

Ichthyosis Focus



Vol. 22, No. 3

A Quarterly Journal for Friends of F.I.R.S.T.

Fall 2003

Lamellar Ichthyosis and Congenital Ichthyosiform Erythroderma (non-bullous CIE)

By Mary Williams, MD



Lamellar Ichthyosis (LI) and non-bullous Congenital Ichthyosiform Erythroderma (CIE) are considered two of the five main types of ichthyosis (the others being Ichthyosis

Vulgaris, X-linked Ichthyosis, and Epidermolytic Hyperkeratosis). LI and CIE can be two of the more severe forms of ichthyosis, although there is a great deal of variability in severity among patients with these forms of ichthyosis. They occur in approximately 1 in 300,000 births.

Lamellar Ichthyosis (LI) and non-bullous Congenital Ichthyosiform Erythroderma (CIE) have been considered distinct forms of ichthyosis by some authorities, while others have lumped them together, usually under the common name of Lamellar Ichthyosis. Recent genetic studies have shown that LI and CIE "phenotypes" (meaning how the condition appears or manifests) may be caused by mutations affecting several different genes. Three of these genes have already been identified; they are the gene encoding the epidermal enzyme, Transglutaminase 1, and two genes encoding two distinct but related enzymes, 12(R)-lipoxygenase and lipoxygenase-3. The epidermal enzyme, Transglutaminase 1, is required for the formation of the cornified envelope, a protein structure that surrounds the outermost skin (stratum corneum) cells. The lipoxygenase enzymes affect the production of molecules involved in stimulating inflammation and cell division. There is also evidence for more genes that are yet to be identified.

It is now apparent that LI and CIE represent

a phenotypic spectrum, where the LI appearance (thick, usually plate-like scales with less prominent redness) and the CIE appearance (red skin with finer, whiter scales) can be considered the two "poles" at either end of the spectrum. Many individuals have appearances somewhere between these two ends of the spectrum. People with the LI phenotype are likely to have a mutation in their Transglutaminase 1 gene. Some people with the CIE phenotype also have a mutation in the Transglutaminase 1 gene, but others have mutations in one of the lipoxygenase genes, and still others have mutations in the as yet unidentified genes. These conditions are all recessively inherited, meaning that each parent of an affected child is an asymptomatic carrier of the gene defect, and individuals must inherit two recessive genes (one from each parent) to show the disease.

Both LI and CIE are characterized by overproduction of skin (epidermal) cells, but in CIE this overproduction is more pronounced. These cells reach the stratum corneum (the outermost layer of skin) in as few as four days, compared to the normal fourteen. The cells are made faster than they are shed and, therefore, build up in the stratum corneum and underlying layers. In LI, the skin cells are produced at a more normal rate, but they do not separate normally at the surface of the stratum corneum (the outermost layer of the skin) and are not shed as quickly as they should be. The result is a build-up of scales.

In both LI and CIE, the scaling condition affects the entire body surface. In LI, the body is covered with broad, dark, plate-like scales separated by deep cracks. In CIE, the scales are usually fine and white on the face, scalp, and torso, but scales on the legs can be large

and plate-like (more like the scales of lamellar ichthyosis). Additionally, the skin is often quite reddish beneath the scales. People with LI or CIE often have trouble closing their eyes completely because of the tightness of the skin around the eyes and eyelids. In some cases, the skin around the eyes pulls so tightly it causes the eyelids to turn outward exposing the inner red lid and causing continuous irritation. This condition is called "ectropion." If the eyelids cannot close completely during sleep, it is important to use drops that will maintain moisture over the cornea (e.g., Lacrilube®). Some physicians recommend plastic surgery to correct ectropion because, if it is left untreated, damage to the cornea can develop leading to impaired vision. People with LI or CIE may also have thickened nails and hair loss due to the thickness of the scales on their scalp. However, it is important to

continued on page 4



**Do
you
have
3 minutes
today?**

Take that time to complete our new online survey! Your responses will help us better understand the diverse needs of our members. To access our online survey, see page 4.

Copyright © 2003
by the Foundation for
Ichthyosis & Related Skin
Types

Ichthyosis Focus is published
quarterly by the Foundation for
Ichthyosis & Related Skin Types

Requests to reprint information
contained in Ichthyosis Focus
should be directed to the editor.

**The Foundation for Ichthyosis
& Related Skin Types**
650 N. Cannon Avenue
Suite 17
Lansdale, PA 19446

215.631.1411
800.545.3286
215.631.1413 fax
email — info@scalyskin.org
www.scalyskin.org

Executive Director
Jean Pickford

Editor
Maureen Tierney

Medical Editor
Amy Paller, M.D.

Editorial Assistants
Louis Giuliana
Tiffany Karst

The Foundation for Ichthyosis &
Related Skin Types is a 501 (c) 3 char-
itable organization supported by public
and private donations. All contribu-
tions to the Foundation are tax
deductible to the full extent of the law.

The editor invites your correspon-
dence. We welcome your comments,
observations and suggestions. Please
send your letters to Ichthyosis Focus
at the address listed above.

Ichthyosis Focus is provided as a
service to members of the
Foundation as a medium for the free
exchange of information. Neither the
Foundation for Ichthyosis & Related
Skin Types, its Board of Directors,
its Medical Advisory Board, nor the
Focus Editors endorse any treatments
or products in Ichthyosis Focus.
Views and opinions expressed in this
publication do not necessarily reflect
the views of the Foundation or
Foundation officials.

Correspondence Corner

Dear Friends:

I suffer from dry eyes related to ichthyosis. The dryness is not too severe, but is uncomfortable in the morning with the occasional (once a year), painful, spontaneous scratching of the cornea. I am near-sighted and very keen to have laser surgery. I am curious to know if my dry eye condition makes laser surgery more risky, or its side effects more severe. If any of you have any insight, please email me a short note at khosla_deep@hotmail.com.

Thank you in advance,

Deep Khosla
Toronto, Canada

Hi Jean:

You referred me to Dr. Cunningham last year for my daughter who has ichthyosis. We have had two dermatology appointments since then, and Dr. Cunningham is wonderful. The treatment she suggested, Tazorac, is really helping.

Ichthyosis is very challenging. Just when you think you have a handle on it, you don't. Our daughter's face and scalp were the most affected with the ichthyosis; the Tazorac has helped get those areas under control. But now it is showing up in other places. Our daughter Kennedy, is fifteen months old and a very sweet happy baby.

Thank you for the ichthyosis foundation. I tell people every day about this skin condition, and I will let people know about ichthyosis during national awareness week.

Sincerely,

Beth Aplin
Long Beach, CA

Editor's Note

Dear Friends:

Seniors Speaking, a new column dedicated to the special needs and experiences of our members 55 and older, debuted in our Fall 2002 newsletter. We had a wonderful response from our senior members and were able to print several contributions in three issues of the newsletter. However, we have not heard from anyone since. Seniors, we need to know if this column meets your needs, or not. If you have strategies or concerns to share with your peers, we want to hear from you. Your perspective is valuable to us at the Foundation and to our younger members, and our medical advisors. The experiences that you shared with us led us to develop and implement the recent survey on ichthyosis vulgaris and overheating. Please continue to share your experiences and advice with the ichthyosis community and us.

