



# The National Ichthyosis Foundation

## ICHTHYOSIS FOCUS

VOLUME 5, NUMBER 1

FEBRUARY 1986

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.

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\*\*\*\*\* FROM THE EDITOR'S DESK \*\*\*\*\*  
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The main news from the editor's desk is that there's someone else sitting behind it. That someone is me, Valerie Lutters, voted into this position at the Board of Directors' meeting Saturday evening, December 7. There is little to say about me personally except that I have a fairly extensive background in writing, reporting and editing. I could say I'm newspaper trained, but that makes me sound like a puppy. Lets just say I worked as a reporter/editor for two weekly newspapers on the East Coast for over ten years, and I hope that training and experience will stand me in good stead as the new editor of FOCUS.

At the moment I don't think FOCUS will change very much despite a new person behind its main desk. For one thing, I think continuity is important. For another, I think Charles Eichhorn, the previous editor and my present mentor in this project, has done an excellent job, as have his predecessors. In the spirit of "If it ain't broke, don't fix it," I plan to leave FOCUS pretty much as it stands. I like our newsletter just as it is.

That's not to say I'm adamantly opposed to any changes. Some will be inevitable as every individual, myself included, has his own style. Furthermore, I'd like more input from you, the readers. This should be an audience participation show, and I want every reader to not only tell me what he or she would like to see in FOCUS, but to contribute to it as well. One suggestion I've heard is that many of you want to see more human interest stories, more personal looks at various individuals with ichthyosis and how they are living their lives. Well guess what, folks; you're it -- "it" being the folks other folks read about. So, all of you who would like to see more personal stories are hereby assigned to write in and tell us about yourselves.

This newsletter should be, I hope, a dialogue. It's your newsletter, not the editor's, no matter who the editor might be. So help me out with your feedback -- what you like, what you don't like, what you'd like to see more of, what you want your newsletter to be. And, within budget limitations, I'll do my best to accommodate you.

All best wishes for a great New Year for each of us and for the Foundation as a whole.

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\*\*\*\*\* WHAT'S NEW \*\*\*\*\*  
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The month of December seems to be the highlight of the whole year for the National Ichthyosis Foundation and December, 1985, was no exception. The main event was, of course, the annual conference which this past year took place in Las Vegas on Saturday, December 7. Details of the conference appear in a separate article in this newsletter.

Other events of interest surrounded the conference, too, notably: a reception on Friday evening, December 6, sponsored by D.E.B.R.A., the foundation for victims of Epidermolysis Bullosa (EB); on Saturday evening, a meeting of N.I.F.'s Board of Directors; and finally on Sunday morning, December 8, a meeting of the Patient Advocate Coalition. Important goals were reached at each of these events.

**THE D.E.B.R.A. RECEPTION - A FETOSCOPY REGISTRY FOR SKIN DISORDERS** Friday evening Mrs. Arlene Pessar, Executive Director of D.E.B.R.A. presented a check for \$15,000 from D.E.B.R.A. to Drs. Karen Holbrook and Virginia Sybert of the University of Washington, Seattle. These doctors collecting data from prenatal diagnosis of EB, ichthyosis, and other inherited skin disorders which have been made from fetal skin biopsies via fetoscopy (a procedure for taking a skin sample from an unborn child).

The doctors hope to compile the information from these procedures wherever they are done in order to establish further criteria for diagnosis, and develop statistics for future genetic counseling of families concerned about giving birth to a child with an inherited skin disorder. They plan to publish this information and disseminate it to the entire medical community.

According to Dr. Holbrook the information obtained and collated into this fetoscopy registry will have an added advantage of increasing understanding of the expression of certain disorders at their earliest appearance. They hope the information will lead them to markers for these disorders in the amniotic fluid which would make it possible to diagnosis them without using fetoscopy in the future. It could then provide insight into both normal and abnormal skin development.

There are about six medical centers doing fetoscopy throughout the country at this time.

Further information is available from: Dr. Karen A. Holbrook, Department of Biological Structure, SM-20, University of Washington School of Medicine, Seattle, Washington 98195.



