Ichthyosis Focus

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

Vol. 22, No. 2 | A Quarterly Journal for Friends of F.I.R.S.T. | Summer 2003

Fears, Be Still

By Justine O. Seman, LSW

When we first descend into the world of weird skin diseases, it is a frightening and lonely place. We quickly become our baby's first protectors, teachers, and daily skin specialists. Through time and effort, we overcome our anger and confusion, fears and sadness and settle into a steady routine of creaming, bathing, and enjoying our baby. During our toddler days, we handle "skin issues" with a measure of confidence because we control the volume of staring strangers, limit exposure to the steaming sun, know what band aids stick, feel whether our child is overheated, or give them a cue to ignore idiotic comments from others. As in the eye of a hurricane, our mood brightens and we realize a day has gone by where we have not once thought of our child's skin.

Then, they start school. Confusion, fear, anger whirl around again. We formulate a list of terrors to plan battles against in order to cope with dangerous new elements. Is the bus too hot? The classroom? Will the school staff react to our child's appearance like rude jerks? Will the other kids act horrified or disgusted when they see our child? These thoughts; piled on the usual concerns about academic readiness, on top of our own queasiness upon seeing and smelling an elementary school, are enough to send us running for Home School guides.

Fears, be still. There are actions we can take to keep our skin-challenged children safe and happy. Examining the potential dangers is the most important action. We must assess the physical environment of the school. Is it sweltering and sterile, or comfy, cozy, and welcoming? Is the physical education department run with Gestapo tactics, or is it encouraging of a child's strengths and forgiving of weakness? Is the school/classroom clean enough if my child goes shoeless or has a tendency towards infection? We have to gather our courage ever tighter when we hand over our precious ones to the in loco parentis. It is a daunting challenge.

School personnel can be your allies or nemeses. Just as we educate medical staff, we share our wondrous specialty with teachers. Training of staff begins before your child walks to school that opening day. If your child with ichthyosis is your first child in the school, it will require more effort than if you already have children there. You'll have to judge how big skin issues will be. A visit with your child to the school nurse is a good place to start. The nurse can help you assess the school's response to your requests. She is often your best ally in explaining skin matters to school staff. Help her by providing a written description of ichthyosis, emphasizing that it is not contagious. Be realistic about your child's needs as well as the school's ability to accommodate your requests quickly.

When my son Tom began kindergarten in Texas, I directed the school in writing, " If the temperature is 85+ degrees, my son will become feisty, irritable, argumentative, then tired and lethargic. Always honor his request for water, shade, or air conditioning, or he will get heatstroke AND DIE." By communicating directly in writing to key players in the school theater, we can assure our child's safety. Key players are, at minimum, classroom teacher, nurse, and principal. While house hunting in San Antonio, I found it best to reside near his school to avoid busing. Now, living in Pennsylvania, busing is ok temperature wise, but the schools are generally not cooled, and some days he is forced to stay in the only air-conditioned room, which is the nurse's office.

We must clearly and forcefully advocate for our children's physical well being during their younger years. But, since our ultimate goal is to rear inde-

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Designate Funds

through

A United Way
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or

Giving Programs

(see page 3 for more details)

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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

Hello:

My name is Margaret Campbell. I am 77 years old and have ichthyosis. However, I don't have a clue as to which one. I really enjoy the Focus newsletter. It gives me lots of information that is helpful. I use the Problem Dry Skin (PDS) cream products. Some of them were samples sent through the mail, which I appreciate very much.

I find using a loofah sponge on my body helps to keep the flaking down and my skin appears much smoother. Please keep the newsletter coming. It's so nice to know there are people who care.

Margaret Campbell
Highland, UT

Dear FIRST:

I am a graduate student in the University of the Sciences in Philadelphia studying Biomedical Writing. I had never heard of Ichthyosis before I came across the term when I was writing about an organelle-related disease called adrenoleukodystrophy. I had an idea of what the symptoms of the disease might be, but I decided to do a *Google* search to check out the condition more thoroughly. I was really impressed by the website. It was very informative and professional. It had excellent, science-based information, and it was conveyed intelligently and at just the right level. I was so impressed that now that we're covering a chapter on skin, I plan on doing my assignment on ichthyosis.