Sincerely,

Maureen Tierney
Program Director
Focus Editor

Foundation Resources

Ichthyosis Awareness Cards

Facing a world that judges us by our physical appearance every day can be a challenge for people with ichthyosis. Our members often report their frustration with the stares and rude comments of strangers. In response, the Foundation has developed an Ichthyosis Awareness Card to help our members deal with this issue.

The card, which is business card size, reads:

I was born with a rare disease called ichthyosis. My skin does not function normally due to a genetic mutation that I inherited at birth. It is my personal goal to educate the public so others with ichthyosis are not subjected to stares, pointing, and teasing. Ichthyosis is not contagious, a bad sunburn, or the result of poor bathing habits. If you would like more information about ichthyosis, or want to support research to find a cure, contact the Foundation for Ichthyosis & Related Skin Types at 215-631-1411, or visit their website at www.scalyskin.org.

The reverse side of the card is blank and can be used for your own information or message. To order the cards, please call Maureen in the national office, 215-631-1411, or 1-800-545-3286. Or email us at info@scalyskin.org. We have enough cards to be able to offer five to those members who request them.

Doak Dermatologics Brochure



Doak Dermatologics, makers of Carmol products, recently partnered with the Foundation for Ichthyosis to create a comprehensive brochure about ichthyosis and the Foundation's mission and resources. The colorful and informative brochure was mailed to every practicing, non-cosmetic dermatologist in the U.S. The brochure not only serves to educate dermatologists about ichthyosis and the Foundation, it also encourages doctors to refer their patients to the Foundation and to get involved with the ichthyosis community themselves. Patient Response Cards and a Physician Response Card are included with the brochure. The Patient Response Card offers patients an easy way to contact the Foundation for information about our programs and services. The Physician Response Card asks the doctors to think about supporting our efforts by joining the Board of Directors, Medical Advisory Board, Research Committee, or Physician Referral List.

The next time you are in your dermatologist's office, ask if he or she received the brochure and what he or she thought of it. Please remind your doctor to share it with other patients with ichthyosis. If you would like a copy to share with your family physician or another medical professional who manages your care, please contact Maureen in the national office, 215-631-1411, 1-800-545-3286, or email info@scalyskin.org.

The Foundation sincerely thanks Doak Dermatologics for their support in creating and distributing this great resource. We also want to thank our members who gave permission for their pictures to be used in the brochure.

"How To" Guide for Grassroots Fundraising

Jean Pickford, Executive Director, has written a "How To" Guide for Grassroots Awareness and Fundraising which is now available to all our members. The Foundation relies on dedicated volunteers to help raise funds in their community to benefit Foundation programs and services. The guide is an easy-to-follow manual on how to organize a community fundraiser and/or awareness event. It contains great information about how to contact your local media and essential steps in creating a successful event including: event ideas; a planning checklist; helpful hints; and sample copies of ichthyosis fact sheets, press releases, and formal and informal letters. The guide is free to anyone who requests it. Please call the office at 215-631-1411, or 1-800-545-3286, or email us at info@scalyskin.org to ask for your copy. Please be prepared to give us your mailing address.

Skin Care Products List

The Foundation's Skin Care Products List is an extensive list of lotions, creams, soaps, shampoos and other products that our members have recommended to us. We are in the process of expanding and updating the list to include new products and current information on old favorites. If you are using a product that you love, either over-the-counter or prescription, please share the name of the product with us. Call Maureen at 214-631-1411, or 1-800-545-3286, or email info@scalyskin.org.

Lamellar Ichthyosis and Congenital Ichthyosiform Erythroderma (non-bullous CIE)

(continued from page 1)

make sure that a fungal infection is not the cause of hair loss, because fungal infections can be treated by appropriate medications. The thickened scales in ichthyosis provide a hospitable environment for the growth of fungi that commonly infect people, such as the fungus that causes athlete's foot. Increased itching or a new rash can be a sign of a fungal infection. Bacterial skin infections can also be a problem, especially in infants. Most people with LI or CIE have some degree of reddened skin (erythroderma). Thickened skin on the palms of the hands and soles of the feet can be the cause of painful fissures. Decreased sweating is also common and is caused by scales blocking sweat ducts. Heat intolerance can be a serious problem for some individuals because of this. They may need to wear a cooling vest or frequently douse their skin with cool water during hot weather or strenuous exercise.

Lamellar Ichthyosis / Congenital Ichthyosiform Erythroderma (LI/CIE) is present at birth. Most individuals are born as "collodion babies," so called because they are covered with sheets of thickened skin that resemble a film of collodion. Sometimes described as having a shellacked appearance, these newborns have skin which is taut, dark and split. Often the eyelids and lips are forced open by the tightness of the skin, and there may be contractures around the fingers. The collodion membrane is then shed within a few days to a few weeks. Problems with temperature regulation, high blood sodium levels, water loss, secondary infections, and systemic infection can occur in the newborn with LI/CIE.

LI/CIE can be treated topically with skin barrier repair formulas containing ceramides or cholesterol, and/or moisturizers containing petrolatum or lanolin, and/or mild keratolytics (products containing alpha-hydroxy acids). Severe LI/CIE may be treated systemically with oral synthetic retinoids (Accutane®, Soriatane®). Retinoids are only recommended for more severe cases of LI/CIE, due to risks of bone toxicity and other complications. Females of childbearing age must be aware that oral retinoids cause serious birth defects; they should only be used in this setting in conjunction with extremely effective birth control measures. People with severe forms of LI/CIE can experience numerous social and psychological repercussions. They and their families may need a significant amount of support in dealing with these issues. *

Help Us Help You!

Membership Profile Online Survey

The Foundation wants to hear from you. Input from our membership is crucial to help strengthen and improve our programs and services. The Foundation has made it easy for you to share your thoughts with us. In combination with Zoomerang.com, we have developed a quick and simple online survey for our members. Go to the home page of the Foundation's website, www.scalyskin.org and click on Ichthyosis Survey. Or go to <http://www.zoomerang.com/survey.zgi?04231H702QE8HFXKXXGL2K2K> to access the survey. The survey will take only a few minutes of your time. The information gathered will help us better understand our membership and shape the future direction of the Foundation. Please note, your responses will be kept completely confidential. If you have any questions or comments, please be sure to let us know.



New Emollient for F.I.R.S.T. Members (30% Urea + 10% lactic Acid)

MONEY BACK GUARANTEE

Hundreds of F.I.R.S.T. members use our odor free, non-greasy 10% urea + 10% lactic acid lotion to improve skin & scalp instead of prescription products.

