



The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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Published Six Times a Year by volunteers of The National Ichthyosis Foundation, P.O. Box 252, Belmont, CA 94002. Telephone (415) 591-1653. NIF is a non-profit California corporation, for the benefit and education of its members and the public regarding medical, psychological and social aspects of ichthyosis, a genetic skin disorder. Letters, suggestions and contributions are welcome. Valerie Lutters, Editor.

***** FROM THE EDITOR'S DESK *****

I wasn't doing any work for the Foundation at the moment. I wasn't preparing the next issue of Focus. I wasn't thinking about Ichthyosis. I wasn't even thinking about skin. It was evening, it was the weekend, I had just turned on the "tube" without even bothering to check the listings and took "pot luck" with whatever channel was on the dial. So you can imagine my surprise when five minutes later someone on a situation comedy casually mentioned Ichthyosis.

Casually mentioned Ichthyosis? Those of us who have this disease have pretty much resigned ourselves to having an ailment that no one, anywhere, has heard of. We've even had doctors say, "Gee, I'm not really familiar with that." And now somebody on a television situation comedy casually mentions Ichthyosis?

Well, as a matter of fact they did. The show was called "All Is Forgiven" and it aired on Saturday, April 12, at 9:30 pm. Did anyone else happen to flip on that show? Did anyone with a VCR happen to record it? The show, which I had never seen before, apparently features people who are staff writers, producers, etc., of a soap opera, a kind of show-within-the-show. In the episode I saw, the writers have to come up with a disease for a character in the soap, and one says, "How about Ichthyosis? It's a horrible skin disease." Another writer, or perhaps the producer, replies, "No, we can't do that. He has it written right into his contract, No Skin Diseases." And from there they go on to other things.

That little chance conversation blew your editor's socks off! It seemed not only surprising, but extremely timely. It gave us a chance to respond to specific event -- the TV show -- and remind people we might otherwise not reach, about the existence of the Foundation. Furthermore, it came about just as our president, Susan DeHaan, was about to testify before Congress regarding a budget for the new National Institute of Health for Arthritis, Musculo-Skeletal and Skin Diseases, a time when the Foundation reps, publicity chairman, and everyone else was urging people to write to their Congressmen to urge support for that budget.

Our publicity director, Bill Geismann, wrote to some NBC affiliates, and I wrote a Letter to the Editor of TV Guide. We mentioned the Foundation and its services, urged support for the new Institute's budget, and mentioned that the show may have implied that Ichthyosis could be caught -- we definitely wanted to clarify that issue. So far I haven't seen the letter printed in TV Guide, and it's probably too "old" by now for them to do so. I also wrote to the producers of "All Is Forgiven" telling them thanks for mentioning Ichthyosis-- we need all the publicity we can get!-- but: 1) let's make sure you haven't implied that it's contagious, and 2) how did you come up with Ichthyosis-- there are so many diseases and Ichthyosis is so rare....? So far I haven't heard from them, either, but if I do I'll put the response in Focus.

Meanwhile, if anyone taped that show, please let the Foundation know so we can get a copy. Also, it seems to have been moved to Thursday nights at 9:30 on NBC -- perhaps we can hope for a re-run during the summer and watch it -- and record it -- then.

COMING SOON -- The National Ichthyosis Foundation's annual conference is scheduled for December 6, 1986 in New Orleans, LA. Several of you have written to us asking when the next conference would take place so you could plan vacations, etc, around that event. In general, the conference takes place during the first weekend of December; the location varies.

A program committee has been elected to put together what we hope will be the best annual conference ever. Chairman of that committee is Ellen Rowe who would welcome any and all suggestions for program changes, additions, alterations.... any ideas you have about issues you would like the conference to address, the manner in which the conference is run, anything at all. Have you been to previous conferences and noticed things you would have done differently? Tell Ellen. Have you decided not to attend conferences in the past because the program did not seem to address issues you were interested in? Tell Ellen. Ellen is our North Carolina representative and her address and phone number can be found in the list of current reps and chapters elsewhere in this issue.

