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The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

Send all correspondence to:

The National Ichthyosis Foundation

VOLUME 2, NUMBER 3

WINTER, 1982-1983

FROM A MEDICAL POINT OF VIEW

Naturally Derived Drugs and Skin Disease

Introduction

Drugs derived from natural products, or closely related to chemicals found in nature, are some of our most potent. Cortisone and its derivatives, thyroid hormone, the sex hormones, and the fat-soluble vitamins A and D are excellent examples of this basic principle.

A new era in systemic and cutaneous pharmacology was introduced in 1980 by the use of potent oral vitamin A derivatives in clinical practice. These drugs are effective in treating many inherited and even some acquired disorders of keratinization; therefore, an understanding of vitamin A chemistry, physiology, and pharmacology is essential. This broad topic will be covered in a number of articles by members of the Medical Advisory Board.

History

Arctic lore relates stories of those who have eaten large amounts of bearded seal or polar bear liver and have rapidly developed hypervitaminosis A, including prominent scaling, due to their diet rich in fish and fish livers. Deficiency of vitamin A often is associated with scaling of the skin, as seen in experimental animals fed vitamin A deficient diets.

During the Chinese civil war, patients with dry, scaling skin with prominent follicular hyperkeratosis were treated. Skin lesions responded to a nutritious diet containing cod-liver oil. The lesions were attributed to vitamin A deficiency, but their exact etiology still is debated. The report in the late 1930s of this response to vitamin A led to the search for associations of vitamin A deficiency with many skin diseases and to many therapeutic trials using cod-liver oil or purified vitamin A to treat various skin



Our guest columnist is Dr. Lowell A. Goldsmith, the James H. Sterner Professor of Dermatology at the University of Rochester School of Medicine and Dentistry, Rochester, New York. He has been involved in diagnostic and therapeutic approaches for genetic disorders of keratinization for over a decade. He is chairman of our Medical Advisory Board.

diseases. Darier's disease and various forms of ichthyosis and keratosis palmaris and plantaris were studied for correlation to vitamin A deficiency.

Vitamin A -- Physiology

Vitamin A is necessary for growth, bone development, reproduction, vision, and the maintenance of epithelial tissues in their normal, functional states. In the skin, when vitamin A is low, keratinization is increased and may become apparent in tissues which usually do not keratinize. Higher than normal doses of vitamin A may interfere with normal keratinization but may be beneficial for those with abnormal or altered keratinization. Since the effect of vitamin A can be profound or even destructive for certain tissues, control mechanisms are present. Certain tissues contain binding proteins for retinol (vitamin A alcohol) and transretinoic acid (vitamin A acid). These cellular proteins allow tissue to respond to circulating vitamin A but also control and modulate the response of the tissue to excessive amounts of natural vitamin A and its deriva-

tives. Once in the cell, it is widely believed that vitamin A acts in the nucleus of the cell by directing the cellular machinery to produce new proteins and probably glycoproteins (sugar-containing proteins).

Vitamin A -- Sources and Metabolism

Humans have two sources of vitamin A: that which is directly absorbed from the diet and that formed from B-carotene in the diet. The latter usually is the major source of vitamin A for humans. Vitamin A is traditionally measured in units (1000 units = 0.3 mg of vitamin). Daily requirements of vitamin A are set at 5000 units per day. Vitamin D is fat soluble and is stored principally in the liver. The storage mechanism also provides a means for regulating vitamin A levels.

B-carotene in the diet is provided by leafy green and yellow fruits and vegetables. In the intestinal cell, B-carotene is converted under the influence of iron and oxygen to retinol (vitamin A alcohol). After another conversion, the vitamin A formed by this mechanism enters the lymph as retinyl palmitate to be carried to the liver.

Even individuals who eat pounds of carrots daily and have a very high carotene level in the blood do not have problems with vitamin A excess. A possible explanation is that the synthetic reaction may have a mechanism for monitoring the vitamin A level.

