



ICHTHYOSIS FOCUS

Vol. 21, No. 3

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

Fall 2002

Understanding Alpha-Hydroxy Acids

By Julia A. Kneedler, Sharon S. Sky, and Linda R. Sexton

The skin-rejuvenating properties of certain alpha-hydroxy acids have been known for centuries. Cleopatra allegedly bathed in spoiled milk, which contains lactic acid, and the women of the French court washed their faces in spoiled wine, which contains tartaric acid. Today, alpha-hydroxy acids (AHAs) are widely used in skin care products. They are the most popular ingredient to enter that marketplace in recent years. Approximately forty-five companies manufacture over two hundred AHA-containing products, ranging from over-the-counter moisturizers and cosmetics to chemical peels administered by physicians.

Alpha-hydroxy acids are weak organic acids. Although they are found throughout nature in sugar cane (glycolic acid), in sour milk (lactic acid), and in fruits (malic, citric and tartaric acids), the AHAs used in dermatologic and cosmetic products are usually synthetically produced.

The principal cosmetic actions of alpha-hydroxy acids on the skin are increased exfoliation and moisturization, which have the following effects:

- **Increased exfoliation.** Low-concentration alpha-hydroxy acids appear to facilitate shedding (exfoliation) of the outer layer of the surface of the skin (stratum corneum) by interfering with inter-cellular bonding, thereby reducing corneocyte cohesion at the lower level of the stratum corneum. Corneocytes are the cells, arranged in multiple layers, that make up the stratum corneum. Higher concentrations of alpha-hydroxy acids further reduce corneocyte cohesion and cause the thickened, hyperkeratotic stratum corneum to shed in sheet-like fragments, becoming thinner and more compact. In general, lower concentration AHA products simply accelerate cell loss and increase exfoliation, resulting in cosmetically improved skin.
- **Moisturization.** Alpha-hydroxy acids are useful as moisturizers on the face and body. The moisturizing qualities of cosmetic AHA formulations help diminish the appearance of

fine lines and maintain the skin's proper moisture level. Moisturization helps relieve rough and flaky skin conditions; softens dry, cracked and sun-damaged skin; and maintains the proper moisture level in healthy skin.

Initial research on alpha-hydroxy acids focused on their use in treating ichthyosis and other dry-skin conditions. Doctors Eugene Van Scott and Ruey Yu introduced the term "alpha-hydroxy acid" and described the effectiveness of AHA products in the topical treatment of ichthyosis and similar dermatoses. Their research reported that alpha-hydroxy acids decreased corneocytes adhesion, allowing removal of the thick scales of ichthyosis, psoriasis, and seborrheic keratoses. Today, the use of alpha-hydroxy acids has expanded to consumer lotions and creams that are used to moisturize dry skin, diminish the appearance of fine lines and wrinkles, improve skin tone and texture, and restore a youthful glow to the skin.

Alpha-hydroxy acids remain an effective treatment for ichthyosis. Formulations containing up to 12% glycolic acid, lactic acid, and its derivatives are typically used. A reduction in epidermal thickness is seen on histological examination within two weeks of the start of twice-daily topical applications of AHAs. A soaking bath once or twice a week helps to remove scales from areas where they are tightly adherent. With sustained treatment, normal or near-normal thickness and appearance of the epidermis can be achieved and maintained. Dr. Van Scott and Dr. Yu's research found that this regimen could be as effective, and often more effective than, systemic therapy with a retinoid.

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Correspondence Corner

Dear Jean:

Wow... I don't even know where to begin. Saying thank you to you and Maureen seems so inadequate. I had no expectations going into the conference, but if I did, I can't imagine their not having been met. The two of you, as well as the others involved in planning the weekend, should be very proud. It was a wonderful experience; one that I wish my entire family could have shared. I was impressed with how well organized everything was, as well as with the quality of the content. I also liked how the kids were always involved in the plans, i.e. chicken fingers and mac-n-cheese for Saturday dinner.

As you know, this is still all very new to my family and me. While four months with ichthyosis seems like years, we are still way at the bottom of the learning curve. The amount of information I got is staggering. The quality of the contacts I now have is impressive. As I said to a number of people during the weekend, I feel fortunate that Adam was born in 2002 versus 1992, 1982, or 1972. The amount of information available and the easy access to resources can only help us on this journey.

When I got home, Kelly asked me how everything went. My first comment to her was that I've never met a nicer, happier group of people. Now I know why so many try to make it to every conference. As I wrote on my evaluation, thank you for letting me be part of the family. I truly meant it.

Thank you for giving me the opportunity to laugh a little, smile a little, and cry a little. I needed to do all three. Kansas City... here I come.

Best regards,
Mark Klafter
Alpharetta, GA

P.S. I wish I had David Roche's speech on video so I could watch it every time I start to lose my focus.

Dear Maureen:

Thank you so much for all your help in finding out about trichothiodystrophy. With your help and the help of others, I have been able to send our doctor information that has helped make the process of finding Collin's diagnosis so much faster and easier. Our doctors at Cedars Sinai have already been in contact with Dr. DiGiovanna, thanks to your help. Today, a pathologist is coming to look at Collin's hair under a microscope in a more detailed way. After they get the information they need, it will be forwarded to Dr. DiGiovanna. Then, we will be on our way to Maryland to see him. This way we will be able to diagnose Collin with some certainty and start doing research on him and trichothiodystrophy.

