



The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

The National Ichthyosis Foundation
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**** FROM THE EDITOR'S DESK ****

MORE THAN JUST CHARITY -- We hope you consider NIF more than just another "charitable cause," looking to you for a "charitable contribution." If you or a loved one has Ichthyosis, you should consider doing your share to support the Foundation for very selfish reasons. We can provide information, referrals, a helping hand, and hope for a better future for you and your children. NIF is an **investment**, not just a charity!

NO PAIN, NO GAIN? -- We don't think your contributions to NIF should have to hurt. Here's a relatively painless way you can make a substantial donation and hardly feel it! The **UNITED WAY** campaign now allows both government and private company employees to make donations to specific organizations (like NIF) either directly or through the payroll deduction plan. If you will be making a donation to the United Way this year, please ask for the special form to make a contribution earmarked just for NIF. Many members tell us they donate through United Way, and have a hard time making any extra donations. Now you can use your "painless" United Way donation for our most worthy and personal cause. Tell your friends so they will know their United Way donations are doing good.

MONEY, MONEY, MONEY -- Unfortunately, money is an absolute necessity for us to continue operations. The 1984-85 Financial Report in the next issue will show you where the money goes. You'll notice there's nothing listed under "salaries" for the NIF staff. We're all volunteering our time and energy, as well as money. Jeannette Jensen, our tireless Secretary/Treasurer, has turned her apartment into a post office to handle the NIF mailings, correspondence and telephone answering machine. For the past year, NIF has been using my small office computer for all the NIF work: survey database as well as the membership records and mailing list. NIF's needs have outgrown my machine and we have to buy a used machine that can handle the increasing burden. We need a small office to centralize our records and work. Financial donations for this special purpose would be most welcome. The only way we can keep up the newsletter is through our mailing list. The only way we can offer the scientific research community a body of information about Ichthyosis is through our new database. The computer is the center of all our operations, and a special gift from members to offset the additional costs would be sincerely appreciated.

***** WHAT'S NEW *****

LAS VEGAS, HERE WE COME!! -- The 1985 NIF National Conference will be held in Las Vegas, Nevada at the Best Western Mardi Gras Hotel. An open reception jointly sponsored with the Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (DEBRA) is scheduled for Friday evening, December 6, 1985. Great hors d'oeuvres and a cash bar. The high point will be the presentation of a grant to Dr. Karen Holbrook to fund a registry of all prenatal testing done to discover skin diseases like Ichthyosis and epidermolysis bullosa. Tickets for this reception are \$12.00 per person.

The next day, Saturday, December 7, NIF will present its Third National Conference from 8:30 AM until 5:00 PM. The morning program will include medical presentations by members of the Medical Advisory Board. Dr. Mary Williams, will present information on the different types of Ichthyosis, explaining the difference between normal skin and Ichthyotic skin. Dr. Eugene Van Scott will offer the latest information on topical ointments, creams, lotions, etc., that are particularly effective and safe in removing scales and treating Ichthyosis. Systemic treatments, focusing on synthetic vitamin A derivatives, will be discussed by Dr. Leonard Milstone of Yale. The possibilities for treating

Ichthyosis with a pill are always of great interest. Last, Dr. Peter Elias will describe the most recent research into the causes and treatments for Ichthyosis, and explore future directions for research projects. These presentations will be accompanied by visual aids and all of the speakers will be available for questions from the audience.

A delicious buffet style lunch with a choice of entrees will be served right in the hotel, and the afternoon session will follow immediately. Ichthyosis can have a powerful psychological impact on the patient, his or her family, and others in society. The problems are more than skin deep, and Susan DeHaan, L.C.S.W., will share valuable insights with all of us living with Ichthyosis.

Another afternoon session will be an address by Dr. Alan Moshell, Skin Diseases Program Director of the National Institute of Health. Dr. Moshell will explain the national research system on Ichthyosis, its focus and progress, and how the federal funding process for such work operates.

The final session will be an update on the foundation's activities in 1985 and presentation of the 1986 Annual Plan. A highlight will be the publication of the information derived from the national survey taken earlier this year.

From 5:00 to 7:00 PM, an informal reception open to all members and their families will be held in the hotel. The rest of the evening (and weekend!) is free for you to enjoy in fabulous Las Vegas!

NIF has arranged for a block of 25 rooms to be held for NIF members at the reduced rate of only \$35 per night for Friday and Saturday. **Reservations must be made directly with the hotel**, on a first-come, first-served basis. Child care by qualified personnel will be available at the hotel during the Conference. Many airlines offer special fares for tickets purchased at least 30 days ahead. Look for bargain fares to Las Vegas in your Sunday paper travel section. Remember, a travel agent can be a great help, and their services are free to you. Check with your tax advisor about the deductibility of Conference expenses, as well as travel, etc.

Tickets for the DEBRA-NIF Reception on Friday, December 6, 1985, are \$12.50 each. Registration for the NIF National Conference, including buffet lunch and reception to follow, are \$35 per person and \$50 for families. Registration forms will be mailed to you October 1, 1985, and must be returned within thirty days. Hotel accommodations at the Best Western Mardi Gras in Las Vegas must be made directly with the hotel. Call Best Western toll free at 800-528-1234, and ask for the National Ichthyosis Foundation arrangements. Do it today!