Naturally, we can't promise to follow every directive -- time and money are major restrictions for us -- but we can promise to welcome and seriously consider any suggestion. We want all the input and feedback we can get. The conference structure is neither sacred or cast in stone. We want it to evolve into whatever form and content best serves the largest number of people in the ichthyosis community.

Meanwhile, those of you who haven't attended a conference in the past are urged to make an effort to do so this year. At the end of each of our previous conferences those who attended expressed enthusiasm about how much they had learned and how beneficial it was to meet and talk with other people "in the same boat;" friendships were formed and new volunteers and human resources were added to the NIF fleet. We're giving you as much advance notice as we can to give you the opportunity to influence the upcoming conference and to attend it. Hope to see you there.

 HAPPY MOTHER'S DAY**
 *****HAPPY FATHER'S DAY***

We're dedicating this issue of Focus, which is following so closely after Mother's Day and Father's Day, to all the parents of people with ichthyosis, parents who have a whole set of problems of their own related to dealing with the disease. Sometimes those of us who have the disease forget that it doesn't affect only us; it affects our whole family, especially the parents who have to deal with its expenses, its worries, the physical, emotional and social demands of the children who suffer from it...Parents, in a sense, "have" ichthyosis, too. This issue includes a few "thank yous" from those of you who recognized you aren't really alone with this disease and wanted to express your gratitude to the moms and dads who helped you cope with it.

Dear Mom and Dad,

I just want to say "thanks" for being two wonderful people. Nineteen years ago the Lord presented you with me on Mother's Day. What a gift, huh? You two have helped me live each day believing that life goes on and things do get better. You were there when times got rough and you didn't turn away when you saw I was different. There were lots of times when I was ready to give up and said it's not worth all the hurt, but with a family like mine, you guys made things easier. I love you both so very much; thanks for being you.

Love always,
 Paula (Lange, age 19)

From a Double Perspective:

When I was born 26 years ago I was the third child following a brother and sister with perfectly normal skin. To our knowledge, there was no other family member who had ichthyosis. My hospital stay lasted one month, most of the time spent in an incubator, better known now as an isolet. My skin was raw and red and the doctors knew very little.

After I had been home for two or three days, my Mom took me back to the hospital. I was kept for another week and then the doctors reassured her that my condition would improve -- and she would survive, too! But my skin was still red and raw; I was in constant pain and always crying. Finally, when I was two months old, my Mom called my grandfather in the middle of the night, crying herself because the prescribed medications seemed to be irritating me instead of helping me. My grandfather, a very wise Greek man, reminded Mom of the story in the Bible where Jesus puts olive oil on a man's sores to heal them and soothe him. He suggested Mom stop using the medications and try this. She did. The olive oil coated the raw spots and lubricated the skin, and for the very first time I slept through the night.

My parents let me know early in life that I had everything to be thankful for -- two strong legs and arms, a healthy mind, a supportive family, and a God who made me in His image! With all of those things in mind, I was able to overcome all the ridicule in first and second grade, and all the silly questions and rude people in stores. I stayed busy trying to keep up with (and sometimes defend myself from!) my older brother and sister, and grew interested in playing guitar and singing. A doctor in Laurel, MS, suggested ocean salt water, and my parents packed us all up for Panama City Beach, FL where I spent two weeks in salt water that cleared me up. I later went to college in Florida with the intent of staying there, but my home, heart and family were all in Mississippi, and I wasn't going to let my skin rule my life.

My concern now lies in the future children who must deal with this disease. When I was born the doctors knew immediately that I had a severe form of ichthyosis, but it was not until my own child, Anna, was born that I knew I had the EH form. An hour and a half after Anna's birth we found out she had a skin disorder, but the doctor was unsure of its diagnosis. He had never seen ichthyosis on a newborn so he narrowed our choices to either ichthyosis or.....