I am also a pharmacist and have thought of a few other possible treatments. If these are generally known, I apologize. Vitamin C-containing skin products are great because they also help to improve skin turnover. Additionally (and I'm not sure if these would be too irritating, but they are really helpful in removing dry skin), St. Ives makes some wonderful apricot scrubs. They even have one with salicylic acid (called "medicated"). I use these to keep another skin condition at bay. Other helpful "beauty" remedies that work are bath salts that are mixed with oils. These are wonderful when used directly on the skin because they really trap moisture in and scrub off dead skin (but they make the tub very slippery).

On a final note, I just wanted to say that I was glad to stumble upon your website. My class assignment was to create a "brochure" on a skin condition, and many others have picked common knowledge topics such as chicken pox. I don't feel that topic will add to the class's knowledge base. Covering a condition like Ichthyosis will. I hope that in some small way, I can increase the awareness of this condition.

Julie Gerhart
Philadelphia, PA

Editor's Note

Dear Friends:

You may have noticed that the *Ichthyosis Focus* has a new look. We are working with a new newsletter designer and printer to bring a more dynamic and user-friendly publication to you. We hope you enjoy the new look and that the new graphics help you find your favorite features more quickly. Please let us know what you think of the *Focus'* new look.

Sincerely,

Maureen Tierney
Program Director, Newsletter Editor

In Memory of Peter Steinert

It is with deep sadness that the Foundation reports the passing of skin biologist Peter Steinert, PhD. Dr. Steinert was the Director of the Skin Biology Laboratory of the National Institute of Arthritis and Musculoskeletal and Skin Diseases since 1990. He died suddenly on April 7, 2003.

Dr. Steinert was a long-time friend of the Foundation and the ichthyosis community. He authored more than 200 technical articles dealing with such research interests as structural biology, molecular and cellular biology, and muscular, skeletal, and skin sciences. He recently contributed an article to the *Ichthyosis Focus* titled "Current Ichthyosis Research." It appeared in the Summer 2002 issue. Much of Dr. Steinert's research added to the body of knowledge about the ichthyoses.

Dr. Steinert was also a generous contributor to the Foundation. His will stipulated that memorial donations be sent to the Foundation, and he bequeathed a substantial gift upon his death. In honor of his dedication to ichthyosis research, his bequest has been designated for continuing research into the causes of and treatments for ichthyosis. The Foundation and the ichthyosis community have lost a true and generous friend, and a dedicated researcher. Our deepest sympathies go out to his family, friends, and colleagues.

United Way and Combined Federal Campaign Programs

The United Way of America is the national organization dedicated to leading the United Way movement in making a measurable impact in every community across America. The United Way movement includes approximately 1,400 community-based United Way organizations. Each is independent, separately incorporated, and governed by local volunteers. The Foundation for Ichthyosis is the recipient of funds from many of the United Way community-based organizations. Through the Donor Choice Program, you can designate all or a portion of your donation to the Foundation. Simply write in "Foundation for Ichthyosis & Related Skin Types" on the Donor Choice Option form, and your gift will be sent to our office. Be sure to include our current mailing address and phone number, 650 N. Cannon Ave., Suite 17, Lansdale, PA, 19446, 215-631-1411.

The Combined Federal Campaign (CFC) is the annual fundraising drive conducted by federal employees in their workplace each fall. Federal employees and military personnel raise millions of dollars each year through the CFC that benefit thousands of non-profit charities. The Foundation is the recipient of funds from many CFC organizations throughout the country. The Foundation's CFC code is 0810, which is listed in the charitable organizations directory.

