The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

The National Ichthyosis Foundation
P.O. Box 252
Belmont, CA 94002
(415) 591-1653

VOLUME 4, NUMBER 2 FALL/WINTER 1984

From a Medical Point of View

In the upcoming newsletter issues we will print articles from the material presented by our Medical Advisory Board members at the Foundation's Dec. '83 Chicago Conference. The first in this series is a Research Update by Mary L. Williams, M.D.

Mary L. Williams, M.D. is assistant professor of pediatrics and dermatology at UC Medical School, San Francisco, CA and associate professor of research and education at Veteran's Administration Medical Center, San Francisco.

Research Update—1984
Mary L. Williams, M.D.

INTRODUCTION

For lay persons, unfamiliar with the process of scientific discovery, research progress in a given medical field may seem disappointingly slow. In the case of ichthyosis research, this has been due in part to the relatively few researchers in this field. But even in areas of active medical research, testing of a hypothesis requires many experiments to yield what seems to be a small truth or a small advance in knowledge. The slow, painstaking pace of expanding this body of knowledge can be very frustrating to those who suffer from the disease in question and who need concrete answers now (or yesterday!). Medical science is premised on the belief that if one can discover the basic cause of a disease process, this will lead to a more rational and effective therapy for the condition; the ultimate goal of medical research, of course, being cure of disease. Although this proposition has been true many times in the past, there are usually many steps (and delays) between learning the cause of the disease and devising a cure. Sometimes, as in the case of virus-caused infections, we may be successful in identifying the cause of a disease, but be frustrated in our efforts to find a cure, e.g. a specific drug to counteract the infection. Also, it must be appreciated that there may be many steps between the fundamental genetic defect and production of the signs and symptoms of the disease. To devise a treatment, it is important to study and understand this cascade of events between the original cause and the final effect.

In a general way, a genetic disease may be thought of as one in which there is a change **(mutation)** in one of the fundamental building blocks of heredity, or **genes.** Genes transmit information to the cell. Specifically they direct the cell to manufacture a specific **peptide** or **protein.** This protein may become an important structural material of the cell. In the case of the skin **(epidermis),** an important group of structural proteins are the **keratins** and **filaggren,** which together form the tough insoluble fibrous material typical of outer epidermis **(stratum corneum).** There is now some evidence that abnormal production of filaggren occurs in two types of ichthyosis.

Genes may also code for a class of proteins called **enzymes** that direct the cell to make other substances, such as fats (or **lipids**) and **carbohydrates.** Enzymes are proteins that facilitate chemical reactions. For instance an enzyme may facilitate the combination of compound A with compound B to form the new chemical, AB, while remaining itself, unchanged by the reaction. If a genetic mutation results in a change in the code for a given enzyme, the cell may not make that enzyme at all or it may produce an enzyme that it is chemically altered too much to function properly. In either case the cell will be unable to produce AB or will do so at a much reduced rate. As will be discussed later, recessive x-linked ichthyosis (RXLI) represents an example in which an enzymatic defect has been identified. We do not know yet in the case of RXLI whether the enzyme is truly missing, i.e. not made by the cell at all, or if it is made but is a defective, non-functional enzyme. This is one area of ongoing research.

Next one needs to consider the consequences of the genetic mutation. These consequences are the signs and symptoms of the disease. In some instances the steps involved may be rather straightforward. But in other instances, symptoms may be several steps removed from the basic defect. Thus one may understand the basic defect in a genetic disease but not understand how that defect results in the clinical disorder. Thus in RXLI a current area of investigation is into how absence of activity of the enzyme **(steroid sulfatase)** results in a scaling skin disease. Conversely, we may learn about important aspects of the disease process and yet still be ignorant of the underlying genetic defect. Recent research in lamellar ichthyosis is an example of this.

Finally, I would urge foundation members to take encouragement from research advances in all the forms of ichthyosis. While it may be personally frustrating when little progress seems to be happening with your particular type of ichthyosis, the progress in our knowledge of one of these closely related diseases is likely to lead to insights relevant to other forms. Indeed research in genetic diseases, in general, is currently leading to an explosive expansion of knowledge and therapeutic possibilities. Some of these advances will be directly applicable to the problems of ichthyosis. I would like to summarize specific research progress in the ichthyoses. The many contributors to this work have not been identified here but I would like to emphasize that this progress report summarizes the work of many investigators from many institutions.

