



The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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

IF YOU'RE NOT FOR US, YOU'RE AGAINST US -- I am happy to report that our call for donations to support NIF and the newsletter reached some of you. Over 50 people sent in donations, - many very generous - to keep us going. To those people we send our most heartfelt and sincere thanks - you keep **all** of us afloat. But we are discouraged and ashamed to think that in the last two years only about 250 people have donated any money to support the Foundation and its goals, including the newsletter. It also means about 6,750 people (and the odds are that **YOU**, dear reader, are one of them) do **NOT** support the newsletter and what we are trying to do to help this generation and the generations of parents and children to come who suffer with Ichthyosis. Why should the government or drug companies spend any time on research or aid if the Ichthyosis community itself shows no interest in its own problem?

The members who support us financially obviously hope the Foundation will continue to grow and provide the newsletter. They appreciate our efforts with the pharmaceutical industries and in Washington to increase research and education about Ichthyosis. But I wonder about all the people who never communicate with us at all. Are you readers actually **voting against us** by withholding your contributions? Yes, **every dollar is a vote** that shows whether you are for us or against us, whether you value what we are trying to do, or think we are just wasting our time.

I expect every single person who reads this sentence to write a check to NIF for at least \$25 and mail it today. You think \$25 is too much? It's a couple of tanks of gas; a few movies; a shirt. What would you pay to erase the pain Ichthyosis has caused you or a loved one? Every little bit helps - send us what you can. Ichthyosis is a crippling physical and emotional affliction, and it has touched your life or you would not be reading this. You have a moral duty to help us with a contribution. I hope you won't let us -- and yourself -- down.

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

1985 LAS VEGAS NATIONAL CONFERENCE -- This year's major conference for members and medical professionals will be held in Las Vegas, Nevada at the Best Western 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. The next day, Saturday, December 7, NIF will present a National Workshop from 9:00 AM until 5:00 PM. Presentations will include the latest information on diagnosis, treatment, research, and psychological effects of Ichthyosis. Fees, child care, special price rooms, and registration information will be published in the next issue of the Newsletter. Sunday is open, so make plans now for a fabulous weekend in one of the country's most exciting resort cities.

SECOND CALL -- NIF is still looking for a few good men (and women) with organizational and business skills to serve on the Board of Directors. Who do you know? Please introduce us!

COMPUTER SURVEY -- Amazing early results! We find most people don't even know what kind of Ichthyosis they have! This can make a **big** difference in treatment and in passing it on to children! The survey is a big project and we still have more work to do. Still haven't sent in your questionnaire? **HURRY!**

ICHTHYOSIS IN PRINT -- The National Health Information Clearinghouse, under the US Dept. of Health and Human Services, is publishing an excellent multi-page fact sheet on Ichthyosis for national distribution. We reviewed the article and made some suggestions. As soon as copies are available, we'll let you know.

CONGRATULATIONS -- Many readers will remember Deatra Landwehr, daughter of Barbara Landwehr, one of NIF's founders and its first President. Deatra was an inspiration to many through her contributions to the newsletter. Deatra is married now and we were excited to hear that she and her husband are expecting a baby in August! Congratulations and Best Wishes!

MAKE MINE RARE, PLEASE -- Atypical Ichthyosiform Erythroderma, Sjogren's Syndrome, Rud's Syndrome, Refsum's Syndrome, Ichthyosis Hystrix, and Erythrokeratoderma Variabilis are some of the very rare forms of Ichthyosis. Some of these are connected with other disabilities, but all are members of our International family.

RESEARCH SCOREBOARD -- We just received word from Dr. Alan Moshell, the Skin Diseases Program Director at the National Institute of Health dealing with skin diseases in Washington, D.C. that there are over thirty research projects currently underway overseen by this branch of the US Department of Health and Human Services. A third of these are the work of members of the NIH Medical Advisory Board.

Some of these projects deal with basic research to understand how the skin works. Others focus on abnormal keratinization - the scaling phenomenon. Still others are focused on the effects of vitamin A on skin, genetic abnormalities, fetal skin research, and the steroid sulfatase deficiency that has been linked with causing Ichthyosis in some patients.

