthetic Vitamin A for pregnant women, but of "very large doses of vitamin A itself for pregnant women." And members of F.I.R.S.T.'s Medical Advisory Board have also cautioned women who might be or become pregnant of the dangers of taking retinoic acid; they have also cautioned anyone, pregnant or not, against taking massive doses of Vitamin A.

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You may have noticed in the last issue of Focus that the list of regional representatives did not appear. If you look carefully at this issue you'll see that the listing the members of our Medical Advisory Board does not appear. Because of space limitations, I plan to alternate between these two lists from issue to issue. If space permits, I'll include both lists in a single issue, but thus far, space has been at a premium. So, hold on to your issues of Focus so you'll always have current list. Our reps remind members that they are there for help, support, camaraderie, whatever. Why not get in touch with the rep nearest you? Stay in touch, reach out, make some new friends....

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 \*\*\*\* BIG STRIDES MADE IN RESEARCH ON X-LINKED ICHTHYOSIS \*\*\*\*  
 \*\*\*\*\* SUBJECTS NEEDED FOR FURTHER INVESTIGATION \*\*\*\*\*  
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Larry Shapiro, M.D., a professor of Pediatrics and Biological Chemistry and Chief of the Division of Medical Genetics at the University of California at Los Angeles, has announced that the medical community is "very excited" about some new discoveries relating to the gene for steroid sulfatase which is missing in people with X-linked ichthyosis. He notes that in most genetic disorders, the errant gene is damaged or otherwise imperfect, but in this disorder he finds that the gene is missing entirely. The next question to be answered, he says, is why that gene is missing, and the means to answering it may lie in investigating not only people with X-Linked Ichthyosis but members of their immediate and extended families as well. He feels the discoveries relating to causes of X-Linked Ichthyosis will be of interest to people with this particular disorder, of course, but also to people with other types of ichthyosis and to the field of genetics in general. Dr. Shapiro here discusses his findings and his hope that members of our foundation will be able to help him with his continued research.

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**X-LINKED ICHTHYOSIS -- RESEARCH ADVANCES AND  
 A NEED FOR ASSISTANCE  
 Larry J. Shapiro, M.D.**

One of the most common forms of ichthyosis is X-Linked Ichthyosis. It is also one of the best understood of the inherited scaling conditions at a genetic and chemical level. This form of ichthyosis is typified, as its name would indicate, by a unique pattern of inheritance that has been known for over 100 years. As with hemophilia and Duchenne muscular dystrophy, which are also X-linked, only males are affected, but the disorder can be transmitted in families through normal-appearing carrier females. This is because the gene responsible for the disorder is located on the X chromosome.

Chromosomes are physical structures which can be viewed under a microscope. Each chromosome consists of thousands of individual functional units called genes. Genes are too small to be seen directly, but their structure can be determined indirectly, in precise molecular detail, by modern methods of genetic engineering or DNA technology.

Each human being has 46 chromosomes, half of which are derived from the individual's mother, the other half coming from his or her father. Two of these 46 chromosomes are sex chromosomes, either X chromosomes or Y chromosomes. Each female human being has two X chromosomes, one inherited from the mother, one from the father. The male has one X chromosome, inherited from his mother, and one Y chromosome, inherited from his father.

Most individual genes are present in two copies in human beings, one copy on a paternally derived chromosome and one copy on a maternally derived chromosome. This provides a certain redundancy or back-up such that if one gene fails to function for some reason there is a second gene which can carry out its necessary job at an adequate level. This dual back-up system also operates for genes on the X chromosome for females for there are two X chromosomes. Males, however, have only a single copy of X-encoded genes, and so if one fails to function, there is no back-up available. Thus, females are protected from X-linked mutations or loss of function of X-encoded genes, but males are not. Thus, if a woman has a single defective X-linked gene, she will not display the disorder because her healthy gene takes over. She may, however, pass that bad gene on to her sons who, since they receive no other functioning copies of the gene, would manifest the defect.