Vitamin A in the circulation is bound to a protein, vitamin A-binding protein. The protein serves two purposes: it transports vitamin A to peripheral tissues (e.g., eye, testes, skin) and it regulates the availability of vitamin A. When the capacity of the retinol-binding protein is exceeded, vitamin A toxicity is more apparent.

Toxicity

Natural vitamin A is toxic and large amounts of it should only be used under a physician's direct supervision. Medication of oneself or child may be dangerous since

(continued on next page)

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ON CHARITABLE DONATIONS



by John Brennan
Accountant and
Member
Board of Directors

So you just wrote a check to the National Ichthyosis Foundation and mailed it off. For your money, you're probably getting our newsletter, the knowledge that you are helping in the fight against Ichthyosis, and a warm feeling. Now you should also get Uncle Sam to refund you some of that check!

You can do this by claiming a deduction on your income tax return.

First, determine if you are eligible to itemize deductions. If you are, simply include your contributions to N.I.F. on Schedule A of Form 1040, along with your medical expenses, mortgage interest, and other deductions. Schedule A will have special lines for contributions.

For 1982, you need total itemized deductions of \$3,400 to be eligible, if you are married and file a joint tax return. Single people will need \$2,300 to be eligible.

Starting in 1982 (for the check you write today!) even non-itemizers can get a tax break for their charitable contributions. Their deduction will be 25% of total contributions. The maximum deduction is \$25. For example, a \$100 contribution gives the maximum \$25 deduction.

In most states, if you are allowed a federal income tax deduction, your state income taxes will also be reduced.

Newsletter and membership fees paid to N.I.F., as well as regular contributions, qualify for deduction.

Consider keeping your returned check in a special place or marking your checkbook. This will help you remember the deduction at tax time next year.

So, when deciding how much you can afford to give, remember how much you will get back from Uncle Sam in tax savings. And give a little more!

Medical Point of View (continued from page 1) vitamin A produces many side effects, including skin dryness, hair loss, brittle nails, loss of appetite, and liver enlargement. The slight improvement and mild-to-moderate toxicity of vitamin A result in an unfavorable benefit/risk ratio. Natural vitamin A, therefore, is a known but not enthusiastically embraced therapy for the disorders of keratinization.

Vitamin A Acid (Accutane®), 13-cis Retinoic Acid, Isotretinoin)

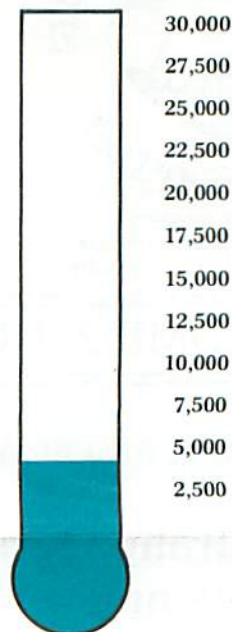
13-cis retinoic acid and the aromatic retinoid (etretinate) are new vitamin A analogues with the potential for a good benefit/risk ratio and different yet more selective interactions with the skin. Their efficacy in treating lamellar ichthyosis and epidermolytic hyperkeratosis will be discussed at a later date.

FUND RAISING

The San Joaquin Valley Chapter held their 1st annual wine and cheese tasting party and silent auction on October 2, 1982. The amount raised was approximately \$2,000.00

Oklahoma is planning a fund raiser in the near future. If anyone is interested in helping to insure success, please contact Betty McMasters, 1838 So. Muskogee, Sapulpa, Oklahoma 74066 or call her at (918) 224-9099.

\$30,000



WHAT CAN YOU AND YOUR CHAPTER DO TO
HELP US REACH OUR GOAL???

A Member's Story



My name is Jim Griffin. (This sounds like To Tell the Truth). Thirty years ago my mother gave birth, six weeks early, to what my father described as, "a blistering hunk of raw meat." The blisters, exuding a yellowish serum, gradually dried and thickened into a scaly layer of skin. Around my eyes, the skin was so tight that my eyelids were turned out giving my eyes a red appearance.

