



# The National Ichthyosis Foundation

## ICHTHYOSIS FOCUS

The National Ichthyosis Foundation  
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Belmont, CA 94002  
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From a Medical Point of View

## PRENATAL DIAGNOSIS OF THE ICHTHYOSSES



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, CA. A founding member of NIF, Dr. Williams is the Foundation's medical liaison to our Medical Advisory Board.*

Prenatal diagnosis refers to the ability to diagnose genetic (inherited) or congenital (present from birth but not necessarily inherited) disease before the baby is born. In the past several years, attempts have been made to diagnose some forms of ichthyosis prenatally and this has been successful for two of the four major forms of ichthyosis (epidermolytic hyperkeratosis and recessive X-linked ichthyosis). Additionally, it appears likely that in the near future lamellar ichthyosis (non-bullous congenital ichthyosiform erythroderma) will be identifiable by prenatal diagnosis. Finally, there are ichthyosis syndromes (these are for the most part rare genetic diseases in which ichthyosis is not only abnormality, but is only one feature of a disorder that affects many parts of the body), which have already been diagnosed (Sjogren-

Larsson Syndrome, Harlequin fetus) or are potentially diagnosable (Refsum disease, multiple sulfatase deficiency) prenatally.

There are two techniques currently used in the prenatal diagnosis of ichthyosis: 1) amniocentesis and 2) fetal skin biopsy. These methods currently differ greatly in the risks involved to the fetus, as well as the availability of the procedures at medical centers.

### Amniocentesis

Amniocentesis is the method most widely used in the prenatal diagnosis of congenital disorders. This procedure is performed at the 14th week of pregnancy. The position of fetus and placenta is determined by sonogram (non x-ray, non-invasive technique of visualization using high frequency sound waves) and a sample of amniotic fluid obtained using a 20-22 gauge needle. The advantages of amniocentesis are its low rate of complications (major complication: induction of miscarriage, < 1/2%) in experienced hands and its widespread availability. If the genetic disease can be detected by a change in the chemical composition of the amniotic fluid or if the disease produces a change in the appearance or chemistry of the cells which are present in the fluid then prenatal diagnosis may be possible.

Prenatal diagnosis of the ichthyoses by this relatively safe and widely available method is unfortunately hampered by our limited knowledge into their underlying biochemical causes and effects. More simply stated, in most forms of ichthyosis, amniocentesis cannot be used for prenatal diagnosis because we do not know what to look for and measure biochemically.

There are exceptions to this statement. Recessive X-linked ichthyosis (RXLI) represents a form of ichthyosis in which the underlying metabolic defect has been identified. These people lack an enzyme called steroid sulfatase, and this biochemical abnormality can be detected by study of

amniotic fluid cells. Refsum disease and multiple sulfatase deficiency represent two very rare genetic diseases in which the non-skin manifestations of the disease are severe and far outweigh the ichthyosis in medical importance. In both, the underlying metabolic abnormalities are sufficiently well known to permit prenatal diagnosis by amniocentesis.

### Fetoscopy and Fetal Skin Biopsy

Using an amnioscope the fetus is directly visualized (fetoscopy) and a small portion of skin removed for examination under the powerful electron microscope. The amnioscope is a fiberoptic instrument that is passed through a thin cannula inserted into the uterus through the anterior abdominal wall under ultrasound guidance. This newly developed procedure is performed at about the 20th week gestation. Because of its more invasive nature, it is substantially riskier to the fetus than amniocentesis. Even when performed by the most experienced individuals the incidence of fetal loss (resultant miscarriage) is at least 5%. And currently this procedure is only available at a few medical centers in North America and Europe. Nonetheless, at present fetal skin biopsy is the only available method for diagnosis of the severe forms of ichthyosis (Harlequin fetus, Sjogren-Larsson syndrome, epidermolytic hyperkeratosis and possibly, lamellar ichthyosis). Not only is the procedure technically difficult to perform but interpretation of the results of the biopsy (i.e. does the infant have ichthyosis or not) is difficult due to: 1) limited knowledge of the appearance of normal human fetal skin during early pregnancy; 2) even more limited

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(cont. from page 1)

knowledge of the appearance of the different forms of ichthyosis before birth; and 3) the small size of biopsy material available for evaluation.

