

## The National Ichthyosis Foundation

# ICHTHYOSIS FOCUS

Send all correspondence to: Barbara M. Landwehr 151 Toyon Drive Vallejo, Calif. 94590 Tel. (707) 644-5205

VOLUME 1, NUMBER 7

APRIL-MAY, 1981

#### FROM A MEDICAL POINT OF VIEW

#### SCALE IN ICHTHYOSIS

Scale is a nuisance. It clutters the floor, it catches on clothing and is unsightly. It is the common feature of the various forms of ichthyosis. Why does scale accumulate, what is different about the skin that permits scale to build up? First we have to ask the obvious question - why does scale not accumulate on normal skin? The answer is that cells from the outer, dead layer of the skin (stratum corneum) are lost at the same rate as cells are being added to the inner, living layer of the epidermis. This results in what is called a steady-state or equilibrium in which the number of cells added to the skin by division of living cells equals the number of dead cells lost from the surface. This explanation is too simple however; it does not explain why cells are lost before they form a scale, which is a thickened and abnormal stratum corneum

The normal stratum corneum is a protective membrane that serves as a barrier between the body and its environment. It protects against water loss from the body and it protects against the entry of bacteria and liquids from the outside. The stratum corneum is composed of very flattened large cells that are filled with submicroscopic threadlike proteins, the keratins. Between the cells is a complex mixture of lipids that probably account for the impermeability of the skin to water a very important characteristic of epidermis. The flexibility of the stratum corneum is related to its water content; when it is dry it is brittle, when it is moist it is flexible.

Squames, the flattened dead cells of the stratum corneum, are shed regularly. What is not well under-

stood are the factors that control the rate of shedding. If the control of shedding of squames from normal epidermis were understood, then the reasons for the abnormal accumulation in ichthyosis might be less obscure.

Scales formed in the different ichthyoses have characteristic shapes and probably result from different kinds of errors. There is an over-production of skin cells in epidermolytic hyperkeratosis and lamellar ichthyosis. In x-linked ichthyosis, production of new cells is not increased, and in ichthyosis vulgaris the rate of cell division is either normal or reduced.

The control of scaling by medications in epidermolytic hyperkeratosis and lamellar ichthyosis is more difficult than in ichthyosis vulgaris and X-linked ichthyosis. In epidermolytic hyperkeratosis and lamellar ichthyosis, the rate of cell division is increased and the rate of formation of scale is increased. Regardless of the effectiveness of the scale removal techniques in these disorders, scale accumulates rapidly. In contrast, when scale is removed in x-linked ichthyosis or ichthyosis vulgaris, the skin remains scale-free for a while. The results of treatment are more lasting than in epidermolytic hyperkeratosis or lamellar ichthyosis.

Since little is known about the factors controlling the loss of dead stratum corneum cells from the normal epidermis, how can we plan rational treatment in ichthyosis? Most individuals with ichthyosis are better in summer than in winter. This is true for ichthyosis vulgaris, lamellar ichthyosis and x-linked ichthyosis, but not necessarily true

for epidermolytic hyperkeratosis, which may be unchanged in the summer or even perhaps worse. What are the major differences between summer and winter? Temperature and humidity are two obvious differences. When temperature and humidity are increased, scales are shed spontaneously or are more easily removed. Certain chemicals accelerate the loss of scale; however the chemical basis for their effect is not firmly established. The following compounds in various formulations are often effective in promoting scale

- a. salicyclic acid
- b. urea
- α hydroxy acids these include lactic acid and glycolic acid
- d. propylene glycol
- e. salt baths

These agents should be considered separately from lubricants such as eucerin and aquaphor which help to seal moisture inside the stratum corneum and increase plasticity of this outer dead layer. A separate category of treatment is the systemic use of 13-cis retinoic acid, a relative of vitamin A which is being used experimentally.

In a subsequent Newsletter, practical remedies for scale removal and the status of 13-cis retinoic acid treatment will be discussed. If you have any treatment secrets send them to the Newsletter indicating what kind of ichthyosis you have.

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

#### **CHAPTER NEWS**

#### CONNECTICUT CHAPTER

There's something new on the East Coast!

The Foundation has just sprouted another flower — the Connecticut Chapter. Although we are just a seedling - barely having broken ground - we feel confident that the upcoming year will be rewarding. Our leaves will be nourished by those who gave us our start and our roots will spread, breaking ground in many of the areas around us.