RECESSIVE X-LINKED ICHTHYOSIS (RXLI)

The enzymatic defect in this form of icthyosis is now known: it is **steroid sulfatase** deficiency. This enzyme is responsible for removing the sulfate group from several sterol compounds, including **cholesterol sulfate** and sulfated hormones. When an enzyme is

(cont'd on p. 2)

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(cont'd from p. 1)
missing, precursor compounds frequently pile up in front of the blocked step. Scale in RXLI contains 5 times as much cholesterol sulfate as does normal scale or scale from other ichthyosis patients. Blood also contains more cholesterol sulfate in RXLI than in normals. Although this blood cholesterol sulfate excess is of no known consequence to the health of RXLI patients, it does permit diagnosis of this type of ichthyosis by means of a blood test, a **serum lipoprotein electrophoresis,** that is available in most hospital laboratories. Exactly how accumulation of cholesterol sulfate in the outermost layers of epidermis **(stratum corneum)** leads to build up of scales (ichthyosis) remains to be determined. However, it has been shown that cholesterol sulfate applied directly to the skin of hairless mice produces an ichthyosis-like scaling in that area. Therefore, it is likely that cholesterol sulfate is in some way directly related to the cause of the scaling in RXLI. Indeed in normal stratum corneum both cholesterol sulfate and its hydrolytic enzyme, steroid sulfatase, are sequestered to the **intercellular regions** (i.e. outside and between the cells of the stratum corneum). It has been proposed that normally cholesterol sulfate acts as a "glue" holding stratum corneum cells together. And through progressive action of steroid sulfatase as cells migrate toward the skin surface, sufficient glue is lost to permit cells to detach and shed normally. In RXLI abnormal retention of cholesterol sulfate leads to failure to detach and shed **(desquamate).** Although this is still a hypothesis and much work remains to be done to establish or refute this theory, it does illustrate how study of a genetic disease may lead to understanding not only of that disease, but of normal function **(physiology)** as well.

LAMELLAR ICHTHYOSIS

There has been some disagreement among specialists whether lamellar ichthyosis is a single disease exhibiting marked variability from patient to patient in the severity of the disease or whether there are two distinct genetic diseases-lamellar ichthyosis (LI) and non-bullous congenital ichthyosiform erythroderma (CIE). To resolve this question finally it will be necessary to know the underlying genetic abnormality; i.e. if they are separate diseases, they will have separate genetic defects. But the genetic abnormality in these patients remains unknown. However two groups of patients have been defined on the basis of the **lipid** (fat) composition of their scale. One group (LI) exhibits a lipid profile similar to that of normal palm/sole stratum corneum but different from back or leg stratum corneum lipid. These patients clinically all exhibit a uniformaly severe type of ichthyosis, in which the scales are large and plate-like and often quite dark. Facial involvement is extensive, producing traction on the eyelids and inability to completely close the eyes **(ectropion).** The other group, (CIE) is more variable clinically. When the disorder is severe, the most prominent clinical feature is redness **(erythroderma).** Scales are finer and whiter than in LI; facial involvement is present but often does not result in ectropion. A few patients have improved markedly at puberty. Scale from these patients contains large quantities of a saturated hydrocarbon lipid, **n-alkanes.** How this lipid accumulation relates to the basic genetic defect, if at all, remains to be determined. Once again until the basic abnormalities are defined it will be difficult to state with certainty that these represent distinct genetic disorders. However, the evidence to date favors splitting these into two groups: lamellar ichthyosis and congenital ichthyosiform erythroderma.