Fears, Be Still

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pendent children, we must weave a strong thread of assertiveness into all our teaching. Our children must know that they have a right to tell authorities that they are very hot or thirsty and need water or a cool room. They cannot be burdened with explaining their skin condition to adults when they need to cool down. It takes some time to get all this learning and living down, so get involved. Help out on Field Day or the trip to the zoo, decorate the school with the PTA, and build relationships with the staff until you feel secure about your child's physical well being.

Kermit the Frog says, "It isn't easy being green." It isn't easy having ichthyosis. Walk behind your child in a school hallway and experience the sudden stream of negative words, sounds, and expressions generated by his or her odd appearance. It forces a heartbreakingly protective response within you and your child. Sometimes, the crush of these feelings that are unwittingly displayed upon seeing us grows a blind spot to all the good around us. How does a child deal with this? They may form a detachment from strangers. They may buffer themselves with friends as quickly as possible. They may want to withdraw into a shell. They may do all these things and more. Some things will help and some behaviors might not be for the good. When a person withdraws too far and too often and begins to feel they have no options, their worldview becomes dangerously constricted. When a child with skin challenges understands the relentlessness of the condition, but just doesn't want to cream again, thinks that no cure will be found, or that nothing better than whatever cream they're using will come along, it is a time of sad feelings. These hopeless feelings can lead to serious contemplation of suicide, even in an elementary age child.

If your or any child talks about or leaves notes around about wanting to die, it must be addressed seriously by both parents with the child. The child must understand that it is important to talk about what is concerning them and that help is available. They also need to know that suicide is not acceptable. And it is not inaccurate to say, there is greater hope now for better treatments than ever before. The child should be offered counseling when they feel this low. Direct the child to the Foundation for Ichthyosis website, and help them to meet other kids with ichthyosis. Peer-to-peer works wonders for adolescents and young adults. Most importantly, these feelings must not be ignored or denied.

Legal statutes such as 504 Education laws, Special Education laws, or IDEA laws are used to insure enforcement of safety measures for our children. The gold standard of Special Education laws has always been "the most appropriate education" and "the least restrictive environment" concepts. School districts require that a student be tested in order to receive any services that are considered "special." The testing typically entails a thorough psychological test (commonly known as IQ testing), academic testing, learning disabilities tests, and a parent report regarding developmental milestones, health history, and medical information. The process can take up to 90 days.

Children usually enjoy the testing because of its one-on-one nature and because the staff is trained to help the child give his or her best performance. The information obtained about your child is available to parents by law, and it should be thoroughly explained by the staff that performs the tests. If these reports were ordered privately, they would cost hundreds of dollars; so don't be embarrassed to see your tax dollars at work. The end result of school testing could bolster your request for air conditioning, special busing, gym exemptions, etc. They could also detect learning challenges that require remediation.

During your interactions with the school staff, especially at any meetings in which educational decisions are made, keep foremost in your mind that you are the most powerful member of the school team. Your signature stops or allows any changes to occur. My biggest nightmare as my son approached middle school was that he might encounter a physical education teacher who was unaware of the potential for Tom to become overheated and might demand more of him than was appropriate. I allowed the school to classify him under Section 504 laws as having a physical handicap, but he obtained no "special services." In a school of a thousand students, it was a clear way to assure myself of some extra attention from the staff.

It is important to remember that our children are much more than just their skin. Healthy self-esteem is created by completing undertakings and forging friendships. All their talents and dreams should be encouraged and supported. How our children are treated and how they treat others will shape their lives. Keep the children connected to others, allow them to observe how others deal with handicaps. Connect their experiences of discrimination to the larger world. And, encourage a sense of hopeful waiting for the day when skin matters don't matter at all.

Editor's Note:

Dealing with school issues can be frustrating for you and your child. New problems frequently appear as your child moves forward in his or her school career. The Foundation has materials that can help you educate your child's teachers and school staff about your child's disease and unique needs.

