The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

The National Ichthyosis Foundation
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VOLUME 3, NUMBER 1 SUMMER, 1983

From a Medical Point of View

ICHTHYOSIS: Hereditary Dermatosis

by Ervin H. Epstein, Jr., M.D.

Dr. Epstein is associate clinical professor and associate research dermatologist at the University of California, San Francisco, School of Medicine. He has recently joined our Medical Advisory Board. A longer version of this article appeared in the February 1983 edition of CONSULTANT magazine.

The ichthyoses — "fish-skin" diseases — are a group of hereditary dermatoses marked by scaly skin. Since the diseases are inherited, often the patient will know of someone else in the family with scaly skin. If the ichthyosis is a comparatively mild type, its presence may be known only to the patient's parents and spouse, but not to cousins or even offspring. The more severe forms, of course, cannot be hidden by clothing; thus the presence of such an affliction is well known to family members. Because different forms of ichthyosis have different patterns of inheritance and because different forms of treatment are now available, accurate diagnosis of the type of ichthyosis is worthwhile. Moreover, a patient planning to have children will want to know how likely it is that they will inherit the scaly skin.

An excess of stratum corneum

Ichthyoses may be thought of as diseases caused by the accumulation of excess stratum corneum. We know very little about what holds together the cells of this remarkable, thin, supple, continually regenerating keratinous membrane layer, and hence it is not surprising that we understand only imperfectly how normal shedding occurs. We do know that in some unfortunates the stratum corneum either becomes abnormally thick and scaly or spiny, or sheds abnormal quantities of excess scale. Obviously, such an excess, as with any other metabolic product (such as uric acid), may be caused by either excessive production or impairment of "loss."

If too much stratum corneum is produced, the excess scale is shed. The forms of ichthyosis in which new scale is produced in excess are fortunately [redacted] epidermolytic hyperkeratosis.

When new cell production is normal but shedding is impaired, the stratum corneum thickens but no scales are shed. The two most common forms of these so-called retention hyperkeratoses are ichthyosis vulgaris and X-linked ichthyosis.

Ichthyosis vulgaris

The more frequently encountered of these is ichthyosis vulgaris (vulgaris means common), affecting approximately 1 of every 250 persons. It is inherited as an autosomal dominant trait — that is, one parent also has abnormal scaling.

Because the scaling of ichthyosis vulgaris is comparatively mild, the patient may not realize that other family members also are affected.

Ichthyosis vulgaris typically produces polygonal scales, most prominently on the outer sides of the patient's calves, although the thighs, buttocks, trunk, and arms also may be involved. These [redacted] usually are spared. Although the palms and soles often have an unusually large number of superficial wrinkles, especially when atopy coexists, they have no cracks or fissures.

At birth, the skin appears normal — the scaling usually begins during infancy, unlike the less well-defined winter dryness that plagues older persons.

Recessive X-linked ichthyosis (RXLI)

The second most common type of scaly skin is recessive X-linked ichthyosis (RXLI), which affects approximately 1 in 6,000 males. Typically, the skin is normal at birth, but scaling begins to be noticeable by several months of age. Clinically, this condition looks very much like ichthyosis vulgaris. In patients with RXLI, the scaling tends to be more severe — the scales are likely to be larger, darker, and loosely adherent or "stuck on" and shieldlike, rather than small and white. The appearance of an apparently unwashed neck is distinctive, since the sides of the neck frequently are sites of hyperpigmented scales.

In affected men, and in women who are carriers of the trait, corneal opacities may be visible by slit-lamp examination, but they do not interfere with vision. The family history may include brothers and maternal uncles or a grandfather with scaly skin.

How noticeable the condition is, even to the afflicted person, however, can vary considerably. In certain environments, the condition actually may be undetectable even by knowledgeable observers.

Biochemical detection of RXLI

During the past 5 years, research has produced fundamental insights into the biochemical cause of RXLI. The seminal observation is that fibroblasts grown from the dermis of patients with RXLI lack steroid sulfatase, an enzyme that removes sulfate groups from steroids and sterols. This finding has sparked intensive research into the role of this enzyme in normal epidermal differentiation and stratum corneum shedding.

Congenital ichthyosiform erythrodermas

The two other principal types of ichthyosis are epidermolytic hyperkeratosis, an autosomal dominant disease, and lamellar ichthyosis, an autosomal recessive disease. Both conditions have much more severe manifestations; fortunately, they affect far fewer persons — the incidence is probably 1 to 5 cases per million.