ICHTHYOSIS VULGARIS

Filaggren, one of the unique structural proteins of epidermis, is completely lacking in epidermis from individuals with severe ichthyosis vulgaris. Their family members, who do not have icthyosis, have normal amounts of filaggren in skin. People with less severe cases of ichthyosis vulgaris have reduced amounts of skin filaggren. It has only been possible to precisely measure skin filaggren content recently. Previously, however, it was noted that ichthyosis vulgaris skin lacked a characteristic microscopic granule (the **keratohyaline granule**). This is very interesting, because filaggren is the protein constituent of these granules. This work suggests that the basic genetic defect in IV may be one of an inability to make filaggren protein, but additional studies will be needed to establish or refute this hypothesis.

EPIDERMOLYTIC HYPERKERATOSIS

Filaggren is also of interest in this form of ichthyosis, because one patient with EHK exhibited markedly increased epidermal filaggren content. This would again seem to correlate with the microscopic observation of abnormal appearing keratohyaline granules. Keratin peptides, the fibrous protein of stratum corneum, have also been abnormal in 3 EHK patients. But because the specific changes in keratin peptides have been somewhat conflicting between different investigators and because these kind of changes have also been seen in non-ichthyosis patients, these changes in keratin peptides may not reflect the primary abnormality. This question can only be resolved by study of additional patients.

SUMMARY

In summary, several research advances in the ichthyosis have been reviewed. Of course, is has not been possible to cover all of these, but some of the areas under current investigation and some of the questions still to be answered have been mentioned. Most importantly, I wished to support the hopes of all ichthyosis families that significant research progress into these diseases is being made. Nonetheless, I would caution against unrealistic expectations that the cure must be just around the corner.

State of the Foundation

Dear Friends and Members of NIF:

Thanks to all of you who have generously contributed since our last Newsletter. We now have approximately $3,000 in our savings account. Most of this will go toward day-to-day operations and communications. We're still hoping to hire someone early in 1985. Your contributions will help us toward that goal. Now for the update.

Mike W. O'Connor, a Southern California teacher, who has a young son with Epidermolytic Hyperkeratosis (EH) has become our volunteer fund-raising chairman. Mike has been working very hard for the Foundation. There is a message from him in the feature section of this Newsletter.

Charles Eichhorn and Jeannette Jensen have been working with Betty McMasters in Oklahoma planning two, day-long, regional conferences. The first will be on Saturday, December 1st in Washington, D.C. It will be held in conjunction with the Annual Meeting of the American Academy of Dermatology. Our Medical Advisory Board (MAB) will also meet in early December and our representatives will attend the Patient Advocate Group of the Coalition of Skin Foundations.

The second regional conference will be on Saturday, December 8, in Tulsa, Oklahoma. There will be a special mailing about the conferences to all Foundation members in the south and east. Members of our MAB will make presentations during the morning session and the afternoon will be devoted to member issues, such as

Feature

The following is a special letter from Mike W. O'Connor, our Fund Raising Chairman.

To ALL NIF Members:

Greetings! Let me begin by introducing myself. I am married, a special education specialist, have five children — one who is named Sean, a very special 6 year old boy. He has the bullous-type epidermolytic hyperkeritosis form of ichthyosis.

A few months ago the NIF Board asked me to be chairman of the Fund Raising Committee. This is my first letter to all of you. I hope you share with me the desire to bring relief to all ichthyosis sufferers. If you do, then with a collective effort, we may succeed. The success of anything is due to planning, commitment, follow-through and PEOPLE. Since the human element is the most essential, this is where I will begin.

Fund raising with some organizations is a fairly polished science. They have "x" number of dollars to spend for mailing lists, publicity, advertising, etc. With other organizations, fund raising is people-centered. Specific goals are not set — whatever is raised is the amount the organization operates with. There are many other kinds of money raising approaches in between. However, all of the fund raising organizations in the world, from the most efficient to the least productive involve and use people. That's where you and I fit in. The more informed and educated you and I are about the needs of NIF, the more successful we will all be. Since I naturally think positive, I'm going to make this letter positive, yet real honest. And if each of you responds positively to this letter, NIF will grow and achieve its objectives. As you know, our goals are lofty — to find a cure for all the forms of ichthyosis and to bring relief for all its sufferers. It's up to all of us to do something about it. If we don't, who else will?