Discovering two years later that I couldn't sweat, my parents moved from Phoenix, Arizona to San Diego where it was a shade cooler and moister. After being stared at and inspected by many doctors muttering something about ichthyosis (what an 'ichy' name, I just call it dry skin), and after bathing in this tub and that with these chemicals and those lotions and a myriad of other treatments, I think I finally convinced my parents to give up and let me get on with living. The outcome of all of the above was:

I had sweat glands, but they didn't function, so my skin was dry. They didn't think it was hereditary, and my

glands might start working when I went through puberty. In the interim, daily baths in Alpha Keri oil and applications of a suitable ointment for the cracks and fissures would have to suffice.

As I remember, life didn't get interesting until I left the sheltered existence of a private school and entered the public schools at the Junior High level. Now, I've always been slow at things and growing up was one of them. I entered the eighth grade at the towering height of 4' 10" weighing a massive 78 lbs. and, of course, covered with scaly skin. To top it all, at a time when the Beatles made long hair popular, I had to have my head shaved (the skin on my head was so thick that my hair would mat up underneath the dead skin as it grew and would get infected). I usually ignored the teasing remarks from the other kids such as "Hey scuzzard, can I borrow your comb?" But once, I remember responding, "OK, but it doesn't have any teeth on it."

I had three wishes when I was that age: 1) that someday I would be able to grow my hair long, 2) that, physically, I would grow and 3) that my skin would heal. The first wish came true when I was fifteen years old. My father brought home an electric scalp massager. Using it for 15 minutes every day kept the skin broken up enough that my hair could grow out! I still use that massager to this day.

Being so small and unable to control my body temperature, I wasn't much good in sports, but I decided to try golf; it didn't look too strenuous and my size wasn't limiting. However, invariably after 9 holes or so, I was the guy running from tree to tree trying to stay out of the sunlight which

CHAPTER HAPPENINGS



by Susan Nye

This is the second in a series of articles being written to assist you in organizing chapters. The information is based on what has been learned through the experience of the San Joaquin Valley, CA Chapter which began its efforts in January, 1982. Since our report in the last Newsletter, the Chapter has successfully completed its first benefit (see separate article). In addition, they have located thirty-seven families with ichthyosis in their community and, during the past six months, they have raised more than three thousand dollars.

The Chapter reports that the Executive Committee approach is still working well for them. During the initial phase of organizing, there are many questions regarding chapter certification, setting up a budget, accounting for expenditures, handling correspondence, responding to individual member needs, handling inquiries from the community and gathering support from your medical community. The Chapter says to expect and anticipate these questions as simply a part of getting organized. If you use your Executive Committee structure and remain flexible, the Chapter will begin to take direction and shape. Specific questions regarding chapter organization and development may be addressed directly to our Assistant Director, Susan Nye, who is assisting President Barbara Landwehr with chapter organizing.

When you've decided to organize and have petitioned the National organization for chapter certification, one of your major tasks will be to notify your community and others who have ichthyosis, about your activities. This must be done on a regular basis each time you meet or have any information for the public to build community awareness about ichthyosis. The most efficient and least expensive way to do this is through the use of Public Service Announcements (PSA). Radio and television stations are legally required to give a certain amount of time to publicizing community service activities at no cost. They are aware of the law, expect to do this advertising as a matter of course and generally like to do it. However, whether your announcement receives priority depends on how well you

HOW TO PREPARE A TELEVISION PSA

1. Proper form: Name of Organization
Address and Telephone Number
Name of contact person submitting copy
Date copy is delivered
Dates copy is to run
(This information placed in either corner at top of page)
2. Just ONE announcement to a page.
3. Telephone numbers, street names, titles, etc., should be written in full. Abbreviations can be confusing.
4. Always give the phonetic spelling of hard-to-pronounce names in your PSA.
5. REMEMBER that what you write will be read out loud, therefore, it should be informal and easy to understand, but not breezy.
6. "Copy" refers to the written message you will provide the station. Copy should be timed to station preference. The following are guidelines. Using a stop watch will also help you determine time.