At present, we are sending letters to all dermatologists in Connecticut with the hope they will support us and inform their Ichthyosis patients about us. We are also starting to get newspaper coverage in the hopes this will spread to the other media. Once we have established contact with a few more people — those with Ichthyosis and/or our concerned friends — we will hold our first meeting. Hopefully, we will announce this in our next article in the newsletter. From that point on watch how fast we grow - like the weeds in your garden!

We in Connecticut, are extremely fortunate to have a team of dermatologists (two of whom are on the Foundation's Advisory Board) who are "up" on the newest break-throughs in Ichthyosis. We are also grateful to have Yale School of Medicine within easy reach.

If you or a friend wish to learn more about the Connecticut Chapter or even to join us, please contact Mrs. David Kummer, 69 Church Street, Seymour, Conn. 06483. Telephone (203) 888-0037.

#### KANSAS/OKLAHOMA CHAPTER

Our Chapter consists of eleven families which have Ichthyosis. We write back and forth relating our success and failures in the care of the skin. This is the list of my "family" who are very special to me. As we try to live and learn about this rare skin disorder, I am sure they would love to hear from each and every one of you.

 Arlita Hummelke — daughter with E.H. 345 N. Erie Wichita, Kansas 67214

- Kathy Rogers daughter with Lamellar 7208 W. Rim Austin, Texas 78731
- Teri Thompson sons with Lamellar
   349 Silver Springs Court Colorado Springs, Colorado 80919
- Spike DeWitt daughter with Lamellar 6304 North View Drive, Rt. 3 Cedar Falls, Iowa 50613
- Jim Thomas Lamellar 5404 Huddleston Oklahoma City, Oklahoma 73135
- Michael Witten Lamellar 906 N.E. 9th Wagoner, Oklahoma 74467
- Sharon Cole daughter with Ichthyosis
   Colonial Drive Williams Berg Monca
   Calparso, Indiana 46383
- Irvin L. Nailor X-Linked Ichthyosis SOS Cypress Station Dr. Lemontree Apts. #1013 Houston, Texas 77090
- Elise Jacobsen sister with Lamellar 5651 Broad Street Greendale, Wisconsin 53129
- Mrs. Robin daughter with Ichthyosis
   8303 S. Indianapolis Place Tulsa, Oklahoma
- Betty McMasters daughter with Lamellar 1838 So. Muskogee Saplupa, Oklahoma 74066

Dr. Paul Shackelford of Tulsa, is now on our Medical Advisory Board helping all he can. Also his son, Ted Shackelford, is on the Board of Directors. Ted is Gary Ewing on "Knotts Landing." I would like to thank them both: Dr. Shackelford, for being such a wonderful doctor to Katy, my daughter, and his son, Ted, for sharing his time and support in our Foundation.

Now Parting Thoughts
Happiness is good.
The place to be happy is here.
The time to be happy is now.
The way to be happy is to help make others happy.

But Most of All
A good thing to remember,
And a better thing to do,
To work with the construction gang,
and not with the wrecking crew!
So help support your Chapters and
let these people know we have a
Foundation and we do exist.

May God Bless You, Betty McMasters

#### **NEW YORK CHAPTER**

We are taking New York by storm . . . so the saying goes. We have been alerting dermatologists and hospitals letting them know we are an organization now and that no one with Ichthyosis will ever be alone again!!!!!

Also from the Big Apple, Eyewitness News on ABC will be doing a story on Ichthyosis in the near future. Karen Santus who works with Storm Field on this television station, wants to do an in-depth interview with both parents and physicians involved. A date of airing has yet to be agreed upon. Details at a later date. "O.K., world, look out because here we come!"

We will be having a New York raffle. We have printed and distributed tickets to all participating members and hope you will make every effort to sell as many as possible. The drawing will take place on July 15, 1981. First prize will be a 15" black and white TV set donated by the grandparents of Timothy Kaufman who has E.H. Our warmest thanks to the Kaufman family.

On a personal note . . . we thank EVERYONE from the New York area who has sent donations in to keep our Foundation alive.

In closing, here's to all of our devoted loved ones who have stood by us through thick and thin . . .

"I have always been delighted at the prospect of a new day, a fresh try, one more start, with perhaps a bit of magic waiting somewhere behind the morning."

Till Next Time . . . Donna DeAngelis

#### PENNSYLVANIA REPRESENTATIVE

Pat Giuliana is interested in establishing a Pennsylvania Chapter. Anyone interested, please contact her at 12536 Deer Run Road, Philadelphia, Pennsylvania 19154. Telephone (215) 637-7220. She is looking forward to hearing from you.