Very recently, Drs. Holbrook and co-workers at the University of Washington, Seattle, using the electron microscope have visualized in some amniotic fluid cells obtained from a fetus affected with epidermolytic hyperkeratosis (EH) the same abnormal appearance that is seen in fetal skin cells. This offers the very exciting possibility that in the future, prenatal diagnosis of EH may be possible through amniocentesis alone. However, to date it must be cautioned that this has only been tried with one fetus and further studies will be necessary to determine the accuracy of the method and the earliest or best time to do the test before it can be offered with confidence of its reliability.

The purpose of this article has been to present the currently available methods for prenatal diagnosis of ichthyosis. The ability to diagnose an inherited disease prenatally has permitted many couples at risk for one of these devastating disorders to have the normal children they might not otherwise attempt to have. For such diseases in which prenatal diagnosis is technically possible, the decision whether or not to perform it rests entirely with the family. This is because only the family can evaluate the impact on them of having a child with the disorder.

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Please mail correspondence and articles for the Newsletter to Susan Nye, L.C.S.W., 1922 Mayfair Drive East, Fresno, CA 93703.

## Ask the Doctor.



The "Ask The Doctor" and "Correspondence" Columns will begin with the next newsletter.

## NATIONAL ISSUES NEWS



*Attorney Charles Eichhorn is coordinator of the National Issues Committee. Recently elected to NIF's Board of Directors, he has ichthyosis and practices law in San Francisco.*

### Medical Advisory Board News:

As National Issues Chairman, one of my responsibilities is to act as liaison between the Board of Directors of the Foundation and its Medical Advisory Board (MAB). The MAB is the silent partner of your Board of Directors, offering guidance and support as well as professional medical acumen.

Dr. Lowell Goldsmith of the University of Rochester Medical Center in Rochester, New York is Chairman of the MAB. It is comprised of nationally prominent physicians and researchers actively involved in the investigation and treatment of ichthyosis. Members contribute feature articles to the Foundation's newsletter and will be answering your medical queries in the TELL ME DOCTOR column starting with the next issue. Our computer information bank on ichthyosis will be designed and set up with the close cooperation of MAB members.

First, we want to bid farewell to Dr. Michael Jarratt of the Texas Medical Center in Houston and wish him success in his busy new private practice.

At the same time, we want to welcome Dr. Ervin H. Epstein of Oakland, California, to the MAB. Dr. Epstein is a prominent dermatologist working with ichthyosis. An abridgement of one of his recent articles appeared in the most recent newsletter.

### National Meeting in Chicago

The National Meeting of the NIF this year in Chicago on December 2nd should be the premier event of the year. Dr. Goldsmith and other MAB members are helping to make the meeting a success by arranging a series of medical presentations on ichthyosis: its genetic origins, diagnosis and therapy. The panel discussion topic that should receive the greatest interest is "New Research in Ichthyosis." Try to make it, since it may be a tax-deductible trip for you.

### Money Makes the World Go 'Round

To help finance the National Meeting, the Foundation has asked over forty pharmaceutical companies all over the country for help. Contributions are coming in, but very slowly. When the final numbers are in, we'll let you know who supported us.

In case you didn't know, the National Ichthyosis Foundation is a non-profit organization run entirely by volunteers. Sure, our overhead is low, but we don't make any "profit" on our work at all, so our budget depends entirely upon the interest and generosity of our members and friends. The success of the Foundation will be the success of its members, so invest in **yourself**: donate whatever you can to keep the Foundation moving forward on your behalf.

### Smoke-Filled Rooms

Dr. Peyton Weary of the University of Virginia Medical Center is an active member of our Medical Advisory Board and of the American Academy of Dermatology. He helps us monitor legislative activities in Washington, D.C. that will have an impact on ichthyosis research.

In recent months, a potentially important bill has been working its way through both houses of Congress. The Senate version of the bill calls for the formation of a new National Institute of Arthritis, Musculoskeletal and Skin Disease. Skin Diseases, such as ichthyosis, is a targeted area for research under this version of the bill. The House of Representatives version, however, doesn't even mention "Skin" in the title, and leaves it out of a number of places in the body of the bill.