HELLO! IS ANYBODY THERE? -- No one has recommended candidates for the Board of Directors. Please think harder. Also, NIF needs volunteers to work in National leadership roles: we'll need a new President next year, and nominations (even self-nominations) from the membership are most welcome. A Board of Directors meeting will be held in Las Vegas December 8, 1985.

GETTING THE WORD OUT -- Valerie Lutters, who recently moved to San Francisco from Connecticut, is working on a series of short pamphlets on Ichthyosis. We plan to distribute them widely across the United States to hospitals, libraries, and schools, if we receive enough donations to afford it. Be sure to read Valerie's article, "Ghosts," in this issue.

ICHTHYOSIS, AN "ORPHAN" DISORDER

HOW RARE IS RARE? -- The federal government considers a disease rare if fewer than 200,000 Americans are afflicted. Ichthyosis, divided among its many forms, easily qualifies under this definition. The problem with having a rare condition is that it becomes a low priority. Our democratically oriented political institutions are supposed to respond to the greatest need, considering the greatest numbers. This means that cancer and heart disease, afflicting tens of millions of people and killing hundreds of thousands annually are higher priority problems than Ichthyosis, which has a low mortality rate, and affects fewer than one million people, even in its mildest forms.

Abbey Meyers is Executive Director of the National Organization for Rare Disorders, Inc., a small private foundation like NIF in New York that has operated primarily as an information clearinghouse, referring people to special groups like NIF. Abbey keeps us informed about the political aspects of medical research affecting orphan disorders. NORD recently merged with the National Orphan Drug and Device Foundation. Jack Klugman, the popular actor, is the celebrity spokesman for the group, and episodes of his television show, "Quincy," have focused on rare disease research issues.

Recent legislation has ensured that even those with rare diseases and disorders are not forgotten. Recognizing that commercial research was impractical, because of its tremendous cost in relation to the minor payoff that could be expected, Congress passed the Orphan Drug Act in 1983. The purpose of the Act was to encourage pharmaceutical companies to do research on rare disorders by providing tax benefits and grants.

HOT TIPS

HOT TIPS -- Practical information from many sources. Neither the Foundation nor the Medical Advisory Board recommends any particular "Tip". We do not provide medical advice, nor do we endorse any particular product. NIF acts only serve as a clearinghouse of news. Ask your doctor about Hot Tips, and follow his or her advice before acting on any information.

SCALP: Two tips: Pet stores sell a steel-toothed, very fine pet comb. It does a great job on flakes in the hair. Careful of the sharp teeth. Tip #2: If you're ever in the San Francisco, consider a visit to the HAIR FARM, operated by Christine Barteau. Chris believes healthy hair comes from a reasonable diet, good circulation, and a clear, clean scalp. Her treatments rid the scalp of old dead cells to open the hair follicle pores. Her inexpensive (\$25) treatments are easy, safe and really work!

LACHYDRIN: We're getting enthusiastic reports from users of Westwood Pharmaceuticals' Lachydrin lotion. Lachydrin is now "legal" in the US, but is hard to find, despite a growing popularity. Rx Allstates, the discount mail order pharmacy in Chicago, has Lachydrin and Herald's Aqua Glycolic lotion. Call Rx Allstates at (312) 280-7711 for availability and a price list.

BODY ODOR: An unpleasant topic and problem. Odor is caused by bacteria and oxidizing skin. Getting rid of the old skin and the bacteria solves the problem. (Oxidization also contributes to the dark color of scales.) The key is removing the built up scales. Bathe, lubricate, and use topical or systemic treatments recommended by your dermatologist.

COOL WEATHER: Mothers, don't forget children with Ichthyosis may feel the autumn cool sooner than playmates with regular skin. Your child may need to be the first to wear a sweater at school. Give your child a break: explain the problem to the teacher ahead of time.

BREAST-FEEDING: A mother with Ichthyosis in Mississippi says her skin cleared up completely for the first time while she was breast-feeding her new baby. The baby, also with Ichthyosis, is doing particularly well with applications of olive oil and Aquaphor.

SAUNA SUITS: Many users find an occlusive suit over medication (like propylene glycol and water, or other, prescription products) very effective for removing scale. Always work under your dermatologist's direction, however. Some topical remedies may be toxic if left on the skin too long. Some people overheat in a sauna suit. Many pharmacists require prescriptions, for good reason.

CONTACT LENSES: Your eyes may be too dry from medication, or you may have Ichthyosis of the cornea. Mention these possibilities to your optometrist, who measures your eyes for glasses and contacts. Consider consulting an ophthalmologist, who is a medical doctor specializing in diseases and disorders of the eye.

GHOSTS

by Valerie Lutters, Contributing Editor

It seemed fitting to me that the National Conference in Chicago in 1983 and the Regional Conferences in Oklahoma and Washington, D.C. in 1984, should take place in December, so close to the holidays. It was apropos because adults with Ichthyosis, confronted by children with Ichthyosis, saw suddenly the ghosts of Christmas Past, while parents of those children may have seen in us the possible ghosts of Christmas Future. For me, anyway, one of the adults with Ichthyosis, the experience was both moving and a bit unsettling.