\$15.99 for a 16-oz bottle

Now try our more potent 30% urea + 10% lactic acid lotion
\$12.99 for a 4-oz bottle



To order: (800) 668-8000 • www.dermaltherapy.com

Foundation and Friends Honored with Gold Triangle Award

The Foundation for Ichthyosis & Related Skin Types and Foundation members Heather and Caitie Gattuccio were recently honored with the American Academy of Dermatology's Gold Triangle Award, which acknowledges achievement in raising awareness of dermatology. The awards were presented on Saturday, July 26, 2003, at the Academy's summer meeting in Chicago, IL.

Jean Pickford, Executive Director, accepted the prestigious Gold Triangle Awards, which saluted winners in media, industry, health community, public service, and individual effort for excellence in promoting dermatology awareness and encouraging healthy behavior in the care of skin, hair, and nails. The Foundation was honored for its website, www.scalyskin.org, which serves as the source for concise, accurate, and user-friendly information about the ichthyoses for the general public. The Gattuccios were honored for their National Public



Executive Director Jean Pickford accepts the Gold Triangle Award for the Foundation.

Radio address entitled, "Caitie's Story," which poignantly depicts the life of Caitie Gattuccio, a young girl affected with lamellar ichthyosis.

"This year's Gold Triangle Award winners are to be commended for their efforts in increasing

awareness of dermatology and greatly impacting the lives of people throughout the country who are affected physically, emotionally, and financially by these conditions," said dermatologist Raymond L. Cornelison, Jr., MD, President of the American Academy of Dermatology and host of the 2003 Gold Triangle Awards.

The American Academy of Dermatology, founded in 1938, is the largest, most influential, and most representative of all dermatologic associations. With a membership of over 14,000 dermatologists worldwide, the Academy is committed to: advancing the diagnosis and medical, surgical, and cosmetic treatment of the skin, hair and nails; advocating high standards in clinical practice, education, and research in dermatology; and supporting and enhancing patient care for a lifetime of healthier skin. *

Camp Discovery Celebrates 10 Years!

The American Academy of Dermatology's Camp Discovery Program celebrates its 10th anniversary this year. Since its inception, the program has made a huge impact in the lives of many kids with skin conditions. In fact, many of the campers report that they look forward to returning to camp year after year. Some have attended the kids' camp, moved on to the Teen Camp, and have even returned to help younger children by serving as junior counselors.

Camper Sarah Harris, 15, has atopic dermatitis and has been attending Camp Discovery for the past five years after being referred by dermatologist Clay J. Cockerell, MD. She said that the camp is pretty typical of summer camps happening all across the United States every year. "It's like any other camp you go to. Everybody does things as far as their comfort level goes. There is horseback riding, tubing, swimming, arts and crafts, archery - the whole camp experience," she said.

What makes this camp different is that all of the campers have some kind of skin condition. The camp provides them with a normal, fun summer experience under the supervision of dermatologists who can, if necessary, attend to their medical needs. "The doctors tag along and when somebody

gets hurt they are there with bandages to wrap it up," said Justin Aquilar. Justin, 15, has also been attending Camp Discovery for the past 5 years. He has epidermolysis bullosa and was referred to camp by Gary A. Bellus, MD.

Because all of the kids share the experience of having a skin condition, they say it creates a trusting atmosphere. "It is the only place that I can feel that nobody judges me for my skin," said Justin. Sarah agreed saying, "The environment is really accepting, and it is the one week where you are not defined by your skin disorder... it's tons of fun, too."

Both Justin and Sarah said that the feeling of acceptance that they experienced at Camp Discovery carries over to their everyday life. Part of this is the lasting friendships that the kids form with their peers. Sarah said that the campers try to help each other out - but never in a way that makes one kid feel less able than the next. "There is a definite system of helping each other, but it is subtle. It is all done with an incredible understanding," she said. Justin said that he has made "a whole bunch of new friends" at camp and he stays in touch with them via letters and e-mail throughout the year. Sarah added that she has "learned how to be non-judgmental

and empathetic" from the ongoing friendships she has made at the camp.

Both Justin and Sarah said that there are many memories of the camp that really stand out for them. For Justin, one thing that he particularly enjoyed was a nighttime boat ride that the campers took around the chain of lakes in Minnesota where Camp Knutson, one of the Camp Discovery branches, is located. "It was on Carnival Night and it was a historical tour about the lake where the camp is located," he recalled.

Sarah said she brought back a great memory from this year's camp when two of the counselors bought a birthday cake for Rachel, another camper. Sarah and her friends all helped Rachel celebrate. "We spent the majority of the night eating, having burping contests, and turning our cabin into a 'mosh pit.' It was absolutely crazy but really fun and hilarious," she said.

For more information about the Camp Discovery program or how to volunteer, contact the American Academy of Dermatology at www.aad.org or 847-330-0230.

Reprinted from Dermatology World, September 2003. *

Camp Horizon 2003

By Maureen Tierney, Program Director

Executive Director Jean Pickford and I spent a wonderful day volunteering at Camp Horizon again this year. Our early morning departure brought us to camp mid-morning, where we immediately went to work at the arts and crafts pavilion. Projects for the day included printmaking, crazy hats, tie-dyeing t-shirts, and craft foam picture frames. Campers rotated through activities at one-hour intervals, so everyone got to try a little bit of everything. Printmaking seemed to be the most popular activity, with some real artistic talent being showcased as the prints were pulled and set to dry. Tie-dyed t-shirts and colorful foam picture frames added splashes of color to the pavilion, already bright with an overwhelming array of craft and art supplies. We met a number of campers with ichthyosis, as well as those affected by a variety of different skin diseases, such as Alopecia Areata, Ectodermal Dysplasia, Epidermolysis Bullosa, Mycosis Fungoides, Psoriasis, and Vitiligo.



1



2



4



3

days, campers are free to be whoever they want to be without the baggage of being "different" from everyone else.

The sultry August weather took a little breather that day, so the morning passed quickly and fairly comfortably. The lunch bell signaled us to clean up and head for the dining hall.

for dinner when we saw the "pie ladies" arrive. Women from local church groups bring homemade desserts to the campers and staff one night out of the week.

Following daily announcements, counselors headed out of camp for a well-deserved afternoon off, while volunteers helped campers get to their afternoon activities. Jean and I took a few minutes after lunch to meet with the ichthyosis group. Speaking with campers, counselors, and volunteers helps us to understand their personal experiences with ichthyosis. We then headed back to the crafts pavilion to help with hair wrapping, lanyards, and hemp bracelets and necklaces; in another year we'll be experienced camp crafters. Campers could also take a dance class, make ice cream,

fish, swim, take a hay ride, or (the most popular activity) ride a "hog." Members of a local Harley Davidson club come to camp every year and spend an afternoon taking campers for motorcycle rides. I saw more than one camper pass by on these big noisy machines, enjoying every minute of it.