On behalf of its members, the Foundation immediately fired off personal letters to each of the eighteen Senators and eighteen Representatives on the Committees involved, urging them to make **Skin Disease** a part of

the title and charter for the new Institute. I'll have a report on our success in the next issue.

#### News That's Fit To Print

Have you ever seen a local newspaper story about someone with ichthyosis? Most of these stories are reasonably well-balanced, sympathetic, accurate and even helpful. Once in a while, however, a paper or magazine will stoop to using crass sensationalism to boost its circulation. These stories may just be in poor taste, but as likely as not, they also will contain damaging material misstatements of fact about ichthyosis and people who live with it.

Here are some suggestions about ichthyosis publicity:

(1) If you read **any** story about ichthyosis, even just a brief comment, make a copy and send it to me for our national library. Tell me when and where it was published.

(2) If you read a story that puts a bad light on people with ichthyosis, let us know. We'd like to set the facts straight. Telling the **truth** about ichthyosis makes a good enough story without adding errors and falsehoods.

(3) If your local paper would like information about ichthyosis so that it can print an accurate story, let us help. We have the latest information, statistics, graphs, etc., on ichthyosis. We will gladly cooperate with responsible journalism in every way we can to educate and enlighten the public.

#### Reaching Out Across the Land

The National Organization for Rare Disorders is a small, but growing organization operating under the wing of the National Huntington's Disease Association headquarters in New York City. If a physician, health care professional or lay person has a rare disease (like ichthyosis) and doesn't know which way to turn, N.O.R.D. acts as a beacon in the night, pointing out the direction of a medical center, physician or organization (like NIF) that can help.

Another idea that has taken on a national scope is the Computerized Birth Defects System, located in Boston, Massachusetts. This computer system provides doctors and researchers with articles and diagnoses on over 1,000 different birth defects, including ichthyosis. A brand new defect can be entered and later occurrences matched up to look for a trend. Diagnostic assistance is available by answering the computer's questions.

#### One Byte At A Time

NIF's own specialized computer registry of ichthyosis patients is still in its developmental stages. We are working closely with the Medical Advisory Board to design a database and questionnaires that will be statistically valid and protect the privacy rights of participants. Watch this column for details in the near future.

## How NIF Works Today

by Susan Nye, L.C.S.W.

The National Ichthyosis Foundation is still a "baby"... barely three years old. Even so, we have a mailing list of three thousand people with ichthyosis. We've received hundreds of your letters and know there are many others - family and friends - who have ichthyosis and are not yet known to us. Hopefully, as we grow and more people become involved in working with the Foundation, we'll be able to locate everyone with ichthyosis. In the meantime we'd like to bring you up-to-date on how NIF is working today and what our needs are.

At present, the day-to-day work of the National office is done by an executive committee of the Board of Directors. All of these people are volunteers who have families and full time occupations. As chapters form and we find people interested in fundraising, we will be able to hire staff to help with the voluminous correspondence, phone

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## Contributions needed.

We are expanding at a rapid rate and in need of contributions for the December 2nd Meeting as well as money to run the day-to-day operations of the Foundation. Please help by sending your donation and annual subscription to Ichthyosis Focus today!

NAME \_\_\_\_\_ Male \_\_\_\_\_ Female \_\_\_\_\_

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#### Your 1983 NIF Board Executive Committee:



#### Charles Eichhorn

Attorney Charles Eichhorn has ichthyosis. He has practiced law in the Bay area for the past 10 years. A member of NIF for the last several years, he became active in the Foundation during our recent reorganization. Aside from coordinating the National Issues Committee, Charles is working with the Medical Advisory Board to develop a computerized data base about the characteristics of ichthyosis. This will aid research efforts in identifying the causes of ichthyosis and ultimately finding a cure. Recently married, Charles' hobbies include photography and motorcycle racing. He is shown here working at his computer.

calls, questions, bookkeeping, the newsletter and all the work of putting together a growing foundation. In the meantime, please be patient - all the work is done during the off hours of our dedicated volunteers.

