F.I.R.S.T.
Foundation for Ichthyosis and Related Skin Types

ICHTHYOSIS FOCUS

Vol. 21, No. 4 A Quarterly Journal for Friends of F.I.R.S.T. Winter 2003

Smallpox Vaccination in Patients with Ichthyosis

By Leonard M. Milstone, MD

The goal of immunization programs is simple: to reduce the chance of serious illness or death in people who are at risk. Smallpox is a highly contagious disease that is usually transmitted by inhalation. Most people who contract smallpox will have a serious illness, but will recover without long-lasting effects. Up to 20-30% of those who get widespread blisters on their skin will die from the disease. There is no curative treatment for smallpox. There are few infectious diseases in which the risk of death is as great.

Smallpox is caused by the variola virus. Two closely related viruses, the cowpox virus and the vaccinia virus, cause localized blisters in people, calves, and other animals. More than 200 years ago, William Jenner recognized that people exposed to cowpox virus were protected against infection with variola. During much of the twentieth century, vaccinia virus was used to "vaccinate" people in order to protect them against variola (smallpox) and in 1980, the disease smallpox was declared eradicated from the world.

Vaccination involves scratching the skin, inoculating the vaccinia virus, and allowing it to produce a local infection. Long-lasting immunity to reinfection is the result of successful vaccination. Vaccination is very effective and, by comparison with smallpox, is safe. However, 1 in 1,000,000 individuals will die from their vaccination. Less severe complications, including widespread blisters may occur in as many as 1 in 50,000 vaccinated individuals. Making decisions about the relative risks and benefits from an immunization program is never easy. The seriousness of smallpox, balanced against the real risks from vaccinations, make this particularly true for programs designed to prevent epidemics of smallpox. Prevention programs rely on "herd immunity," meaning that epidemics are prevented when a very large fraction, but not necessarily all, of the people in a community are immunized. The smallpox program is made more complicated by the implied goal of preventing risk to individuals.

Not everyone shares equally the risks from vaccination or from smallpox. People whose immune systems do not function well comprise the majority of people who die from vaccination. People with some, but not all, skin diseases are at higher risk than most to develop widespread blisters. Unfortunately, there is little hard data that would allow us to quantify the increased risk or to identify all groups of patients that are at increased risk. The additional risk conferred by skin disease makes the current debate about reinstitution of vaccination programs of special interest to the ichthyosis community.

The risk of developing widespread disease after local infection with the vaccinia or herpes simplex viruses is definitely increased in individuals who have atopic dermatitis and Darier's Disease. It is less certain that the risk is increased in other skin diseases. However, it would not be surprising if individuals with some forms of ichthyosis were at greater risk. One might expect that individuals with Netherton Syndrome are at greater risk because of their poor skin barrier function and their atopic-like immune responses. Individuals with epidermolytic hyperkeratosis, whose skin blisters easily, might be expected to be more at risk from virus infections that cause blistering. Unfortunately, we cannot quantify the risks for individuals with Netherton Syndrome and EHK because they are such rare diseases. On the other hand, it is notable that there have not been reports of widespread, serious illness following vaccination in individuals with ichthyosis vulgaris or X-linked ichthyosis. Because these forms of ichthyosis are common, we can be cautiously optimistic that lack of reported problems probably means lack of increased risk. While reports of severe reaction to vaccination in individuals with inflammatory form of ichthyosis, such as lamellar ichthyosis/CIE or erythrokeratoderma variabilis, are extremely rare or absent, it may well be that most individuals with those problems were never vaccinated in the past because of their inflamed skin. When assessing risks, we should remember that individuals with greater risk from complications of vaccination are also likely to have a greater risk of having a severe case of smallpox.