Thank you, again, for all your help. You have no idea how much this means to me. We have been trying to find a diagnosis for over a year; of course, it is a guessing and waiting game. We have been to three hospitals, two of which gave up on Collin. It means so much to know that we have a resource in the Foundation. It is hard to be a parent sitting back and feeling powerless. THANK YOU!! I will always be grateful.

Julie Presley
California

Correspondence Corner

continued from page 2

Dear Jean, Maureen, Laura, and your entire committee:

Thank you so much for a terrific F.I.R.S.T. conference in Seattle. I was impressed with the very well-rounded program, age-appropriate agendas, and the valuable participation of so many doctors, the clinical screenings, and the amenities of the hotel. It was a watershed experience for my son Peter and me, as every conference we've attended has been. I hope you'll send out an attendees mailing list. Thanks again for providing us with a vital resource.

Sincerely,

Mary Fitzpatrick, Peter Van Pelt, Pasadena, CA

Dear Jean:

Thank you for an amazing family conference in Seattle! Kenny and I really had a life-altering experience. I met so many beautiful people, and they all asked for a copy of *Kenny*. Can you announce in your newsletter that anyone interested in the documentary about Kenny can go to the site and email me: www.kennythemovie.com.

Lisa Regina, New York

Hello all:

I wanted to write and thank all of you for all your hard work and for giving my daughter, my mom, and me such a wonderful weekend in Seattle. I am very excited that you will all be coming to my part of the country in two years. Please let me know if there is any way that I can help you for the next conference. I plan to contact our local newspaper and TV station and ask them to do a story on ichthyosis. When we get closer to conference time, I will try to get some local Kansas businesses to contribute to the raffles.

Thank you so much. Please let me know what I can do to help.

Your FIRST friends,

Meshell and Rose Boydston, Wichita, KS

Dear Jean:

Thanks so much to you and everyone at F.I.R.S.T. for bringing me to Seattle and making me feel welcome and appreciated. And for a grand successful weekend filled with heart and executed with great professionalism. Count me part of the family now!

Warmest regards,

David Roche

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Skin Care Tips for Dry Winter Skin

The dry cold air of winter that is common in many parts of the country can make the dry, scaly skin of ichthyosis much worse for some people. Water loss from the skin is increased by the low humidity and cold of winter air and by the dry, warm air inside centrally heated homes, offices, and public places. Wind also increases evaporation from the skin. The following are some effective strategies for dealing with dry winter skin:



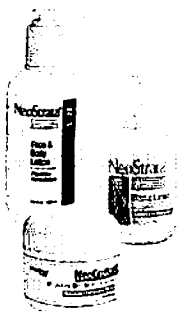
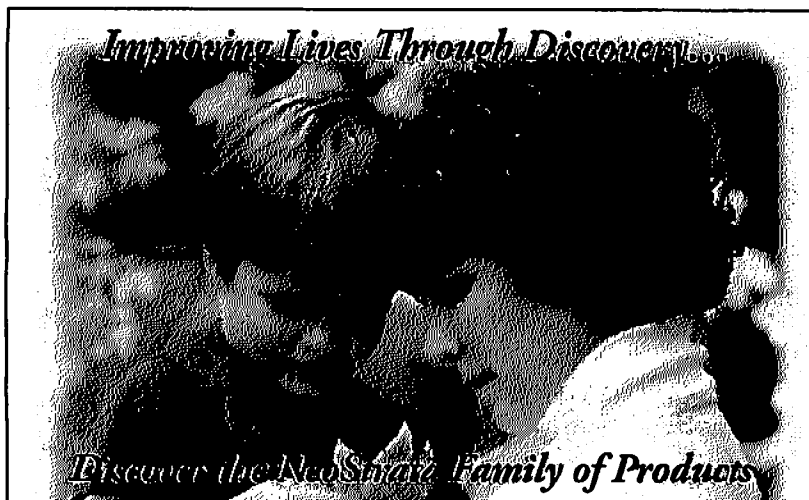
baths are better, as long as moisturizers are applied immediately after bathing. Short warm baths help make dry scale easier to remove and makes the individual more comfortable. Some people find salt and oatmeal baths soothing.

- Physicians may tell individuals with normal skin to reduce bathing and contact with water if they have dry winter skin, but for people with ichthyosis more

- Applying lotion and creams to wet or damp skin works better than applying them on dry skin. The lotion or cream seals the moisture into the skin.

- A pumice stone, loofah, or nylon scrubby sponge rubbed lightly on thickened skin may help loosen scale. Try this when the skin is wet and soft.

- Products containing urea or alpha-hydroxy acids, lactic acid or glycolic acid, seem to help some individuals with ichthyosis. Some people get relief from pure lanolin, which is easier to spread when mixed with water.
- Try adding a few ounces of pure glycerin to your favorite lotion or cream; the skin will stay moist longer. Glycerin bought by the gallon is less expensive than in smaller bottles. Your local pharmacist may be willing to order a gallon for you.
- Give any new lotion or cream a decent trial. Sometimes a product needs to be used for two to three weeks before results are noticeable.
- Natural fibers, such as wool and cotton, tend to wick moisture away from the body. Consider cotton blends for clothing worn next to the skin. However, some people with ichthyosis find rayon and other synthetics to be very irritating.
- To protect hands during the winter months, apply a hand cream and wear gloves whenever you are going outside, even when you just plan to be in the car.
- Generously apply cream to hands and feet at night and then cover with cotton-blend gloves and socks to hold the moisturizer in and protect your bedclothes.
- Some people find that installing a water softener and a whole house humidifier helps their skin in the wintertime. On a smaller scale, you can add bath salts and salt-based scrubs to your bath or shower. Houseplants and bowls of water, placed around the rooms you spend the most time in, will add moisture to the air.
- Share your strategies for dealing with dry winter skin with the Ichthyosis Focus! Write, email, or phone Maureen with your winter skin care routine and the products that work for you.