TIME	TELEVISION	RADIO
10 seconds	20 words	25 words
15 seconds	30 words	35 words
20 seconds	40 words	50 words
30 seconds	60 words	75 words
60 seconds	120 words	150 words

7. Visual material. For television PSAs check with the station to determine their individual preferences.

For further information:

Susan, Nye, Assistant Director National Ichthyosis Foundation San Joaquin Valley Chapter	2609 E. McKinley Fresno, CA 93703 (209) 485-8581
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approach and work with the media. The San Joaquin Valley Chapter suggests the following approach.

First, assign a Publicity Coordinator to work with the media. The media will get used to working with this person and you will make good and steady progress. Initially, the coordinator should phone the Public Affairs Director of each radio and television station in your community and request information regarding their station's procedures for public service advertising. (Some stations may have a guide they will mail to you.) Inform them that the chapter needs the public service information because you wish to promote the **chapter's** activities. This is very important. The public service media may not be interested in the story of one individual's experience with ichthyosis, or, if they are, it may only be on a one-time basis. This will not help you organize your chapter over the long run. Therefore, it is essential that **chapter promotion** be stressed.

When you have all the information, then prepare your PSA. Your announcement should contain the phone number of your Self-Help Coordinator as the person to contact for further information and it should be accompanied by a cover letter that briefly explains the PSA. Send the announcement to all radio and television stations in your community.

Whenever you publicize, expect to be "bombed" with phone calls. Have a procedure for responding to calls worked out beforehand. For example, the Self-Help

Coordinator may take the calls, give all pertinent and necessary information to the callers and pass the inquiries along to the Membership Coordinator for follow-up. In addition, our model chapter stresses that you **not** present individuals with ichthyosis, *particularly children*, to the media at this stage of organizing. The reason is two-fold. First, not everyone has the individual's well-being in mind and you are not prepared at this point to deal with people like this. Second, your primary task is to locate persons with ichthyosis, notify your community that you exist and stimulate support for the chapter. Public service advertising will do this for you.

Working with newspapers is a similar process, although they are not under the same legal guidelines as radio and television. Fortunately, most newspapers will be willing to print your press releases because they are interested in your community and what's happening with it. Therefore, follow the same general guidelines as working with radio and television. (The newspaper term is "Press Release", not P.S.A.)

In conclusion, how well the media responds to your chapter, to the larger Foundation and to the plight of those with ichthyosis, depends in large measure on your Publicity Coordinator's public relations skills. It's essential to choose someone who truly reflects and represents you as a chapter of the National Ichthyosis Foundation.

Best wishes and we hope to hear from you.



The San Joaquin Valley Chapter of the National Ichthyosis Foundation held a wine and cheese tasting party and silent auction on Saturday, October 2nd at Home Federal Savings and Loan which donated its building for the event. The Chapter Executive Committee began planning the event in May. While it took a lot of work, the success of the event made it all worthwhile.

The Chapter spent approximately \$300.00 on the event. Major costs incurred were for the equipment to set up the fund raiser — i.e. wine glasses, tables, tablecloths. All of the wine and cheeses were donated, as were the services of the violinist, who added a nice touch to the affair.

Local merchants and artists supplied 52 items for the silent auction which raised approximately \$500.00.

Tickets sold for \$10.00 each and approximately 150 people attended the event which netted \$2,000.00.

Drs. Peter Elias and Mary Williams, from



U.C. Keratinization Clinic, and the Board of Directors traveled to Fresno early and presented their research findings on ichthyosis to Fresno area dermatologists and pathologists prior to the fund raiser.

The Chapter also welcomed Elli Dooley from Washington, Board of Directors members Betty McMasters from Oklahoma and Judy Droste from San Mateo, as well as President and Founder of the National Ichthyosis Foundation, Barbara Landwehr.