Should individuals with ichthyosis get vaccinated? The answer depends on the type of ichthyosis and upon the perceived risk of getting smallpox. The risk of a smallpox epidemic in the general popula-

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Ichthyosis Focus

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

Correspondence Corner

Dear FIRST:

My name is Jennifer Cruz and I have CIE. For twenty-four years I have lived with the ups and downs of life and have always gotten through it okay. I am currently working full-time and love my job. But working with people who don't understand ichthyosis is very hard. All my life, I have never had real trouble explaining to people what I was born with, but sometimes it is hard to get people to accept you for who you really are.

There is a topic that really doesn't get mentioned that I feel might be good to discuss with others with ichthyosis. The subject is that of an odor that comes from the skin. Since there are so many layers of skin the skin can't breathe in the right manner, so it lets off a smell from the sweat trapped beneath the skin. I was wondering if there is anyone else who has this problem. It has been a small problem for me for twenty-four years. I do take great care of my skin and use the best products I can find. My skin is very clear and it really doesn't peel.

Thanks for the help,

Jennifer Cruz
714-448-8797
California

Hi Maureen:

Thanks for calling me back so quickly today. I enjoyed talking to you. I would like you to send me the form for becoming a peer counselor for Conradi-Hunermann Syndrome. My daughter Cassidy and I both have it. Also, could you make an announcement in the newsletter about a Conradi support network? My goal is to get those of us who are affected involved with each other so we can deal with things together. I would like to start an email meeting or a newsletter for those of us affected by Conradi. Please pass this information along to anyone who would like to contact me about Conradi.

Thanks again,

Shannon Huff
2316 SW 115th Street
Seattle, WA 98146

Dear FIRST:

I would like to share a little story with you because it touched my heart. I have a nephew who was born last February with Harlequin Ichthyosis. He is doing great!! When I told my 6-year-old daughter about your Foundation, she asked me if she could do anything around the house to get money to you, which would help people like her cousin.

My nephew has been an inspiration to us all. We are so blessed to have this baby in our lives. The information we learned on line was more helpful than the doctors, for every doctor said my nephew would not survive. He is not just surviving, but thriving. He is our "miracle," our angel on earth. I would love to help and make a difference and pay back the help we received. The greatest gift we have been given by people who have ichthyosis is HOPE!! And I would love to give others the same.

God Bless,

Lizz Jaguden
Huntington, NY

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In Memory of Mark Levitan

It is with deep sadness that the Foundation reports the passing of former Executive Director, Mark Levitan. Mark served as Executive Director of the Foundation from the Fall 1996 to January 1998. He passed away on November 13, 2002.

Mark's extensive background in healthcare, management, and consulting offered the Foundation accomplished experience in healthcare leadership. During his tenure as director, he oversaw moving the Foundation from Raleigh, North Carolina, to Ardmore, Pennsylvania, and generated an increase in membership as well as a substantial increase in financial assets. Mark was also an active advocate for the Foundation and the rare diseases community, testifying before the House of Representatives about the need for increased research spending, continued support of the National Registry for Ichthyosis, and increased funding for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

Our deepest sympathies go out to his family. Sentiments may be sent to the Levitan family in care of the Foundation. Please note "Levitan Family" on your cards or letters and the office staff will forward any communications to them.

Correspondence Corner

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Dear FIRST:

First, I would like to thank you for everything that you do. I am eighteen and have lamellar ichthyosis. My parents and I have been members of the Foundation since 1995, when my new dermatologist recommended you to us. Before reading your newsletter I had never had contact with any other person with my disorder. You have, with no exaggeration, changed my life.

It was through your newsletter that I first heard about Camp Horizon. I went there as a camper for two years, and then went to Teen Camp in Minnesota for two years. I am now a counselor at both Camp Horizon and Camp Discovery, which brings me to the point of this letter. While at Camp Discovery this year, I met a guy who also has lamellar ichthyosis. Since then, we have been maintaining contact and have plans to visit each other. I would greatly like to know if there are any other couples out there that both have lamellar and how it affects their relationship. Even if only one of you has lamellar, I would still like to hear from you. You can write to me at my college address or email me at shellymrm@yahoo.com.