If you have dealt with a particular school issue in a creative way, please let us know so we can share your strategy with other parents. Contact Maureen in the national office, by phone at 800-545-3286, or email at info@scalyskin.org, to request help or to share your story and strategies.

* * *

Dealing with Skin Disease Face to Face

By Karen Mallin, Psy.D.

The profound impact of skin disease on children's lives is not disputed. The stigma of disfiguring skin disease creates considerable challenges in maintaining self-esteem, building self-confidence, and coping effectively with the invasive and often rude negative reactions of peers and others. Attempts have been made to determine by which age children acquire the negative reactions to visible differences and disfigurements that adults show. One study found that children begin to make negative judgments based on minor differences in facial appearance around the age of eight. Younger children tend to ask questions out of curiosity and interest. This finding has significant implications for pediatricians, psychologists, teachers, parents, and others who are in contact with and treat children with skin disease. It suggests that adults need to address how to teach children the skills needed to divert insensitive questions and taunting from bullies. Unfortunately, little attention has been paid to the psychological and social problems directly experienced by children who are considered different or unattractive because of their skin disease.

Because skin diseases often affect a child's appearance, the effect on their social and emotional functioning may be different from, or more complex than, other less visible diseases. Self-perception relates to the way the child's skin disease makes them feel about themselves. Negative self-perceptions are common among children with a skin disease and can often include lack of self-confidence, frustration, shame, embarrassment, feelings of social isolation, inferiority, low self-esteem, anxiety, depression, anger, and worry about others' negative opinions of them due to their visibly different skin. Early identification of these and many other psychosocial problems is important for both the child and the family, so they can build the skills needed to counter these possible negative outcomes.

Addressing the culture of meanness.

School is the most powerful social environment a child can experience. The family teaches a child the social skills necessary to interact with others, beginning in infancy. In the school setting, the child is challenged to prove those skills with peers and adults in authority. For children with a skin disease that makes them stand out from the crowd, the challenge becomes difficult.

The following should be considered to assist parents in finding ways they can help and support their children. It is important to listen to how children feel about their appearance to understand better what influence a skin disorder has on their emotional and social adjustment. The effects of skin conditions on emotional states often vary greatly among children depending on the severity of the disease, their coping ability, temperament, age, family and peer support systems, and the child's understanding and perception of their disease. Several studies have found that parents' attention to emotional and behavioral problems in children can actually lead to improvement in their child's skin disease. In addition, the type of family support system available to the child is consistently recognized as a contributing factor to psychological and social adjustment.

Improving children's quality of life.

The best predictor of a child's ability to adapt to circumstances later in life is often current functioning. Parents can help facilitate their child's healthy adapting as they prepare for the school year. That parents educate teachers, school administrators, and the child's classroom at the beginning of the school year about the nature and physical impact of the skin disease is key. The discussion should include information about the child's unique abilities and strengths, so they are not defined solely by their disease. Explain why children may be limited by their disease at school, such as not being able to participate in physical activities. Often, children with skin diseases are not taken seriously or given the individual respect they deserve. The extent to which the disease interferes with the child's ability to get their work done at school, being on time, communicating with classmates and teachers, being effective in discussions, and participating fully in special

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Ichthyosis Awareness Week

National Ichthyosis Awareness Week

The Foundation relies on its many members to help educate our local communities about ichthyosis. Now is the time to think about getting involved in an awareness week activity for this year.

October 5 through October 11 2003

Who: This national awareness campaign has been created for you, our members, and all those who are affected by ichthyosis. It is for all the beautiful children who journey through childhood with different-looking skin, adults who enjoy life despite the relentless hours of skin care, and the seniors who see hope through the eyes of their family.

What: One week out of the year in which our members host awareness campaigns and fund raising events to raise money and educate the public about ichthyosis.

When: Ichthyosis Awareness Week will be officially celebrated during October 5 – 11, 2003. In actuality, Ichthyosis Awareness Week can occur anytime during the year – when you can devote your energy to raising awareness or funds for the Foundation.