#### FROM MUTUAL SUPPORT GROUP TO NATIONAL FOUNDATION

Often tagged as being impulsive and being accused of acting before reviewing the possible consequences, our founder, Mrs. Barbara Landwehr has a tendency to jump in where angels fear to tread. To quote her, she often gets stuck with her foot in her mouth.

Six years ago, while the Landwehrs were living in southern California, an incredible chain of events began to occur as the result of her storming the set of the National Easter Seals Telethon. This impulsive action ultimately led to the formation of the National Ichthyosis Foundation.

It happened on Palm Sunday when Mrs. Landwehr discovered that her children's favorite television program had been preempted by the Easter Seals Telethon. Listening to the appeals of the host, she took the negative appeal as a personal affront. The memories of all the times she had asked for help from this organization, and others like it, came back. Landwehr had been told that her daughter's disease, Lamellar Ichthyosis, was not on their list. "What right do they have to decide which congenital birth defect is actually a birth defect," wondered Landwehr.

If the host had turned her off so strongly, imagine how many others were also turned off. She decided to confront him personally.

It was about noon when Landwehr packed her daughter Deatra in the car and drove the forty miles from her home to the television studio. Once inside the studio she still couldn't get into the Telethon. One of the celebrities who had just appeared came to her aid and helped them get inside the Telethon.

Mrs. Landwehr doesn't call her actions courageous like so many others say. "It was just plain anger and brazenness," she says. She assertively expressed her feelings to the host. Much to her surprise, he made a national plea in her daughter's name stating that "a great injustice had been done." People from all over the United States responded with donations earmarked for DEE DEE.

A graduate of California State College at Hayward, Landwehr holds a Bachelor of Science Degree in Recreation Therapy and is a Certified Recreation Therapist. She has a well diversified background in the planning and organization of programs for normal and mentally retarded children and adults. She also has been the Administrator of a Residence School for mentally retarded children.

An immediate result of the Telethon appearance was her introduction to Dr. Jeffrey Herten, then a Dermatology Resident at the University of California at Irvine. Landwehr recalls that it was because of his compassion and understanding that the years of anger, hostility, frustration and anxiety began to melt away.



Barbara Landwehr and her daughter, Deatra.
—Photo by R. Blaich, Valley Indep. Press

The Landwehrs relocated to Mrs. Landwehr's hometown of Vallejo in 1977. And in January, 1979, Dr. Herten referred the Landwehrs to the University of California Keratinization Clinic and Drs. Mary Williams and Peter Elias. It was at this time that Deatra was invited to participate in the experimental program involving the drug called 13 cis-retinoic acid.

"Parents with children who have lehthyosis have felt desperate and very alone," reflects Landwehr. Deatra, now fifteen, was thirteen before they met anyone else with lehthyosis. This is not uncommon. The Landwehrs were aware that other cases existed, but were unable to find them. Doctors couldn't give them names because of the confidentiality factor.

Landwehr has found that people (usually as children) tend to experience many social and emotional problems as a result of having Ichthyosis. Other people tend to pull away from them because of their own ignorance. Children are condemned by other children because they look different. In a way, they experience the same type of rejection that a very fat child or a mentally retarded child experiences. They're different! They do not fit the norm! Therefore -Reject! Landwehr and Williams recognized a need for a mutual support group and acted on it.

"We started as a local parent support group, and overnight we were a national organization — The National Ichthyosis Foundation," declares Landwehr.

Since its beginning in August, 1980, the National Ichthyosis Foundation has established Chapters in San Francisco, Ohio, New York, Oklahoma, the Carolinas and Connecticut. There are also requests from parents in Virginia and Pennsylvania to start Chapters.

"Since we started our organization, we have come in contact with adults who have lived with Ichthyosis, as well as parents whose children suffer from Ichthyosis," says Landwehr, "but we have reached only a handful. We want more people to know that we exist and what Ichthyosis is all about."

Of primary concern at present is the necessity of reaching all Dermatologists. By making them aware of the National Ichthyosis Foundation, more people will be reached and helped.

The Foundation is now incorporated, thanks to William Nachbaur, attorney. State tax exemption has been achieved and Federal tax exemption is being sought.

The National Ichthyosis Foundation offers hope, up-to-date information on research, and much needed mutual support.

The various Chapters are in the process of a variety of fund-raising events ranging from raffles to Bowl-a-Thons.

The Foundation is planning a twoday workshop to coincide with the American Academy of Dermatology in December, 1981. There will be both educational and practical segments included in the format.