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NeoStrata 15 Face and Body Lotion, with 15% glycolic acid, aggressively exfoliates scaling skin, leaving it soft and smooth. Not for use on sensitive skin. Use once or twice a day as tolerated with daily use of a sunscreen.

To order, call 1-800-628-9904 or for more information, visit our website at www.neostrata.com.

Seniors Speaking

Seniors Speaking is a new column devoted to the special needs and experiences of our members who are 55 and older. Please direct comments, suggestions or contributions to this column to the Foundation office by calling 1-800-545-3286, or email us at info@scalyskin.org.

Dear Maureen:

I hope the conference was all you hoped it would be. Please consider what we talked about before this conference; next time, have a section for discussion of topics related to seniors, 55 and older.

I would like to submit a topic for the "Senior Forum" that we discussed. I have contacted seniors who have emailed me, and they are willing to contribute. We know research is being done, but we are also in the twilight of our years. So the care and upkeep of our skin, at a fair price, is what is important to us. With your help and input, we can communicate on subjects that are important to us.

I'll go first! The lubrication of my skin is as important to my day as the water I drink and the air I breathe. I have used and found comfort in a cream that I read about in an issue of the Focus about ten years ago. I continue to try, and appreciate, the samples of creams sent to us, but I always go back to using Melrose Cream. I talked to Vernon Furlow, the company owner, and am happy to share with you that it is available in Wal-Mart stores across the country. If you don't see it on the shelf, ask someone to get it for you; it comes in a four-ounce jar. There is a website where you can read about the product and view other client satisfaction. It is www.melrosecream.com. If you don't have access to a computer, you can call Vernon at 806-372-4691.

I have used many of the new lubricants with urea; the moisture may go down into the layers of the skin, but the moisturizing is temporary. I don't have the time or energy to apply four times a day. Melrose Cream is not greasy or sticky. I find once a day, after a shower, is most beneficial. Some of the ingredients in the product are water, glycerin, petroleum and

lanolin. Softening lubricants are so important to our aging skin. Also, you might compare the cost, which is also important to us on a fixed income.

Please share the way you make it through the day. Your care routine would be very helpful for future senior columns.

Beverly Browne
El Dorado Hills, CA

Dear Focus:

I grew up in a small New England city. Our family had no idea what was wrong with my skin and my brother's. I suffered so much during the winters (physically and mentally — kids can be cruel) and had heat stroke during the summers. I used baby lotion on my skin because it made my skin look better, but I was never cured. Years later, I was diagnosed with ichthyosis at the Philadelphia Naval Hospital. It was the first time a name was given to my condition. At that time, I was given some topical cream to relieve the itching, and the cracking and peeling on my feet. That same year, I was asked to pose for a medical journal because I was a "perfect ichthyosis" subject. It was the first time I was "perfect" at anything. Anyway, I learned to live with it - you know, slacks and long sleeves.

Recently, I was at a dermatologist's office for a completely different reason. When the doctor saw my skin, he said, "Neostrata 15 should help your skin." I purchased a bottle from the doctor. Within a month, all the scales on my legs and arms had disappeared! I saw the skin that was underneath the scales. In fact, I took a picture of my legs and sent it to my mother; she has ichthyosis too.

Since then, I use the lotion every morning after my shower. I apply it to my skin while still damp from the shower and follow it with a moisturizing lotion, Keri Lotion. I'm sure any good lotion would suffice. I'm now able to wear shorts and sleeveless blouses and feel good about my skin. People admire the skin on my face! It's really a miracle for me.

I buy the Neostrata 15 through my

doctor's office. I don't see the doctor, not since my first visit. I order the lotion, two bottles at a time. They are \$25.00 each and will last almost a year. The website for Neostrata is www.neostrata.com; the address is Neostrata Company, Inc., Princeton, NJ, 08540, and the phone number is 888-437-9598. In case you are wondering — no, I do not work for the company nor do I own any shares! This was a gift from God to me and I hope it will be for others who want to try this product.

Feel free to use my name and letter. Thank you for the informative Focus. I have passed all this information on to members of my family who also have ichthyosis.

T. Joyce Phaneuf
Port Hueneme, CA

Hello FIRST!

I want to thank you for sending me a sample of Ultra Mide 25. I have tried it for a week and IT WORKS! It has a very different quality from anything I've used before. My last miracle was Calmurid (urea), twenty years ago. This new cream lasts far longer and gives a suppleness to my skin that I have never known before. It makes walking more comfortable when I put it on my feet, and it also works better under the tinted sunscreen on my face. I am now in the process of finding out if I can get it on the NHS or even if it is available in this country. Thanks again.

It has also been very interesting "talking" to Beverly Brown via email, after her letter in Correspondence Corner. We are both agreed that older people have a place in the scheme of things too, and tend to be overlooked. Very many thanks again.

Norma Montague
Kingston upon Thames, London

Editor's Note: Our international members can try ordering Ultra Mide 25 online from www.cyberpharmacy.com, or by calling 1-800-WEB-DRUG. Ultra Mide 25 is made by Baker Norton Pharmaceuticals, Inc.