Where: The possibilities are limitless! Awareness and fund raising can take place anywhere in your local community, such as your yard, a local park, a supermarket parking lot, your child's school, the YMCA, your church, etc.

Why: Educating your local community can make life a little easier for those who are affected. The simple knowledge that ichthyosis is a genetic skin disease which is not contagious, a bad sunburn, or the result of poor bathing habits can help the public better understand the disease and its symptoms.

How: For those of you who have experience putting together fundraisers or creating publicity for an event, we encourage you to use your skills. Be creative and organize something that interests you and your family, or is popular within your community. As always, the Foundation staff is available to help you in any way or provide literature for distribution to your audience.

For those of you who have always wanted to do something to help raise awareness and money for the Foundation, but have little experience…we have the answer!! The Foundation staff created an easy-to-follow manual of how to organize a grassroots fundraiser. It is available free of charge to anyone who requests it. It contains great information about how to contact your local media and the essential steps to create a successful event, plus much more. Please call the office at 800.545.3286 or email us at info@scalyskin.org with your mailing address to receive a copy.

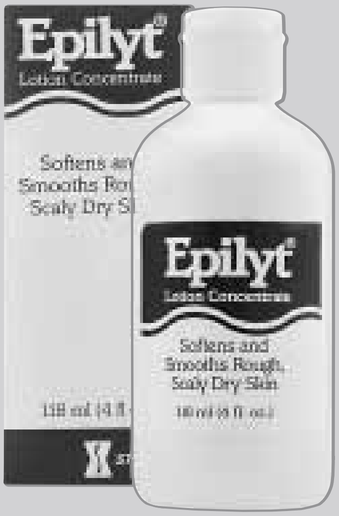
Here are some ideas to help get your creative juices flowing:

- Auction
- Bake Sale
- Bingo
- Book Sale
- Bowl-a-thon
- Candy Sale
- Car Wash
- Collection Cans
- Dance
- Distribute brochures to your community
- Dog Wash
- Donations in lieu of birthday gifts
- Dress Down Day at Work or School
- Garage Sale
- Golf Tournament
- Halloween Costume Contest
- Punt, Pass & Kick Contest
- Raffle
- Skate-a-thon
- Submit a personal story to local newspaper, radio or TV stations
- Submit a personal story to your company's newsletter
- Walk-a-thon
- *Release the Butterfly* Fundraiser – This fundraiser is easy to do and has been very successful in previous years. Order a batch of colorful butterfly shapes from Tracie Pretak and place them in your local community businesses for sale at $1.00 each. Community members can have their names written on the butterfly and posted in the store. You can contact Tracie directly at 814.929.5970 to order your butterflies. ✻

The National Ichthyosis Registry Needs You

The National Registry for Ichthyosis and Related Disorders wants **you** to enroll yourself or your family in the Registry. Enrolling in the Registry offers you a number of personal benefits, as well as benefits to the whole "ichthyosis community." Some of those benefits include: confirmation or clarification of your diagnosis; genetic testing and counseling; and promoting the understanding of ichthyosis, and how it affects individuals with the disease, to the medical and research communities. The Registry's connection to the medical and research communities is particularly important right now. This year, President Bush signed into law two acts that are critically important to the rare disease community. The Rare Diseases Act creates an official Office of Rare Diseases at the National Institutes of Health, which will promote and coordinate research on rare disorders. The Rare Diseases Orphan Product Development Act provides millions of dollars a year for clinical trials of new drugs, diagnostic tools, medical devices, and medical foods for rare diseases. These new laws are creating an environment where, at the highest level of our government, research into rare diseases is considered important.

The National Registry stands ready for this focus on rare diseases research with an extensive database of information from individuals affected by the ichthyoses, characterizing their disease types and how their disease affects them, and a list of well-characterized individuals willing to consider being research participants. Please consider joining the Registry and helping to provide a valuable resource for investigators interested in studying and treating people with ichthyosis. To contact the Registry, call 1-800-595-1265, or email info@skinregistry.org, or visit their website at www.skinregistry.org.