The newsletter, *Ichthyosis Focus*, is the primary tool in the Foundation's network of communication, but families can request publication of their address in order to receive direct communication from others.

In the future, hopefully, Research Grants will be made available.

"We are very excited about our National Ichthyosis Foundation," says Mrs. Landwehr. "We dream that someday it will be as big as Muscular Dystrophy, or better still, that we can completely dissolve because Ichthyosis won't exist anymore."

Won't you help us realize our dream?

## A Member's Story . . . .

My name is James Borden and I'm a 32 year old dairy and fruit farmer from upstate New York. I was born with Lamellar Ichthyosis. I am married and have a normal  $1\frac{1}{2}$  year old son.



Jim Borden with his wife, Linda, and son, Christopher.

At birth, the doctors first diagnosed me as having Sclerema of the Newborn, and the first consulting doctor gave me 48 hours to live (18 years later that same doctor had to give me my college physical!). After they decided finally that it was Ichthyosis, my parents took me to many doctors for advice and help. I was seen in clinics in New York and Boston.

I was treated with salt water baths (helped some), ultraviolet light treatments, large doses of vitamin A, goat's milk, dozens of lotions and oils, and even hypnosis. None of these had any lasting effect on me.

In my elementary school years, I was somewhat of a loner, but not by choice! I heard such names as "alligator, crocodile, dirty face, or scabhead." I did what activities I could but this meant no team games. Because of my appearance, no one wanted me on their team — they didn't care about seeing if I had the ability. Finally, I was saved from this isolation. One day, a popular, athletic boy told his classmates while choosing up sides for a game, "If you want me, then you choose Borden, too!" This was very crucial to my development, because I was finally involved in playing with the other children.

In high school, I found that my personality had to be my strong point because my appearance could not be used as a drawing card. When a girl said "no," it hurt deeply. I tried so hard to let them see the inner me, hoping they would forget the outside wrapping. So I would wipe away the tears, pick myself up, and ask another for a date. I was surprised to find that there were people who would not let the outside

keep them away from the inside. For every success I had, there were ten setbacks. But I kept trying.

I had a keen love of sports (I still do!) and wanted to participate. However, because my parents thought of protecting my health, they tried to discourage me. They tried to keep me inactive in High School sports and to push me into more studies. This is probably why I became so active in college sports.

I wanted a chance to live a dream — to make the team. I tried wrestling but when I finally won a match, my temperature reached 106 degrees. The next day, the doctors banned me from wrestling. So, I tried baseball, but without any past experience, I didn't have much opportunity to play.

Finally, I turned to track and cross-country. I gave it everything I had and made both teams.



Jim Borden and a member of his bucket brigade in action.

Since the Ichthyosis would not allow me to sweat, my body temperature would start to rise as I ran. Teammates and friends formed a "bucket brigade" and threw or squirted water on me as I ran by, just to keep my temperature down. This went on for three years. I also splashed or dove into ponds and streams in cross-country races.

My teammates, coaches, and the college were fantastic in their support. I tried not to let them down!

While my teammates raced against the clock and our opponents, I also had to run against my body temperature, telling myself I wasn't as hot as I thought.

On the cross-country team, I was usually the number two or three man. On track, before I graduated, I owned the school two-mile record — an accomplishment I'd never even dreamed of! The

coach told me it was incredible to do what I had done without sweating and wondered what I would have done if I had been normal.



James Borden (on the right) with Coach Bell (center) and Jim Longo

Now, I am back on the farm and working outside as I love to! Yes, the heat and humidity did bother me. I always carried a canteen of water to wet my shirt during the hot days. I found my patience, reflexes, coordination, and steady hands left me when I was overheated. But this has changed in the last two years.

I am on the experimental 13-cisretinoic acid program and travel to New Haven, Connecticut, for checkups every other month. My skin is almost clear and I sweat very easily. I am so comfortable, it's like a miracle and the side effects are very minor. I only wish I could try college track again!

With 13-cis-retinoic acid, maybe today's children with Lamellar Ichthyosis have a chance to live a more normal childhood. This is a giant step against Lamellar Ichthyosis and I am confident that big help for us is on the way.

But until 13-cis-retinoic acid (or a similar medicine) is available to everyone, the biggest help I can offer you, both parents and children, is to suggest you build and diversify your personalities. Acquaint your children with all fields of interest and be their lost friend, while keeping them in contact with other children. Personality — a good one — is the key, I believe.