I think our children deserve any help that is available. So, from now on, I hope you consider yourself an involved member of NIF. With your mental, physical, and yes — financial commitment, we will not be separate sufferers of itchthyosis. Thinking positive, I believe we can end that suffering — TOGETHER.

Let me now state the primary goals and needs of NIF. We need to be financially solvent. We need to hire an Executive Director to be a fulltime representative and spokesman for us all. And we need to raise enough money for major research to be done in all areas of ichthyosis. You can help in the first two areas. When we achieve the first two goals we place ourselves in the situation to seek and receive research grants. Here is how you can help in the first two areas.

If you will donate $15.00 yearly as a subscriber to the NIF Newsletter, you will immediately help our solvency needs. In return you will receive 6 newsletters yearly, as opposed to the present 4. This will help each of us to keep abreast of NIF conferences, plans, research discoveries, etc. You need to know the $15.00 yearly for the newsletter is not a money-maker, folks — it is a commitment marker. It means you want to become involved, to help. And it shows you are serious.

Achieving our second goal, to hire an Executive Director, can best be accomplished by a two-fold approach. We need to raise money from within our own ranks, and we need to solicit for outside sources. If you help with the first, it will be easier to get private sources to help. Few outside sources donate money until they know an organization is doing what it can to help itself.

We would like to raise $30,000 before 1984 is over. We believe this will allow us to hire our Executive Director and cover all our office expenses — to begin in January 1985.

It is very difficult to ask for a specific dollar amount from each of you. If each of us would seriously search our own minds, and perhaps be willing to sacrifice two weeks of lunch money or one night's entertainment with the family — we would be off to a meaningful start. What we sacrifice for, we tend to have a keen interest in. I would like to ask if there are any of you who can make a substantial donation — all of us would be sincerely appreciative. I'm sure all of you know that as a nonprofit organization, all donations are tax deductible.

In closing, let me add my sincerest thoughts about fund raising. I believe we will be successful — the need is certainly justified. You are the key factor now. When it comes to the bottom line — I can think of no better cause than to be associated with NIF. I know in the course of time the suffering of those afflicted with ichthyosis will be lessened. With your help we will collectively accomplish this. And won't that make us all feel terrific!

I hope I see and meet many of you in our upcoming area conferences. Thank you in advance for your support.

Sincerely,
Mike W. O'Connor
Chairman, Fund Raising

"Ask the Doctor" Column will appear in the next newsletter

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.

Please mail correspondence and articles for the Newsletter to:

Susan Nye De Haan
Ichthyosis Focus
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Filer, ID 83328

National Issues News

Attorney Charles Eichhorn is Co-President of NIF for 1984. He is coordinator of national issues and has worked closely with our Medical Advisory Board in compiling our first computer research survey which is in this issue. Mr. Eichhorn has Ichthyosis and a private law practice in San Francisco.

The Patient Advocate Group (PAG), comprised of leaders of the various dermatology-related patient support groups (like NIF) left its annual meeting last December in Chicago all charged up and ready to go!

In December 1983, at the time of the PAG meeting, federal legislation to establish a new National Institute of Health focusing on skin diseases was all set to pass. The Senate had approved one version, and the House, another. Final details were being worked out. Although there was some debate over the exact title of the Institute, its purpose was clear: to investigate and research skin-related diseases and their treatments and cures, along with other medical concerns. Passage of the bill was imminent.

Then politics got in the act. (Pardon the pun.) A rider dealing with the abortion/right to life issue was attached to "our" Bill, and the whole thing ground to a halt. To date, the bill still hasn't been passed, almost a year later.

We all expected the Bill to pass last January, and the PAG had planned an April luncheon in Washington to meet with concerned congressional staff. This luncheon has been beneficial to all involved in the past. Leadership from all the skin groups meets with the

(cont'd on p. 5)

First National Ichthyosis Computer Survey!!

Enclosed with this month's newsletter is the first survey form for the NIF database. The primary purpose of the database is to create the largest central pool of information about ichthyosis patients available. The information will be compiled and sorted, providing statistical information for NIF, research and government. The results will be available first to our Medical Advisory Board in December, at the annual meeting of the American Academy of Dermatology in Washington, D.C.