**NOMINEES SUGGESTED TO SPEAK BEFORE CONGRESS** Late in 1985 the United States Congress passed, over Presidential veto, a bill creating a new agency called the National Institute of Health for Arthritis, Musculo-Skeletal, and Skin Disease Research. This is important news for N.I.F. for it is the first time skin diseases have been specifically named in a government research agency. Previously government research agencies could look into skin disease research but they did not have to; this agency, however, has a stated responsibility to look into skin research as mentioned in its title.

The agency is part of the overall National Institutes of Health, falling under the general umbrella of the Department of Health and Human Services which is part of the executive branch of the federal government. As such its advisory board and advisory council members are appointed by the President, and one-third of those members are "laypersons," people who are neither doctors nor people with positions within the institutes. Usually such people are patients with the particular disease or disorder named in the agency title, prominent educators, or otherwise involved non-professionally with the disorder.

On Sunday morning, December 8, the Patient Advocate Coalition for Skin Research (PACSR) was formed and as its first order of business nominated individuals for positions on the advisory board and advisory council of the newly-created National Institute for Skin Research. PACSR is an organization composed of representatives from the various skin foundations -- N.I.F., D.E.B.R.A., The Psoriasis Foundation, and a number of others, most of whom were also in Las Vegas in December.

Among those nominated was Charles Eichhorn, N.I.F. co-president. His name will now be submitted for possible appointment as a lay member to the new institute's advisory board. If appointed, Mr. Eichhorn will have the opportunity to testify before Congress about the importance of the new institute, the importance of giving it adequate funding, and about the importance of skin research in general.

"This is the most crucial year ever for the National Institute of Health for Arthritis, Musculo-Skeletal, and Skin Disease Research," Mr. Eichhorn says. "This is the year when it will get its first funding -- extremely important since most increases in budgets are based on a percentage of a previous budget. Therefore, getting a substantial budget for 1986 will also mean better funding in years to come."

Budget considerations aren't the only crucial issues for the new agency in 1986, however. This will be the year it sets its policies and obtains its crucial ground-floor personnel and representatives. "Supporting the newly-created National Institute of Health for Arthritis, Musculo-Skeletal and Skin Disease Research should be the top priority for N.I.F. in 1986," Mr. Eichhorn says, because agencies such as this "are the way to get things done." He says the N.I.F. membership can get behind this first agency charged specifically with skin disease research by letting local Senators and Representatives know that you support this cause and support funding of it with your tax dollars.

**VACANCIES FILLED ON BOARD OF DIRECTORS** A meeting of the N.I.F. Board of Directors took place Saturday evening following the annual conference. Present were members Charles Eichhorn, Susan Nye DeHaan, Jeannette Jensen, and Betty McMasters. The board decided to fill some of the existing vacancies on the board and voted in Marge Boyd, Sarah Massey, and Valerie Lutters.

Marge (Mrs. Kenneth) Boyd is the grandmother of a little girl, Elizabeth, with ichthyosis. Mrs. Boyd says she and her family had never heard of ichthyosis until Elizabeth was born and diagnosed with Lamellar three years ago. Since then she has been very active with the Oklahoma chapter of N.I.F. The Boyds are also members of the local Moose Lodge which has raised money for the Foundation through Bingo, auctions, and other fund-raising activities. Mrs. Boyd says she has made many new friends in the course of her activities related to ichthyosis, and has interested numerous organizations and individuals in the disease.

Sarah Massey is the mother of a son, Robert Anthony, now 13, who has E.H. Mrs. Massey has been active with the N.I.F. since its inception. She has been in touch with dermatologists in all the major cities in her home state of South Carolina, and has stayed in touch with other families with ichthyosis in a three-state area in an effort to keep them abreast of N.I.F. activities and other pertinent information. She has also worked on some publicity by putting articles in local and city newspapers, some of which were picked up by the Associated Press for wider distribution.

Valerie Lutters, who has E.H., is originally from Connecticut and moved to San Francisco in the spring of 1985 to do volunteer work for N.I.F. Her background includes some freelance writing and ten years of newspaper reporting. She is working on brochures on ichthyosis and was also elected the 1986 editor for the ICHTHYOSIS FOCUS at Saturday's board meeting.