Thank you,

Michelle Myers
Campus Box 1927
Susquehanna University
Selinsgrove, PA 17870

Seniors Speaking

Greetings!

I was very happy to see the "Seniors Speaking" section in the Focus. You were several steps ahead of me, as I was getting up the nerve to suggest just that! At 53 and counting, I am interested in learning if anyone has ideas on how to treat night sweats along with ichthyosis. On the "up" side of lamellar ichthyosis, I find as I age it seems to get a bit better. Perhaps I just take more time now than when I was raising children and working, but it is one plus towards aging (and I find there are not many!).

The sample of *Ultra Mide 25* sat on my counter for a long time before I tried it this summer. I thought, "Another failed attempt at a lotion." I was pleasantly surprised that it does work for me. Now, if I can only find somewhere to purchase it and am able to afford it.

My dermatologist prepares a prescription for a cream specifically for me. I have no drug insurance and it is very expensive, but it works. Over the years we have fine-tuned it to my needs and it works quite well. The more often I use it, the better. I should admit that my lamellar is not terribly bad. My doctor did take photos years ago to use at conventions when he gave speeches.

When my copy of Focus arrives, I take my time and read it cover to cover. You folks do a wonderful job of gathering information for us! Keep up the good work.

Barbara Karas
Gladstone, MI

Dear Friends:

Elizabeth Lane, one of our senior members, recommends *Nail Tek* products for splitting fingernails. Elizabeth has Darier's Disease, which can cause ridged and splitting nails. She reports that the *Nail Tek* product had almost instantaneous results, and her long pretty fingernails are back. Elizabeth also recommends *Cetaphil Gentle Skin Cleanser* for itchy spots and bacterial problems. She says, "These products are worth everyone knowing about."

Elizabeth Lane
Tulsa, OK

Nail Tek products are made by Prima Technologies, 110 Lake Avenue South, Suite 42, Neconset, New York 11767. Call 800-67NAILS or log on to www.nail-tek.com. Also, www.beautydeals.com (650-348-2754) carries Nail Tek at discounted prices, or you can purchase the products at your local beauty supply store. Cetaphil is made by Galderma Labs and can be found in your local pharmacy or drugstore.

Executive Director's Report

Dear Members and Friends of F.I.R.S.T.:

It is hard to believe that it's 2003 already! It is even harder to believe that I have been with the Foundation for three-and-a-half years. So many great things have been happening around here that time has passed quickly.

One notable achievement is that our membership increased 34 percent over the past year. The reason for this increase is a combination of dermatologist and member referrals and the Internet. New members are easily finding us through our website and are able to join with just a few clicks of a button. It is extremely rewarding to be able to offer our programs and services to everyone in the ichthyosis community.

The Ichthyosis Support Network (ISN) is working well. To date, we have 15 Support Network Coordinators who serve as leaders and refer callers to one of our 163 Volunteer Peer Counselors. The combined efforts of these volunteers result in excellent advice, support, and important resources being shared regarding ichthyosis. If you have not registered as a member of the ISN, I highly encourage you to join. Contact our Program Director, Maureen Tierney, at the national office for more details. The Foundation would also like to acknowledge Beiersdorf, manufacturers of Eucerin and Aquaphor, for their very generous donation in support of the ISN. Their financial contribution ensures the continuation of this very valuable resource.

The first few action items in our five-year strategic plan have been completed. Our volunteer committees are focused on an intense effort to increase ichthyosis-related research. Our first step in achieving this goal was accomplished this year; the Foundation increased its grant funding to the Dermatology Foundation from $20,000 to $40,000. You will be hearing much more from the Foundation about this important initiative.

We recently welcomed two new members to our Board of Directors, Peter Woodford, an adult affected with Ichthyosis Vulgaris, and Amy Paller, M.D., a pediatric dermatologist at Children's Hospital in Chicago. Peter comes to the Foundation with his personal experience dealing with ichthyosis, along with a wealth of knowledge in finance and strategic planning. Dr. Paller has been treating patients with ichthyosis for many years and has a vast knowledge of the disease. Dr. Paller is also a member of the American Academy of Dermatology Board of Directors.