Executive Director's Report

Dear Friends and Members of the Foundation:

Summer is a busy time in the Foundation office. Some of the major initiatives and programs that the staff is focusing on include:

Research

Raising money for research is a priority within our five-year strategic plan. A lofty goal of $100,000 has been set for the Foundation to achieve in the first year. I am proud to announce that the campaign has raised almost $35,000 in just five months. This is a major accomplishment for a small group representing a rare disease. Congratulations to all! I am grateful for the commitment from our membership to this program. Please continue your support of our important work. The Foundation could not survive without you!

Last year, the Foundation committed $40,000 for research through the 2003 Dermatology Foundation Grant Program. I am pleased to announce that the award recipients are Jiang Chen, MD, at Baylor College of Medicine, whose research will focus on "Testing Gene Therapy Approaches for Epidermolytic Hyperkeratosis," and Gabriele Richard, MD, at Thomas Jefferson University, whose research will focus on "Mapping the Clinical and Genetic Spectrum of Connexin Defects in Disorders of Cornification." Congratulations to both of these outstanding researchers. You can look forward to more information about these projects in the future.

Ichthyosis Support Network

Another benefit to serving in the Ichthyosis Support Network (ISN) has just been added, the *ISN Exchange*. The Foundation established an email list serve through which all members of the ISN can communicate with one another via email. Members can post questions, thoughts, or concerns and receive replies from other individuals who are experienced with ichthyosis. If you are interested in becoming a volunteer in the Support Network, contact Maureen in the national office at 800.545.3286 or info@scalyskin.org.

Membership Renewal

Don't forget to renew your membership for 2003. Our renewal campaign was included in the last newsletter, Spring 2003. If you have misplaced the envelope, please let us know. Your membership fee for one year is only $35.00. If the office does not hear from you, your name may be deleted from our database, and you will stop receiving the newsletter and other mailings. Our office accepts Mastercard, Visa, and American Express, so don't hesitate to call us; we can take your membership renewal over the telephone. You can also renew online at our website, www.scalyskin.org; and click on "Become a Member."

Upcoming Events

The office is busy preparing for several upcoming events. In October, the Foundation will celebrate Ichthyosis Awareness Week (see page 6 for more information). In November, the Foundation's Board of Directors will meet for their bi-annual face-to-face retreat in Philadelphia. And, finally, our staff is busy planning the 2004 Family Conference, *A Fountain of Knowledge*, to be held in Kansas City, Missouri.

Sincerely,

Jean

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.

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

Special Offer

For Readers of this F.I.R.S.T. Newsletter

MANUFACTURER'S COUPON | EXPIRES 06/30/2005

Save $2.00
on any
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Product

(NO TRIAL SIZES)

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Consumer: Coupon good on the purchase of any Aquaphor® product, no trial sizes. Limit one coupon per item purchased. Any other use constitutes fraud. Not good with any other special offer. Consumer must pay sales tax.
Retailer: You are authorized to act as our agent to redeem this coupon and we shall reimburse you at face value plus 8¢ handling in accordance with our redemption policy. Copies available upon request. Offer void if copied and where prohibited, taxed or otherwise restricted. Cash value 1/100¢. Mail to: Beiersdorf Inc, PO Box 880504, El Paso, TX 88588-0504. Good only in USA.

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Conference Chatter

A Fountain of Knowledge

2004 Family Conference
July 2 — 4, Kansas City, Missouri

You Came, You Spoke, We Listened…

Exciting plans are underway for the 2004 Family Conference, *A Fountain of Knowledge*. The Foundation staff is creating a special program designed to meet the needs of every family member affected by ichthyosis. Your feedback from the 2002 conference in Seattle provided us with valuable information about our members' needs and desires, which will help make the upcoming conference a wonderful experience for everyone.