This is only the first of a series of questionnaires to expand the body of knowledge about ichthyosis, but it's the most important. We need a questionnaire filled out and returned by December 1 by **every** person with ichthyosis. Pass the questionnaire on to relatives or acquaintances with ichthyosis and encourage them to complete it and mail it in. If a child has ichthyosis, answer the questions for him or her. Each person or child should complete a **separate** questionnaire. (Make photocopies, if necessary.)

The information is strictly confidential. Although the general statistics derived from the information will be available to the public through articles, etc., the specific personal information (names, addresses, etc.) will not be made available to **anyone** at **any time** without your written permission.

This survey is an important step in "putting the focus on ichthyosis." Please help make it a success — for you, as well as for your fellow members! Fill out the questionnaire right now and get it in the mail TODAY!

COMPUTER DATA INPUT SHEET — SURVEY ONE

DEADLINE: December 1, 1984

This information will be used only by NIF. None of the following information will be made available at any time to any person or organization without your prior written permission.

Note: Please complete one questionnaire for **each** individual with ichthyosis. If you need more forms, either photocopy this one, or call or write to NIF. We need to have a completed questionnaire for **every person with ichthyosis,** so mention the survey to family, friends, and acquaintances.

Patient name _____ Today's Date _____
Street Address _____
City _____ State _____ Zip _____
Date of birth _____ Place of birth _____
Present Marital status: Single _____ Sep _____ Div _____ Widowed _____
Children? Yes _____ No _____ Children with ichthyosis? Yes _____ No _____
How many? _____ (Survey for each one, please!) Number of doctors **you** have seen regarding ichthyosis: _____ Non-"M.D." doctors? _____ What type of ichthyosis?
Lamellar? _____ Vulgaris? _____ X-Linked? _____
Epidermolytic Hyperkeratosis? _____ Other? _____
If "Other", please explain: _____
When was your case **first** diagnosed? (Age) _____
Was the diagnosis correct the first time? _____
When was your case **last** reviewed and/or diagnosed? Month _____ Year _____
New diagnosis? _____
Present/last doctor _____
Address _____
City _____ State _____ Zip _____
Current treatment and frequency _____
_____
_____
On a scale of 1 to 10 (1=poor, 10=excellent), rate the success of your present treatment: _____
Past unsuccessful treatments? Describe: _____
_____
Is your ichthyosis condition constant? Yes _____ Changes seasonally _____
Changes with locations _____ Does it cause physical pain? Always _____
Often _____ Sometimes _____ Never _____ Typical Degree 1-10 _____
Does it cause emotional pain ? Always _____ Often _____ Sometimes _____
Never _____ Typical Degree 1-10 _____ Do you have any other chronic illnesses? _____
Any other body parts affected? (Nails, hair, etc. — Please list) _____
Do you know that ichthyosis is an incurable **genetic** defect? _____
Do you know that **some** kinds of ichthyosis can be inherited? Knew _____
Didn't Know _____ Do you know if your ichthyosis can be inherited? Know _____
Don't know _____ Can be _____ Can't be _____ Learned about NIF from Doctor _____
Other medical person _____ Member _____ TV _____ Magazine _____ Other _____
How many other **living** people with ichthyosis have you met? (number) _____
Your relatives, living **or** deceased, with ichthyosis:

Name	Relationship	Age	Type of Ichthyosis	State

Other information that didn't fit above? _____
_____
COMMENTS: _____
_____

(cont'd from p. 4)

legislative and appropriations staffs, and the staffs gain a better understanding of our needs and positions. The PAG also planned to meet at the same time to discuss the proposed appointments to the staff of the new Institute.

I'm sure all of you share the disappointment we felt when we learned that the Bill was bogged down in Conference Committee indefinitely. All our plans have been put on "Hold". The PAG will meet again this December in Washington. If we don't see some action by that time, I will formally propose we call on the united membership of all the patient support groups, (including NIF), to start a letter and telegram campaign to get the ball rolling again. The abortion/right to life issue is an important one, but it should not be mixed with a separate matter, of equally great concern to so many. The new Institute is very important to every one of us, and pork barrel politics isn't going to stand in our way!