Several years ago, our laboratory identified the specific gene responsible for X-Linked Ichthyosis. It is a gene which normally directs cells in the body to produce an enzyme called steroid sulfatase or STS. Cells from patients with X-Linked Ichthyosis fail to make any STS. Work at several universities has begun to reveal how the lack of STS can produce ichthyosis, and these results have led to advances in our knowledge of the causes of several kinds of ichthyosis and to such improved diagnostic and therapeutic methods as well as to effective genetic counselling. More recently, our research group has precisely pinpointed the location of the STS (X-Linked Ichthyosis) gene on the X chromosome and has actually succeeded in physically isolating this gene and determining its detailed structure through use of recombinant DNA or molecular biological methods. This has enabled us to ask, at a molecular level, precisely what the nature of the defect in the STS gene is in patients with X-Linked Ichthyosis.

It is at this point in our recent work that we encountered a surprise. In contrast to what has been observed in several other human genetic disorders studied in this detail, we find that most patients with X-Linked Ichthyosis are actually missing their entire steroid sulfatase gene. In other conditions the disease-related genes are often altered in structure but are still physically present. It is our hope that further research into the cause of the complete loss of the STS gene in X-Linked Ichthyosis will enable us to better understand this condition and may also lead to more accurate

methods to actually diagnosing carriers of X-Linked Ichthyosis. Our studies may provide the unique opportunity to gain insight into basic processes of genetic alteration or mutation in many diseases.

HOW YOU CAN HELP

In our efforts to determine the cause of this deletion, we need the help and collaboration of several families with X-Linked Ichthyosis. Further progress of this research will not be possible without the assistance of interested families. All that is required from participants is a single, small blood sample. If you or a close relative has been diagnosed as having X-Linked Ichthyosis, and if both parents of an affected person as well as both maternal grandparents are alive and available for study, you could be of enormous assistance. All costs of participation, including travel, will be covered, and results will be held in confidence except for the participants. If you would like to help us with this research project, or need additional information, please call or write:

Larry J. Shapiro, M.D.  
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Harbor-UCLA Medical Center  
1000 W. Carson Street  
Torrance, CA 90509  
Tel: (213) 533-3751

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Dr. Shapiro was born in Chicago and received his undergraduate and medical training at Washington University in St. Louis. Following research training at the National Institutes of Health in Bethesda, MD, he joined the faculty at the UCLA School of Medicine where he is currently Professor of Pediatrics and Biological Chemistry. Dr. Shapiro is Chief of the Division of Medical Genetics at Harbor-UCLA Medical Center and is an Investigator of the Howard Hughes Medical Institute. Active in many research societies, Dr. Shapiro currently serves on the Council for the Society for Pediatric Research, the Board of Directors of the American Society for Human Genetics, and as President of the Society for Inherited Metabolic Disorders.

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\*\*\*\*\* ANNUAL CONFERENCE -- AFTERNOON SESSION \*\*\*\*\*  
\*\*\*\*\* THE SOCIAL AND PSYCHOLOGICAL IMPLICATIONS OF ICHTHYOSIS \*\*\*\*\*  
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The afternoon session of the 1986 Annual Conference in New Orleans took a slightly different turn from previous conferences, with a presentation on the social and psychological implications of ichthyosis by Dr. Wilmer Betts, followed by group discussions on the same topic. Dr. Betts, a psychiatrist from Raleigh, N.C., who has been in practice for over thirty years, is the father of four grown children, three of whom have ichthyosis. Dr. Betts shared his knowledge, experiences, and expertise with a rapt audience of about 50 people, most of them parents of children with ichthyosis. A synopsis of his comments follows.

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God grant me the courage to change the things I can,  
The serenity to accept the things I cannot change,  
And the wisdom to know the difference.

The message of that now-famous "serenity prayer" was the foundation of Dr. Betts's comments when he spoke to parents about raising a child with ichthyosis. He hoped parents would put more energy into accepting the disease than in trying to find a cure for it; more energy into raising an emotionally well-adjusted child who copes well with the disease than into elaborate physical treatments and endless searches for the "right" doctor. And the good news is that while they may not be able to do as much as they would like to alter the condition of the skin, there is a great deal they can do to ensure their child's social and emotional well being.

To fully accept the reality of the disease, it is crucial for the parents to accept that they did not cause the disease, nor can they cure it. They must accept the reality of living with a chronic disease -- reduce cosmetic problems, relieve discomfort, help the child toward healthy ego development.

As soon as the child is born, he said, the parents must develop an objective, unemotional attitude about the disease, separating the child from the disease and the problems surrounding it. They must overcome any tendencies to blame themselves, or each other, and must also work to reduce conscious or unconscious hostility or rejection of the child because of the disease; he added that individual or group counselling may be needed. Dr. Betts recommended that parents also get good genetic counseling and not automatically deny themselves more children for fear they might all have ichthyosis.

