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hands together as one family

The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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FROM A MEDICAL POINT OF VIEW

Our guest columnist is Dr. Frank Yoder from Westerville, Ohio. He has been involved in the experimental drug program involving 13-cis retinoic acid for a number of years. He is also a member of our Medical Advisory Board. Thanks to Dr. Yoder's hard work and dedication our Ohio Chapter is a reality.

"THE WEATHER AND YOUR SKIN"

When I first entered my training in Dermatology, I was taught that water was very bad for patients with Ichthyosis. Although the statement did not seem to make much sense, I assumed it to be accurate because it was espoused to me by a fine, highly educated, well intentioned dermatologist. I was surprised to learn, when I began to do research in the treatment of Ichthyosis, that the opposite was true. Actually, water is quite helpful to patients with Ichthyosis. This has never been better illustrated than when I was working at the National Institutes of Health. I was to see a patient from California who had flown to Bethesda, Maryland to be treated with the experimental medicine, 13-cis retinoic acid, which we were just beginning to use at that time. Although I had never seen the boy before, his dermatologist informed me that he definitely had severe Lamellar Ichthyosis, and would be a very good candidate for the experimental therapy, because none of his past medications seemed of much help.

It was an early morning appointment at the Clinical Center at the National Institutes of Health. I quickly made rounds, seeing my hospitalized patients first, and then proceeded down to the out-patient clinic area to meet the boy who had flown in from California. As I passed the waiting room, I looked to see if I could find the patient with Lamellar Ichthyosis but I did not see anyone with such a condition. Asking the clinic nurse if "John Doe" had checked in yet, she replied, "Why yes, he did, and he is presently in the waiting room." To make a long story quite short, the boy with Lamellar Ichthyosis indeed was in the waiting room, but I had been unable to recognize him because he had just performed his weekly ritual of a six hour bath, which made his skin appear almost normal. It was then that I realized three important things: First, many physicians, including dermatologists, knew very little about Ichthyosis. Secondly, water was great therapy for Lamellar Ichthyosis, and thirdly, many patients with Ichthyosis knew more than their physicians regarding treatment of their disorder.

Now that I have admitted that I do not know all the answers, and conceding that you probably know more than I do in your particular case, let me tell you of a few observations that I have noted concerning weather effects upon patients with Ichthyosis. Humidity is the most important weather effect. With decreased humidity, everyone's skin tends to dry out and will often scale slightly. In patients with Ichthyosis this

normal event is exaggerated to the point that the scaling becomes a significant problem. That is why water is good for most Ichthyosis patients. It increases the humidity and it increases the water content of the skin which causes less scaling. Usually, high humidity is associated with warmer weather; cold weather, and especially artificial heating, causes decreased humidity and causes a decrease in the water content of the skin. Therefore, most patients with Ichthyosis are much better in the summer and much worse in the winter. It is interesting to note that patients with Ichthyosis Vulgaris and X-linked Ichthyosis clear almost entirely in the summer or in hot humid climates. It has also been my observation that Epidermolytic Hyperkeratosis is only slightly affected by the weather compared to other forms of Ichthyosis.

Because of the beneficial effects of increased humidity, a warm, humid climate is preferable to a cold, dry one for people with Ichthyosis. This is well illustrated by a patient who lives in the Midwest. She travels to Hawaii and her skin improves tremendously during that period of time without any change in her therapy.

Although warm, humid climates seem to improve most forms of Ichthyosis, a caution is certainly needed. Patients with Ichthyosis, especially Lamellar Ichthyosis, do not sweat normally. Many of them will have a history of not sweating at all. This becomes extremely dangerous in very hot, humid

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weather because they are much more susceptible to developing Heat Stroke. That is why many patients will find that in very hot, humid weather, especially with physical exertion, they will turn quite red because the body is trying to get rid of excess heat. Another feature that is linked with the inability to sweat normally is that patients with Lamellar Ichthyosis will often develop itching in hot, humid weather. This is because the sweat is trapped by the skin scale clogging the pores of the sweat glands and therefore the sweat irritates the skin, occasionally causing small blisters and often irritation and itching of the skin.

A final point regarding heat intolerance, is that patients especially with Lamellar Ichthyosis, who have high fevers are more susceptible to hyperthermia, that is, where the body retains too much heat to the point of danger. It is my impression that febrile seizures occur more frequently in children with Lamellar Ichthyosis because of this, and obviously, those children with prolonged high fever should be watched very carefully.

A positive point is that patients with Lamellar Ichthyosis who have never sweated and are treated with 13-cis retinoic acid, give a history of beginning to sweat normally and are therefore able to exert themselves more in hot, humid weather. This has been noted by several of the patients whom I have treated for Lamellar Ichthyosis.

In summary, the major effect of the weather on patients with Lamellar Ichthyosis is secondary to the humidity factor. There will be decreased scaling if the skin's water content can be increased, whether this is due to a six hour bath or a trip to Hawaii.

CHAPTER NEWS

NEW YORK CHAPTER

We are proud to announce that the New York regional chapter has, to date, raised more money than all the other chapters combined. We challenge all the rest of you to beat us.