The terms of these three people began January 1, 1986 and will run for three years. There are still a few vacancies remaining, but the board decided they should be filled at a slightly later date so terms will continue to be staggered, thus avoiding major upheavals in the composition of the board at any one time.

It was also voted at Saturday night's meeting to put Betty McMasters, N.I.F. First Vice President and president of the Oklahoma chapter, in charge of regional reps. The Board of Directors would like to see more emphasis put on regional representatives, and Mrs. McMasters will oversee and coordinate these volunteers throughout the country.

William Geismann, an English teacher from Skokie, Ill., was elected to handle national publicity. Mr. Geismann introduces himself to FOCUS readers with his coverage of the conference elsewhere in this issue.

**UNITED CONTRIBUTIONS** Don't forget, you can contribute to NIF in a relatively easy and "painless" way through the United Way's Designated Charity Program which allows you to earmark all or part of your contribution to a specific charity -- like The National Ichthyosis Foundation. If you will be donating to the United Way this year, whether directly or through payroll deduction, ask for the special form to direct your contribution to a specific organization. If the payroll deduction plan is through a private company this option is called the Donor Option Plan; if it's through the government, it's called the Designated Contributors Plan.



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 \*\*\*\*\* NIF FINANCIAL REPORT \*\*\*\*\*  
 \*\*\* July 1, 1984 to June 30, 1985 \*\*\*  
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Beginning bank balance: \$ 1,643.70

Income:  
 Donations: 6486.34  
 Membership: 2710.00  
 Conference Registrations: 560.00  
 Chapter Fundraising: 1052.23  
 Interest: 7.00

Expenses:  
 Office expenses: 286.81  
 Telephone: 810.85  
 Postage: 793.00  
 Licenses, permits: 215.00  
 Transport/travel: 1103.46  
 Printing: 952.70  
 Lodging: 625.98  
 Food/misc: 1127.88

Total: +10,815.57

Total: -5915.68

Closing bank balance: 6,543.59

NOTES: Fiscal Year 84-85 expenses include two regional conferences and visits to Appropriations Committee Congressmen in Washington, DC. Newsletter expenses were offset by a contribution of services from Hermal Pharmaceutical Company for part of the year. Some lodging was also contributed by members and their families.

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 \*\*\*\*\* CURRENT REPRESENTATIVES AND CHAPTERS: \*\*\*\*\*  
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- ALASKA: Lynette Finstad, 1606 Marika Road, #4, Fairbanks, AK 99701 (907) 456-6842
- CALIFORNIA: Jeannette Jensen, 641 Old County Road #209, Belmont, CA 94002 (415) 595-3817  
 Mrs. Gina Bergland, 625 East Richmond, Fresno, CA 93710 (209) 431-3776  
 Mrs. Elaine Lefler, 9639 Domino Drive, Lakeside, CA 92040 (619) 443-2922  
 Al and Lois Enzenbacher, 4432 E. Sycamore, Orange, CA 92669 (714) 633-2597  
 Carolyn Gramlich, 1390 Cochran, Simi Valley, CA 93065 (805) 526-0945
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- IDAHO: Mrs. Carol Lambright, 3547 Chuck Wagon Avenue, Boise, ID 83701 (208) 322-5285
- ILLINOIS: Mr. William Geismann, 7091 North Keeler, Skokie, IL 60076 (312) 677-1842
- INDIANA: Tony Baswell, 516 Gatewood Apts 3, Marion, IN 46952 (317) 662-9693
- IOWA: Mrs. Ann Pech, 505 Monroe, Emmetsburg, IA 50536
- LOUISIANA: Sammy Williams, Route 1, Box 130E, Franklin, LA 70538  
 Brenda Lyle, 518 Barrow Street, Morgan City, LA 70380
- MASSACHUSETTS: Mrs. Cynthia MacEachran, 46 Wilmor Road, Topsfield, MA 01983 (617) 887-8055
- MICHIGAN: Dick and Carol DeLoughary, 24166 Cranbrook, Novi, MI 48050 (313) 478-0886
- MINNESOTA: Rex and Judy Rhein, 304 East Sidney, St. Paul, MN 55107 (612) 227-4528
- MISSISSIPPI: Mrs. Andrea Thorn, Route 2, Box 346D, Jackson, MS 39209 (601) 366-5254
- NEW JERSEY: Pat Mondy, 989 Linwood Place, North Brunswick, NJ 08902  
 Joe Galluccio, 1408 Williams Drive, Wall, NJ 07719 (201) 681-6824
- NEW YORK: Mrs. Marisa Mandia, P.O. Box 12992, Albany, NY 12212  
 Mrs. Debra Butler, 647 Latta Road, Rochester, NY 14612 (716) 621-8742
- N. CAROLINA: Mrs. Ellen Rowe, 6316 Secret Drive, Raleigh, NC 27612 (919) 848-3821
- OHIO: Geraldine Schooler, 3410 Wellington Drive, Dayton, OH 45410  
 Ken and Marge Boyd, 7427 E. 31st Place, Tulsa, OK 74145
- OKLAHOMA: Mrs. Pat Guiliana, 12536 Deer Run Road, Philadelphia, PA 19154 (215) 637-7220
- PENNSYLVANIA: Mrs. Sarah Massey, 125 Blueridge Drive, Fountain Inn, SC 29644
- S. CAROLINA: Mrs. Sarah Massey, 125 Blueridge Drive, Fountain Inn, SC 29644
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- WASHINGTON: Richard Kelley, 12305 SE 73rd Place, Renton, WA 98056
- BR. COLUMBIA: Valerie Munroe, 2492 West 45th Ave., Vancouver, B.C. V6M 2J8 Canada (Chapter)