EPIDERMOLYTIC HYPERKERATOSIS. Infants with epidermolytic hyperkeratosis may have blisters and oozing, progressing later to a drier and more spiny skin. The spines may be so thick as to resemble porcupine quills. Light microscopy reveals empty spaces

(cont. on next page)

Printing costs for this issue of Ichthyosis Focus have been defrayed by a grant from the educational division of Hermal Pharmaceutical Laboratories, Inc., Oak Hill, N.Y. 12460.

Medical Point of View
(cont. from page 1)

in the epidermal cells — a quite distinctive feature that accounts for the designation "epidermolytic." When these spaces are examined by electron microscopy, however, they are seen to be filled with whorls of filaments. Occasionally the hyperkeratosis is limited to the palms and soles.

LAMELLAR ICHTHYOSIS. In patients with lamellar ichthyosis, the entire skin surface is abnormal, with broad scaly plaques (lamellae) separated by deep grooves as well as generalized redness (erythroderma) of varying degrees. At birth, the skin may be covered by a thin, transparent, glistening membrane resembling cellophane, which dries, becomes brittle and cracked, and is shed during the first week or two of life. Infants with this condition sometimes are termed "collodion babies." The skin may appear to be almost normal for some months, but then the more characteristic thicker scales appear.

New developments that offer hope

Two new advances hold out some hope for ichthyosis patients and their offspring. One such development is prenatal diagnosis, which may be used in cases of epidermolytic hyperkeratosis. Since the skin of afflicted persons manifests "epidermolytic" changes even in early embryonic life, fetal skin biopsy in utero can establish the diagnosis. Through this technique, an affected parent can know in early pregnancy whether this disfiguring disease is present. Ordinarily, with an autosomal-dominant disease, the chance of having normal children is 50%.

In utero histologic diagnosis has not yet been attempted for the autosomal-recessive lamellar ichthyosis. It is not clear whether the characteristic stratum corneum thickening could be recognized early.

The second promising advance is the development of vitamin A synthetic derivatives known as retinoids. Vitamin A has long been known to reduce keratinization and in certain epithelia to cause the cells to switch from a pattern of keratinization to one of mucous formation, but it can produce serious systemic side effects. Chemists now have succeeded in modifying the vitamin A molecule so as to preserve its beneficial effects while minimizing its adverse ones.

The most frequent use of isotretinoin, or 13-cis-retinoic acid, is likely to be for cystic acne. In the more severe ichthyoses, the drug's inhibition of keratinization is dramatic. The retinoids are by far the most effective drugs available for such patients.

Common side effects include cheilitis and epidermal fragility, as well as an inconsistent elevation of serum triglycerides, the long-term consequences of which are not known. Although hepatotoxicity may occur, it is much less common than with vitamin A. When measured against the severity of the disease and the social ostracism patients so often suffer, however, these problems seem small.

Many other types of ichthyosis can be differentiated clinically, usually on the basis of associated abnormalities, such as deafness, brittle hair, or mental deficiency. These conditions are extremely rare and usually rather poorly defined.

Acquired ichthyosis

In addition, I should call attention to a less unusual but very important condition: so-called acquired ichthyosis. Since it is not hereditary, it is not a true ichthyosis. Nevertheless, such patients also develop, as adults, scaly skin resembling that of lamellar ichthyosis or of severe ichthyosis vulgaris.

The importance of acquired ichthyosis lies in its role as a cutaneous sign of internal malignancy. An association has been reported between this ichthyosis and various types of cancers. Hodgkin's disease and other lymphomas are those most commonly involved. Hence, if a middle-aged or older patient with no history of ichthyosis develops this type of marked scaling, you would institute a search for such a cancer. In this condition, topical therapy is not sufficient.

In summary, then, the ichthyoses are a group of congenital skin diseases whose manifestations can range from the annoying to the socially and psychologically crippling. In the milder forms, judicious topical therapy can cause significant, worthwhile improvement, and the systemic retinoids can provide substantial help to patients with more severe forms of the disease.

State of the Foundation

A Message From Your Board of Directors

Dear Friends,

The Foundation's major project for 1983 will be our first national workshop on November 30th and December 1st in Chicago, Illinois, just prior to the American Academy of Dermatology meeting.

At the workshop, you'll learn about the latest developments in ichthyosis treatment and research. You'll also learn how to organize local chapters and work along with the Foundation. Dick DeLoughary, member of the Board of Directors, is helping with plans to make the workshop a truly outstanding event.