As more of our sister patient support groups (like the National Psoriasis Foundation and the Alopecia Areata Foundation) obtain the services of Executive Directors, they are able to spend more time and effort pursuing important topics like this one. If you want results, the answer is clear: NIF needs an Executive Director, and the Time Is Now!!

parent support, education and building self-esteem in children. For those interested in attending, please fill out the pre-registration form in this Newsletter and mail it to the National Office. For information about the Oklahoma Conference, contact Betty McMasters (918) 224-9099 of the Oklahoma Chapter, who is hosting the Conference.

On another topic, we have had a request from the University of Utah, School of Medicine, Department of Dermatology, for the bequeaths of ichthyotic skin. If you are interested in more information about this, please contact the University of Utah, School of Medicine, Department of Dermatology, Salt Lake City, Utah, or Charles Eichhorn at (415) 550-1320.

Finally, 1984 is coming to a close. It has been a steady year for the Foundation. While we have had steady growth, communication and getting the work done that needs to be done, remain problems. All of us who are volunteering our time, as well as many of you, are aware of the need for a fulltime staff person. This is the theme throughout this Newsletter. With your continued help we will be able to accomplish this goal. Thanks again for all your support.

Sincerely yours,
Charles Eichhorn, Esq.
and Susan Nye DeHaan, CSW
Co-Presidents, 1984

CONFERENCE PRE-REGISTRATION

I/we would like to attend the (circle one) Washington, Oklahoma Conference. Please send more information.

____ Number of persons attending. Enclosed is:

____ $20 for individual ____ $30 per family

NAME: _____

ADDRESS: _____

PHONE: _____

Mail to NIF, P.O. Box 252, Belmont, CA 94002

Correspondence Column

Dear Ms. Nye:

Hello, I don't know if you remember me or not, but we spoke about a year ago about forming a Los Angeles chapter of NIF. I'd like to get a support group going more than anything else. As you well know, there are a lot of conditions where kids especially need someone to look up to, like a baseball player with diabetes, for example. But with Ichthyosis it is not that likely, and I know from myself that the idea that you are the only one with this odd condition is really pretty scary. My primary goal is to let other sufferers know that they aren't alone.

Anyone in the Los Angeles area wanting to form a chapter may be in touch with me.

Sincerely,
Carolyn Gramlich
14922 Cranbrook
Hawthorne, CA 90250
(213) 973-6320

Dear Susan:

I was born with skin called Lamellar Ichthyosis. I have a lot of experience dealing with my own family. When I was born my parents had the guilt of seeing me with a different skin than other children. I have been locked down in the basement for 5 years because of my skin. . . I would like to reach others who have had the same problems as I have had to go through. I hope that we can work together on making something out of what we have.

I am interested in corresponding with someone with whom I can relate. I was wondering if you have something like a pen-pal list that I can refer to.

Yours truly,
Gracie Seto
Apt. 101, 1023 - 15th Ave. SW
Calgary, Alberta T2R 0S5 Canada

Dear Ms. Nye:

Enclosed you will find our application to establish a British Columbia chapter of the Foundation. Canadian members interested in joining our chapter, please contact us.

Yours sincerely,
Valerie Munroe
Executive Committee Coordinator
2492 West 45th Ave.
Vancouver, British Columbia
V6M 2J8 Canada

OKLAHOMA DOES IT AGAIN!

A letter from Betty McMasters to Jeannette Jensen:

Dear Jeannette:

The Greater Tulsa chapter has been doing a lot of work. We met with members of Moose Lodge No. 862 who voted to take our chapter on as an annual project. This year they sponsored a Bingo. It was great to see people interested in the skin problem that we fight from day to day. Marge Boyd donated a beautiful quilt again this year which was raffled off during intermission at the Bingo. Ken and Marge's granddaughter has Lamellar Ichthyosis. They deserve a special thanks for all the time, effort and love they have put into our chapter. So far we have raised about $1,000 this year which will go towards helping with the Regional Conference.

Our special thanks to the wonderful people of Moose Lodge No. 862 and "their guy" in charge, Terry Wald.

Love from Oklahoma,
Betty

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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