I knew it would be the same as mine, but until the dermatologist came that evening, my diagnosis was put on hold. I knew exactly what I needed to do for my baby, but was unable to touch her until "proper diagnosis" was made. It was 16 hours after Anna's birth before she received any treatment at all on her skin. It was red, raw and worsening. I knew if I could just dab on some of my Albolene cream it would soothe her, but she just lay on top of a diaper, stark naked on a sheepskin with no one to help her.

Once diagnosis was made they started "washing" her with Cetaphil lotion and rubbing Aquaphor over that while using a cortisone cream to touch up the raw spots. The next day she didn't appear any better, so my Mom reminded me of the olive oil treatment she had used so successfully more than twenty years before. The dermatologist thought that would be an excellent liquifier and used this instead of Cetaphil, keeping all other treatments the same. Within the next 12-24 hours her raw red color disappeared. Anna's hospital stay lasted for 2 weeks -- one week to stabilize her skin and body temperature and another week to battle and conquer a common denominator for this disease -- staph infections.

A year later, Anna's skin condition is hardly noticeable. She seems to have a mild form of EH and her experience may seem trivial compared to what many of you (and I) experienced during our infancy. The point I want to make is that an excellent, top rated hospital staff had no idea how to help Anna, an experience common to many of us. I want to stress how important it is to educate the medical profession, as well as the general public, and I urge everyone to help in this endeavor so that our future children won't have to suffer like we did. Anna had an advantage over myself and many others; my parents and I knew how, basically, to handle the disease. I will be able to relate to her frustrations and struggles in the future. Childhood will hopefully be easier for her than it was for me. But as my parents always pumped down me and what my husband and I will always pump down Anna is: Be thankful that you are healthy and whole in every other aspect. You are made in God's own image, so you are beautiful, skin and all!

Andrea Thorn
 NIF representative in Mississippi

A Few Thoughts of My Own

Caring for a child with EH was a full time job and then some for my parents. Dressing up like a gummy gave me Halloween 365 nights a year, and changing those dressings was a nightly ritual for my father for nearly ten years. Family, friends, members of my grandmother's church all saved their worn out sheets and gave them to my mother who ripped them into strips and rolled them into coils. The house frequently looked as though painters were either about to leave or expected momentarily as Mom's color coordinated furniture was draped all over with more white sheets to protect it from my oozing

sores, escaping salves, or the ever-present greasy kid stuff all over the original greasy kid.

My skin was an integral part of every day of their lives, but for some reason one particular incident stands out in my mind. I was about 4 or 5 years old at the time, and we were midway into a six-hour trip to my grandmother's house, with suitcases stuffed in the trunk. Included was the ever-present "bandage bag" with the rolled up sheet strips, the zinc oxide, the tongue depressors used for spreading the salve on compresses, bandage scissors, the works. We had stopped for dinner at a roadside diner, one of those classics from 30+ years ago with the silver exterior and pink interior, and a set of killer cement steps that I managed to fall down on our way back to the car. If I hadn't had EH the fall would have been little more than a knee scratcher and a good excuse for another one of those multi-colored giant lollipops that stood like pinwheels of temptation at the cash register. But I did have EH and the fall rubbed me raw in a number of places and peeled a spot about six inches square off my thigh. The skin rippled into an accordion-pleated wad, leaving the flesh raw, exposed, hurting and ready to adhere to clothing that would just have to be ripped off again in a few hours.

My father began searching the trunk for the bandage bag, but apparently it was buried beneath suitcases in the trunk with a trailer attached besides. I don't remember those details too well, but I do remember that he decided to use a little ingenuity instead of his usual tools. He had an extra tube of salve in the glove compartment, and he had this intriguing piece of pleated skin that had remained intact like the peeling from a skilled carver's apple..... My father slowly, carefully, unpleated that piece of skin, spread the salve onto it, then replaced it onto the open wound. Then he got back behind the wheel and kept on driving.

My father never went to medical school. He graduated from a trade school and worked not in a hospital but in the telephone company. Like most ichthyosis parents he had never heard of the disease before I was born. Yet there he was, with little to go on but necessity, performing minor skin graft "surgery" in the back seat of a '48 Chevy on the shoulder of U.S. Route 6.