Altogether, these ten primary and twenty three secondary government supported projects represent a total investment of \$2,855,000 in grants. The new budget will tell how much attention will go to Ichthyosis next year. A report on Orphan Drugs and Diseases in the next issue of FOCUS will explore the research process further.

NEXT ISSUE -- The Politics of Medicine and Ichthyosis; **NORD** -- The National Organization for Rare Disorders; Financial report; NIF Plans for the Future?

CORRESPONDENCE CORNER

Mrs. Brenda Lyle of 518 Barrow St., Morgan City, LA 70380 would like to hear from members in Louisiana. How about dropping her a line?

Grace Seto, 20, of Canada, is looking for pen-pals. Write her at 1023 15th Ave. SW, Apt. 101, Calgary, Alberta, T2R 0S5 Canada.

PLEASE ANSWER THE CALL -- During the past several months we have heard from many of you who are interested in being a regional representative or starting a Chapter. Regional representatives are primarily support persons to talk with and share information. Chapter organizing is a more formal process and we have a "How To" manual available on request. We are delighted to learn of your interest, so please contact **Susan De Haan, RR #1, Filer, ID 83328, Tel. (208) 326-5154**, for details.

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 ***** 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.

WATER, WATER, EVERYWHERE: Ichthyotic skin needs water. A reader has suggested that facial steam sauna machines (under \$100) may be a good way to hydrate the facial skin. It can soften and moisturize while cleaning. A good lotion is probably necessary as a followup to hold in the moisture. The machines are widely available in catalog and department stores from different manufacturers.

OATMEAL: A West Virginia reader has suggested oat flour from Arrowhead Mills of Hereford, TX as a very inexpensive bulk source of oatmeal for the bath. From the National Health and Nutrition Chain of stores. Very fine and quick dissolving.

LACTIC vs. GLYCOLIC: The same reader also likes LactiCare Lotion by Stiffel Labs in Coral Gables, FL. Easier to find than glycolic acid preparations and almost as effective.

ACCUTANE: First the good news: Many patients with severe ichthyosis have had good results with a drug called Accutane, a synthetic derivative of Vitamin A. Now the bad news: National magazines have lately reported that Accutane has been found to cause malformation of bones in growing children and serious birth defects in newborn babies where the mother has been taking the drug. Accutane is a **short term treatment for acne**. The Food and Drug Administration has **not** approved Accutane for use in treating ichthyosis, except in **experimental use only**. Make sure you understand all about the drug's possible side effects before you consider taking it or giving it to children. Ask your doctor.

SWITCH-HITTING: Many readers have reported that a treatment they like at first loses effectiveness after a while. They try something else that works well, but that, too, loses effect. For many people the answer is simple: switch back and forth between your favorite treatments every few weeks or when maximum effectiveness slips. Sometimes a third type of treatment needs to be included to keep the skin guessing! All in all, the variety works better for some people.

EXERCISE: Fitness walking (serious stuff) is an increasingly popular method of aerobic exercising that may be well suited to ichthyosis patients. Great workout without raising a sweat. And its almost impossible to hurt yourself, as opposed to running.

SAUNA SUITS: The occlusive suits from The Sleep Sauna Co. in Elkins Park, PA (Feb '85 FOCUS) seem to work best with a lotion or gel type of topical treatment. Very watery solutions may slowly evaporate overnight, providing insufficient moisture for the best effect. Of course, the tradeoff in comfort is considerable. Another suit model of a new material may be available soon.

LACHYDRIN: A new preparation from Westwood Pharmaceuticals is a 12% lactic acid lotion that a 15 year old in Iowa with lamellar ichthyosis really likes. Talk to your doctor: It's not widely available yet.

AIR CONDITIONERS: Many people have them for themselves or children. Don't forget they need service- particularly the filters. Dirty filters trap bacteria and impair efficiency. (PS - an air conditioner may be tax deductible if it is medically required.)

DOWN TO THE SEA: Rumor has it that Hippocrates, the father of medicine, described patients with ichthyosis and commented that those living near the sea seemed to do better.

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