Don't be afraid to talk about it or be asked about it. I try not to let it bother me. Remember:

IT'S NOT THE QUESTIONS THAT HURT. IT'S THE IGNORANCE!!!

## FIRST ANNUAL NIF BOWL-A-THON

Plans are being formulated for the First Annual NIF Bowl-aThon in October, 1981. The unique aspect of the Bowl-a-Thon, other than that it will be a first for NIF, is that it will be restricted to junior bowlers. Kids helping kids — this makes it

more meaningful.

A local official of the AJBC (American Junior Bowling Congress) has been contacted and approval has been given for the tournament to be held in western North Carolina. At present, more than ten bowling establishments in the western North Carolina area will be involved. Each bowler will obtain as many sponsors as possible to pledge money for each pin they knock down. Other officials of the AJBC across the country are being contacted as are the leaders in the AJBC home office.

We plan to publicize the Bowl-a-Thon in the AJBC magazine and when the time has been finalized to contact other media.

We need all the assistance we can muster from NIF chapters across the country in obtaining the cooperation of their local AJBC leaders. We need your help to make to make this Bowla-Thon a success.

As more details are finalized, they will be published in subsequent newsletters. Please contact Karen Stone at (704) 298-6499 or by letter at 26 Springwood Drive, Asheville, NC 28805, for more information.

## **A LIVING MEMORIAL**

So often money is wasted on flowers that quickly die. Make your remembrance of your loved one a gift that will live on, giving hope to those afflicted with Ichthyosis. Such a gift will help the National Ichthyosis Foundation reach others with Ichthyosis, educate the public, and assist in finding treatments.

To make such a gift, just send us the name and address of the person you wish to honor and remember. We will acknowledge all gifts and notify the family of this special tribute. The amount of the donation will be confidential.

Give the gifts of love and hope! The memory of your loved one will live on in the lives of those with Ichthyosis as they live more comfortable lives. What could be more thoughtful or lasting?

## PARTING THOUGHTS



Marisa Mandia

Spring is blossoming all around us. Our foundation is blossoming, too, like a fresh new flower. The most important thing we can do for one another is to help spread the word about our growing group. Who would ever have dreamed we

would come so far? Who would have thought we would see that dream come true?

Thanks to all the many doctors and their patients who have helped to make us what we are today. Without their help we never would have gotten this far. Thanks to all those who have donated their time and emotions to us.

Our main goals at this time are to raise money for education and public awareness, and to maintain our network of communication. Won't you help? We have so much that has to be done and so much to say to the world! JOIN US . . . and in doing so you will add another link to our evergrowing chain of friendship!

May God Bless You all and bring you all the happiness and peace of

mind you deserve.

"Fight for the Right" Until next time . . . Marisa Mandia

#### 1981 MEMBERSHIP FORM

- ☐ Here is \$10 to cover my 1981 newsletter subscription.
- □ Enclosed is my additional contribution to further the goals of the Foundation.
- □ I wish to continue to receive future mailings but am unable to contribute at this time.
- □ Please delete my name from

Please Check: Parent D Friend Physician Teacher Relative D Patient -Agency -Professional Other (Please Specify)

A STATE OF THE STA	member $\square$ Renewal $\square$	
Name (Please print)		
Address		
City	State	Zip
Phone ( )	Birthdate	
Diagnosis (If Applica	ble)	
I give my permission	to NIF to release my na	ame and address to
other members.		
Signature		

MAIL TO: THE NATIONAL ICHTHYOSIS **FOUNDATION** 151 Toyon Drive Vallejo, California 94590

#### NATIONAL ICHTHYOSIS FOUNDATION

The National Ichthyosis Foundation is a charitable organization. All the money collected by it will be used for charitable purposes, such as education, counselling, and ichthyosis research. The organization's major expenses are mailing its newsletter and printing

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Midwest Reg. Chapter John & Patricia Arick 985 Palmer Rd. Grandview, Ohio 43212 (614) 488-4285

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

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

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. An application for determination of the organiza-

Carolina Chapter Mrs. Karen Stone 459 Bull Creek Rd. Asheville, N.C. 28805 (707) 298-6499

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Judy Droste 2nd Vice Chairman San Mateo, California

tion's tax exempt status under Federal Law has been filed with the Internal Revenue Service, All contributions to the organization are deemed tax-deductible under California law and we expect will also be deductible under Federal Law.

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#### **HELLO FROM HANS**

Hello. My name is Hans Kummer and I'm nine years old. I was born with Ichthyosis, the Epidermolytic Hyperkeratosis kind. Although it "bugs me" at times, I've learned to live with it and most times don't even think about it. Sometimes I think to myself how lucky I am if I have to have something "wrong" then this isn't so bad.