I want to take this opportunity to thank our Board of Directors for their dedication and hard work. These individuals volunteer countless hours of their time to serve the ichthyosis community. All participate on various committees and serve as excellent ambassadors to the medical community, our members, and the general public. I am truly inspired by their level of commitment to our important mission. Thank you for all you do.

Sincerely,

Jean

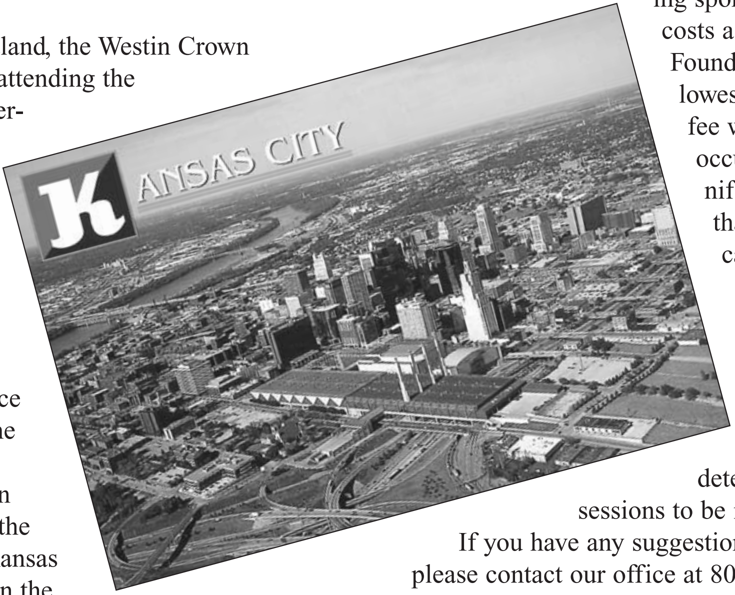
Jean Pickford
Executive Director

2004 Family Conference: Kansas City, Missouri

Start planning now! The location and dates have been set for the 2004 Family Conference in Kansas City, MO. The event will take place:

Thursday - Sunday, July 1- 4, 2004
The Westin Crown Center
One Pershing Road, Kansas City, MO 64108

In the heart of the heartland, the Westin Crown Center will offer everyone attending the Family Conference a wonderful experience. A dramatic five-story lobby waterfall and warm friendly staff welcome guests. Adjacent to the hotel are the many shops, theaters, and restaurants of the Crown Center, which is directly connected to Science City at Union Station via the *link*, an attractive covered walkway. The Westin Crown Center is also located near the many wonders that make Kansas City a favorite destination in the heartland — museums, performing arts, and the famed Country Club Plaza.



The Foundation is extending the length of the conference from three days to four. The opening reception will take place on Thursday night, July 1. There will be activities all day on Friday and Saturday, July 2 - 3, and the program will conclude after lunch on Sunday, July 4.

The Foundation is hard at work seeking sponsors to help keep registration costs as low as possible. The Foundation has also contracted for the lowest hotel rates available. The room fee will be $89.00 + tax, unlimited occupancy. This rate has been significantly reduced by the hotel so that as many families as possible can afford to attend.

We hope that by publishing the dates and location so far in advance, our member families can make plans to attend the conference. The program for the event has not yet been determined, but you can expect the sessions to be informative and well organized.

If you have any suggestions for specific session topics, please contact our office at 800.545.3286. More details will be published in upcoming issues of the newsletter and posted on our website, www.scalyskin.org.

Foundation Resources

Ichthyosis Support Network

The Ichthyosis Support Network offers our members moral support, practical advice, education and guidance, and resource information through telephone and email contact with volunteer peer counselors. Experienced support network coordinators and their volunteer peer counselors offer a voice of experience to others affected by the ichthyoses. Over the past year, eight new peer counselors have joined the network, but we can always use more. The network is particularly in need of people to represent the more rare forms of ichthyosis, such as Palmoplantar Keratoderma, Pachyonychia Congenita, Pityriasis Rubra Pilaris, Epidermal Nevus, and Sjogren-Larsson Syndrome.