My point is not that an unbroken piece of skin can be used to patch a wound, although that make-shift patch did actually work. My point is not to tell anyone to make sure their bandage bags are not buried under suitcases. My point is simply that I don't think that this kind of on-the-spot creativity is at all unusual for ichthyosis parents; in fact, it may be the norm. Over and over we hear how no one, not even doctors, seems to have the necessary experience and expertise to tell these parents how to handle this ailment; the parents don't either, but somehow they work things out for themselves because they have to. They make it up as they go along, learning through trial and error, teaching themselves, calling upon faith and imagination because there is nothing else available.

Hopefully that isn't the case quite so much anymore. It is one of the goals of the National Ichthyosis Foundation that no parent should have to "wing it" with ichthyosis, but should have, instead, the informed aid of educated doctors and experienced fellow parents, no matter where they live, not matter what type of ichthyosis they are dealing with. I hope we reach that goal. But to my parents, and all the others who had to deal with the problem before those resources were available, and to all the other parents for whom they are still unavailable, I want to say thanks. Thanks for the moxie, the imagination, the guts to forge ahead without a signpost in sight. Thanks, even, for some of the incredible Rube Goldberg-esque contraptions you put together to make some of our activities less painful and for the "hoax-brew" recipes for salves and ointments. Believe it or not, they really did make our lives a bit more comfortable -- and a lot more colorful, too!

Valerie Lutters
Focus editor

P.S. And thanks to everyone who contributed to this column.

***** VOLUNTEERS WANTED *****

Doctors on the East and West coasts are looking for volunteers to help with their skin research. Since the National Ichthyosis Foundation supports research into ichthyosis, and since it wants patients everywhere to be aware of any treatments or investigations into the disease, we are pleased to inform our readership of any such programs. We cannot, of course, endorse or participate, either directly or indirectly, in such research and cannot be held responsible for any particular program. As always, we urge you to check with your own physician before participating in any program of treatment or research.

Dr. Irwin M. Freedberg, chairman of the Department of Dermatology at New York University wants to study the skin of patients with ichthyosis. Anyone in the New York area who would like to volunteer can reach him at NYU Medical Center, 550 First Avenue, New York NY 10016, 212-340-5245.

Dr. Samuel Ayers, Jr., a dermatologist practicing in Los Angeles, is enthusiastic about treatments using Vitamin A and Vitamin E together. He feels that the proper combination of these vitamins can be effective in treating diseases of keratinization without the high (and toxic) doses that would be needed to get results from Vitamin A (or its synthetic derivatives) alone. He feels this combination therapy produces "excellent results and no side-effects," and has offered to treat five to ten ichthyosis patients without charge. Anyone interested can reach him at 1245 Wilshire Boulevard, Los Angeles, CA, 90017, 213-977-1305.

***** CORRESPONDENCE *****
***** CORNER *****

In every issue of Focus we try to include the names and addresses of people who want to correspond with others in the ichthyosis community. In February we included a request from Mrs. George McHugh in New Jersey who has a grandson, 1 year old, with EH. Mrs. McHugh wrote to me in May saying, "...I have now heard from six families who deal with EH -- all through NIF....I have corresponded with many lovely and feeling people and had the benefit of their experiences....My daughter and son-in-law read everything that anyone sends....Just knowing that other people have handled the same situation and are doing OK gives us all encouragement and confidence." So -- if you think you might have something, no matter how small, to offer the people who ask to correspond, go ahead -- write, reach out. As Mrs. McHugh's letter points

out, your letters do matter, they do make a difference.

Melody Fiesbeck would like to correspond with people in the Midwest. She is 34 years old and has Lamellar Ichthyosis. You can reach her at 1413 Pleasant Street, Burlington, WI 53105

Joyce Conneely of 546 Benton Road, East Meadow, N.Y., 11554 would like to hear from other parents of young children with Lamellar Ichthyosis. Joyce has a four-year-old with this condition.

