

The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

Send all correspondence to:
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INTERESTING INFORMATION...

This month we have decided to talk about the much asked about **RETINOIDS**.

Dr. Gary Peck, of the Dermatology Branch of the National Cancer Institute in Bethesda, Maryland has graciously answered the following questions that many of us have asked.

Question: What are the retinoids?

Answer: The term "retinoid" was coined recently to indicate the group of chemicals that include vitamin A and all its natural and synthetic relatives.

Question: In what diseases are the retinoids effective?

Answer: The first oral synthetic retinoid that was used to treat ichthyosis in the United States was 13-cis-retinoic acid, which was shown to be effective in lamellar ichthyosis. The second retinoid, which is designated Ro-10-9359, is at least as effective as 13-cis-retinoic acid in the treatment of this condition and is more effective in other conditions, such as epidermolytic hyperkeratosis, ichthyosis vulgaris, keratoderma palmaris et plantaris, and x-linked ichthyosis.

Question: What are the side effects of these two retinoids?

Answer: The side effects differ considerably between these two retinoids. For instance, 13-cis-retinoic acid produces much more drying and chapping of skin and mucous membranes than does Ro-10-9359. This leads to chapped lips, chapped skin of the face, dry nose, and irritated eyes. On the other hand, Ro-10-9359 leads to more hair loss, peeling of the skin of the palms and soles, itch-

ing, and accentuated peeling of the outer layer of the skin when scratching. Internal side effects are uncommon but both retinoids can cause arthralgias (joint pains), temporary low-grade elevations in blood tests that measure liver function, elevations of serum triglycerides (one of the fats in the blood), and the potential risk of developing birth defects is the retinoid is taken during pregnancy, especially Ro-10-9359.

Question: When will the retinoids be available?

Answer: The FDA must review and approve new drug applications for the retinoids before they can be prescribed. One rough estimate is that the 13-cis-retinoic acid could be approved in two and one half years. Approval for Ro-10-9359 would take longer.

Editor's note--Dr. peck was the first to use the new retinoids in the United States, and has, by far, the most experience of any physician in the States with these drugs.

THERAPUTIC HOTLINE...

As parents, we realize that there are a number of various treatments, some of which are more successful than others. If you have found something that has really worked for you please feel free to write and tell us about it. Send us your name, address, phone number, and the form of ichthyosis you are involved with. Make sure you use the complete name and company of the product and be very specific about your techniques and directions.

THANK YOU!...

It's time again to express our sincerest appreciation and gratitude to Ortho Pharmaceutical for their nice donation. Thank you for helping our Foundation get started. And a special "Thank you" to Dr. George Thorne for making it happen.

YOU CAN HELP...

Our foundation is growing. Oh Boy! Is it growing! We are receiving calls or letters almost everyday from people who have seen or heard of our Newsletter. They now realize that there are others (not just in their town or city) across our nation that have friends or loved ones with a common problem. But more important, they now know that there are other people who know and understand the physical and psychological problems faced, and WHO CARE!

Our NEWSLETTER has been the ribbon that has helped tie us together; but like any gift, it can be expensive, especially if it is mailed. This is one package that cannot be emptied when unwrapped and opened. As a matter of fact, people keep adding to it. They have contributed articles, facts and information, useful data, and more, which is helping our Newsletter expand. This is why we need YOUR help! In other words, to wrap a bigger package, we have to buy more ribbon. We know the expenses with ichthyosis (the creams, medications, special needs, etc...) can be quite a financial burden. This is why it is quite difficult for us to ask for your help; but we DO need YOUR help.

We have received some contributions to the Foundation, but much of this has been used up primarily in printing, postage, supplies, and incorporation fees; all of which are helping to construct a firm cornerstone on which our Foundation can be built.

Any contribution you can make, no matter how small or large, please send to:

THE NATIONAL ICHTHYOSIS
FOUNDATION
c/o THE AMERICAN SAVINGS &
LOAN
TENNESSEE STREET OFFICE
901 TENNESSEE STREET
VALLEJO, CALIFORNIA 94590

Also, you could contact the numerous organizations and businesses in your area and ask for contributions. It's amazing the sources of revenue you can find if you just put your mind to it.

For example:

\$5.00 prints 100 single sided pages
\$10 prints 100 2 single sided pgs
\$15 prints 100 3 single sided pgs
or mails 100 Newsletters
To print and mail 500 3 single sided Newsletters per month costs \$120.00. It will cost us \$70.00 to apply for and receive a bulk mailing permit.

We want to keep our monthly Newsletter because in keeping it, we maintain contact with each other. How much does our Newsletter mean to YOU?

MUCH THANKS!...

Our grateful appreciation also is extended to Ivy Research Laboratories, Inc. for their thoughtful donation. And a special thank you to Dr. Albert M. Kligman for helping it happen.

NEWSLETTER NAME...

In case you hadn't noticed when you opened this Letter, we have a new name. After much deliberation we selected the name ICHTHYOSIS FOCUS that was submitted to us by David and Alise Kummer of Seymour, Connecticut. Thank you David and Alise. We hope you are very proud of our new name, because we sure are.

TEEN TOPICS...

by Deatra

Hi there! Here I am again with some of my personal thoughts and feelings.

Sometimes I resent having ichthyosis because of the things people say and do. Sometimes the things people say can really hurt.

There have been many times when people come up to me and ask, "What's the matter with you?" At first I didn't say anything. Then later on I started to say, "I was born this way," but now, whenever I feel very pushed, I just say, "I was born this way: What's your excuse?"

There have also been times when people stare and say things just to be mean and nasty. I used to go off and cry; but because people don't want me around when I cry, I decided to take a new approach. Now I say, "If you don't like the way I look, and you can't accept me for me, then talk to God. Maybe He can change things!"

Remember, keep your chin up and don't let people get you down. You are a person, and God created you to His own image!!!

With Love,
Deatra

P.S.

Beauty is in the eye of the beholder, and I think you are all beautiful!!!

SAN FRANCISCO BAY AREA CHAPTER...

We held our first very heart warming meeting on Sunday, November 2nd. Parents with children, and adults, with various forms of ichthyosis shared openly and deeply about their feelings. We were all touched by each person's sharing. We elected officers, decided to have a Christmas party, and had a raffle. Punch and cookies were enjoyed by all.

HAVE A HAPPY THANKSGIVING!!!

PARTING THOUGHTS...

At the close of another newsletter with all good news, all I can ask for is that we all count our blessings, for we all are truly blessed! So many good things are happening and so many good people have offered to help us.

Won't you please remember one another at this Thanksgiving season with love in your hearts?

We're here for you whenever you need us because caring...is the HEART of loving

Til' nexttime...

P.S. Thank you for being you!!

If you are interested in being added to our permanent mailing list, please fill in the form below and send to Barbara Landwehr, 151 Toyon Dr. Vallejo, Calif. 94590.

Name _____	Birthdate _____
Address _____	Phone () _____
Diagnosis _____	

COMMENTS: Why you are interested in our Foundation. If you don't have Ichthyosis who do you know that does? If you have it, tell us something about yourself and your family. Feel free to attach a separate sheet.