The network is also in need of individuals who are fluent in a language other than English. Experienced young adults, adults, and parents of children with ichthyosis are welcome in all the disease networks. The more peer counselors that we have around the country, the better able we are to connect someone in need with a friendly voice close to home.

The time commitment of a volunteer peer counselor is minimal, but the rewards are great. If you feel you have something to offer someone else struggling with your disease, please call Maureen in the national office, 1-800-545-3286, to find out more about how you can help.

Dermatologist Referral List

Thank you to all of our members who shared the name of their dermatologist with us. As a result, our dermatologist referral list has expanded from a short list of about 30 doctors to over 100 doctors throughout the country. If you have a caring dermatologist, please think about sharing his or her name with the Foundation. Our goal is to keep expanding the referral list so that we can refer our members to a knowledgeable physician as close to home as possible. Take a moment to mail us a note, call us at 1-800-545-3286, or email info@scalyskin.org with your doctor's name and contact information.

> **"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 06/30/03

Save $2.00
on any
Aquaphor®
Product

(NO TRIAL SIZES)

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. Cash value 1/100¢. Copies available upon request. Offer void if copied and where prohibited, taxed or otherwise restricted. Mail to: Beiersdorf Inc, PO Box 880504, El Paso, TX 88588-0504. Good only in USA.

115402

5 72140 33082 3 (8101)0 11540 0603

National Ichthyosis Awareness Week 2002
October 6-13, 2002

One week out of each year, the Foundation celebrates Ichthyosis Awareness Week (IAW). This week is designed to encourage our members to promote ichthyosis awareness in their communities. Educating your local community can make life a little easier for the individual affected with ichthyosis. Maybe the next time that person is in the supermarket, bank, or a local shop, the looks and stares may not be quite as bad. Simply knowing that ichthyosis is not contagious and is not caused by a fire, lack of sun protection, or bad bathing habits can give the general public a better understanding of why these individuals have different looking skin.

Among the many promotional efforts to announce this special week, the Foundation sent a press release in three formats (letter, fax, and email) to 70 major newspapers throughout the country and sent an email to everyone in the national office's address book. The results from that email were tremendous. The following individuals took the time to place literature in their dermatologist's office, workplace, church, synagogue, supermarket, or community centers. Brochures were also distributed to family members and friends. The Foundation gratefully thanks these individuals and recognizes their help in spreading the word about this disease. Most of these individuals represent areas in the United States, but several represented other countries: Australia, Canada, England, India, Ireland, Italy, Mexico, Spain, and the United Arab Emirates.

Merritt Andrews
Robin Blair
Kirsten Brennan
Rita DeMarco
Lynne Denney
Michelle Doherty
Sarah Dugan
Kate A. Elliott
Rhayne Evans
Debbie Fedewa
Lawrence Fernandes
Kathy Gaffney
Carmen Cuervo Garcia
Melissa Gay
Christina Glanzbergh
Kim Gunn
Katherine Hamilton
Muhammed Hashif
Lizz Jaguden
Bonnie Jayjohn
Karen Kirwin
Lena Kolstad
Prochi Madon
Olivia Markonic
Lisa Mellberg
Norma Montague
Barbara Myers
Dan O'Donnell
Eustolia Perez
Estella Ragland
Lynne Rich
Melisa Ridenour
Thomas Ronholt
Gloria Silvey
Jeanne Smith
Katie Smith
Joyce Stewart
Sue Thompson
Andrea Thorn
Shannon Tormey
Diana Walton
Michelle Weckwerth

While some promoted ichthyosis awareness, others raised significant funds toward the Foundation's mission. As always, the Foundation wishes to thank and recognize these individuals for their dedication and hard work.