During the latter part of 1982 it became apparent to the NIF Board of Directors that if we were to respond to our growth and remain a viable organization we needed to create opportunities for people to participate and expand the leadership of the Foundation. The Board adopted a plan for mobilizing NIF. Several committees were formed:

**The Board's Executive Committee:** This group guides the day-to-day work at the National Office and works to implement the Foundation's major goals — self-help support, education and support for research. It reports to the membership through the newsletter and to the Board's officers directly.

**National Issues Committee:** This group works with allied organizations, legislators and our Medical Advisory Board to keep the Foundation advised and informed about national issues that impact on ichthyosis. The committee is chaired by attorney Charles Eichhorn.

**Chapter Development Committee:** This group assists members who want to start chapters of NIF in their communities. The purpose of chapters is to implement NIF goals of self-help, education and research support in communities just as other health organizations do. A Chapter Manual has been written and may be obtained by requesting a copy from the National office. The committee is chaired by Susan Nye, L.C.S.W.

The work of the Education, Public Relations and Fundraising Committees is being shared by the Board and its Executive Committee. We hope to find members in the Foundation who want to help activate these committees fully.

Our major project for 1983 is the First NIF National Meeting to be held in Chicago on Friday, December 2nd. (See separate article) We hope all of you will attend.

#### How to participate in NIF

1. The National Board has been expanded to twenty. We have vacancies. Members who are nominated by their chapters and advisors (i.e., attorneys, accountants, other professionals) who have worked in NIF may be elected to the

Board. It meets at least once a year. Members serve two year terms and may be reelected.

2. The Board elects the working Executive Committee (5 people) from its officers and those chairing the National Issues, Chapter Development, Education, Fundraising and Public Relations Committees. These are the people responsible for coordinating the daily work of NIF at the national level.
3. Much needs to be done. If you want to help, please contact us. We need help in fundraising, public relations, education, chapter development and national issues.
4. If you would like to work in your community through a chapter of NIF contact the representative closest to you listed on the back of this newsletter. If you want to start a chapter please contact Susan Nye, L.C.S.W.

## State of the Foundation

### Message From Your Board of Directors

Dear Friends,

Many of you have written to inquire about how we are doing and how the Foundation gets along on a day-to-day basis. This newsletter's feature article will give you an idea of what the massive task of putting together a national Foundation is like in its beginning stages. We've come a long way in less than three years but we still have a way to go.

During the first half of 1983, NIF underwent a major reorganization — expanded its leadership and activities — and is now moving ahead at a rapid pace. We want to thank all of those who extended their supportive assistance to us during the reorganization, especially our Medical Advisory Board and its marvelous Chairman, Lowell Goldsmith, M.D., Jim Tombros of Hermal Pharmaceutical Laboratories, our chapter leadership and regional representatives.

The reorganization represents a major thrust toward realizing our goals of finding people with ichthyosis, providing self-help support, education and support for research. NIF is pushing forward and we look forward to seeing all of you in Chicago at our First National Meeting on December 2nd!

Sincerely yours,

Your 1983 Board of Directors

#### Judy Droste

Executive Secretary, Judy Droste, has served as President of NIF during 1983. She is one of two sisters and a brother who have lamellar ichthyosis. Judy has been a member of NIF's Board of Directors since the Foundation began. She has worked on fundraising, participating in several Bay Area Walk-A-Thons. Prior to moving with her family to Pewano, MI, in August of 1983, Judy helped the Foundation during its reorganizing phase. She gave our correspondence and educational materials the professional touch and had reams of information copied for us. Judy enjoys jogging and gourmet cooking.

#### Susan Nye

Susan Nye, L.C.S.W., is a psychiatric social worker. She is in private practice and teaches as a member of the Behavioral Science Faculty in the Department of Pediatrics, UC Medical Education Program, Valley Medical Center, Fresno, CA. Susan has been active in the Foundation for the past several years, helping to start the San Joaquin Valley Chapter, coordinating Chapter Development, writing the Chapter Manual, and serving on the Board of Directors. She became involved in the Foundation while working professionally with a child who has lamellar ichthyosis. Susan is chairing the 1983 Board Executive Committee. Her hobbies include writing, jogging and horseback riding.