Gary and Katie Foxe, 4690 N. 67th Street, Milwaukee, WI, 53218, have a 7-year-old son with ichthyosis and they would like to hear from other ichthyosis parents who have children in the public schools. Since many children with ichthyosis cannot sweat and often have a problem with overheating easily, the Foxes would like to know if other parents are having any success in getting their school systems to install air conditioning. Since this problem could potentially affect many readers, perhaps any parents who have suggestions could send them to the Foxes and to Focus so all our readers can benefit from them.

 ***** HOT TIPS *****

An East Coast member says her husband who has Ichthyosis (she didn't mention which type) has had good luck with a product called Domol. She says they are satisfied with the product but not with the price which apparently keeps increasing. She says they tried to buy the product in larger quantities (economy size), but were told by the manufacturer that it comes in sizes no larger than 8 ounces. They are interested in finding out if any other distributors anywhere else are producing Domol or a comparable product in larger, more economical sizes. If anyone has information, we'll try to pass it on through Focus.

A similar hope comes from Florida where a member has had "remarkable results" from Neutrogena Norwegian Formula Hand Cream. Unfortunately, he says, it comes only in 2-oz. tubes. He's hoping that if other members find the product as helpful as he has, that perhaps the company can be persuaded to package it in larger sizes.

A member from the West Coast says she and her sister both have Ichthyosis Vulgaris and "skin like sandpaper after we had baths when we were young." They were given a tablespoon of Maltine Cod Liver Oil in a half glass of orange juice every day and within a month began to notice a change for the better. They stopped after a year and their skin got worse again. She says regular cod liver oil didn't have much effect and doesn't promise that the Maltine will help anyone else, but she did find it worked for her and her sister.

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We need informal 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 / Missouri-Kansas-Nebraska / Vermont-New Hampshire-Maine / North and South Dakota-Wyoming-Montana / West Virginia-Kentucky-Tennessee / New Mexico-Arizona-Utah. Please contact Betty McMasters, 1838 So. Muskogee, Sapulpa, OK 74066 (Tel: 918-224-9099) for details.

The North Carolina Chapter held its first chapter meeting in April, N.C. representative Ellen Rowe reports. She says ten people attended, ranging in age from 7 months to 70 years. The next meeting is planned for October. And the Oklahoma Chapter is gearing up for its fund-raiser in September.

 *** A CLOSER LOOK AT SYSTEMIC TREATMENT? ***

NIF President Susan DeHaan has called our attention to a small article on page 346 of the May 1986 issue of Vogue magazine. The article warns about some of the adverse side effects connected with long term use of Accutane or isotretinoin, including an increase in blood levels of triglycerides and cholesterol that could mean increased risk from cardiac disease. It also mentions the severe birth defects which can befall children of women who take the drug while pregnant.

The Foundation has also received some correspondence from users of systemic therapies who have found they lead to unpleasant side effects, including bone and joint problems. We have also heard from others, however, who feel systemic treatments are the best thing they have ever found for treating their ichthyosis.

We'd like to compile some of your comments about systemic treatments. What drug did you or your child take? What were its effects -- good or bad, expected or unexpected? If you could turn back the clock, would you decline this type of therapy or would you wish you could have begun it sooner? Did you participate in a formal program of research? Please write to Focus soon and tell us your experience. Give us as many details as possible.

We want to address this issue as thoroughly as possible. There are people in our membership who feel strongly and want to "warn others of the dangers." Others feel just as strongly that every effort should be made to make these treatments more readily available in the United States. We'd like to discuss the matter here in Focus, so please share your experiences with us. With a little help from all of you who have first-hand knowledge of systemic treatment, we'll try to pass on as much accurate information as we can get our hands on.

Just a Reminder -- Ichthyosis Focus is sent out six times a year to members of the National Ichthyosis Foundation. The annual membership fee is \$15 for regular membership, \$25 for contributing member, \$50 for 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 at a recent Board of Directors meeting it was suggested that we might begin designating one month per year as "Renew Your Membership Month." An annual membership drive could make it easier for individuals to remember to pay their annual 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 the Ichthyosis Foundation 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. And you can designate 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.

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