Lynne Alba saved her register receipts from Genuardi's Supermarket, which gives a percentage back to the Foundation. **LouAnna Dugan** hosted a Tupperware party and designated her commission and a portion of the proceeds to the Foundation. **Joti Anand** solicited her co-workers at CMB Research for donations in support of our important work. **Patti** and **Hunter Steinitz** placed brochures in their church, one of which was seen by a member of a local civic organization. This organization will be sending a generous donation. Patti's sister, **Bobbi**, successfully solicited a charitable donation from her company to the Foundation. **Susan Suda** organized "Jeans for FIRST," a fundraiser where local company employees donated money to dress in blue jeans for a day at work. Susan involved the community by submitting her story to the local newspaper and involving her local Chamber of Commerce. **Greg Licalzi** hosted an educational campaign during IAW to educate his fellow college students. By the end of his three-day campaign, he had educated almost the whole school of 1200 students. Even though his purpose was purely to educate, he raised money from caring individuals who wanted to lend their support. **Lee Ann Bruno** hosted a "Kids Clothing Sale," which was sponsored by her own organization, Rare Kids, Inc. This organization will donate a portion of their proceeds to the Foundation. **Ronda Whitney**, a Tupperware consultant in her region, has designated the Foundation as a regional charity and will be sending donations on a regular basis. **Sandy White** contacted her local television station and went on the air during a daily segment on community events to talk about ichthyosis. **Karen Halverson** placed our IAW announcement on the "Family Finders" email bulletin, which was seen by hundreds of people. **Tracie Pretak** and her daughter, **Bailey Jones**, hosted their 6th annual "Release the Butterfly" Spiritual Concert, which always generates awareness and caring from their community. Attendees made a free will offering in support of our work, which raised significant funds. During IAW, **Darin Height** placed himself strategically behind a table in front of his school, Florida Atlantic University, and spoke to others about ichthyosis and how it has affected his life. **Dona Hoar** and her family participated in a Demolition Derby fundraiser, which generated funds for the Foundation. **Jeff Gerber**, who serves as his area's United Way solicitor, organized his many co-workers to designate a portion of their charitable donation to the Foundation. **Nicole McMillian** and her mother, **Grace**, solicited funds from their family, friends, and co-workers, bringing in generous donations for our programs.

Congratulations to everyone who has given back to the Foundation in some way. In the event that this listing does not recognize your efforts, please accept our apologies. Our staff tries to include everyone who has contacted us. Please let us know what you have done so we can recognize you, too! The Foundation can be reached at 800.545.3286 or email us at info@scalyskin.org. We love to hear from our members.

What's New, What's Hot & What Works…

Dear FIRST:

I thought I should write to inform others who have ichthyosis vulgaris about the remedy I have found for treating problems with dry, flaky scalp. I had been using regular strength NeoCeutical's Problem Dry Skin treatment. It was very effective, but messy and smelly.

I tried using Dermal Therapy Alphahydroxy Lotion. It works just as well as the cream without the mess. I now use it every other day after shampooing and the results are great.

Sincerely,
Frank Mosunic, Morgan Hill, CA

Hello:

My family are members of FIRST; our daughter, Caroline, has Netherton's Syndrome. I would like to share the following tip with the newsletter.

We coat Caroline with *Aquaphor*, as well as other lotions and potions, several times a day so her clothing becomes soaked with petrolatum. We've discovered that using approximately 4 scoops of *OxiClean* in the laundry (combined with hot water and a laundry detergent for sensitive skin) removes most to all of the residue on her clothes. Nothing else works quite as well. Just agitate the laundry load for a few minutes, let the laundry soak for an hour or so, and then complete the laundry cycle. You will see the petrolatum rise to the top and stick to the sides of the machine's interior.

Kind regards,
Diane Taranto, Middeltown, NJ

Dear FIRST Team:

First I want to say thank you for the information about ichthyosis which you sent me some time ago. I have found very interesting and helpful information in your brochures and materials.