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Executive Director's Report

Dear Members and Friends of the Foundation:



Every three months, when I sit down to write my report for the newsletter, I have a chance to reflect on the many accomplishments of the Foundation. I am continually proud of all the active participation from our member families, professional individuals, and corporate supporters. The Foundation grows stronger and reaches more affected individuals every day. Through our programs of awareness, support, and education, the Foundation continues to fulfill the mission of helping people affected by ichthyosis.

Our spring membership campaign and summer appeal were once again successful fund raising campaigns. The membership campaign reached its projected goal, and the summer appeal surpassed its goal by \$1500. Thank you to everyone who took the time to send a donation. Whether your gift was large or small, every donation counted and helped us achieve our goal.

Our Board of Directors is engaged in a personal letter writing campaign. Board members are sending letters to their friends, relatives and colleagues requesting a donation in support of the Foundation's important work. The outcome of this campaign is twofold, raising funds and educating the public. This is just one example of the personal commitment of our Board of Directors.

Awards from the Jane Bukaty Membership Assistance Fund were distributed to three members of the Foundation in September, following the fourth cycle of applications. This fund, which began more than three years ago, was made possible by an anonymous donor and continues to help meet the financial needs of member families. Our fifth cycle of applications are now being accepted. Please see page 14 for more information or contact the office for an application.

As you can see on pages 8 and 9, the family conference was an incredible event. It was truly a heartwarming experience to meet our affected members and their families. The invitation to attend a family conference is one of the most rewarding benefits of membership. This unique opportunity to meet with other individuals and families, talk with knowledgeable doctors, and learn new information about ichthyosis is just another way the Foundation serves its members. Plans are already in place for our next family conference, to be held during the summer of 2004 in Kansas City, Missouri. More information will be announced in upcoming issues of the newsletter.

Our website, www.scalyskin.org, continues to be a major communication tool for our members and the general public. The office is receiving many requests for the newly-published fact sheets on overheating, scalp scale, ear wax & scale, and retinoids, which were introduced on our website. The office regularly receives new member applications and many inquiries, all of which are generated from our website. I am currently working with members of our Medical Advisory Board to provide more accurate pictures in our "Types of Ichthyosis" section.

In early September, the National Institute of Arthritis, Musculoskeletal and Skin Diseases hosted a meeting of medical professionals and lay advocacy groups to begin discussion on how to evaluate the burden of skin disease. The Foundation was represented at this meeting by Dr. Philip Fleckman. Dr. Fleckman is a member of the Foundation's Board of Directors, a member of the Medical Advisory Board, and Principal Investigator of the National Registry for Ichthyosis and Related Disorders. The discussion focused on how to calculate the medical burden, as well as the psychological/emotional burden of affected individuals and their families. This process has only just begun. I will report on this initiative as it progresses.

In coming months, the office staff and volunteer committees will focus on achieving the first few goals of our five-year strategic plan. These goals center on the most effective way to increase funds for research, redefining the Research Committee, and reviewing grant opportunities.

And finally, Ichthyosis Awareness Week took place during the week of October 6 - 13, 2002. Many of our members contacted the office about fund raising and awareness events in their local communities. Even though we encouraged participation during this particular week, your involvement is not only limited to this specific time. Our members are always urged to support the Foundation in any way. If you would like to organize an event in your area or have an idea for an event, let us know. We will be happy to help!

Best regards,

*Jean 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.

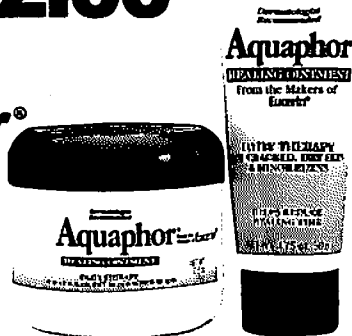
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2002 National Family Conference

Conference Highlights ...

- 225 members traveled from all over the world: Belgium, Bermuda, the Netherlands, Hong Kong, Pakistan, Switzerland, New Zealand, Canada, and the United States.
- The sharing of information between parents and caregivers went on during and between sessions and never stopped.
- Private one-to-one appointments with physicians who specialize in ichthyosis were invaluable. For some people, this was the first time a specific diagnosis was given as to what type of ichthyosis affects their family.
- Breakout sessions addressed areas of greatest interest and concern to people with ichthyosis. The program content and the faculty were great!
- Teen and pre-teen programs offered the opportunity to share stories and coping techniques, and to have fun with other kids who live with the same experiences.
- The child-care room was great fun for the little ones. Some children couldn't wait to get back to the room after lunch!
- Our closing speaker, David Roche, was truly inspirational. His approach to living with a facial disfigurement was very uplifting.
- There were over 100 raffle prizes! Everyone went home with a conference T-shirt and a gift bag of lotions, creams, and other goodies.
- An organized tour of Seattle was a perfect way to end the conference. It offered the opportunity to see this beautiful city while socializing with new friends.



Our closing speaker, David Roche, shown here with President Laura Phillips and Jessa Karst, offered a wry, funny, and inspirational look at living with a facial disfigurement.



Kenny Krips and Lisa Regina received a Distinguished Service Award for their work on Kenny, a documentary about Ken's life with lamellar ichthyosis.



Levs Avakian and Merritt Andrews, with President Laura Phillips, received the Volunteer of the Year Awards for 2001 and 2002, respectively.



Conference faculty volunteers Merritt Andrews, Deb Vilas, and Elise Sturgeon lent their knowledge and experience to the program plan.



Pre-teens had their own group and programs.



Teens Jordan Brooks-Smith, Peter Van Pelt, and Margaret Frost, became fast friends.