The results of our latest fund raising event was a raffle. The winners were:

1st Prize
Mr. Stern, Baldwin, N.Y.

2nd Prize
Mr. Ferrari, Cold Spring Harbor, N.Y.

3rd Prize
Jill Barret

Coming up in the near future . . . Tupperware parties given by our local community with the proceeds going to the Ichthyosis Foundation.

OKLAHOMA/KANSAS CHAPTER



The first formal meeting of the Oklahoma/Kansas Regional Chapter of the National Ichthyosis Foundation was held recently.

The meeting opened at 9:00 a.m. with a get-acquainted period. The group discussed individual reactions when each first realized their children had a skin disorder.

Dr. Paul Shackelford, Tulsa dermatologist and member of the Medical Advisory Board, addressed the afternoon session. At the close of his presentation, there was a question and answer period.

WORKSHOP POSTPONED

The Workshop which was to have been held December 5th & 6th has been postponed. Further information will follow in future issues. We regret having to postpone it; but even though there was a lot of enthusiasm, there was a definite lack of volunteers.

However, we will still have an exhibit booth at the American Academy of Dermatology, December 6, 7, 8 & 9 and we still need volunteers to help man the booth. If you would like to help, please call Judy Droste at (415) 348-3309 in the evening.

BIRTHDAY WISHES

Happy Birthday to all the following:

August:

Charles Eichorn
Deatra Landwehr - Sweet 16
Randy Maggert
Martha Markham - 18
Robert Jones

September

Carol Flynn
Marianna Keishk - 4
Hans Kummer - 10
Adam Royds - 2
Jennifer Bell - 10
Todd Thompson - 1
Timothy Kaufman - 2
Michele Cotter - 8
Robin Mandia - 3

October

Kim Hayes - 18
Lois Richter
Donald Davis

CORRESPONDENCE CORNER . . .

Francis Nailor (Ms.)
R.D. #1
Downington, PA 19335
Son - Age 21 - X-Linked
Would like to find someone near his age to write to.

Lisa Herbert
101 Lennon St.
Gardner, MA 01440
(817) 632-2923, 15 years old - 6-15-66

Betty Livingston
49 Richmond St.
Gardner, MA 01440
Would like to correspond with someone about Ichthyosis.

Diane Measle
3525 Heatherfield Ct.
Romeo, MI 48065
Wants to correspond with someone with Lamellar.

APOLOGY

We extend our sincerest apologies to Dr. Joe McGuire. He has contributed to the **Medical Point of View** column in our last two issues and proper credit was inadvertently omitted. We thank Dr. McGuire and hope he will continue to contribute informative articles to Ichthyosis Focus.

HELP US HELP OTHERS



Hello. My name is Vicki Caffoe. I am a 17 year old Senior high school student, and a volunteer for the National Ichthyosis Foundation here in Vallejo. You are probably wondering why I'm writing to you, right? Not a bad question.

I began working with Barbara Landwehr in April, and after just the first few days, I knew there was something special this lady had started. On her own, she began this foundation and with the help of so many people, it became nationwide within months. Letters, some donations, and requests for more information filled her mailbox

daily, and she found herself amidst people who needed help, who could give support and love to each other, who could medically treat others, and who could help run the foundation by forming their own local chapters. Without all these people, this foundation would not be what it is today.

All these people are you! We need you! We need your support for all the others, for the frightened, young children who can't understand some of the things that are happening to them. We need you to be there for advice, for love, for understanding and for the compassion that each one of us needs every day.

We need YOU, and you know who you are. Please don't be scared — there's nothing to be afraid of. Go ahead and send in those personal stories, all those poems, prayers, jokes, anything at all. People do want to hear about all you know. It doesn't have to be anything wonderfully spectacular, just a part of you that you want to share. We want to hear from you, and we are really ready to listen. Just let us know you're there.

We know you are, so please . . . Help us help each other, because a little love goes a long way. We know you're out there. And you know we're here.

PARTING THOUGHTS

For this issue, our parting thoughts were submitted by Teri Thompson, Colorado Representative. If we would all listen with our hearts to the words of this poem, our children would be better for it.

It is important to remember that the skin our children were born with is THEIR problem. It is only your responsibility to teach them to deal with THEIR own special problem.

"The Monument"

by Blaine M. Yorgason
(excerpted from "Charlie's Monument")

God,
Before He sent His children to Earth
Gave each of them
a very carefully selected package
of problems.
These, He promised, smiling,
Are yours alone. No one
Else may have the blessings
These problems will bring you.
And only you
Have the special talents and abilities
That will be needed
To make these problems
Your servants.
Now go down to your birth
And to your forgetfulness. Know that
I love you beyond measure.
These problems that I give you
are a symbol of that love.
The monument you make of your life,
With the help of your problems,
Will be a symbol of your
love for me, Your Father.

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City _____ State _____ Zip _____

Phone () _____ Birthdate _____

Diagnosis (If Applicable) _____

I give my permission to NIF to release my name and address to other members.

Signature _____ Date _____

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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 organi-

zation'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 law and Federal law.

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