Of particular note is our members' request for more time together. Based on this suggestion, the conference will begin midday on Friday, July 2, and conclude on Sunday afternoon, July 4. The program will include plenty of time to socialize and experience all that Kansas City has to offer. Did you know that Kansas City is second only to Rome, Italy, in the number of fountains found in the city?

Keeping Your Registration Costs as Low as Possible…

Many members face a financial challenge in attending the family conference. The combination of travel costs, hotel accommodations, and spending money can quickly add up to a big expense. Our staff is keenly aware of these challenges and is working to make the conference as affordable as we can.

Because the conference can be a life-changing experience, our goal is to have as many members as possible attend by keeping program expenses and registration fees low.

How You Can Help…

The registration fees you are asked to pay cover less than half of the true cost of your attendance. The Foundation staff works very hard to secure sponsorships and donations from generous individuals and corporations to make up the difference and ensure an enjoyable and successful conference. This year we are asking for your help to reach our goal.

You will be surprised how easy it is to raise funds for something that is important to you and your family. When you approach someone who knows you, your enthusiasm will shine through and become contagious. Your energy can turn into something greater than you imagined. Please just take that first step and ASK your employer or organizations that know you for conference support. Many companies and organizations make charitable contributions to causes that are important to their employees and members. Every donation is tax-deductible, which provides an additional incentive. Your company or organization may ask for a formal request. We have attached the following page of information for you to use when soliciting for a donation.

The Possibilities…

Let's shoot for the moon! If each of you secured a $500 donation to help underwrite conference expenses, we could host the best conference in the Foundation's history!

* * *

Fall 2003

Dear _____________:

The Foundation for Ichthyosis & Related Skin Types, Inc., a national non-profit organization, will be hosting a family conference on July 2 - 4, 2004. The conference will bring together families who are affected by ichthyosis, a set of rare genetic skin diseases, and related diseases.

Founded in 1981, the Foundation is the only organization in America devoted exclusively to helping individuals with ichthyosis and their families. Because ichthyosis is so rare, people affected by the disease can feel alone and isolated. The family conference provides an opportunity for affected individuals and their families to meet others with the same diseases. The conference provides them the opportunity to talk with others who share the same experiences, and with physicians who specialize in treating ichthyosis.

In addition to spending personal funds to travel to the conference, members need to pay a registration fee to help the Foundation defray food and beverage costs. The Foundation must also spend its own funds to cover the costs of items necessary for a successful event, such as audio visual equipment and room rental fees.

I am requesting your help in supporting the 2004 Family Conference, *A Fountain of Knowledge,* with a fully tax-deductible donation. Please complete the section below indicating your support of this important event. Because the Foundation is a small organization, it relies on the generosity of our corporate friends and individuals to help fund our activities.

Name____

Company ____

Address ____

Phone __________________________ Email_______________________________

I/We are proud to support the 2004 *Fountain of Knowledge* Conference with a donation of
___ $500 ____ $250 _____ $100 _____ Other

Please make checks payable to the "Foundation for Ichthyosis" and mail to 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446. The Foundation's federal tax identification number is 94-2738019. **Thank You.**

All contributions are tax deductible to the full extent of the law. A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

Dealing with Skin Disease Face to Face

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projects is important for a positive quality of life.

These factors give rise to the primary reason why parents seek psychological treatment for their children who suffer from skin disease.

Communicating with others effectively.

This is the most empowering skill one can have. Children learn to express themselves, convey emotions to others, and stand up for their beliefs by observing how their parents do this. Often, when someone unknown asks an insensitive question of a young child, the parent steps in to reply. Parents who respond with positive, simple, straightforward explanations usually experience a more positive exchange. For individuals who are intrusive or rude, an assertive rather than aggressive answer demonstrates who is in control of the situation and who is out of line. Children listen to these exchanges, learn from them, then practice these skills by role playing. Hearing of their positive features and abilities from parents' conversations also reinforces a positive self-esteem. Children prepared with several responses to social queries also learn they have choices of how much to share depending on their feelings and that talking about their skin disease is actually okay.