Puneet Anand, Chris Phillips, Rachelle Geilen, and Amneet Anand take a break from dancing to pose for the camera.

A Family Affair: Caring, Sharing, & Support



Ichthyosis Support Network coordinators Tom and Carol Frost take a turn on the dance floor.



Ryley Ann Johnson, Alexis Johnson, Autumn Sproull, and Shelby Riggs — girl power!



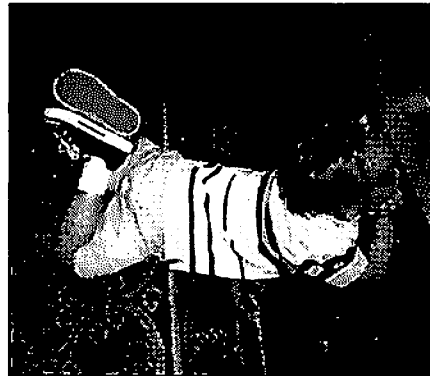
Autumn Sproull, Laura Ashton, and Hunter Steinitz share hugs and smiles.



Sofie and Patrick Spurling flew all the way from Zurich, Switzerland, to join us.



Geoff Hamill, RN, Registry Coordinator and conference volunteer, was everywhere.



Anthony Sperduto takes a break in a convenient spot.



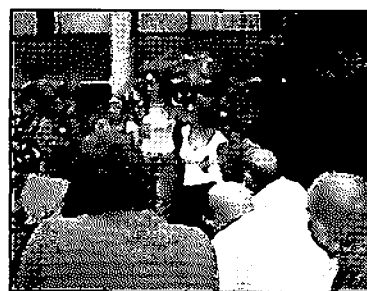
Jason Adams adds some sparkle to Saturday night's party.



Ah massage! Relaxing breaks were available throughout the day.



Becky Butler, Nicole McMillian, and Chandra Rogers renew their friendship.



Teen girls shared with the Dad and Men's discussion group what it is like to live with ichthyosis.

Plans are underway for the next conference in 2004. It will take place in Kansas City, Missouri. The conference committee is hard at work selecting the hotel location and program topics. If you would like to become involved or have a suggestion, email us at info@scalyskin.org or call 1-800-545-3286. Your ideas are encouraged!

Acknowledgements:
The Foundation is extremely grateful to our generous corporate and individual donors who supported the conference. See page 10 for a complete list of corporate sponsors.

Volunteer Recognition

The following awards were presented at the 2002 National Family Conference

Volunteer of the Year Award

Presented to members whose leadership and heartfelt dedication to the Foundation best exemplify the spirit of giving

2001

Les Avakian, Fresno, CA

2002

Merritt Andrews, Orlando, FL

Frances Bernstell Memorial Award

Presented to a member(s) whose outstanding grassroots fund raising efforts help to contribute to the financial strength of the Foundation.

Dawn Johnson, Friendswood, TX

Past President Award

Presented to a past president in recognition of that person's leadership and dedication to the Foundation.

Donna Rice, Katy, TX

Distinguished Service Awards

Presented to members for their extraordinary contribution or service to the Foundation in helping us grow in strength, membership, or recognition.

Kenneth Krips & Lisa Regina
Moise Levy, MD
Laura & Chris Phillips
Patrice Russell

Mary Spraker, MD
Eugene Van Scott, MD
Janet Weary & Peyton Weary, MD
Mary Williams, MD &
Peter Elias, MD

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The Foundation for Ichthyosis & Related Skin Types wishes to express its sincere thanks to our 2002 National Family Conference Corporate Sponsors. Their financial contributions ensured the success of the conference.

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Allerderm, Johnson & Johnson CPC, Merz Pharmaceutical, and Summers Lab sent displays of their products, and provided trial samples to conference attendees.

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Spotlight On... Karen Price & Family

In May 1998, our family was blessed with a precious little angel, my granddaughter Ryley. Ryley was born with a few medical problems; one in particular would affect her for life. At first, we didn't understand what the doctor was telling us, all we understood was that it was very rare.

I remember the word "ichthyosis." I made the doctor spell it twice for me and wrote it down. I wanted to make sure I got it right, so I could search for information on the computer when I got home. On the way home, I had many visions of what Ryley's skin might look like. When I pulled up information on the computer and saw the pictures, it was like nothing I had imagined. My heart broke, knowing that this precious child would live the rest of her life with something so rare. Ryley's doctor advised us to learn as much as we could. It has been my goal, since then, to learn as much as possible, any way possible, and to get the word out so others are aware of this rare skin disease.

I learned of the Foundation for Ichthyosis & Related Skin Types and was excited to know there was an organization that could help us gain more knowledge and meet others with this rare disease, so we could have the support system we needed. Ryley's mother, Shauna, and I attended our first conference in Philadelphia. We learned more than we could ever imagine, and we were so excited. We couldn't wait until the next conference, when we could bring Ryley with us.

As the conference in Seattle drew closer, I was somewhat worried about how our family could get there. Although it was most important to get Ryley there, I felt it was also important for those closest to Ryley to be there and learn as much as possible. After all, the whole family looks after her well-being and sees to her needs. But getting us all there was going to be hard.



Karen Price, far left, with family (left front to right) Alexis Johnson, Shauna Johnson, Ryley Ann Johnson, and Vicky Johnson.