The attendance fee is $15.00 per person, $30.00 per family. We'll try to arrange accommodations for those who would like to stay with a member of the Foundation while in Chicago. If you plan to attend, please fill out the attached form and send it to us. (The workshop program will be printed in the fall Newsletter.)

The Foundation now has several active committees. Among them are: National Issues, chaired by Charles Eichhorn; and Chapter Development, chaired by Susan Nye.

As always, we are in great need of financial support. Your contributions and donations are very helpful in meeting the ongoing costs of postage and telephone. However, the workshop will be an extraordinary expense and we need your help. Please send your contributions. If you're interested in participating in fundraising, contact Susan Nye whose address is on the back page.

If you'd like further information regarding the Foundation and its committees, you may write to us directly at the national address. We hope you will become active in the Foundation and that we will hear from you.

Sincerely yours,

Your 1983 Board of Directors

I (We) plan to attend the workshop in Chicago.

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Foundation Activities News

Ted Shackelford Appears on AM San Francisco for us . . .

Members of the San Francisco Bay Area and San Joaquin Valley Chapters recently traveled to San Francisco for an appearance with Board member, Ted Shackelford, on the AM San Francisco Show. Miss Penni Householder and her mother, Mary, represented the Foundation onstage, while other members were interviewed in the audience. Before the show, Larry Parks of Bakersfield, CA, had a long visit with Jim Griffin of Santa Cruz, CA, and Charles Eichhorn of San Francisco. It was the first time in his 28 years that Larry had met someone else with ichthyosis. A special thanks to all who attended the show, especially to Ted who did such a great job for us. We love you Ted!

Barbara Landwehr appears on television . . .

Barbara Landwehr, past president of NIF, recently appeared on a number of television talk shows around the country geting the word out about ichthyosis. Many thanks, Barbara!

Channel 40 Sacramento does news show . . .

Board members, Judy Droste and Charles Eichhorn, along with Penni Householder and her mother, Mary, were recently interviewed by Channel 40 in Sacramento, CA, which did a major report on ichthyosis and the Foundation. Thanks to all of you for a splendid job!

Ted Shackelford with Board Chairperson, Judy Droste, and "our kids." (Left to Right): Charles Brazell, age 7, Pixley, CA; Tricia Harvey, age 8, Porterville, CA; Penni Householder, age 11, Milpitas, CA; Jamie Brown, age 4, Fremont, CA.

Ted Shackelford enjoys a laugh with San Joaquin Valley Chapter Executive Committee Members Les Avakisn (l.) and Bill Soares (r.).

Penni Householder and Ted Shackelford before the AM San Francisco Show.

Bay Area Chapter member, Sonia Guaragna, enjoys breakfast with her daughter, Leslie, after the AM San Francisco Show.

Chapter Development News

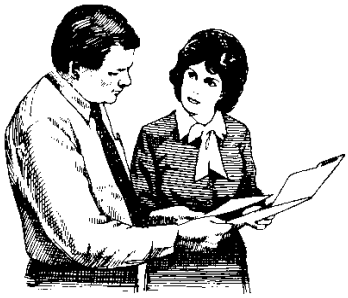
The Bay Area and San Joaquin Valley Chapters participated in a Walk-a-Thon sponsored by the Volunteer Bureau on May 7, 1983. The chapters raised over a thousand dollars. All the sore muscles were worth it!

Welcome to the Greater Rochester New York Chapter organized by Debra Butler and to the Minnesota Twin Cities Chapter organized by Rex and Judy Rhein. Our two newest chapters are on their way. We also have chapters beginning to develop in the Cleveland, Ohio, East San Francisco Bay and the South Carolina regions.

Anyone interested in starting a chapter or wanting more information about chapter development may contact Susan Nye or the National Office (addresses on back). We now have a Chapter Manual which provides step-by-step information and instructions on how to get organized. The Chapter Manual is available upon request by writing to the National Office.

Ichthyosis Focus is published by the National Ichthyosis Foundation, Inc., for the purpose of developing and expanding interest, research and national support for those afflicted by ichthyosis. Opinions expressed in the ICHTHYOSIS FOCUS newsletter do not necessarily reflect the view of the Foundation or its Medical Advisory Board.

Ask the Doctor.



NOTICE:

Beginning with the next Newsletter we will have a "Member Correspondence Column" and an "Ask the Doctor Column". Please send your letters and questions for these columns to us as soon as possible for inclusion in the next Newsletter which will be out in the early fall.