I think I have lamellar ichthyosis and want to pass on a skin care tip. This has helped me very much to clear the scales on my scalp. You need lactic acid (in German: Milchsaure) 89.9 percent. I get it from my family doctor or a drugstore. I put 10 milliliters lactic acid in a 250 milliliter bottle and fill it up with water. After my daily bath I put a handful of this mixture on my scalp and massage it in. Then I put on a shower cap and let the mixture take effect. After half an hour I take off the shower cap and try to separate the scales from my scalp with a very fine comb. As the scales are very soft from the mixture, this is no problem. Since I have been using this method I do not have problems with thick scales. I have lost some of my hair from the thick scales.

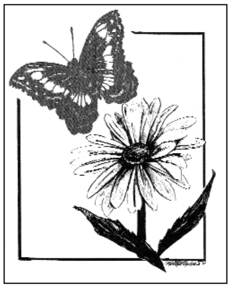
I think many people with ichthyosis have problems with their scalp and so I hope you will pass my information on to many people!

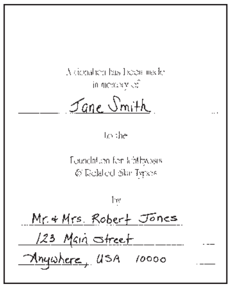
Sincerely,
Kathrin Gusner

Why Should I Buy Honor and Memorial Cards?

Sending greeting cards is a common practice for most of us. Greeting card prices have skyrocketed during the past few years, and the card companies are making a lot of money. On average, you can spend about $4.00 per greeting card at a card store or supermarket. If you are like me and don't think ahead, you find yourself buying cards at least a few times per month.

The Foundation has created two cards that can be used for any occasion. One card is designed to honor a specific event and the other is to acknowledge someone's passing. They are creative, simple, and very effective. When your family, friend, or loved one opens the card to see a donation has been made in his or her honor to our organization, it will be a deeply touching experience. Not only have you thought of him/her on that special occasion, but you were also caring enough to consider others who can benefit from your thoughtfulness.





A donation has been made
in memory of
Jane Smith
to the
Foundation for Ichthyosis
& Related Skin Types
by
Mr. & Mrs. Robert Jones
123 Main Street
Anywhere, USA 10000

Imagine you are at home and your brother calls to remind you of your aunt's 81st birthday. Quickly, you run out to the store, look through 25 cards, stand in line to pay, fill out the card, find a stamp, and take it to the post office. The Foundation's card program can eliminate that hassle. Or imagine that your friend's mother has passed away and you want to send an acknowledgement to her family. The Foundation's card program is the perfect way to send an appropriate sympathy card.

Simply dial 800.545.3286 and order a card over the phone. Our staff will take the information, fill out the card for you, and mail it that same day. We will keep a record of how many cards you send per month and bill you or we can charge your credit card. It doesn't get much easier than that!

Now, for a limited time only, the cost per card is $4.00. Cards are also available for purchase in packs of six to keep on hand at your home. The cost per pack is $20.00, a saving of $4.00!

Send a card for

Birthdays • Anniversaries • A Good Report Card • A New Job • A New Baby
College Graduation • A New Home • Promotion • A Special Thanks to a Coach or Mentor
Mothers'/Fathers'/Grandparents' Day • Sympathy/Memorial

Call us today!
800.545.3286

Honor/Memorial Card Order Form

Name ______________________________

Address______________________________

City, State, Zip ______________________________

Phone, Email ______________________________

Payment Method: ___ check___ credit card (Visa, MasterCard and American Express)

Account # ______________________ Expiration Date______________

Mail to Honor/Memorial Card Program, 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446.