He urged them not to worry or give in to unrealistic fears about the future, noting that he had never seen the disease get worse, and he has seen it improve. He added that both parents should share in the care of the child, including skin care, under the guidance of their doctor. And he urged them to avoid becoming isolated with their problems, adding that getting together with other families in similar circumstances (via F.I.R.S.T., for example) could be extremely helpful. He said that one of the best things that could have happened to his children was that they "had each other, there were three of them, and no one had to feel all alone. They ended up being their own self-help group."

A combination of acceptance and denial of the disease was something Dr. Betts recommended, in as much as parents need to accept the skin and its problems, yet must deal with the child "like any other kid, like there's nothing wrong." You don't deny the disease by searching for cures, et cetera, but you do deny it in terms of how you treat the child as a person, and you definitely deny it if that child tries to use it as an excuse to withdraw from other children, to get out of activities, to imply that he deserves special treatment or privileges.

When the child is still an infant, he went on, touching is very important. Dr. Betts emphasized that babies with ichthyosis are no different from other babies in this regard -- they need touch, they can pick up on parents' feelings and attitudes through touch, they communicate and learn through touch. He suggested that skin care be part of this touching, and that it be handled by both parents and done in a positive, affectionate manner.

He said parents can strive to give the child a positive body image, emphasizing that his body is just fine despite a problem with its "envelope." Towards this end he urged parents to keep in check their tendencies to over-protect. Don't use the disease as a reason to limit a child's activities, he said; children naturally want to participate -- don't automatically assume "he can't." There may be some things the child legitimately can't do and he'll find those out on his own -- but ichthyosis is probably no reason to avoid swimming, dance recitals, gymnastics, et cetera. In fact, going swimming or undressing for gym in front of other people is probably a good idea, so that something which initially might be embarrassing becomes, over time, something that the child does without any thought; result-- he can easily do something which he could have found paralyzing if he'd initially been allowed to give in to his fear or embarrassment.

Parents should do all they can to encourage a positive self image in the child, even a bit of a shell through which he can screen out some of the unpleasant realities of living with a disease that affects his appearance -- rude questions, lingering stares, dumb jokes. Let them know that people who treat him this way are sick or disturbed, he said.

When the child first starts school, said Dr. Betts, it's a good idea to let the teacher know what his problems are -- and what they aren't! Hopefully the child has already had a lot of contact with peers, and hopefully the family won't have to move frequently so that he can be in the same schools and with the same kids over a period of time. Kids who know him for a long time will literally forget the disease and see him only as an individual, while new kids will see the disease first. In addition to school, there are church groups, neighborhood children, Little League teams, dance classes .... all sorts of opportunities for repeated interaction with other children. And, if the child with ichthyosis balks at joining these groups, if he wants to withdraw or avoid other children, Dr. Betts suggests that a little gentle but firm pressure to socialize is better than allowing the child to become isolated.

As part of seeing the child rather than the disease, he urged parents to try not to take it all that seriously. He suggested that while visiting the doctor might be necessary from time to time, those visits should be kept to a minimum so the disease is not allowed to be the central issue in the child's life -- or the parents'. And what skin care is needed should be turned over more and more to the child himself; it's part of accepting the disease, part of not thinking of himself as a dependent person. And, while clothes might have to be adjusted a little to accommodate the skin, he said that the child should be allowed to have clothes "just like everyone else's" as much as possible. Clothes are important because they are part of our body image, and this is an opportunity for the child's body image to be one of sameness, not different-ness.

For children approaching and entering adolescence, Dr. Betts suggested that parents continue with more of the same -- positive body image, continued socialization.... He added that it would be very helpful if young people with ichthyosis could meet adults with the same disorder, adults who had gone on to participate fully in important life situations -- career, marriage, children, etc. He felt peer support groups for young people with ichthyosis would also be helpful.

Dr. Betts went on to say that in adolescence the child with ichthyosis is faced with greater emotional and physical intimacy with peers, and that it is important for him or her to realize that people with ichthyosis do date, go steady, marry and have children. He said parents need to encourage and support talking and sharing of feelings, "self-disclosure." He added that with an adolescent it is usually best if the child initiate discussions but that parents be ready to listen. He added that these sorts of close relationships should also have developed with peers -- a best friend during childhood, heterosexual relationships in adolescence.