Camp Horizon is a weeklong, overnight camp for children with skin diseases. As part of the American Academy of Dermatology's Camp Discovery program, Camp Horizon is completely funded by the Academy. Camp Director Howard Pride, MD (a dermatologist at Geisinger Medical Center), Howard's wife, Kathy, and countless volunteers provide a full camp experience for kids ages eight to twelve. Campers enjoy all the traditional camp activities, like archery, crafts, games and competitions, swimming, fishing, and a rockclimbing wall. They do all this in the company of skilled medical professionals, volunteer counselors who have the same diseases, and other campers who look and feel just like they do. For seven

- 1: Camp Director Howard Pride, MD, is everyone's favorite climbing tower in the pool.
- 2: Autumn Sproull tries her hand at making ice cream.
- 3: Kayleigh Fasanella is ready to ride and rumble.
- 4: Hunter Steinitz is excited about a letter from home.

Wednesday is pizza day with plain, pepperoni, and veggie choices. Tossed salad, drinks, and pudding rounded out lunch. Howard Pride and his staff have this portion of the day running like a well-oiled machine. Tables were set, campers settled, food passed, drinks poured, and clean up accomplished in record time, considering there are over one hundred people participating in meals. We almost considered staying

The afternoon passed quickly and pleasantly, occasionally punctuated by the roar of Harley engines and shouts of kids from the pool. The walk I took around camp to take pictures showcased exactly what the Camp Discovery program is about, kids relaxing with their friends and enjoying a great carefree summer afternoon in a wonderful setting where their skin disease doesn't matter.



A Team Effort: Raising Ichthyosis Research Dollars

By Jean Pickford, Executive Director

During the past four years, I have spoken with many, many individuals or family members affected by one form of ichthyosis or another. Whether it is CIE, Darier's, EHK, Ichthyosis Vulgaris, or one of the many other forms, the personal stories always have common similarities. Effective treatments, genetic implications, social issues, and finding knowledgeable doctors are among the most common concerns. By far, the single most-asked question is, "What is going on in research?"

Supporting and increasing ichthyosis-related research is fundamental to the Foundation's mission. Our primary goal for the next five years is to raise significant funds to support ichthyosis-related research. (Please see page 11 for the Foundation's Research Case Statement.) In combination with researchers, dermatologists, corporate partners, Foundation staff, and the ichthyosis community, we can raise the money to make a difference. It will take great teamwork to reach our goal. I am officially recruiting you to join our team to make that important difference!

Here's how you can help. If you are like me, your life is filled with so many responsibilities that it seems impossible to add another job to your long list. But in the back of your mind, you have always wanted to do something to help find a cure for ichthyosis. Well, here is that opportunity. It doesn't take a lot of time, it is very inexpensive, and it can have a huge impact for future generations. I call it the "Personal Letter Writing" Campaign.

A few months ago, I personally contacted several members of the Foundation to enlist their support to test this fund raising program. I was stunned at the positive response! I am proud to say that these 13 volunteers raised \$8600 in just a few months. Now, I know it can work, and I know it can work very well. I have personally recognized these volunteers, who have generously participated in the

trial phase of this fund raising campaign, in my report on page 8.

There are many benefits in making the effort to write these letters:

1. It's relatively simple and a low-cost way to raise money.
2. Writing personal letters provides you with the means to reconnect with family and friends. Writing to them will allow you to explain clearly the impact of this disease on your family and will lessen any confusion or misunderstanding on their part.
3. People will want to help.

Make a list of at least 25 people. This list should include your relatives and a close circle of friends (and the closest friends of your parents and in-laws). Start your letter with a personal statement. A plea for help or a description of the affected individual's situation is a great way to begin. Then, briefly describe what ichthyosis is and how their donation can make a difference. Be creative in telling your story. Let everyone know his or her entire donation will be restricted specifically for research. Send the letter to your

list, making sure to include a self-addressed, return envelope so the donor can easily send a donation back to you. Here are some helpful hints to ensure a successful mailing:

- Statistics show that the week prior to Thanksgiving is a good time to request donations.
- Include a photo of the family member affected with ichthyosis. Be sure to attach a sticker on the outside envelope that says "Fragile," which will bring attention to your letter.
- Include a brochure in your mailing. Our office will provide a batch of brochures for your letters.
- When purchasing postage, ask for stamps with themes of love.
- Have all donors make their checks payable to the "Foundation for Ichthyosis." Send the checks back to the office within two weeks of receiving them so all donors will receive a "thank you" letter from the office in a timely manner. The thank you letter will also serve as documentation needed for charitable deductions on their federal income taxes. *

How to Turn \$15 into \$500

<i>Mailing List</i>	<i>Expenses</i>
10 relatives (siblings, cousins, parents, uncles, aunts, etc.)	Stationary- envelopes = \$5.00
10 friends, co-workers, neighbors, etc.	Postage: 25 letters x \$.37 = \$9.25
5 friends of your parents, in-laws, uncles, cousins, etc.	
25 - Total number of letters sent	Total Expenses - \$14.25

An average donation of \$20 per letter will result in \$500.00

Executive Director's Report



October 2, 2003

Dear Members and Friends of the Foundation:

As I write this report, our office is gearing up for Ichthyosis Awareness Week (IAW), which begins in 3 days! This week is always an exciting time for our staff and members, but this year is especially exciting. So many great things are happening for IAW. First, 110 members responded to my request of distributing brochures to their doctors and local communities during this special week. Second, a press release was mailed, faxed, and emailed to 70 major newspapers in the US. Third, two pharmaceutical companies, NeoStrata and Bradley Pharmaceutical, posted press releases announcing IAW on the national newswire. And finally, our new brochure for physicians, sponsored by Doak Dermatologics, is being mailed to each non-cosmetic practicing dermatologist in the country (see page 3) to coincide with the celebration of IAW.

I am proud to announce that the Foundation's support of ichthyosis-related research for the upcoming year is \$40,000. Once again, we will be funding this research through the Dermatology Foundation's grant award program. It is anticipated that several meritorious grant applications will be submitted for consideration.

Speaking of funding research, there is even more exciting news to report! Our 2003 Research Campaign is in full force. The Foundation set a goal to raise \$100,000 for research by the end of this year. This goal was a stretch, but isn't that what goals are for? Through the efforts of many dedicated supporters, the Foundation has raised close to \$70,000 so far. These funds are a combination of donations from a few pharmaceutical companies, a bequest, and donations from the Foundation's members and friends.

For several years now, members of our Board of Directors have participated in a personal letter-writing campaign to raise funds for the Foundation. A few months ago, I branched out to enlist the support of 13 members of the Foundation to write letters to their friends and family asking for research donations. It was a tremendous success, raising close to \$10,000 for research. I want to publicly acknowledge their willingness to help with this program. A big thank you goes out to Anita Adams, Les Avakian, Jennetta Barrow, Marcy Blanton, Denise Benedetto, Lori Florian, Terri Hamrick-Oeschger, Darrin Height, Ken Krips, Ann Pokalsky, Stephanie Sawyer-Ames, Maria Tessinari, and Melissa Tierney-Osterloth.

Many other great things are happening at the Foundation. We are currently working on updating our Skin Care Products List. This extensive list of over-the-counter and prescription lotions, creams, soaps, and shampoos is exclusively for members of the Foundation.