An opportunity came to me in December 2001. After suffering from obesity most of my life, I lost 165 pounds taking an herbal weight loss product. The company who made the product ran a contest in which you had to write your weight loss story. The prize was \$10,000! I almost didn't enter. Then I read that the application asked what you would do with the money if you won. I didn't think twice about what I would do. I wanted Ryley, her parents, Shauna and Mike, her sister Alexis, her other grandparents, my husband, and me to go to the conference in Seattle! The conference would be the perfect opportunity for all of us to learn more and for Ryley finally to meet others like her with lamellar ichthyosis.

In January 2002, E'ola presented me with a check for \$10,000. Yes, I won and we were going to Seattle! We shared our story on the news and in the papers, and

as a result communicated with others in our state with ichthyosis.

The conference was very informative, and we received many ideas on how to deal with Ryley's lamellar ichthyosis. But more important, Ryley realized for the first time that she was not alone. The support from others who suffer from a rare disorder and their families makes it all easier to deal with. I want to thank the doctors who were on hand for their research, for the knowledge they share, and for the time they spent with each individual. You are wonderful!

I have so much to be thankful for, especially for our little Ryley, who has helped us learn, love, and accept. Thank you, also, F.I.R.S.T. for all your hard work and efforts in helping us learn more about this rare disease.

**Karen Price
Clearfield, UT**

ASK THE READERS: What Do You Do?

Dear Readers: The "Ask the Readers" column was designed as a forum for our members to share effective solutions to some of the challenges of having ichthyosis. Lately we have had very few responses to the column. We would really like to hear from you; you are the Foundation's best resource for information and solutions. If it seems that this column is not of interest to our readers, we may make the space available for other information. Please let us know how you feel. **Sincerely, Jean and Maureen**

What strategies have you and your doctor found helpful in getting your health insurance provider to cover some or all of the cost of your ichthyosis treatments?

My daughter, Abby, has lamellar ichthyosis complicated by eczema. In the past, my doctor sent a letter of medical necessity to our insurance company, and they covered the cost of her *Aquaphor*. She also sent a letter requesting that *Derma Smooth*, which we use to control her eczema, be covered and dispensed as a maintenance drug. This allowed us to get three refills for the cost of two. The doctor explained that Abby's ichthyosis created special circumstances with the eczema.

Due to changes at my husband's job, our old insurance is no longer offered, and our new one will not cover either the *Aquaphor* or *Derma Smooth* in this way. It never hurts, however, to ask what your insurance company can do for you. Just realize that not all companies will accommodate you, and they don't care what the previous company did.

**Rhayne Evans
Hompstead, MD**

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

I have discovered a remarkably effective treatment for EHK. I am a forty-two year-old man, born with a severe case of EHK with blisters and joint deformities. My life was nothing but pain and misery every day.

One day, I ate some beets, ordinary red beets out of a can. Within a few days my skin cleared up like magic. Most of the scaly stuff came off, and I was clean and decent for the first time in my life. This is not a "cure." I still have the disease. There are a few dry spots and the skin still grows. I still get blisters, but the thick scaly stuff is gone, and I look like a normal human being for the first time ever.

It is important that the beets be used correctly. They stop working if I eat them too much or too often. I eat four large slices or five smaller slices twice a week, on Sunday and Wednesday. If I eat them more often they stop working. But if I am careful to take precisely this amount every week, it continues to work. This strategy has been working for me for over a year now. Please share this news about beets with everyone.

Bill Dault

J.R. and Chandra Rogers shared this strategy for dealing with the questions and concerns of strangers with members in attendance at the 2002 National Family Conference in Seattle.

Chandra has lamellar ichthyosis. When strangers ask questions about her skin and her appearance, she hands them a business card that reads:

"While I understand people ask about how I look out of concern for me or to increase their knowledge, I don't like being asked personal questions by strangers — as do most other people who don't look like the person that's asking. If you really want to help people with ichthyosis, or anyone else, please send a donation to the Foundation for Ichthyosis & Related Skin Types, 650 N. Cannon Ave., Suite 17, Lansdale, PA, 19446, or call 1-800-545-3286. Or donate to any medical foundation, charity or human rights organization of your choice. Thanks for any help you can give."

**Chandra and JR Rogers
Beaverton, OR**

Our Trip to Camp Horizon

By Jean Pickford

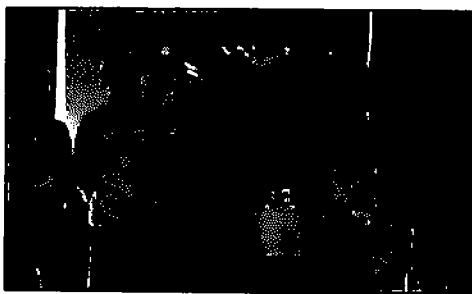
In the middle of August on a very hazy, hot, and humid day, Maureen, our Program Director, and I rolled out of bed at the crack of dawn. After the morning's shower and coffee our heads were clear, and we both shared our excitement about volunteering for a day at Camp Horizon. We jumped into Maureen's Jeep and drove to Millville, Pennsylvania.

Camp Horizon is a weeklong camp for children with skin diseases. It is completely funded by the American Academy of Dermatology, so the child's family does not pay for any expense, including travel. The camp director is Howard Pride, MD, a dermatologist at Geisinger Medical Center. Howard's wife, Kathy, and countless volunteers provide an opportunity for kids, ages eight to twelve, to participate in the full camp experience.