By adolescence and young adulthood he hoped that the child would have learned that it's the things that are inside that count, not the outside. He or she should be encouraged to realize that he need not choose a mate with a defect to be comfortable, nor does she have to choose a physically beautiful mate to compensate for any feelings of inferiority that might still linger.

Obviously, Dr. Betts felt a child's emotional and social development, were well within the realm of parental influence. And that while the fact of the disease might fall within the category of "things we cannot change," the family's attitude toward it, and the child's adjustment to it, were things that parents could definitely and positively change and influence for the better. Parents and children in the ichthyosis family need a bit of serenity and a bit of courage; at the annual conference they were also allowed to share a bit of the wisdom Dr. Betts had acquired through both his professional training and his years of experience raising children -- both with and without ichthyosis.

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After Dr. Betts's presentation, the conference participants broke into smaller groups to discuss issues of particular relevance to particular people. They then presented those issues to the group as a whole.

Children reported: they were more sensitive to other people's feelings as a result of some of the ways they were sometimes treated by insensitive people; they get angry when parents who "make a big deal" about their skin and put skin care at the center of their life; are equally bugged by parents who feel that only adults can take care of the child's skin instead of letting the child do it himself ("we can do a lot more than they think we can!"); worry a little about how to discretely take care of their skin when they're away from home; sometimes give in to feelings of "why me?"

Parents reported that: they have more trouble disciplining the child with ichthyosis than other children; they really need to be able to talk with other ichthyosis parents who have been through the same sorts of things.

Adults with ichthyosis: felt the disorder had helped them become astute in reading others' feelings; found that the skin acted as a screening device to keep shallow or insincere people out of their lives; wondered how they could apply some of Dr. Betts's comments to their adult lives in an effort to parent or re-parent themselves towards healthier attitudes toward themselves and their skin.

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\*\*\*\*\* CORRESPONDENCE CORNER \*\*\*\*\*  
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Ann Cole is 18 and has Lamellar Ichthyosis. She would like to correspond with others in her age range to discuss how ichthyosis affects a young person's social life, particularly their interaction with the opposite sex. Ann, who's address is 61 Colonial Drive, Valparaiso, IN, 46383, is especially interested in hearing from some young men and learning about the male perspective.

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 \*\*\*\*\* HOT TIPS \*\*\*\*\*  
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Two sisters with Ichthyosis Vulgaris, living on the West Coast, find these activities helpful. Swimming regularly in a swimming pool; rubbing the skin with "baby wipes" here and there throughout the day to return a little moisture and to reduce any bacteria on the skin, thus making it feel clean and smooth.

Another tip from the West Coast, this time from a member with Epidermolytic Hyperkeratosis. Her product of choice is Ultra Mide 25 from Baker/Cummins of Miami, FL. She says it is most effective in reducing scale, yet without the irritation she experienced with lactic acid and other products. It doesn't quite make the grade for lubrication, though, so she uses it in conjunction with petroleum jelly. Ultra Mide 25 is available through Rx Allstates as well as in most pharmacies (though it may be behind the counter) and does not require a prescription.

Another member with EH, this one from the East, wanted to get into an aerobic dance program, but when she started she found she was extremely stiff -- not just in her muscles, but in her skin. Her tip -- try taking a bath and lubricating the skin before exercising. It's a bit redundant, but makes moving easier. She still had some skin soreness at first, but "hung in there" and found that when the skin healed, it healed in the more "stretched" position; thus, within a couple of weeks she had little or no skin discomfort from exercising.

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 \*\*\*\*\* MR. EICHHORN GOES TO WASHINGTON \*\*\*\*\*  
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Charles Eichhorn, secretary of F.I.R.S.T. and a member of its Board of Directors, has just returned from Washington, D.C. where he met with representatives of other skin disease foundations to discuss federal budget considerations related to skin disease research. His report follows:

1988 SKIN RESEARCH BUDGET TALKS  
 NEED YOUR LETTERS

On February 25 and 26, 1987, I attended two meetings in Washington, DC, with representatives of other skin disease foundations. The subject was the 1988 federal budget under consideration by Congress, and government-sponsored research programs.