The media covered this event from the planning stages through the night of the event. Two of our members with ichthyosis were interviewed on the 11:00 news which followed the fund raiser.

The Executive Committee celebrated the success of their first benefit and shared their organizing experiences with the Board of Directors the following morning at a breakfast meeting.

Respectfully Submitted
Gina Berglund

Retinoids in the Treatment of the Ichthyoses

By:
Joseph McGuire, M.D.
Leonard Milstone, M.D.

Yale University School of Medicine
Department of Dermatology
New Haven, Connecticut 06510



Joseph McGuire, M.D.

Response of the various forms of ichthyosis to topically applied medications is often unsatisfactory, consequently there is great interest for other medications which may have a greater therapeutic effect. One such medication reported to be effective in the treatment of lamellar ichthyosis and other keratinizing disorders in 1976 by Drs. Peck and Yoder at the National Institutes of Health is 13-cis retinoic acid. Since then, 13-cis retinoic acid has been used in a nationwide multicenter study. In general, the drug has been found to be extremely effective in reducing scale and returning toward normal the appearance of the skin in Darier's disease, lamellar ichthyosis, and in

many patients with epidermolytic hyperkeratosis. The drug has had less extensive evaluation in x-linked ichthyosis and ichthyosis vulgaris.

While 13-cis retinoic acid was being evaluated in disorders of keratinization, parallel studies of its effectiveness in the treatment of cystic acne were going on. 13-cis retinoic acid was found to be extremely effective in reducing the number of acne cysts as well as decreasing sebum production in patients who were unresponsive to other forms of therapy. In April of this year the Food and Drug Administration approved the use of 13-cis retinoic acid in recalcitrant cystic acne; the drug was not approved, however, for the treatment of disorders of keratinization.

The reluctance of the Food and Drug Administration to approve 13-cis retinoic acid for the treatment of disorders of keratinization is based upon their evaluation of the risk/benefit ratio of this drug which must be used in moderately high doses in this group of disorders. Unlike acne, in which long-term remissions occur following a 4 or 5 month course of therapy, remissions are not produced in individuals with disorders of keratinization. When the drug is discontinued or administration of the drug is stopped, scaling and other characteristics of ichthyosis recur.

Vitamin A has been known to be important in human nutrition for many years.

It is required for normal vision as well as for the maintenance of normal skin and hair. Excessive amounts of vitamin A, as well as insufficient vitamin A, produce many medical problems. Chronic hypervitaminosis A is associated with scaling skin, inflammation at the corners of the mouth, pain and tenderness of bones, headache, alterations in sleep patterns, loss of appetite and weight, increased size of liver and spleen, fatigue, and nose bleeds.

13-cis retinoic acid when evaluated in a large number of patients either with acne or disorders of keratinization was found to produce inflammation at the corners of the mouth in nearly all patients, conjunctivitis in about 38%, and musculo-skeletal symptoms in about 16%. About one quarter showed elevations of triglycerides in the plasma. Several individuals treated over two years showed hyperostosis and calcification of tendons. Two children observed at Yale showed x-ray abnormalities in the long bones.

What will be the role of retinoids in disorders of keratinization? In adults, 13-cis retinoic acid appears to be the single best treatment for Darier's disease, lamellar ichthyosis, and epidermolytic hyperkeratosis. The risk factors may be different in children than they are in adults and are difficult to evaluate at the present time. Many children treated with 13-cis retinoic acid have had bone pain. However, of all the children treated, to our knowledge, only two (children treated at Yale) have had x-ray changes probably caused by the drug. In one child the x-ray changes consisted of altered contour of the long bones of the leg without evidence of premature growth arrest. In another child, a boy who had been treated for 4 years with 13-cis retinoic acid, at an average dosage of 3.5 mg/kg, partial fusion of the growth center in the tibia was seen on x-ray. These observations raise questions about treating children who have not attained full growth. It is possible that the growth arrest is irreversible. We do not know how common this finding will be and we do not know to what degree these findings will influence the child's ultimate growth potential. Clearly what is needed is a diagnostic test or study that will identify this effect of 13-cis retinoic acid on bone growth while the changes are still reversible.