#### Jeannette Jensen

Jeannette Jensen stands in front of the Foundation files which were recently placed in her care. The Administrator of a major federal agency in Belmont, CA, and a veteran worker on community projects, Jeannette coordinates the United Federal Bay Area Campaign (fundraising) and is a member of the Belmont Chamber of Commerce Board of Directors. Early this year, after knowing a child with lamellar ichthyosis, Jeannette contacted us to make a contribution and was recruited to help instead! She handles most of the correspondence, phone calls and office work at NIF. She has been a great help serving as Secretary to the Board.

## Chapter Development News

The Chapter Manual is available upon request from the National Office. If you have questions, contact Chapter Development Coordinator, Susan Nye, L.C.S.W. Now that the manual is complete our next project is to compile computerized listings of NIF members in your communities which will make organizing easier.

### Welcome Back Marisa! Hello New York City Chapter!

Hi Everyone! I'm Marisa Mandia. I've been a member of NIF for quite a while now but, due to family illness, I've not been too active. However, now, I'm ready and willing to go full speed ahead!! I'd like to get the New York City Chapter on its feet. So... if you'd like to help out — don't wait.

Some of you may remember me. I've got a little girl, Robin-Lynn, who will be 5 on Sept. 2nd. She has epidermolytic hyperkeratosis (E.H.). Her dad's name is Joseph.

I'd love to hear from all of you. So please write and remember — in order to win, you've got to run the mile. So never give up, keep on going and we'll keep on growing! God bless you all.

Always,

Marisa Mandia  
111 Bucket Ln.  
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(516) 579-9254

*Marisa doesn't mention she helped raise money to get the Foundation going. She is one of our founders and originator of our logo.*



The Mandia Family — Marisa, Joseph and Robin-Lynn, January 1981.

The following are portions of a letter received a couple of months ago from Judy Rhein, founder of the Minnesota Twin Cities Chapter:

Dear Susan,

We had our second meeting last night... We will support each other 100% and with the Task Force and Junior League behind us, I know we will be a great chapter. No one said that growing pains don't hurt but then no one said it would be easy... We will survive!

Judy Rhein  
The Twin Cities Chapter



San Joaquin Valley Chapter Executive Committee members, Linda Ortega, Gerilyn Stone and Les Avakian, get together to work on their Spring 1984 Benefit — a luncheon and fashion show.



Betty McMasters and Rick Boyd (Elizabeth's father) hold the \$900 check representing the proceeds of the garage sale.



Katy McMasters, Betty McMasters and Marge Boyd display the colorful afghan Marge donated.



Gregg Boyd draws the lucky afghan winner's name while his mother, Diana, waits to see who it is. Both Elizabeth and Katy have lamellar ichthyosis.

### Many Thanks Oklahoma/Kansas!

The Oklahoma Chapter was a major help to NIF financially during our recent reorganization. Thanks so much to all of you. Betty McMasters, Chapter Representative and NIF Board member, sends the following report:

The Oklahoma/Kansas Chapter recently held their annual fundraiser. A huge, very successful garage sale raised \$900. During the fundraiser we raffled off a beautiful afghan, donated by Marge Boyd. Many thanks to you, Marge, and all of the many people who donated money, time, effort and items for our sale. It is people like you who make it possible for research into this skin disorder! May God bless all of you in a special way.

During the course of the sale we met many wonderful people who care and found two families who have children with ichthyosis. Besides meeting all the nice people, I hope we got the message out and built up public curiosity about ichthyosis.

We are proud to announce that Janet McHaney Rabon just "tied the knot". But, that wasn't enough. She also finished her registered nurse's training. Congratulations, Janet, to you and your husband.

David and I are busy getting Katy, our four-year old (lamellar ichthyosis) ready for her first dance recital. Boy, are we nervous! Katy loves to dance but you never know what they'll do onstage. We're keeping our fingers crossed!

The Chapter is scheduled for a taped interview on Channel 6 to be viewed sometime in the future. We'll be talking about the Foundation, our Chapter and how we've gotten together. Wish us luck!

God bless all of you.  
Betty McMasters, Oklahoma/Kansas Chapter

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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