I found, especially in Chicago, that the parents, sudden experts in a disease which they had never even heard of one, two or three years before, approached the adults as if we were seers, as if our lives were irrefutable omens of what their children's lives would be like. "When was the hardest time?" "What's your occupation?" "Are you married?"

A simple question like the last took on ominous connotations in this context, and I felt as though a straightforward, "No" would be construed as an oracle of old-fashioned spinsterhood upon all little girls with the same disease.

It was a strange feeling. On the one hand, I finally had a chance to express opinions or feelings that just might make life a little easier for someone else with Ichthyosis; on the other hand, I didn't want to say anything for fear my subjective opinions would be given undue import.

So when, at the Chicago conference, social worker and NIF co-President Susan Nye DeHaan, asked if parents at the conference would like to hear suggestions from the adults, I said nothing, even though the parents seemed eager to hear from us. Yet all around me -- at that conference, at subsequent conferences, at small gatherings of local chapters -- I saw over and over examples of something I would very much like to address, though I still hope to be taken with the proverbial grain of salt.

"Oh, she's doing much better than she was -- just look at this patch right here. She never had clear patches like that before."

"The soles of his feet are so bad -- here, honey, take off your shoes and socks and show Mrs. McGrath your feet."

"Well, we just always told her, 'You're fine with us' and she's always had a very positive attitude."

Statements like these are constantly being made in the presence of the child involved, made by well-meaning, devoted mothers, who would gleefully scratch out the eyes of anyone else who stared or pointed at or otherwise embarrassed or humiliated that very child. Yet the mothers seem totally oblivious to the absolute squirming agony of the children beside them, dutifully holding out the arm with the clear patch or peeling off the shoes and socks.

I've been there. I've shown the patch, pulled up the sleeve, pulled down the sock, done all those things which children in that position hate beyond words but lack the words to protest, feeling, perhaps justifiably, that they have no choice.

We/they rarely, if ever, protested, and when we did, were often told, "Don't be silly, honey, Mrs. McGrath is our friend," (She's your friend, Mom, not mine.) "and besides, she's a nurse." (But this isn't a hospital, and there are people all over.) Or even, "But honey, this is an NIF meeting, and Jackie has the very same thing you do. Now don't you want to help her?" (No.) Somehow Mom and Dad don't see these things the same way the child (or former child) with Ichthyosis sees them.

We can't be too critical of parents, though. It's a trap I think they all fall into, this business of talking about their children as if they aren't there. After all, initially the child really can't understand. He's a tiny baby, blissfully unaware as Mom tells the entire New Mothers Club every detail of his bowel and bladder habits. A few months later she happily announces the arrival of his first tooth, and invites Uncle Joe, Aunt Marie, her sister and a bypassing UPS man to stick their fingers into his mouth and feel it for themselves. And Baby just smiles. Soon it's a habit and a few years later she's still saying, "Oh, he's always making a mess of himself," and "Show Mr. Cunningham how you bit your fingernails right down to the quick." If the child cries or gets angry she might still say only, "Well, he always was moody."

I don't think there's a parent alive who hasn't done it to one degree or another, or a child alive who doesn't hate it. And while it may be a bit insensitive, it's no big deal . . . unless it applies to something as deeply cutting as Ichthyosis. Then it's a very big deal.

It's hard enough to have dignity when you're little and harder still when you feel ugly or different or defective. But even little children have dignity, I think, and they resent it when that dignity is torn down or denigrated, even when it's done unintentionally by a thoroughly well-meaning parent. So I would say to any parent whose child has Ichthyosis, don't ask him to display that part of himself about which he is probably most ashamed -- his skin.

There are times, of course, when a parent has to ask the child to "show off" his disease or its improvements; the doctor's office is an obvious example, but it has an element of privacy. There may be other times, however, when circumstances seem to warrant it -- i.e., when meeting another Ichthyosis parent for the first and perhaps last time. I just hope there are ways to do it with the child rather than to him or in spite of him. Perhaps he could be asked privately, ahead of time, if he would show his skin to someone special. And for goodness sake, if he says no, that no should be respected. It's just a way of respecting, which is exactly what most people are asking of everyone else in the child's life -- that they see him or her as a person and not just as an example of a disease.

And that's it -- a very simple, mundane, every-day type of thing that I as an adult with Ichthyosis would like to tell parents of children with Ichthyosis: Don't talk about your child in front of him as if he weren't there -- about anything, really, but especially not about his disease. It's one ghost of Christmas Past that I, for one, would like to see buried.

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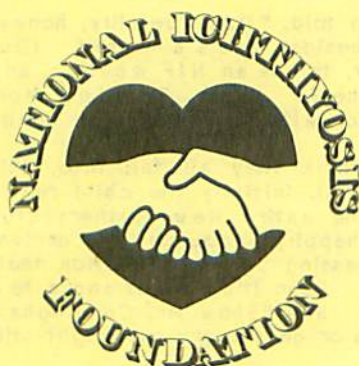
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