The response to our summer appeal mailing has been successful. To date, the appeal has raised 57% over our projected goal. The desire of our membership to support the Foundation's programs and services is overwhelming and gratefully appreciated.

Several applications have been received for the sixth cycle of funding from the Jane Bukaty Membership Assistance Fund. This fund is made available to members to provide financial help with the purchase of products or treatments for ichthyosis. Thanks to an anonymous donor, this fund has provided small grants to 17 individuals since its inception in 1999.

On November 14 - 16, our Board of Directors will meet for its bi-annual Board Retreat. During the weekend retreat, the Board will discuss many important issues that will shape the future direction of the organization. Board members will travel from many different parts of the country to meet face-to-face in Philadelphia. It is a wonderful opportunity to reinforce the goals and mission of the Foundation.

I hope everyone has enjoyed a long and relaxing summer, and I look forward to your continued support this fall.

Sincerely yours,

A handwritten signature in cursive script that reads "Jean".

Jean R. Pickford
Executive Director

In general, the goal in taking care of ichthyosis is to hydrate (moisturize) the skin, hold in the moisture, and keep scale thickness to a minimum.

**Foundation for Ichthyosis & Related Skin Types, <http://www.scalyskin.org>*



Aquaphor® Healing Ointment helps heal dry skin associated with ichthyosis. Its unique petrolatum-based formulation combines a moist environment with the benefits of a semi-occlusive barrier that allows skin to breathe and absorb fluids.

Aquaphor is ideal for daily use because it is hypoallergenic, non-comedogenic, fragrance and preservative-free. Aquaphor Healing Ointment is safe enough for even the most sensitive skin.

*Special Offer
For Readers of this F.I.R.S.T. Newsletter*

MANUFACTURER'S COUPON EXPIRES 06/30/2005

**Save \$2.00
on any
Aquaphor®
Product**

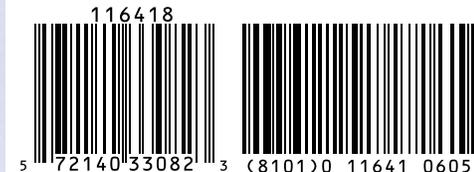
(NO TRIAL SIZES)

© 2003 Beiersdorf Inc



Consumer: Coupon good on the purchase of any Aquaphor® product, no trial sizes. Limit one coupon per item purchased. Any other use constitutes fraud. Not good with any other special offer. Consumer must pay sales tax.

Retailer: You are authorized to act as our agent to redeem this coupon and we shall reimburse you at face value plus 8¢ handling in accordance with our redemption policy. Copies available upon request. Offer void if copied and where prohibited, taxed or otherwise restricted. Cash value 1/100¢. Mail to: Beiersdorf Inc, PO Box 880504, El Paso, TX 88588-0504. Good only in USA.



Conference Chatter

2004 National Family Conference: *A Fountain of Knowledge*

July 2 – 4, 2004

The Westin Crown Center, Kansas City, Missouri

The Foundation's 13th bi-annual national family conference is less than 10 months away. Start planning now to attend this educational and rewarding event. The family conference always is an exciting, fun-filled experience for the entire family.

Official registration will begin on January 2, 2004. The conference registration form will be included in the Winter 2004 issue of this newsletter. The registration form will also be available online at www.scalyskin.org on January 2, 2004.

Here's some exciting information about the 2004 Family Conference, *A Fountain of Knowledge*:

Clinical Screening - For the third consecutive conference, the Foundation will be hosting a clinical screening at the conference. The clinical screening is designed for patients with ichthyosis to be examined by experienced, knowledgeable dermatologists at no charge. These dermatologists volunteer their time to attend the conference and are happy to meet with individuals and families to discuss their type of ichthyosis and answer any questions. Clinical screening appointments will be scheduled prior to the conference. If you are interested in scheduling an appointment, be sure to check the appropriate box on the registration form. The Foundation's staff will pre-schedule all appointments and inform the patient prior to the conference.

Conference Program - The conference program will feature four tracks of programs to accommodate each age group. Track 1 is for adults, ages 18 and over; track 2 is for teenagers, ages 13-18; track 3 is for pre-teens, ages 9-12; and track 4 is for children, ages 1-8. Age

appropriate material will be included in each track. There will be a strict policy that no changes or exceptions will be made to any age group.

The conference will begin on Friday, July 2 at 2:00 pm CST. The program will consist of general and breakout sessions throughout the weekend. Friday evening, July 2, will feature free time for each family. There will be a complimentary shuttle bus available to transport guests to the famed Country Club Plaza in downtown Kansas City,

filled with shops and restaurants. Saturday evening will feature more social time and a group dinner in the hotel, along with entertainment for the entire family. The conference will end just prior to lunch on Sunday, July 4.

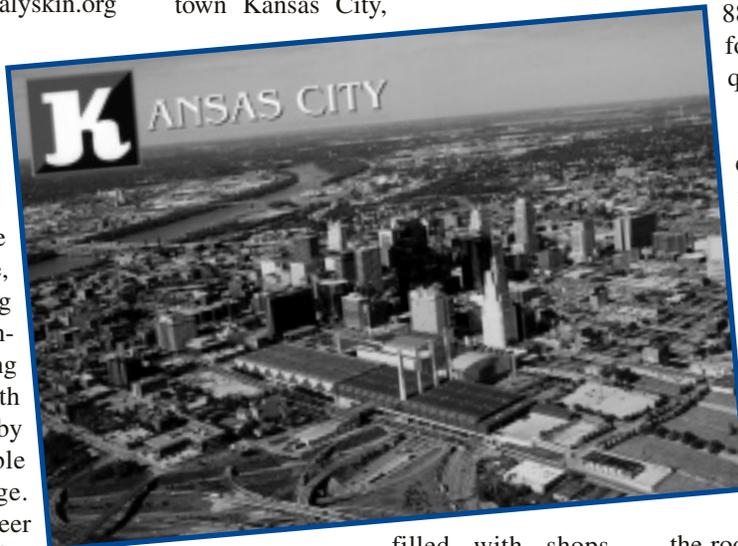
Travel to Kansas City, MO - The Foundation will be contracting with several major airlines offering discounted tickets to the 2004 National Family Conference. The special discount programs will be published in the Winter 2004 newsletter.

Air transportation assistance to the 2004 Family Conference may be available through Mercy Medical Airlift. Mercy Medical Airlift works with Angel Flight America to provide charitable air transportation for patients and patient

families traveling for treatment. Though commercial airlines provide no assistance for conferences, Angel Flight America does. They are a group of volunteer pilots who utilize their own aircrafts to transport patients to important medical meetings. If you live within 1000 nautical miles (approximately 1,200 to 1,300 driving miles) of Kansas City, MO, you may be eligible for free air transportation with Angel Flight. If you are interested, please contact the National Patient Travel Center at 888.675.1405 to obtain a "Request for Transport" Form or answer any questions.