NATIONAL ISSUES NEWS

(Charles Eichhorn is the coordinator of the National Issues Committee. He has ichthyosis and practices law in San Francisco.)

The National Issues Committee is pressing forward in four main areas for 1983:

- Networking with other groups
- Monitoring legislation affecting ichthyosis
- Creating a computer data bank of ichthyosis information
- Preparing for the Annual Meeting in Chicago

NETWORKING

To be most effective in modern society, individuals and groups frequently create networks of communication, support and influence. NIF is developing a network of expertise and cooperation among national organizations and institutions.

On a broad scale, NIF is contacting the March of Dimes and United Way campaigns. We are also interested in a new and important organization, the National Organization for Rare Disorders, which had its first meeting in May. NIF will also be working with sister foundations such as the National Psoriasis Foundation, D.E.B.R.A., United Scleroderma Foundation, and the National Alopecia Areata Foundation, among others.

We hope to benefit from the experience of these groups and to offer our united voices to support increased research of uncommon diseases.

LEGISLATION

NIF is playing an increasing role in monitoring and responding to legislation that affects its members. Dr. Peyton Weary, a member of our Medical Advisory Board, has played an essential role in this area by alerting us to impending legislation and by offering his professional interpretation of the effects such legislation may have on the interests of NIF members.

COMPUTER DATA BANK

Although there has been tremendous progress in continuing ichthyosis research, more information about people with ichthyosis is needed to push back the darkness even further. A centralized pool of carefully organized and verified information is needed so researchers can create a statistical profile of people with ichthyosis.

Researchers need to know about more individuals who suffer from ichthyosis. We need to know the answers to a lot of questions: Are people with ichthyosis generally the same height as the average? Does ichthyosis have an effect on vision? Are people with ichthyosis more susceptible to cold than the average person? Do people with ichthyosis sleep an average amount, or more or less than average?

These are only a few of the hundreds of questions that researchers would like to ask of people with ichthyosis. But in order to obtain a scientifically and statistically valid profile, we need to have answers from a great number of people. Valid conclusions cannot be drawn from just a few isolated cases seen by researchers in clinics.

This Committee will be working closely with the Medical Advisory Board to design and implement a database questionnaire system in the coming months. You can help in two ways: answer questionnaires you receive from NIF, and spread the word about NIF so that everyone with ichthyosis will join the foundation and participate in this critical project.

ANNUAL MEETING

A major topic at the May meeting of the Medical Advisory Board in Washington, DC, was the upcoming Annual Meeting of the General Membership and the Workshop on Ichthyosis to be held in Chicago November 30 and December 1, 1983, in conjunction with the annual meeting of the American Academy of Dermatology.

The Annual Meeting will feature a roundup report of the events of the year past and the year to come. The Chapter Development Committee will present a special Workshop on developing local chapters of the Foundation, and there will be medical presentations of the latest information on ichthyosis, with question and answer sessions and roundtable discussions on various medical issues.

SUMMARY

That's it for this issue. Comments, criticisms and praise are all equally welcome on my desk. If you hear anything of national interest to people with ichthyosis, pass it along to me. I can use all the eyes and ears I can get!

WE ARE NOT ALONE

There are at least four broad types of ichthyosis, divided as follows in the population of the US:

1,000	Epidermolytic hyperkeratosis and Lamellar ichthyosis
20,000	X-Linked ichthyosis (only appears in males, but carried by females, too)
1,000,000	Ichthyosis vulgaris (common ichthyosis)

NIF knows of only a few thousand of these people. Won't you pass the word about NIF in your community? Get the word out! United we stand; divided, we remain lonely, frustrated and ignorant. Let your local media know there's an important story they're missing: Put the Focus on Ichthyosis! Encourage anyone you know with ichthyosis to join NIF.

Contributions needed.

We are expanding at a rapid rate and in need of contributions for the December Workshop as well as money to run the day to day operations of the Foundation. Please help by sending your donation today.

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ANNUAL MEMBERSHIP (includes newsletter)

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From a Social Worker's Personal Notes

by Susan Nye

Susan Nye, L. C. S. W., is a psychiatric social worker. She is in private practice and teaches in the Department of Pediatrics, U.C. Medical Education Program, Valley Medical Center, Fresno, CA. Ms. Nye is First Vice Chairman of the Foundation and coordinates Chapter Development.

Dealing With a Child's Lamellar Ichthyosis.