Risk and benefit factors must be evaluated in each individual. Information that must be considered in arriving at a rational appraisal includes:

- i. The degree of discomfort and disability caused by the disease.
- ii. The responsiveness of the disease to therapy.
- iii. Individual risks related to the age of the patient.

13-cis retinoic acid was synthesized in response to a need to develop compounds with increased therapeutic effectiveness relative to their toxicity and that quest continues. Just as 13-cis retinoic acid was more effective and relatively less toxic than vitamin A, there may be other compounds with increased effectiveness in the ichthyoses with even less toxicity than 13-cis retinoic acid.

would bake the blood in my dilated capillaries. Either that or I would hit the ball into the lake so I could go chase it (you become a little impatient and impulsive when you overheat). So, needless to say, I never did very well. The only time I won anything was when I was appointed Handicap Chairman of a tournament — my handicap went up and I took second, my younger brother took first (I hope no one was suspicious).

My interests turned toward academia. I also joined a Health Club where I started lifting weights. Nature may have made me small and scaly, but I was going to make me strong and smart. By the end of high school I held all the records at the gym in my weight class (we won't mention the fact that I was the only one in my weight class). As far as the smarts go, I graduated from Humboldt State University with a B.A. in Biology and a 4.0 G.P.A. (and that's **not** on a ten point scale either).

I left for college at 5' 5", 120 lbs. and came out 5' 9", weighing 160 lbs. I'm no giant (shorter than my two sisters and brother who have normal skin), but it sufficed to count my second wish as 'granted'.

I decided I wanted to teach science at the high school level. Despite my counselor's advice to look for a job in research in Oceanography where I could go out on a ship away from social contact, I enrolled in student teaching. The Vice Principal of the school suggested I wear bright colored clothing to avert people's focus from my face to my clothing. I thanked him for his suggestion and promptly ignored it. The only real obstacle I had in getting my teaching credential was when it came time to be fingerprinted. My skin is so thick, I have no prints. The police sergeant was furious with me. "You've got to have prints", he said. He finally gave up, and I walked out wondering if I shouldn't pursue a life of crime. . . . Naw, the trail of dead skin flakes would give me away every time.

Well, I've been a math/science teacher for four years now. I tell all my students about Lamellar Ichthyosis and extol its virtues — e. g. never needing deodorants or worrying about underarm stains, that I have my own built-in heater (on cold nights I don't turn on the heater, I just run around the block a couple of times and I'm warm for the rest of the evening), and the fact that I don't get electrical shocks — my skin is too dry to conduct a current).

As for my third wish — well, I think I'm past puberty, although it stretched from age 15 to 22 (I told you I was slow). Anyway, I know the condition is genetic now, and the **only** cure is to eliminate the gene pool — a fact we should all confront when it comes to reproducing. Perhaps Accutane will make my life a bit more comfortable. At any rate, I've come a long way from that initial hunk of raw meat that popped into this world 30 years ago. It hasn't been easy. But whoever said it was supposed to be? Parents and friends have been a great help. If I've gained any wisdom at all, it is this: Live a life led by your heart, not your fears, and don't take things too seriously. Learn to say "So What?!"

Jack Klugman Crusades Our Cause. . .

On October 2, 1982, we were very fortunate to be able to participate in the filming of an episode of the television program, Quincy, M.E., which took place in Southern California.

Jack Klugman, a crusader for many causes, did another show (he did one about 1½ years ago) about ORPHAN DRUGS in an effort to encourage Congress to do something to help those of us who suffer from orphan diseases.

The Orphan Drug Act (HR5238 and SB2130) recently passed but still must be signed by President Reagan.