We need representatives, support persons to talk with and share information, in every state and major city. How about you?  
 Chapter organizing is a more formal process. We have a "How To" manual, currently being updated and reprinted, available on request. Anyone interested in forming a chapter should contact Susan De Haan, RR #1, Filer, ID 83328 (208) 326-5154 for details.



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 \*\*\*\*\* CORRESPONDENCE CORNER \*\*\*\*\*  
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The following people would like to be put in touch with other people who share their situation and know what they go through. Anyone who would like to correspond with others in the ichthyosis community should send us his or her name and address, type of ichthyosis, and age.

- Mrs. George McHugh, 302 Juniata Avenue, Delran, N.J., 08075, would like to contact people with Epidermolytic Hyperkeratosis. Her grandson, Ryan, who is about nine months old now, has EH.
- Paula Lange, Box 325, Utica, MN 55979, is 18 years old and has Lamellar Ichthyosis. She would like to correspond with people her own age.
- Ms. Brenda Lyle, 518 Barrow St., Morgan City, LA, 70380, would like to hear from other people in Louisiana or thereabouts.

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 \*\*\*\*\* HOT TIPS \*\*\*\*\*  
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"Hot Tips" are bits of 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. N.I.F. acts only as a clearinghouse of news. Ask your doctor about any tip and follow his or her advice before acting on any information presented in this forum.

An N.I.F. member from New Jersey writes that after a month of using Lacticare lotion he finds no recurrence of scaling. He says he has had equally good results from using Glycolic lotion, but now finds Lacticare works just as well.

Anyone who has to put dressings or bandages on himself or a child knows what a nightmare can be created by a dressing adhering tightly to a wound. You might want to ask your doctor about some of the latest "no stick" bandages and compresses available. We saw some at the exhibit hall at the A.A.D. meeting in Las Vegas; some were even recommended for burn patients and look as though they could be a real step up from ordinary gauze and other materials that sometimes appear to imitate Velcro when put in contact with an open wound.

Those of you who have enjoyed using Aqua Glycolic Lotion but occasionally had trouble finding it on the shelves in your local drugstore will be pleased to learn that Henry Kamps, President of Herald Pharmacal, has generously offered to sell the lotion, wholesale, to members of N.I.F. Individuals may order the product, by case lots, directly from Herald, PO Box 8990, Richmond, VA 23225, 804-745-3400. A case contains 12 8-oz. bottles and costs \$48 wholesale. Write to the company for an order form.

Anyone who has never used Aqua Glycolic lotion and is interested in trying it before ordering a case may obtain a 2-oz. sample from the Foundation by sending us \$1 for postage and handling. Aqua Glycolic Lotion is available without a prescription, but it's still always a good idea to check with your doctor before trying anything new.