Thank You

	Quantity Ordered	
	Packs *(6 for $20)*	**Cards** *(Only $4 per card)*
Memorial Cards	_____	_____
Honor Cards	_____	_____

News & Notes

Past President Elected to NORD Board of Directors

Donna Rice, immediate past president of the Foundation for Ichthyosis, was elected to the Board of Directors of the National Organization for Rare Disorders (NORD) in Washington, DC, this October. NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. Donna brings a wealth of experience and perspective to this board position. She is the mother of a child with a rare disease and has been a committed advocate for rare disease research, Foundation volunteer, board member, and past President. We congratulate her and wish her well in this new endeavor.

President Bush Signs Rare Disease Legislation

President Bush has signed into law the Rare Diseases Act (H.R. 4013) and the Rare Diseases Orphan Product Development Act (H.R. 4014). This legislation addresses a longstanding unmet need to develop new treatments and cures for rare disorders. The Rare Diseases Act establishes an official Office of Rare Diseases at the National Institutes of Health, which will promote and coordinate research on rare disorders and will create academic Centers of Excellence for research. The Rare Diseases Orphan Product Development Act will provide $25 million per year for the FDA's Orphan Products Research Grant Program, which supports clinical trials of new orphan drugs, diagnostics, medical devices, and medical foods.

The passage and signing of these acts is the culmination of an intense effort by the rare disease community to establish legislation that will have a profound and lasting impact on the millions suffering from rare diseases.

Reprinted from the NORD Media Release, November 7, 2002

Dr. Paller Recognized by Peers

Dr. Amy Paller, a newly elected member of the Foundation for Ichthyosis & Related Skin Types Board of Directors, was recently honored by the American Academy of Dermatology (AAD) for her commitment to improving the lives of individuals with skin conditions.

Dr. Paller and awarding-winning journalist Deborah Norville earned a Health Community Individual Accomplishment award for their outstanding commitment to the "Outside & In: Healthy Living with Eczema" campaign. Both have worked hard to help children who suffer from this condition.

The award was given at the AAD's Sixth Annual Gold Triangle Awards ceremony in New York City on August 1, 2002.

eScrip Fundraising

The Foundation extends its thanks to our members in the Northeast who have supported us through the Genuardi Family Markets' Cash-Back Register Receipt Program. Genuardi's has abandoned this program in favor of an online program through eScrip®. eScrip registers merchants and shoppers through its website and returns a portion of your shopping dollars to the Foundation. If you are interested in continuing to support the Foundation by redirecting your shopping dollars through eScrip, learn how by contacting Maureen in the national office, 1-800-545-3286, or emailing info@scalyskin.org. Or go to www.eScrip.com. Genuardi Markets and other Safeway stores participate, as well as many national merchants, such as: Budget Rent-A-Car, Eddie Bauer, Office Max, Payless Shoe Source, and Spiegel. Many regional merchants also are registered with eScrip; the office can provide you with a list.

This program does not cost you any money or raise the price of the products you normally buy. The registered merchants have agreed to return a portion of their profits to the Foundation if you shop their stores through eScrip. The Foundation's Group ID number is 2440285.

Smallpox Vaccination

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tion seems quite low at this time. If the risk were great, for example if you found yourself in the middle of an epidemic, the recommendations would be different. At present, my recommendation is that individuals with any form of inflammatory ichthyosis, ichthyosis that is red as well as scaly, should not be vaccinated. In addition, those individuals should avoid close contact, for at least three weeks, with individuals who have been vaccinated. There are no compelling reasons to recommend against vaccinating individuals with ichthyosis vulgaris (unless they also have atopic dermatitis), X-linked ichthyosis, or those with most palmoplantar keratodermas. As with many things in medicine, there are always good reasons why general recommendations might not apply to individuals. Patients with ichthyosis should discuss their particular case with their dermatologist.

Editor's Note: For the latest information on smallpox, the vaccine, and our nation's planned response to a smallpox threat go to: www.bt.cdc.gov/agent/smallpox/vaccination/facts.asp.

If you do not have access to a computer or the Internet, call Maureen in the national office, 1-800-545-3286, and ask for a printout of the information from this site.

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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 (LD_{50}>15mL/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

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