In an attempt to show our support for this ORPHAN DRUG ACT, 12 members of



the National Ichthyosis Foundation participated in this filming. They were: Betty McMasters, all the way from Oklahoma, Elli Dooley, Washington; Judy Droste, Nathan Dunn, Barbara Landwehr, Deatra Landwehr and Kerianne Landwehr, all from Northern California; Walt Zimmerer, Simone Smith-Zimmerer, Tony Smith, Matt Smith and Kristy Smith, all from Southern California. In addition to their participation, they have also donated the money they earned to the Foundation to help defray the expenses of the trip.

A special thank you to the Smith-Zimmerer family for their hospitality in providing sleeping arrangements for all participants.

Thank you to all of you, especially Jack Klugman, for your hearty support and dedication. God bless you!



Research Grant Awarded

Dr. Mary L. Williams, V.A. Hospital, San Francisco, and member of our Medical Advisory Board and Board of Directors has recently received the Basil O'Connor Sturter Research Fellowship to study Ichthyosis. Our heartiest congratulations!!!

New Pharmaceutical Service for Members

We would like to introduce you to a low cost pharmacy service for members of the National Ichthyosis Foundation. Quantity purchasing can

reduce your costs even more. See the enclosed price list.

HELP WANTED

We have found it necessary to add another expense to our monthly budget to keep up with your numerous requests for information — A COPY MACHINE. The monthly cost to maintain this machine is \$100, not including paper. The cost to purchase the machine is \$2,500. If any of you could see fit to help us purchase the machine, please send your check and designate what it is intended for.

THANK YOU FOR YOUR HELP!

PLEASE CARE!

I DO CARE ABOUT THE NATIONAL ICHTHYOSIS FOUNDATION !!!

Name _____ Phone () _____

Address _____

Enclosed is my immediate contribution in the amount of
\$500.00 _____ \$250.00 _____ \$100.00 _____ \$75.00 _____ \$50.00 _____ other \$ _____

I also pledge \$ _____ per month for the next _____ months.

Signature Date

Billing statements for the Ichthyosis Focus will be in the mail shortly.

The National Ichthyosis Foundation is a charitable organization. All the money collected by it will be used for charitable purposes, such as education, counseling, and ichthyosis research. The organization's major expenses are mailing its newsletter and printing educational material. Articles of Incorporation as a non-profit organization have been approved by the California Secretary of State and its Tax Exempt Status has been approved by the California State Franchise Tax Board. All contributions to the organization are deemed tax-deductible under both California and Federal Law.

National Headquarters

Nat'l Ichthyosis Found.
151 Tison Drive
Vallejo, California 94589
(707) 644-5205

Regional Representatives

San Francisco Area
Ms. Judy Droste
710 Laurel Ave.
Apt. C12
San Mateo, Calif. 94401
(415) 348-3309

Colorado/Utah/Wyoming
Mrs. Teri Thompson
349 Silver Springs Court
Colorado Springs,
Colorado 80919
(303) 598-8020

Massachusetts Chapter
Rita Karassik
287 Lexington Street
Watertown, Mass. 02172
(617) 926-2426

New Jersey Chapter
Mrs. Patricia Mondt
989 Linwood Place
North Brunswick, NJ 08902
(201) 246-2085

New York Chapter
Claudia Kennington
12 Cresthill Court
Huntington Station
New York, NY 11746
(516) 423-0277

Rochester Chapter
Debra Butler
647 Latta Road
Rochester, NY 14612
(716) 621-8742

Michigan/Midwest
Regional Representative
Dick & Carol DeLoughary
24685 West Highland Ct.
Farmington Hills, MI 48018
(313) 879-8022

Kansas/Oklahoma
Mrs. Betty McMasters
1838 So. Muskogee
Sapulpa, Okla. 74066
(918) 224-9099

Pennsylvania Chapter
Pat Giuliana
12536 Deer Run Rd.
Philadelphia, Pa.
(215) 637-7220