There's good news for fans of Lac-Hydrin, too. It's back! But you do need a prescription for this product from Westwood Company in Buffalo, NY.

Both Aqua Glycolic Lotion and Lac-Hydrin contain alpha hydroxy acids, the key ingredient for releasing scales in topical treatment. Ask your doctor. Aqua Glycolic Lotion is also available through Rx Allstates. Lac-Hydrin may be, also. Write and ask: Rx Allstates, 360 West Superior Street, Chicago, IL 60610, (312) 280-7711.

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 \*\*\* N.I.F.'s THIRD ANNUAL CONFERENCE -- \*\*\*  
 \*\*\* A FIRST TIME ATTENDEE'S IMPRESSIONS \*\*\*  
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The Third Annual Conference of the National Ichthyosis Foundation was held at the Best Western Mardi Gras Inn in Las Vegas, NV, on Saturday, December 7, 1985. The morning sessions consisted of medical presentations by Dr. Mary Williams and Dr. Peter Elias, both of the Veterans Administration Medical Center, San Francisco, CA; Dr. Eugene Van Scott of Temple University Health Science Center, Philadelphia, PA; and Dr. Leonard Milstone of Yale New Haven Hospital, New Haven, CT. All four doctors are members of the N.I.F. Medical Advisory Board. The afternoon session consisted of presentations by Susan Nye DeHaan on the psychological aspects of ichthyosis and by Charles Eichhorn on the state of the Foundation; they are N.I.F. co-presidents. Also during the afternoon, Dr. Alan Moshell, Skin Diseases Program Director with the National Institutes of Health, spoke about funding for research.

William Geismann of Skokie, Ill., reports on the conference for Focus. He will cover the morning session in this issue, and the afternoon session in the next.

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I have ichthyosis, Ichthyosis Vulgaris, to be exact, but I never even knew it until just two years ago. This fact spotlights how little I knew about my affliction throughout most of my 53 years and, fortunately, how much I have learned recently, especially at the conference in Las Vegas.

My coming upon the National Ichthyosis Foundation was quite coincidental. A friend suggested I call the American Academy of Dermatology in Evanston and ask if there was an association for people with ichthyosis. I thought this was a very remote possibility. But sure enough, such a group of skin sufferers existed--with a California address and even a charter! I immediately sent for membership. I just missed the nearby Chicago conference, but, after a few other delays in between, was able to attend the conference in Las Vegas.

That conference was a real stunner to me. For the first time in my life I met other sufferers. (As the conference went on I learned that lack of adequate information about our disease and a sense of isolation are major themes for all



members). And I verified what I had begun to deduce from newsletters: my case is mild compared to that of most others. But mostly I learned a lot. I learned so much about a very personal affliction, something that had always been so vaguely defined to me and yet was as intimate and inescapable as, well, my own skin. All my life I had known so little about an irritating malady which, though not crippling certainly had caused some physical limitation and, in my earlier years, tremendous anxiety, worry, rejection, and the inevitable chase for a cure. And now, in one weekend's seminar, more light was cast on my personal darkness than in all my previous years.

The informative morning presentations were led off by Dr. Williams who described normal skin and ichthyotic skin, defining some of the differences between the varieties of ichthyosis. She described the layers of normal skin and how something can go wrong in these areas, resulting in ichthyosis. Noting that normal skin sheds at about the same rate it is produced, she explained that in ichthyosis skin cells either fail to shed at the proper rate or are produced too quickly (hyperproliferation). She also noted the discovery of an excess of cholesterol sulfate in the skin in X-linked ichthyosis. She stressed good nutrition and medical attention for all these varieties, but especially those involving hyperproliferation -- EH and CIE.

All five types of ichthyosis are genetic--inherited-- disorders, she went on to say, though, again, their patterns differ. Epidermolytic Hyperkeratosis and Ichthyosis Vulgaris are dominant; CIE and Lamellar are recessive; and X-linked ichthyosis is recessive and sex-linked, meaning males get it and females carry it. She added that a new case can "spring up" for the first time in a family through a new mutation, but from that person forward it will follow the genetic pattern of that particular disease.