Accommodations - All conference attendees will make their own room reservations at the Westin Crown Center. Westin's discounted room rate is \$89.00 per room, per night, flat occupancy + applicable taxes. Simply call 888-627-8538 to reserve your room at the Westin Crown Center. The Reservations Center is open 24 hours a day. Be sure to name the "Foundation for Ichthyosis" to receive the discounted rate in the room block. If you are interested in extending your stay in Kansas City, this rate is available from June 28 through July 7, 2004. However, you must make your reservation by June 4, 2004 to guarantee this discounted rate. After June 4, 2004, the rooms will be available on a first-come, first-served basis.

Volunteers - Volunteers are needed to help the Foundation's staff. Responsibilities will range from stuffing gift bags, to helping with registration, to selling raffle tickets, to any other job that may come up. If you are interested in volunteering some time, please email Jean or Maureen at info@scalyskin.org or call the office at 800-545-3286.



Foundation for Ichthyosis & Related Skin Types, Inc.



Case Statement: Research Campaign

The Foundation for Ichthyosis & Related Skin Types is a 501(c)(3) non-profit organization that supports research into causes, treatments, and cures for the more than 25 forms of ichthyosis and related skin conditions. Because the ichthyoses are rare diseases, there is only sparse interest among the general public and medical researchers in finding ways to prevent, care, and cure for these conditions.

Over the past 15 years, promising research has revealed new, valuable, and groundbreaking information about ichthyosis and related skin types. For example, over 25 individual genes that cause ichthyosis or related skin diseases have been identified in the past 10 years. This research, frequently undertaken with small amounts of support and/or funding from the Foundation, was a major beneficiary of the well-funded, widely supported, international effort known as the human genome project.

The next great challenge is to translate the newly acquired understanding of the genetic causes of ichthyosis into better treatment. There will not be a centralized effort to accomplish this important goal, which was an implied promise of the human genome project. Therefore, it is imperative that The Foundation takes the challenge to stimulate more ichthyosis-related research.

To further these efforts, the Foundation has created a research fund and a goal of raising \$100,000 annually for the next five years. Small nonprofit organizations can achieve breakthrough results through the judicious targeting of research funds. Our goal is to stimulate new and promising areas of investigation and to inspire greater interest from leading investigators and their students.

The Board of Directors of the Foundation for Ichthyosis & Related Skin Types, in conjunction with the Foundation's Medical Advisory Board and a team of leading dermatologists, researchers, and geneticists, will analyze research options to determine the most beneficial and meritorious program(s) to benefit people affected with ichthyosis. The Foundation invites you to be part of this important effort.

The National Ichthyosis Registry

A Definitive Diagnosis Focuses Treatment

The Foundation staff hear from people every day who are living with ichthyosis but do not know what form of ichthyosis they have. While many forms of ichthyosis have similar symptoms and challenges, each form requires different treatment options in order to achieve improvement. And each form has different genetic implications.

The National Registry for Ichthyosis and Related Disorders can help you determine what form of ichthyosis you, or your child, have, if you do not yet know. The Registry can confirm or clarify your diagnosis and offer genetic testing and counseling. Genetic testing does not seem important to some people, but knowing what genetic mutation you carry can help your physician focus on effective treatment options and can inform future generations of your family about the disease, and its potential to

affect them. (See page 12 for more about genetic counseling.) The Registry also works to educate the medical and research communities about ichthyosis and how it affects individuals with the disease. The Registry also provides valuable information to researchers interested in investigating ichthyosis.

Please consider joining the National Registry for Ichthyosis to clarify or confirm your diagnosis and receive complete information about the disease that affects you and your family. To contact the Registry, call 1-800-595-1265, or email info@skinregistry.org, or visit their website at www.skinregistry.org. The Registry is located in Seattle, Washington, and is on Pacific Time.

Note from the Registry: The Registry does not enroll individuals with ichthyosis

vulgaris. Ichthyosis vulgaris is the most common form of ichthyosis (estimated incidence between 1 in 250 and 1 in 5,300) and is the most difficult to identify. (The genetic defect for vulgaris has not yet been identified.) Because the Registry requires specific criteria for diagnosis, ichthyosis vulgaris is excluded because of the potential for being overwhelmed by people whose diagnosis could not be confirmed.

National Registry for Ichthyosis
and Related Disorders

800-595-1265

Email info@skinregistry.org
www.skinregistry.org

What's New, What's Hot & What Works

Dear Maureen:

I have a cream on the market, RegenaSkin, which would be a wonderful addition to your skin care products list. It was originally designed for my ichthyosis, but it is now used by dermatologists, oncologists, and plastic surgeons to treat people suffering from severe dry skin caused by diabetes, chemotherapy, radiation, aging skin, surgery, scarring, eczema, medications, hepatitis C, lymphedema, and outdoor elements. As rewarding as it has been to have these professionals using the cream, I am thrilled to have RegenaSkin to offer to the ichthyosis community because I know personally the relief and healing that it can bring. Thank you for all that you do! Please feel free to call or check out the website.

Kimberly Bearden
President of RegenaSkin, Inc.
Fort Collins, CO
RegenaSkin@frii.com
www.regenaskin.com

Dear F.I.R.S.T.:

We gave our daughter a tube of "Lay It On Thick" from Bath and Body Works for Christmas this year. It contains an ingredient called shea butter. Katie, who has ichthyosis vulgaris, swears by the stuff! She uses it every morning and evening, and her skin is markedly improved. Even in the extreme cold, or just before another application, it is smooth to the touch. I have never seen her so happy about a product. Many other things we tried work for a week or two, then do no good. This is still performing beyond our hopes!

We wanted to pass on the word.

Cris Hedgepath
Omaha, NE

Editor's Note: "Lay It On Thick" comes in a 6 oz. container and sells for \$15.00 at Bath and Body Works stores. Call Customer Service at 1-800-395-1001 for a store near you.

Dear F.I.R.S.T

I found a really nice lotion called Ecco Bella. The best part is that it's all natural! I used vanilla, which is great smelling, and the unscented. I prefer it because it is for my five year-old son who has EHK. It works really well on the skin, just as good as the expensive kind you find in the stores. I really like Ecco Bella because it's not only all natural, but it works so nicely on the skin too. They also make a hair and scalp treatment with jojoba, omega-3 and neem. I've used that too, with good results. Check it out at www.eccobella.com, and service@eccobella.com.

Michelle McHale
Uniondale, PA

Editor's Note: Ecco Bella can also be reached by calling 1-877-696-2220, M - F, 9 - 5 p.m., EST. International inquiries please contact service@eccobella.com.

Genetic Counseling

By Marsha Lanes, MS

The American Society of Human Genetics adopted the following definition of genetic counseling in 1975: Genetic counseling is a communication process which deals with the human problems associated with the occurrence, or the risk of an occurrence, of a genetic disorder in the family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to (1) comprehend the medical facts, including the diagnosis, probable course of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the alternatives for dealing with the risk of recurrence; (4) choose the course of action which seems to be appropriate in view of their risk, their family goals, and their ethical and religious standards, and act in accordance with that decision; and (5) make the best possible adjustment to the disorder in an affected family member and/or the risk of recurrence of that disorder.