Virginia/Maryland
Mrs. Donna Torney
116 N. Harrison Rd.
Sterling, VA 22170
(703) 430-0585

San Joaquin Valley Chapter
Gina Berglund
372 W. San Madele
Fresno, CA 93704

Ichthyosis Focus —

Editor

Richard M. Loughary
151 Tison Drive
Vallejo, California 94589
(707) 644-5205

Board of Directors

Richard M. Loughary
151 Tison Drive
Vallejo, California

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Sapulpa, Oklahoma

Ed Rollins
Presidential Advisor
The White House
Washington, D.C.

The National Ichthyosis Foundation

151 Tison Drive
Vallejo, California 94589
(707) 644-5205



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DATED MATERIAL

MEDICAL ADVISORY BOARD

Lowell A. Goldsmith, M.D., Chairman
Univ. of Rochester Med. Ctr.
P.O. B. 697
601 Elmwood Ave.
Rochester, NY 14642

Michael Jarratt, M.D.
Department of Dermatology
Baylor Coll. of Medicine
Texas Medical Center
Houston, TX 77030

Paul O. Schackelford, M.D.
St. John's Doctor's Bldg.
1705 E. 19th St.
Tulsa, OK 74104

Joseph McGuire, M.D.
Leonard Milstone, M.D.
Department of Dermatology
Yale University Medical School
333 Cedar St.
New Haven, CT 06520

Carl Eihman, M.D.
Department of Medical Research
Hoffman - LaRoche
Nutley, NJ 07110

Nicholas J. Lowe, M.D.
UCLA School of Medicine
Department of Dermatology
Los Angeles, CA 90024

Arthur Norins, M.D.
1100 West Michigan
Indianapolis, IN 46202

Melodie Buxman, M.D.
Olson Memorial Clinic
16463 S. W. Boones Ferry Rd.
Lake Oswego, OR 97034

Frank Yoder, M.D.
829 W. College
Westerville, OH 43081

James E. Rasmussen, M.D.
Dept. of Dermatology - Box 031
Outpatient Building
Univ. of Michigan Medical School
Ann Arbor, Michigan 48109

Nancy Esterly, M.D.
Children's Memorial Hospital
2300 Children's Plaza
Chicago, IL 60614

Lawrence Schachner, M.D.
1550 NW. 10 Ave., Rm. 301
Miami, FL 33136

Gary L. Peck, M.D.
Dermatology Branch, N.I.H.
Building 10, Room 12N238
National Cancer Institute
Bethesda, MD 20205

Robert A. Briggaman, M.D.
North Carolina Memorial Hospital
Chapel Hill, NC 27515

Gerald G. Kreuger, M.D.
Division of Dermatology
50 North Medical Drive
Salt Lake City, UT 84112

Peyton E. Weary, M.D.
Univ. of Va. Medical Ctr.
Box 134
Charlottesville, VA 22908

Gerald Weinstein, M.D.
Department of Dermatology
University of California
Irvine, CA 92717

Mary L. Williams, M.D.
V.A. Medical Center
Clement St.
San Francisco, CA 94121

Sidney Hurwitz, M.D.
2 Church St. South
New Haven, CT 06519

Howard P. Baden, M.D.
Department of Dermatology
Massachusetts General Hospital
32 Fruit Street
Boston, MA 02114

Laurence H. Miller, M.D.
N.I.A.M.D.D. — E.P.
Westwood Bldg., Room 405
N.I.H.
Bethesda, MD 20205

George Thorne, M.D.
Ortho Pharmaceutical Corp.
275 Old New Brunswick Rd.
Piscataway, NJ 08854

Eugene J. Van Scott, M.D.
Skin & Cancer Hospital
Department of Dermatology
Temple Univ. Health Sciences Center
3322 N. Broad St.
Philadelphia, PA 19140

Peter Elias, M.D.
V. A. Medical Center
Clement St.
San Francisco, CA 94121