Dr. Van Scott next reported on topical treatments. He mentioned that by middle-age our skins would be six inches thick were it not for continuous shedding. He said the goal in caring for ichthyotic skin is to keep the skin thin (shedding) and moisturized (hydrated). Staying damp -- bathing, swimming, using occlusion--aids in moisturizing. "Water is the most important ingredient to all protoplasm."

Alpha hydroxy acids can aid in keeping the scale from building up and becoming too thick. He added that AH acids come from food products and are non-toxic. They aid in shedding by lessening the stickiness of the skin. He also touched briefly on alpha acetoxy acids which, he said, produce the opposite results of AH acids and can actually make normal skin scaly. Ironically, these acids are sometimes used for people with ichthyosis if they are taking a systemic treatment which is "working a little too well" in certain parts of the body -- the lips, for instance. Alpha acetoxy acids are then applied to those too-thin areas to build them up again.

"Topical care is a nuisance," admitted Dr. Van Scott. "Hydrating and using lotions takes time and bother, but if you take the time it's pretty effective, especially with the less severe or moderate forms of the disease." Referring to the controversial systemic treatments, he said, "retinoids are not forever; they can have adverse effects...we must return to external care."

Dr. Milstone addressed the issue of those controversial retinoids, but emphasized over and over that any treatment decision requires a good dialogue between the individual patient and his or her doctor. "This is a genetic disease," he said, "and in most cases we don't know the genetic defect, only the manifestation. We can only treat the symptoms but we can't cure it, and that treatment is going to be long-term, on-going."

Dr. Milstone said that any decision about systemic treatment for a rare disease like ichthyosis must acknowledge differences between individuals. Essential, he said, is a good diagnosis, specific rather than general, based on a complete personal and family history and possibly a skin biopsy. Then the doctor and patient together look into the manifestations of the disease and which of those manifestations bother the patient the most. "If it's infections, then the best course would probably be antibiotics. If it's the appearance, then the patient may want to try retinoids.

"It's two-way communication," he emphasized. "The doctor must listen to which manifestations bother the patient. The patient must listen when the doctor tells him the possible risks. It's the patient who must finally look at the risk-benefit ratio and decide if it's worth it," he said.

Dr. Milstone went on to explain that "retinoid" is a generic term for Vitamin A derivatives which itself is "pretty good at removing scale but is toxic. The retinoids were an attempt to get the benefits of Vitamin A without the toxicity. They've done that -- but not totally." Doctors," he said, "try to use retinoids such as (13-cis-retinoic acid) Accutane or etretinate (Tigason) in doses high enough to gain benefits but low enough to minimize the side effects."

Dr. Elias, a skin researcher, shared some of his latest findings. He compared the top layer of skin, the stratum corneum, to a brick wall, noting that the wall is made up of bricks -- skin cells or corneocytes -- and the mortar that holds them together -- lipids and other substances. "Normal skin sheds cell by cell, invisibly; ichthyotic skin detaches as clumps and aggregates, not invisibly," he said. With EH and Ichthyosis Vulgaris the abnormality lies with the "bricks" themselves; with CIE, Lamellar, and X-linked Ichthyosis, it lies with the mortar. He noted that Vitamin A "loosens the mortar," but in doing so makes the user more susceptible to tearing and blistering.

Dr. Elias enthused that mankind learns from rare diseases, for example, what holds skin together and what doesn't. He added that he suspects sufferers might in the future find some relief through dietary means, noting that diet and nutrition may be a "great research interest for the future," although there has been little progress to date.

Topics raised during the question and answer periods included advisability of surgery for ectropion while a child is still young; (A: It should be cared for before it can lead to problems with the eyes themselves; careful application of topical treatment is okay, but should be done with care.) care of the scalp; (A: Overnight treatments of AH acids and occlusion followed by shampooing.) treatment for itching; (A: Itching should be reduced with regular topical treatment for ichthyosis in general; antihistamines can offer relief but should be used only sporadically because of side effects and a tendency for the body to build up immunity to them) do all systemic treatments cause birth defects; (A: they can, but Accutane disappears from the body more quickly than does etretinate once you stop taking it;) can ichthyosis be caused by any particular behavior on the part of a mother during pregnancy; (A: it has never been known to be connected in that way; since ichthyosis is genetic in origin, it is present at conception.

The morning session was then adjourned.



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