The campers were affected with many different types of skin disease. There were children with Alopecia Areata, Atopic Dermatitis, Congenital Nevus, Ectodermal Dysplasia, Epidermal Nevus, Epidermolysis Bullosa, Epidermolytic Hyperkeratosis, Lamellar Ichthyosis, Congenital Ichthyosiform Erythroderma, Mastocytosis, Mycosis Fungoides, Netherton Syndrome, Neurofibromatosis, Pityriasis Rubra Pilaris, Port Wine Stain, Psoriasis, and Vitiligo.

The camp is situated on twenty acres of beautiful land in the rolling hills of Central Pennsylvania. There are multiple cabins with cots and bunk beds, but no air-conditioning. This presented quite a problem during camp week, since temperatures reached the high 90s. Fortunately, the Med Shed is air-conditioned, so children with overheating issues had a respite. When the night air settled in and the sun went down, the temperature was tolerable. The heat did not seem to bother any of the campers, though. They remained spunky, well mannered, and eager to do more.

After formal introductions with the camp counselors, dermatology residents, and nurses, Maureen and I were assigned our first task. We headed to the big pavilion for arts and crafts. The campers, 80 in all, were broken up into small groups, each headed by qualified camp counselors. Many of the camp counselors had a



skin disease themselves. The groups moved from activity to activity throughout the morning. Maureen helped apply glitter and pipe cleaners to a hat, while I sat on the ground sorting through foam letters to spell "Devon." The "v" was hard to find. Since "crazy hat" night was the next evening, this was serious business. While sitting at the hat table, we could see others making tie-dyed shirts, pillowcases, and socks.

Before we knew it, it was time to eat. Howard rang the familiar bell to let everyone know lunch was ready. We assembled in the dining hall and sat down to enjoy a salad and pizza slices. As usual, Howard addressed the campers about the afternoon's activities. The camp counselors, given the afternoon off, were taking advantage of this time by cruising to the local mall for "real" food, shopping, and air-conditioning.

After lunch each day, the individuals affected with ichthyosis gather to talk. Since Maureen and I were available on this day, Howard made a special announcement to encourage everyone with ichthyosis to meet for an hour in the mess hall. We talked with quite a few campers about the Foundation and its services. Many shared their feelings about skin care products, their friends, their

school, and other issues that were important to them. We answered many questions and made some great friends.

Afternoon activities were plentiful. The campers could rotate among rides on motorcycles (sponsored by the local Harley-Davidson chapter), archery, swimming, arts & crafts, hair braiding, rock climbing, dancing, or fishing. Maureen and I helped at the archery station for most of the afternoon. We blew up balloons to use as targets and walked campers back and forth to the bathroom. It is amazing to see these kids in action and what they can do. Near the end of the afternoon, our services were needed in the swimming pool. (Boy, were we happy!) We swam, played water basketball, and monkey-in-the-middle.

In the pool, I befriended a neat kid affected with Epidermolytic Hyperkeratosis. He challenged me to climb the rock wall. I couldn't pass up the contest, so we headed into the woods where two trained volunteers were manning the rock wall. After getting harnessed into the safety equipment, I surprised myself and made it to the top. My new friend was on the ground encouraging me all the way up. It was hard to believe he was only 11. Soon it was my turn to return the favor. I could see he was getting tired halfway up the rock wall. I gave him the same encouragement he had given me. He outdid himself and reached the top! It was a proud moment for both of us.

At 5:00, the camp counselors were returning from their excursion, and it was time for us to head back home. It was my daughter's second birthday, so I wanted to be home in time for cake and ice cream that night.

It was a wonderful experience for both Maureen and me. Camp Horizon is truly an exceptional program. During the time we were there, we saw children with very mild skin disease to children with major skin problems. But everyone played together and spent time getting to know each other. There was no staring, pointing, or teasing. There was only fun, creativity, and genuine friendship. It was an honor to be a part of this exceptional camp.

Jane Bukaty Membership Assistance Fund

The Foundation is now accepting applications to the Jane Bukaty Membership Assistance Fund for the next review period, which will end in December. Here is an opportunity to alleviate some of the financial burden that may be facing you or your family. It's easy to apply and you will receive the award in cash, if your application is accepted.

To apply:

- Submit a letter stating your need for help.
- State the amount of money you are requesting. Awards generally do not exceed \$100.00.
- Indicate the product or treatment for which you need the funding.

- Describe your financial need for this product or treatment.

Email a request for an application form to info@scalyskin.org or call 1-800-545-3286. Completed forms may be mailed to the Attention of the Jane Bukaty Membership Assistance Fund, 650 N. Cannon Avenue, Suite 17, Lansdale, PA, 19446. **The deadline for applications is December 31, 2002.** The awards will be given in March 2003.

Donations to the Jane Bukaty Membership Assistance Fund are always appreciated and enable the Foundation to make this fund available to more of our members.

Ichthyosis Awareness Week

Ichthyosis Awareness Week was celebrated this fall during the week of October 6 - 13. Many of our members found ways to promote awareness and understanding of ichthyosis in their communities. Watch the next issue of the Focus for details on what they accomplished.

It is not too late for you to participate in ichthyosis awareness activities. All members of the Foundation are encouraged to promote ichthyosis awareness and knowledge. Any effort, at any time of the year, is appreciated. Call the national office at 1-800-545-3286, or email us at info@scalyskin.org to ask for suggestions, advice, support materials, or to let us know your plan.

If you accomplish some activity during Ichthyosis Awareness Week, please let us know what you did and what the outcome was. Write to us at the National Office or email us. We will include a report of your ichthyosis awareness activity in the next Focus. We would love to have pictures too.

The Foundation sent a press release promoting Ichthyosis Awareness Week to over sixty media outlets nationwide. If you see any details about Ichthyosis Awareness Week in your local newspaper, please save the article and let the National office know about it!