We all want research into the prevention, cure and treatment of ichthyosis in its many forms. It is important to understand that practically all research in the U.S. is coordinated and funded by the government National Institutes of Health (NIH) in Bethesda, Maryland. Skin research in particular is within the jurisdiction of the new National Institute for Arthritis, Musculoskeletal and Skin Diseases (NIAMS), a division of NIH created in 1986.

NIAMS performs some research itself, but most work is performed at medical centers around the country by private researchers who are awarded grants by NIAMS based on the value of the proposed research. Many F.I.R.S.T. Medical Advisory Board members are working on ichthyosis research directly or indirectly under NIAMS grants. The NIAMS 1987 budget was \$138 million. The 1988 budget proposed by the White House/Office of Management and Budget is only \$123 million.

NIH/NIAMS has considered the potential grants and research needs for 1988 and is asking for a 1988 budget of \$196 million. Although this is a substantial increase from last year, it must be remembered that last year was the NIAMS's first year in operation. NIAMS is still in its formation period, hiring personnel and gathering equipment. Exceptional research applications are being submitted, and past success points toward more research opportunities than other Institutes have. NIAMS funding is still only on a level with the National Eye Institute.

After listening to a discussion of the pros and cons at a meeting of the NIAMS Coalition, the skin disease support groups, including F.I.R.S.T./N.I.F., agreed to support the \$196 million figure. This proposed budget includes approximately \$2.5 million to create new skin disease research centers around the country.

The House and Senate Appropriations Committees are currently considering the final budget amounts. The head of the Senate Committee is Senator Lawton M. Chiles, Jr., (D-FL). Other Senators on the committee are from the following states: WV, WI, SC, ND, HI, IA, AR, CT, OR, AK, NH, PA, ID, and NM.

The Chairman of the House Committee is Congressman William H. Natcher (D-KY). Representatives on this committee are from the following states: IL, WI, OH, MA, NJ, MD, MI, FL, and MN.

Last year F.I.R.S.T. President Susan De Haan, along with South Carolina rep Sarah Massey and her son Robert, appeared before these Congressional appropriations committees and testified for a generous NIAMS budget last year. This year our Vice-President and North Carolina rep Ellen Rowe will be testifying on behalf of the \$196 million 1988 budget.

Meanwhile, there is a great deal that other members of the foundation can also do to gain Congressional support for the NIAMS budget. If the Chairman or a committee member is from your state, please write to him or her and tell them you believe more research is needed in ichthyosis and on skin diseases in general. Tell them that you support the full \$196 million budget for 1988. Your letters mean more than anything else we can do to maximize the basic research programs needed to beat ichthyosis.

Need a name or address for your senator or representative? Look in your telephone book in the section listing government agencies. If you have trouble locating it there, check at your local library or town hall.

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F.I.R.S.T. President Susan De Haan points out that the 1987 budget of \$138 million was higher than the amount recommended by the White House last year. She feels that the amount appropriated was a direct result of people writing to their Congressmen. Mrs. De Haan thanks everyone who wrote last year and urges us once again to keep those letters going out to our legislators who can influence the amount of money that will go to research and who do listen to the voice of their constituents -- that's you!

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- WASHINGTON: Richard Kelley, 12305 SE 73rd Place, Renton, WA 98056
- BR. COLUMBIA: Valerie Munroe, 2492 West 45th Ave., Vancouver, B.C. V6M 2J8 Canada (Chapter)

We need informaal representatives and support persons in every state and major city. How about you? Would you spend a few hours each month sharing information and "being there" for someone in distress? We particularly need help in the following areas where there is no one for new parents to turn to: Maryland / Kansas-Nebraska / Vermont-Maine / North and South Dakota-Wyoming-Montana / West Virginia-Kentucky-Tennessee-Alabama / Arizona / Arkansas. Please contact Betty McMasters, 1838 So. Muskogee, Sapulpa, OK 74066 (Tel: 918-224-9099) for details.

Representatives who move from their area are asked to let Betty know about the move as soon as possible. Also, please notify Focus directly of your move so we can remove your name from the published list as quickly as possible.

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 IT'S MAY, 1987 -- PLEASE RENEW MY MEMBERSHIP NOW!

NAME: \_\_\_\_\_

MAILING ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_, ST: \_\_\_\_\_, ZIPCODE: \_\_\_\_\_.