Genetic counselors are health professionals with specialized graduate degrees in medical genetics and counseling. They work as members of a health care team including physician geneticists and genetic nurses to provide information to individuals and families who are concerned about a birth defect or genetic condition in themselves or another family member. Patients may be seen independently by a genetic counselor or genetic nurse, but those who are seeking a diagnosis must also be evaluated by a medical geneticist.

A genetic consultation is a valuable first step in providing care for individuals with genetic disorders or undiagnosed conditions because a wide range of conditions can be evaluated. A genetic counselor will ask many questions about family and medical history in parents, siblings, aunts, uncles, cousins and grandparents. Birth dates, ages of death and medical conditions in relatives will be noted and medical records may be requested to document that medical information is accurate. A physical exam-

ination may be performed and medical tests may be offered to clarify or confirm a diagnosis. Multiple sessions are sometimes necessary to allow time to collect information and to receive and interpret test results. Following the collection of all available records and results, it is often possible for the genetics team to establish a diagnosis and rule out multiple diagnoses.

The content of a genetic counseling session is guided by the concerns of the affected individual or family. It is important for a genetic counselor to determine at the beginning of the session what they have been hoping to gain from the meeting and what knowledge they already have. A genetic counselor will encourage them to

A genetic consultation is a valuable first step in providing care for individuals with genetic disorders or undiagnosed conditions because a wide range of conditions can be evaluated.

speaking freely about their reaction to new information presented in the session, and to discuss how they have been coping so far and their needs and options for the future. A genetic counselor can often anticipate questions and will be prepared to interpret medical information and provide support.

Genetic tests may be offered during a genetic counseling session, but a genetic consultation can be beneficial even if testing for the condition is not available. Some genetic conditions are diagnosed based on physical findings alone or in combination with medical tests such as X-rays or skin biopsy. Once a diagnosis has been established, the genetic counselor can explain the expected course of the disease, possible treatments or interventions, risk to family members, and reproductive options, if appropriate.

Genetic counselors do not tell people what course of action to take in any particular situation. Options are presented in an unbiased manner, and the counselor will assist the individual or family in reaching decisions that are consistent with their values and goals for the future. A genetic counselor will support those being counseled in their decisions and provide additional resources for follow-up care and emotional support.

The National Society of Genetic Counselors (NSGC) is the professional organization of genetic counselors whose mission is to promote the genetic counseling profession as a recognized and integral part of health care delivery, education, research and public policy. The NSGC web site (<http://www.nsgc.org>) provides an extensive resource link to genetic counselors in the U.S. and around the world, as well as press releases, position statements, and career information. Approximately 2000 genetic counselors are members of the NSGC, and thirty-three training programs offer master's degrees in genetic counseling in the U.S., Canada, Australia, England and South Africa.

Reprinted from Orphan Disease Update, Spring 2003, Volume XXI, Edition 2. Orphan Disease Update is a publication of the National Organization for Rare Disorders (NORD). Marsha Lanes is a genetic counselor on the NORD staff. ❀

News & Notes

Internet Purchases of Isotretinoin Risky

The American Academy of Dermatology Association (AADA) strongly opposes Internet dispensing of isotretinoin (Accutane®). This means of obtaining the drug may not provide for sufficient patient education about isotretinoin's risks and may not include participation in the risk management program. People in the U.S. currently using Accutane® must participate in a manufacturer-sponsored, FDA-approved risk management program. Patients who purchase isotretinoin over the Internet bypass safeguards designed to protect their health, as well as precautions to prevent pregnancy. Taking even one pill of isotretinoin while pregnant can cause serious birth defects.

Moreover, the U.S. Food and Drug Administration cannot, at this time, safely guarantee the safety of drugs bought from Internet sellers, especially foreign Internet

sources. The safety of patients using these drugs is best served when they have their prescription, with the required qualification sticker attached to it, filled by a traditional pharmacist.

The AADA is compiling a list of Internet sources who are willing to profit from patients who use isotretinoin, while ignoring the rules in place for safeguarding their health. This list will be shared with the FDA, the U.S. Customs Service, isotretinoin manufacturers, and other consumer safety groups. AADA members and consumers can help by reporting any online sales of isotretinoin that come to their attention.

To report an Internet source for purchasing isotretinoin, contact Laura Saul Edwards in the AADA Washington office via email at ledwards@aad.org, or by phone at 202-842-3555. For consumer and prescriber information about isotretinoin, go to

www.fda.gov/cder/drug/infopage/accutane/default.htm.

Excerpted from Dermatology World, September 2003.

New Atopic Dermatitis Guideline of Care posted on AADA and AAD Websites

The American Academy of Dermatology Association's Board of Directors approved the Guideline of Care for Atopic Dermatitis at their meeting on July 26, 2003. This evidence-based guideline, which replaces the original consensus-style guideline on atopic dermatitis published in 1992, has been posted on the AADA website.

The new atopic dermatitis guideline includes prevention measures during pregnancy and after birth, topical therapies, antibiotics and antiseptics, oral antihistamines, dietary restrictions in established

Fight Scaly Skin with

Epilyt® Lotion Concentrate



- ◆ *Loosens and removes scales**
- ◆ *Softens and smooths rough, dry, scaly skin**
- ◆ *Non-greasy, clear, moisturizing lotion*
- ◆ *Controls severely dry skin*

Please bring this ad to your Pharmacist who will order Epilyt® (NDC 0145-0624-04), for you through one of the following Pharmaceutical wholesalers.

Distributor	Item Number
AmeriSource	3433877
Bergen Brunswick	520-601
Cardinal	1412212
McKesson	1102151

 **STIEFEL**®
Research in Dermatology

*Baden HP Management of Scaly Skin with Epilyt. *Seminars in Dermatology* 6:55-57, March 1987. Epilyt® Lotion and Stiefel® are registered trademarks of Stiefel Laboratories, Inc. ©Copyright 2002. Stiefel Laboratories, Inc.

Epilyt® is also available for purchase online at www.webderm.com

Please visit us at www.stiefel.com

News & Notes

atopic dermatitis, non-pharmacological interventions, systemic immunomodulatory agents, and complimentary/alternative therapies.

The new evidence-based guideline is currently awaiting publication in the Journal of the American Academy of Dermatology, but members can view it online at the AADA and AAD websites. To view the guidelines, go to www.aadassociation.org, or www.aad.org and click on "Guidelines of Care for Atopic Dermatitis."

Excerpted from Dermatology World, September 2003.

Medical Editor's Note:

People with Netherton Syndrome, Ichthyosis Vulgaris, and sometimes other forms of ichthyosis may experience atopic dermatitis. Atopic dermatitis is a chron-

ic inflammatory skin condition that is characterized by extreme itching, leading to scratching and rubbing that, in turn, creates the lesions of eczema.