Ichthyosis Vulgaris and Overheating

Ichthyosis vulgaris is the most commonly seen form of ichthyosis, but it is also the most difficult to diagnose. The genetic cause of the disease has not been identified, so doctors rely on a short list of symptoms to help confirm the diagnosis. A skin biopsy may narrow the diagnosis, but there are times when the biopsy is inconclusive.

Overheating is not considered a common hallmark of ichthyosis vulgaris. However, we have had many members tell us that they do experience significant overheating with their ichthyosis vulgaris. Jean and I have brought this to the attention of our medical advisors and they have listened. In order to educate the medical community, and possibly update the medical literature, we will be publishing a survey concerning ichthyosis vulgaris and overheating in a future issue of this newsletter. The survey will be designed with the help of our medical advisors so that the results will provide accurate information to the medical community, and to the Foundation. Watch future issues of the newsletter for this important survey. Please plan to participate and help us to document your experience with your disease.

Maureen Tierney, Editor

Amy Paller, MD, Medical Editor

Seniors Speaking

continued from page 5

Hello,

I am not sure of just how I became aware of F.I.R.S.T., but the literature I received was the first time in my seventy-eight years that I actually learned about my skin condition. As a result, I took part in a study and test of a lotion for this condition. I know now that I have ichthyosis vulgaris and have found that Lac-Hydrin, recommended by my dermatologist, has helped greatly. And it is far superior to using Vaseline for most of my life.

I want to thank F.I.R.S.T. for making me aware that there is help for people who have skin conditions.

Joseph G. Toth, St. Louis, MO

Hello Seniors,

I am an elderly lady who has ichthyosis. Whenever I am ill, overheated, or feverish, I break out in painful red blotches all over my body. It gradually recedes in about a week. I wonder if anyone else has this problem and how they handle it.

B. A. S.

Brookfield, IL

News & Notes

Congratulations

The Foundation wishes to extend its warmest wishes and congratulations to our hardworking friends at the National Registry for Ichthyosis and Related Disorders, Geoff Hamill and Kim Pineda, on their recent marriages. Geoff and Kelly Heuga were married on August 24, 2002 in Seattle. And Kim and his bride, Marika Thompson, were married on August 10, 2002, also in Seattle. We wish both couples a long happy, healthy, and prosperous life together.

NORD Legislative Update

There are very few days left in the legislative session in Washington, DC, before the November elections and the prospects for passage of many important healthcare-related bills are at risk. Both parties are gearing up for a critically important election in November with control of the House and the Senate in the balance. So if you want to make a difference today, now is the time to call your Senators and Representative and let them know that the

time for politics as usual has ended. Let them know that you want Congress to act on the issues important to you, your family, and your friends. Call the Capitol switchboard at 202-244-3121 and operators will connect you to your Senators and Representative. For in-depth information on pending health-care issues, go to <http://www.rarediseases.org> (and click on the Washington office page), or call NORD at 202-496-1296. Or go to <http://thomas.loc.gov>, the official site of the U.S. Congress. Below is a summary of some of the pending legislation that the National Organization for Rare Disorders (NORD) has been actively pursuing in this Congress:

Genetic Non-Discrimination in Health Insurance and Employment Act — S.318 / H.R. 602

The Genetic Non-Discrimination in Health Insurance and Employment Act would prevent health insurers from using predictive genetic information to “deny, cancel, or change the rates of and condi-

tions of insurance coverage.” The bill would further prohibit the use of predictive genetic information by employers in hiring, firing, promotion and other employment-related decisions.

Rare Diseases Legislation - S.1379 / H.R.4013 / H.R. 4014

This landmark legislation would increase funding for both the Office of Rare Diseases at the National Institutes of Health, and the Orphan Product Research Grant Program at the Food and Drug Administration.

The Family Opportunity Act - S. 321 / H.R. 600

The Family Opportunity Act of 2000 is intended to address the two greatest barriers preventing families from staying together and maintaining employment — 1) lack of access to appropriate services and 2) lack of access to the advocacy and assistance services they need to help cut “red tape” in meeting their children’s healthcare needs.

2002 Coalition of Patient Advocates for Skin Disease Research STRATEGIC PLANNING RETREAT

September 6-7, 2002
Bethesda, Maryland



From left to right: Vicki Kalabokes (Alopecia Areata), Shannon Hearron (Vitiligo), Jean Pickford (Ichthyosis), Judy Jones (Mycosis Fungoides), Malinda Heuring (Ectodermal Dysplasia), Lisa Gallagher (Alopecia Areata), Irene Crosby (Eczema), Vicky Whittemore (Tuberous Sclerosis), and Linda Falconiero (PXE).
Not pictured: Tara Rolstad (Psoriasis).

The Foundation is a member organization of the Coalition of Patient Advocates for Skin Disease Research. The mission of this coalition is to support basic science and clinical research, disseminate information to patients and professionals, foster public education and awareness of skin diseases, facilitate in the sharing of mutual experiences and concerns, and address patient care. On September 6 and 7, Jean attended a weekend retreat in Bethesda, Maryland, to evaluate the coalition’s effectiveness, advance its mission, and strategically plan for its future. The desired outcome is to make the coalition a stronger advocate for patients affected with skin disease. Thank you to Fujisawa, Inc. for their generous financial support of this meeting. Fujisawa’s donation of \$14,000 enabled our member groups to meet face-to-face for this important retreat.

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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.¹

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>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.

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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.

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