I'm in the fourth grade in St. Mary's School. It's a great school and small enough so everyone knows everyone else. My subjects are spelling, music, gym, math, English, science, art, social studies and religion. My friends are A-OK. Oh sure, sometimes new kids will ask me what's wrong with my skin and I proudly tell them I've got Ichthyosis. Once in a while I meet kids who have to tease me. Well, I've borrowed DeeDee's saying — "God made me this way, what's your excuse?" - and it really works!



I belong to Cub Scouts and am now working on getting my Bear Badge (hopefully when you read this I'll already have it sewed on my uniform shirt pocket) and during the summer mom and dad said I could go again to scout camp even though I can't go swimming, the crafts, games and hiking are loads of fun.

Besides school, scouts and being an altar boy, I love to play Star Wars, especially my favorite character, Luke Skywalker. I've made a collection of Star Wars playthings and have seen both movies several times. Boy, if I think my arms and legs are sometimes stiff, just imagine what C-3PO and R2D2 feel like!

### PRESIDENT'S MESSAGE

## — A Note of Appreciation!

So many times the "little" things go unnoticed and unsung. So often we overlook and even ignore the efforts and abilities of those around

Reality hit this weekend while I sat in a Newsletter Publication Workshop. I developed a true appreciation of the "behind the scenes" work that goes into our newsletter.

First, special recognition must go to Jim Tombros of Hermal Pharmaceutical Labs, who offered the newsletter sponsorship. Without him we never would have found D.J. Moore Advertising and Mr. Paul Rehm.

I don't know if Mr. Rehm realized what he was getting into when he agreed to take on our newsletter. He is truly an associate editor. He approves the layout, proofreads everything several times throughout

the entire process, and calls me on the slightest discrepancies whenever necessary. He has even taken last minute dictation over the phone because I forgot to include some-

Patience is a virtue which makes Paul a very virtuous person considering all the patience he has had to endure due to my lack of knowledge. I am still certainly no expert in the field of Newsletter Publication, but now I have a true understanding of all that goes into a first class publication. Because of Paul Rehm and Jim Tombros, our Ichthyosis Focus is really a first class publication.

So, "thank you" for all your dedication and hard work. It is definitely appreciated!

> Yours Truly, Barbara M. Landwehr

In sports, I like baseball the best. My favorite team is the N.Y. Yankees and I think the greatest player is Reggie Jackson. I like to help Mom with the cooking, especially when I can lick the frosting bowls. My favorite foods are meats, pizza and french fried onions.

My dream in life is to become an astronaut and to work and fly on rockets and spaceships.

Since NIF started, I've read and enjoyed all the newsletters and even went with mom and dad to the N.Y. Chapter meeting in Brooklyn. It was really very exciting — the trip and the meeting! It was a beautiful day and we got to see the skyline of N.Y. City and the top of the Empire State Building. We saw jet planes taking off and landing at both N.Y. airports. At the meeting I met alot of real nice people, many were kids who had Ichthyosis just like me. Mom and dad did a lot of talking and I got asked a lot of questions — it made me feel important and made me feel like I was helping someone else. Please take care and remember we

that have "it" have to hang in there!

#### PICTURES ARE WORTH A THOUSAND WORDS

We are putting together a photo collage of our members for our exhibit at the next Academy of Dermatology meeting in December. We look forward to adding your picture to ours.

## CORRESPONDENCE CORNER

Many of you have said you'd like to correspond with others facing the same problems. If you will send in your name, address and a short paragraph about the type of person with whom you'd like to correspond, we'll publish it in the next issue of Ichthyosis Focus.

Sally Jo Howen P. O. Box 153 Salem, Wisconsin 53168 Would like to correspond with

someone on the subject of E.H.

#### NOTICE . . .

All materials to be printed in the Newsletter must be received in the National Headquarters Office no later than the 20th of each month.

We like to use pictures. All pictures must be good quality black and white. No color or polaroid pictures will be acceptable for Newsletter publication. Please identify people in the order of appearance and be sure their names are spelled accurately.

#### **BIRTHDAY WISHES**

Birthday wishes for the month of April go out to: Rebecca Harris — 15 years old Irvin Nailor, III — over 21 Casia Ogden — 1 year old And for the month of May to: Shawna Lynn Chappell — 1 year old Teri Jo DeWitt — 7 years old

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We join our hearts and our hands together as one family

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