



The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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

OUT OF BUSINESS -- That's where this newsletter will be if you -- the readers -- don't come up with donations to support it. We're trying to provide a newsletter, organize local support networks, encourage research and education about Ichthyosis. There is enough Ichthyosis work to be done to keep a full-time staff person and a volunteer group busy. But it costs money to do anything at all. Out of over 7,000 people who read this newsletter, **only 200** have contributed to support it in the last 18 months. That's outrageous and unfair! And worse, it won't work. If Ichthyosis is important to you, you can afford to make a contribution to the only organization in the world devoted specifically to it. If it's not important to you, then we're wasting our time trying to help, and you won't miss us if we put out the last candle and go back to loneliness and ignorance.

UNITED WAY DONATIONS -- Did you know the United Way Campaign at work has a Donor Option Plan so you can donate all or part of your regular United Way payroll deduction directly to NIF? Whether you work for a government agency or a private company, you can designate your donations to go to NIF in particular. As long as you're donating anyway, why not choose NIF as recipient? Plan ahead for next year's tax return: make a deductible contribution NOW! You'll get credit for it whether you itemize or not! Your United Way representative can get the right forms for you.

ADDRESSES -- Do we have your address right? Check this copy and let us know if it's not correct. We get a lot of newsletters back - "wrong address." That's money down the drain for us.

EAST COAST MEETINGS -- The 1985 annual meetings of the Society for Investigative Dermatology (SID), the largest research organization of its kind, will be held the first week in May in Washington, D.C. During the meetings, Susan DeHaan, LCSW, Co-President of NIF, will join other skin foundation leaders to address Congressional staff members regarding increasing skin research appropriations through Congress. Following her presentation she will meet with NIF regional representatives in Washington and New York.

1985 REGIONAL CONFERENCE -- Plans are underway for the 1985 NIF Regional Conference to be held in Las Vegas, Nevada around December 1. Stay tuned.

BOARD OF DIRECTORS POSITIONS -- NIF needs the services of three new Board members with business and organizational skills. Do you know a prominent local person with ability and an interest in helping people? Please tell us about it.

COMPUTER SURVEY -- Response to the computer survey has been slow. If you have forgotten to turn yours in, please do so IMMEDIATELY. The information is going into the computer now for analysis and there isn't much time left. Send in your survey form today!

DIAGNOSING ICHTHYOSIS -- Because of its rarity, Ichthyosis can be difficult to diagnose. Treatment and genetic counseling regarding future births depend on accurate diagnosis. For some kinds of Ichthyosis, diagnosis is possible even during pregnancy. Diagnosis questions? Contact a member of the NIF Medical Advisory Board for an appointment or referral to a qualified physician.

THANK YOU, DONORS -- Even though there are only a few hundred supporters of NIF out there, we can't take up that much space to thank each and every one of you in print. Thanks to especially generous recent contributors Michelle Menzla, Dale Wedell, Carl and Shirley Anderson, Betty LaBarbera, Janet Showers, Valerie Lutters, and the Oklahoma and Fresno, California Chapters.

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

HOT TIPS -- Practical info we get from many sources. Neither the National Ichthyosis Foundation nor its Medical Advisory Board recommends any "Tip." NIF cannot and does not give medical advice, but acts only as a clearinghouse for information about Ichthyosis. You should follow your own physician's advice before acting on any tip.

HARD WATER? Mineral -filled water is common. It's also hard on Ichthyosis. Your doctor may recommend a tax deductible water softener device. Or, you may want to try inexpensive **Aveeno Colloidal Oatmeal Bath** (from most drug stores, no prescription). Several members say it really softens their childrens' scales so they can be rubbed off easily after a 30 minute soak. It may take a few soakings per day for a few days to get things going, and you may want to use a good moisturizing lotion after the soaks to keep the skin clear. Ask your doctor.

ECTROPION: The fancy word describing the tightness of skin around the eyes, causing the lids to turn out slightly, exposing the reddened lining of the eyelid. Past treatments haven't been very effective, but some physicians are now recommending a simple plastic surgery procedure that relieves the tension on the eyelid, allowing it to close more normally. Ask your dermatologist and ophthalmologist about your own case.

DEODORANTS: Body odor can be a special problem for people with Ichthyosis even if perspiration is **not** the cause. Because the top layer of skin forms scales and remains attached for an abnormally long period of time, it reacts with oxygen in the air and darkens. It can also develop an odor. Ever notice that a vacuum cleaner bag that's been sitting around for a few weeks can really start to smell? **Step One:** Keep the scales off your skin as much as possible, using any of a number of techniques. **Step Two:** Stay scrupulously clean, so that the scale layer doesn't harbor bacteria which can cause odor. **Step Three:** empty the vacuum cleaner bag more often.

GLYCOLIC ACID REVISITED: This is just one kind of alpha hydroxy acid that helps disintegrate scales. The basic chemicals in this group of acids are simple, but not widely used in pharmacology. It comes in basic pure form, ready to be mixed with a cream, or already in a lotion or cream formula, depending on the manufacturer. If your dermatologist recommends you try one of these compounds, you may have to hunt around awhile to find the stuff. Your dermatologist can help persuade a local druggist to lay in a supply for you. Try Allstate Pharmacy, below.