NEW MEMBERSHIP: \_\_\_\_\_ or RENEWAL: \_\_\_\_\_ (check one)

AMOUNT ENCLOSED: \$ \_\_\_\_\_

Please enclose your check, made out to F.I.R.S.T. and return to: F.I.R.S.T., P.O. Box 410453, San Francisco, CA 94141.

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Dr. Wilmer Betts, a psychiatrist practicing in Raleigh, N.C., and the father of four grown children, three with ichthyosis, spoke on the social and psychological implications of ichthyosis and gave parents advice on how to raise a child with this disorder during the afternoon session of the annual conference. With him here is his daughter, Ellen Rowe, our North Carolina representative and newly-elected Vice President of F.I.R.S.T. Mrs. Rowe coordinated the afternoon program of the annual conference.

F.I.R.S.T. President Susan De Haan, right, presented a Certificate of Appreciation to the Greater Tulsa, OK, Chapter during the afternoon session of the annual conference. Accepting the certificate are Marge Boyd and Diane Boyd. The Tulsa Chapter presented F.I.R.S.T. with a check for \$900 at the conference. The chapter has consistently raised funds, through garage sales, with the help of the local Moose Lodge, and other efforts. Members of that chapter have been long-term, faithful supporters of the national foundation and the local ichthyosis community.



Mrs. De Haan put the finishing touches on the display which the foundation exhibited at the American Academy of Dermatology during the week following the conference in New Orleans. We were able to put together such a display thanks to those members who responded to our request for photographs.



After the conference, plaques were presented to Jeannette Jensen and Charles Eichhorn. Mrs. Jensen, who has been secretary/treasurer and "one-person office staff" since 1983, is stepping down because she is returning to school. She will remain on our Board of Directors. At a recent Board meeting, Mrs. De Haan credited Mrs. Jensen with getting the foundation into sound financial shape. Mr. Eichhorn, former editor of focus and Co-president of F.I.R.S.T. until last April, will also remain on the Board and has been elected secretary. He will be more involved politically and will also remain our legal consultant and computer expert. The Board of Directors and members expressed their sincere thanks to Mrs. Jensen and Mr. Eichhorn for their years of selfless service to the foundation.



Just a Reminder -- Ichthyosis Focus is sent out six times a year to members of F.I.R.S.T. The annual membership fee, due in May, is \$15 for a regular member, \$25 for a contributing member, \$50 for a sustaining member. A contribution of \$75 per year designates a sponsor, and \$100 per year a patron. At this time the Foundation does not send out annual bills, but we will request dues during May, "Renew Your Membership Month." An annual membership drive could make it easier for individuals to remember to pay their dues, and for our hardworking bookkeeping staff to keep track of everyone. Meanwhile, if you can't afford to contribute at this time, you need not worry that the newsletter will stop coming to your home; it won't. As yet, no one has been turned away from any of the services of F.I.R.S.T. based on fees and finances. We ask you to contribute an annual membership fee, but if you just can't right now, we understand, and trust you to help us as much as you can as soon as you can. And, of course, you can make a contribution at any time! The Foundation needs continued financial support in order to maintain its programs. All donations, both large and small, are needed and appreciated; all are tax deductible as allowed by law. And you can designate F.I.R.S.T. (formerly the National Ichthyosis Foundation) to be the recipient of your United Way contribution through its Designated Charity Program; ask for the special form to direct your contribution to a specific organization, whether you will be donating directly or through payroll deduction.

**National Ichthyosis Foundation**

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**1987 OFFICERS**

<b>Susan De Haan, LCSW</b>	<b>President</b>
<b>Ellen Rowe</b>	<b>Vice President</b>
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<b>Charles Eichhorn</b>	<b>Secretary</b>

F.I.R.S.T., the Foundation for Ichthyosis and Related Skin Types (formerly the National Ichthyosis Foundation), is a charitable organization, incorporated in 1981 under the non-profit corporations laws of California. Its tax exempt status has been confirmed by the California Franchise Tax Board and the Internal Revenue Service. All contributions are fully tax deductible as allowed under California and federal tax law.

The opinions expressed in this Newsletter are those of the Editor, and not necessarily those of the Board of Directors, Officers, Medical Advisory Board, or membership. F.I.R.S.T. does not endorse any particular product or treatment for ichthyosis. All medically related news and information is intended to inform and educate, and is not to be taken as a recommendation for use in any particular case. Readers are urged strongly to confer with their own physicians and proceed with treatment only on a doctor's specific recommendation.