Society for Investigative Dermatology Art Exhibit 2004

The Society for Investigative Dermatology (SID) is inviting individuals with skin diseases to submit original artwork, depicting the "Emotions of Disease," to the SID Art Exhibit 2004. The art will be exhibited at the SID meeting in April 2004, at the Biltmore Hotel in Providence, Rhode Island.

This exhibit offers individuals the opportunity to challenge dermatologists and skin disease researchers to look at disease in a different way. The artists are asked to express their disease in emotionally visu-

al terms, other than in the scientific terms that the dermatology research community is used to applying to skin disease.

The SID first sponsored a patient art exhibit at its International Investigative Dermatology meeting last April in Miami. Patients with a variety of skin disorders submitted drawings and paintings that expressed their intense, personal relationship with the disease. These images had a profound effect on their viewers. Many meeting attendees stated that the art had really moved them. These works served as a reminder that the pursuit of scientific discovery is meaningful when it serves to ease the burden of the disease.

Individuals wishing to submit artwork to this exhibit should follow the guidelines for submission detailed below.



Details for 2004 Exhibit Submissions

Exhibit Title:	tbd	Exhibit Theme:	tbd
Dates for Online Exhibit:	Beginning April 28, 2004 - open ended.	Venue:	The Biltmore Hotel; Providence, Rhode Island
Sponsored by:	The Society for Investigative Dermatology	Qualifications:	Anyone may participate, as an individual or as a representative of a group.
Specifications:	Computer graphics, visual art, illustrations, essays, comic strip shorts, drawings, woodblock prints, paintings, poster art, postcard art, and photography.	Required Information:	Title of submission; name(s) of artist; gender; age; address; telephone number; title of each work submitted; brief artist statement about disease
Delivery Methods:	Physical artwork or JPEG and GIF images on MO floppy disk or CD-ROM may be sent to: Society for Investigative Dermatology, 820 West Superior, Seventh Floor, Cleveland, Ohio 44113; Attn: Becky Minnillo-Art Exhibit JPEG and GIF images may also be sent as attachment(s) via virus-free e-mail to: minnillo@sidnet.org	Dimensions / Byte Size of Artwork:	Canvas or paper not to exceed 24" x 36". Essay or poem via e-mail or floppy disk. JPEG or GIF images saved on floppy disk (send by mail to above address) · JPEG or GIF images (no larger than 500k each), as attachment(s) via e-mail to: minnillo@sidnet.org
Closing Date for Submissions:	Submissions must be received no later than April 3, 2004.	[REMEMBER TO SUBMIT YOUR NAME AND TITLE FOR EACH ITEM]	

Notice: Submissions will be returned and insured for up to \$200.00; artists wishing to display works on the website must sign waiver. Works for display will be chosen by a selection committee; all works may not be displayed because of space/cost limitations and/or inappropriateness as deemed by the selection committee.

The First and Only Generic to Lac-Hydrin® 12% Lotion

12%
LAClotion™
(AMMONIUM LACTATE)
LOTION



LAClotion™ 12% (ammonium lactate) Lotion

Rx only
For topical use only. Not for ophthalmic use.

Indications and Usage
LAClotion is indicated for the treatment of dry, scaly skin (xerosis) and ichthyosis vulgaris and for temporary relief of itching associated with these conditions.

Contraindications
Known hypersensitivity to any of the label ingredients.

Precautions
General: For external use only. Avoid contact with eyes, lips or mucous membranes. Caution is advised when used on the face of fair-skinned individuals since irritation may occur. A mild, transient stinging may occur on application to abraded or inflamed areas or in individuals with sensitive skin.

Carcinogenesis, Mutagenesis, Impairment of Fertility
Ammonium lactate was non-mutagenic in the Ames/Salmonella/Microsome Plate Assay. Reproductive studies in rats given lactic acid orally showed no effect on the sex ratio of the offspring.⁵

Pregnancy
Teratogenic Effects. Pregnancy Category C:
Animal reproduction studies have not been conducted with LAClotion. It is also not known whether LAClotion can cause fetal harm when administered to a pregnant woman or can affect reproduction capacity. LAClotion should be given to a pregnant woman only if clearly needed.

Nursing Mothers
Although lactic acid is a normal constituent of blood and tissues, it is not known to what extent this drug affects normal lactic acid levels in human milk. Because many drugs are excreted in human milk, caution should be exercised when LAClotion is administered to a nursing woman.

Pediatric Use
Safety and effectiveness of ammonium lactate have been demonstrated in infants and children. No unusual toxic effects were reported.

Adverse Reactions
The most frequent adverse experiences in patients with xerosis are

transient stinging (1 in 30 patients), burning (1 in 30 patients), erythema (1 in 50 patients) and peeling (1 in 60 patients). Other adverse reactions which occur less frequently are irritation, eczema, petechiae, dryness and hyperpigmentation. Due to the more severe initial skin conditions associated with ichthyosis, there was a higher incidence of transient stinging, burning and erythema (each occurring in 1 in 10 patients).

Overdosage
The oral administration of ammonium lactate to rats and mice showed this drug to be practically non-toxic (LD₅₀ > 15 mL/kg).

Dosage and Administration
Shake well. Apply to the affected areas and rub in thoroughly. Use twice daily or as directed by a physician.

How Supplied
225 g (NDC 0574-2021-08) plastic bottle and
400 g (NDC 0574-2021-16) plastic bottle.

- References**
- Blank IH: Further observation on factors which influence the water content of the stratum corneum. *J Invest Dermatol* 21: 259-271, 1953.
 - Blank IH: Factors which influence the water content of the stratum corneum. *J Invest Dermatol* 18: 433-440, 1952.
 - Middleton JD: Sodium lactate as a moisturizer. *Cosmetics and Toiletries* 93: 85-86, 1978.
 - VanScott EJ and Yu RJ: Modulations of keratinization with α -hydroxy acids and related compounds. In: *Recent Advances in Dermatopharmacology*, P. Frost, E.E. Gomez and N. Zaias (eds) Spectrum Publications, Inc. NY, 211-217, 1977.
 - D'Amour FE: Effects of feeding sodium bicarbonate or lactic acid upon the sex ratio in rats. *Science* 79: 61-62, 1934.

Paddock Laboratories, Inc. Minneapolis, MN 55427
For complete product information, call 800-328-5113
or log on to www.laclotion.com

**Lac-Hydrin® is a registered trademark of Westwood-Squibb Pharmaceuticals, Inc.

2200234(06-01)-2021-06-0802

SMART ALTERNATIVES

Paddock
Laboratories, Inc.

Please help us to minimize our printing costs. Call us at 1-800-545-3286 if you do not wish to receive future issues of *Ichthyosis Focus*. Help F.I.R.S.T. reduce its postage costs – would you be willing to accept the *Focus Newsletter* via e-mail? Let us know.



F.I.R.S.T.
650 Cannon Ave.
Suite 17
Lansdale, PA 19446

PRSTD STD
U.S. POSTAGE
PAID
PERMIT #2
COLMAR, PA