BICYCLING: People with trouble perspiring may experience dangerous overheating during strenuous exercise. Consider bicycling: great aerobics, and the constant movement of air may help to keep you cool.

RESOURCES: Can't find your favorite treatment or chemical locally? Contact **ALLSTATES PHARMACY SERVICE**, 1100 Davis St., Evanston, IL 60201 (312) 864-6922 and ask for their Skin Care Products price sheet.

Got a Hot Tip? Please share! Write to the Editor, **ICHTHYOSIS FOCUS**, PO Box 252, Belmont, CA 94002.

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

Get in touch with a local NIF representative listed below. How about being a local representative for NIF yourself? Please call or write to **Susan DeHaan, RR #1, Filer, ID 83328, Tel. (208) 326-5154**, for info.

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- N. JERSEY:** Joe Galluccio, 1408 Williams Drive, Wall, NJ 07719 (201) 681-6824
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- BR. COLUMBIA:** Valerie Munroe, 2492 West 45th Ave., Vancouver, B.C. V6M 2J8 Canada

1984 MID-ATLANTIC REGIONAL CONFERENCE: AFTERNOON SESSION

by Valerie Lutters, Contributing Editor

After the morning medical presentations, the Regional Conference continued with a report on the state of the Foundation from Mike O'Connor, NIF's new Fund Raising Chairman. Mike noted that the Foundation's progress was slow but steady, and that another milestone had been reached when we realized we needed a full-time Executive Director to maintain momentum. The Director can help raise funds to build a library, physician network, political lobby, educational materials, scholarship and research funds, as well as housekeeping the telephone and mailing activities.

Mike asked the membership to help directly by their donations and indirectly by finding qualified and enthusiastic people to act on the Board of Directors. "Everyone knows someone out there who could help the Foundation: a banker, philanthropist, businessperson, etc. We just need to be put in contact with the right person," he said.

Describing himself as a specialist in education, Mike also addressed the topic of learning disabilities that can stem from conditions like Ichthyosis. Although Ichthyosis is a skin disease, not a learning disability, brain processing is a two-way street, and depends on feedback between the brain and the environment. An inhibiting disease like Ichthyosis can seriously affect learning because, for example, children with severe Ichthyosis often don't crawl as much as other children. They then experience repercussions in eye-hand coordination, short distance focusing, and depth perception. Similar problems result when a child cannot easily manipulate objects with his or her hands.

Mike reminded the group that Ichthyosis is an international problem, without regard for race or color. He mentioned that research is also under way in other countries, and that different treatments are sometimes proposed for Ichthyosis. Mike's presentation closed with an open invitation to parents with questions about learning problems to contact him through the Foundation.

The afternoon session concluded with a discussion by Charles Eichhorn about the psychological aspects of Ichthyosis. Charles emphasized the importance of maintaining an objective perspective on the problem as an important step in dealing with Ichthyosis in oneself or children. Understandably, people with Ichthyosis despise their disfigurement. This is true of anyone with any sort of disfigurement. Indeed, it sometimes seems no one in society is really content with their appearance. Of course, complaining about Ichthyosis is not the same as complaining that you're stuck with brown eyes instead of blue ones, but it's important to remember that no matter what you have, the grass is always greener, and you probably wouldn't be completely happy anyway.

Charles made many suggestions for coping with the mental burden of being less than perfect. He said it is important to make automatic habits of all the little daily processes needed to keep one's physical appearance at a maximum. This is particularly important for children. Next, he suggested learning to accept yourself as less than perfect instead of just complaining about it. Even without Ichthyosis, you wouldn't have been perfect anyway, he said, so just make yourself the best you can, and accept that. This step often requires the help of a competent therapist for both parents and children.

He also said that knowledge about your situation is the greatest weapon in the battle of life. If you know why you are the way you are, you can deal with it better and educate others to do the same.

More subtle, insidious problems can affect parents of a child with Ichthyosis, he said, like an unspoken (and even unadmitted) feeling of guilt stemming from the belief that parents are somehow responsible for anything that affects their children, even an illness. Often, parents then resent the child for causing that guilt and bringing tremendous strains and complications to marriage and parenthood.

All these feelings are normal under the circumstances, but parents will often deny that they exist. They must be faced and dealt with, however, or they will influence other areas of the parents' lives. Charles recommended talking, not only with other parents, but also with a professional. "You have a professional level problem here in almost every case," he said. "Do it for yourself and do it for your child because otherwise there may always be a corner of your mind that resents your child for what you feel he or she has done to your life."

Charles' final topic was relationships with the opposite sex. Frequently, he noted, we are our own worst enemy in these matters. Even though we have managed to be attractive in the eyes of our partner, we cannot believe that the other person will accept us as we are. No matter how successful we have been in improving our cosmetic image, we always feel inside that we are disfigured and unlovable, and may reject others, even though they actually do accept us! The person with Ichthyosis may not be able to accept any one else's acceptance. Worse, he or she may hide behind the Ichthyosis as an excuse to avoid relationships, even though the Ichthyosis is not a real barrier.

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