It has been over two years since Penni Householder's dermatologist referred her to me. Penni has lamellar ichthyosis. She was 7 years old and had recently started second grade at a new school when we first met. She habitually "dug" at her skin and could be heard crying during the night. Those close to Penni wanted desperately to help her but were at a loss as to how. Penni wouldn't talk about what was bothering her. In time, I realized that Penni simply did not know how to tell us.

During the months I met with her and came to know her, I began to understand the emotional consequences this child experiences because her skin is different and because she doesn't look like everyone else.

Penni is a bundle of energy. During our first meetings she was in constant motion. She jumped, skipped, wiggled and literally ran around her house. Her eyes never looked at me. She was afraid and inhibited with strangers. She wanted to be close but didn't know how. It was a new, unfamiliar experience for Penni to have a stranger actively seek her acceptance. Most people did not.

Hungry for Affection.

Penni loved it when I hugged her. She's a very affectionate child but, in her experience, only "mom" touched her affectionately. She was hungry for normal physical contact. But she'd learned to keep a safe distance from people or suffer a painful rejection.

Penni loved to play games that children her age are so clever at devising. She quickly learned to communicate through them. She had secrets, riddles and "guesses" for me. She liked to show me how well she could spell and enjoyed making lists of the "good" friends, those who did not bother her, and the "bad" friends, those who persecuted her. It took a long time before Penni could tell me about their teasing, taunting and refusal to play with her. This made her life at school miserable. Penni desperately wanted friends. She was humiliated by her skin. She so much wanted to be just like everybody else. She wouldn't allow me to mention her skin in any way. If I did, I'd immediately get a "knuckle sandwich."

"I Hate 'it'."

Those of us close to Penni were concerned about her. She was irritable, not sleeping well, didn't want to apply her medication and would cry, "I hate 'it'" or "I can't stand 'it' anymore."

Penni was not building healthy emotional resources. She seemed unable to cope with her life. She was depressed and filled with pent-up rage. She was withdrawing into herself and losing interest in life.

Little in my professional training had prepared me to work with the unique problems of this child or with the effects her ichthyosis had had on her family. This left me feeling uncertain about how to help Penni. I knew there must be ways to bring joy into her life and help her begin accepting herself. I also knew this had to be accomplished if Penni were ever going to feel emotionally well and healthy.

It is my hope in writing this article that it will provide support and encouragement particularly to those parents who are experiencing the isolated desperation and struggling Mary Householder experienced as she lived with her child's suffering and did not know what to do about it. The following is an account of what can happen by taking the obvious and making use of it. It doesn't encompass all that was done. However, we particularly enjoyed the results of our efforts in this area and would like to share them with you.

Knowing the Real Child.

First, it is essential that those close to the child develop the capacity to know who the child "really" is. That is, be able to recognize the child's talents and abilities . . . attributes which are separate from his or her ichthyosis. So much of the child's identity and experiences are tied with his or her skin and opportunities to "get away" from it are necessary. In Penni's case this was easy. We simply channeled her constant motion, a natural athletic bent, into gymnastics and now into tap and ballet. Penni attends small classes with supportive teachers where her gymnastics efforts, rather than her skin, receive the attention. It took time to find the right environment and the cost of lessons was prohibitive for the family. But we were determined that Penni would have gymnastics and a private donor was found.

From the beginning, Penni loved gymnastics. Not only was it just her thing, but it also gave her rage an outlet. She has excelled and is now the best student in her class. The other students want to do as well, and Penni helps them. She's grown stronger emotionally. Her unique personality has begun to shine and she's become quite popular. She has many friends. Most of them were at her ninth birthday party and she spends a great deal of time talking with them on the telephone.

Developing the Child's Unique Talents.

The important point is to recognize the "real" child. The one who scribbles on your walls may be a budding artist. The one who tells you "stories" may be a writer. The one who piles blocks all over your house, an architect or an engineer. The one who likes to play with bugs, possibly an entomologist. Seeing your child in this light and encouraging his or her natural inclinations creates a supportive atmosphere wherein the child's unique talents and abilities will develop. This helps build the emotional resources the child will need throughout life.

Penni is a much happier child today than she was 1-½ years ago. This is not to say she no longer has difficulty. At times she has. But she's better able to handle that difficulty. Knowing her has certainly enriched my life. She's taught me a great deal about how people function. One thing I know for sure, it is who she is that makes it easy for us to care about her and I think she knows how much we all dearly love her.

Penni Householder

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.

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