Dealing with the culture of meanness.

The start of the school year is always a stressful time, especially for young children entering school for the first time. Children become exposed to many new peers and have less adult supervision. Kids are curious by nature and will ask questions of someone who appears different from themselves. Those adopting the attitude that most children are friendly can usually handle the occasional teasing all children experience at one time or another. However, there are some bullies who, because of their own insecurities, prey on those appearing weaker or more vulnerable. Often, they choose children who lose control of their emotions easily. To reduce this occurrence, children can be taught a two-step approach. First, respond with a non-emotional comment that bullying behavior isn't appreciated and that it needs to stop. Secondly, convey a sense of self-confidence by leaving to be in the company of more accepting children. Friendships can boost self-esteem, offer support, and help teach important social skills. If bullying behavior continues, parents should step in and involve the teacher and principal for school-wide problem solving.

Remaining positive and demonstrating a sense of humor.

A quick wit and healthy sense of humor is the best defense to all social pressures from the outside world. Help your child put things into perspective and emphasize keeping a positive viewpoint. You will then see your child's successful responses to the challenges they meet face-to-face on a daily basis.

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Foundation Resources

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 is 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 800-545-3286. Completed forms may be mailed to the Attention of the Jane Bukaty Membership Assistance Fund, 650 N. Cannon Ave., Suite 17, Lansdale, PA 19446. **The deadline for applications is October 31, 2003.** The awards will be given in December 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.

Australia / New Zealand Support List

Members of the Foundation who live in Australia or New Zealand are welcome to place their name on a support contact list for those countries. The list will be maintained by the Ichthyosis Support Network and will be shared only with individuals looking for support contacts in those countries. If you would like to be a resource person for someone else with ichthyosis in Australia or New Zealand, please contact Maureen in the Foundation office, 650 N. Cannon Ave., Suite 17, Lansdale, PA 19446, 800-545-3286, or at info@scalyskin.org.

A current list of international ichthyosis support organizations is available from the Foundation office.

Skin Care Products List

The Foundation's skin care products list is an extensive list of over-the-counter lotions, creams, soaps, and shampoos that our members found helpful in treating their ichthyosis. The list is a few years old and could use some updating. If you are using a skin care product that you love, either over-the-counter or prescription, please share the name of the product with us. If it is not on the current list, we will add it. Call Maureen at 800-545-3286, or email info@scalyskin.org.

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WANTED:
LEGISLATIVE ACTION TEAM!!

DO YOU KNOW YOUR U.S. CONGRESSIONAL REPRESENTATIVE? YOUR SENATOR?

THEY NEED TO KNOW YOU AND THE FOUNDATION!!

The Foundation's newly-formed Advocacy Committee urges you to get to know your U.S. representatives and senators this summer. Congress "recesses" during the month of August, meaning they are not in legislative session in Washington, D.C. Usually, both the members and their staff travel throughout their congressional districts during August.

> ***August is a perfect time for you to meet with your representatives and raise awareness of ichthyosis.***

Think you don't know enough about politics in Washington and related issues to request a meeting? ***WRONG!*** *Here's a quick rundown of the basics:*

Make An Appointment. *- Call well in advance of when you would like an appointment. Contact the "scheduler" or "executive assistant" and explain who you are and what you would like to discuss.*

Staff Are Key. *- An appointment with a congressional staff member is just as effective –* some say more so! *– as meeting with the elected member of Congress. Representatives and Senators juggle many, many issues every day. The staff member is assigned to focus on several issues and is the member's eyes and ears on those issues. You should ask for the "health care legislative assistant" or the district staff person who handles health care.*

Be Flexible, Be Prompt, Be Quick. *– Due to the changing and fast-paced nature of the congressional schedule, you will have to be flexible in scheduling your meeting. Be patient, persistent, and polite. Congressional members and staff are often scurrying between meetings so they really appreciate people who do three things: show up on time; tell their story in less than five minutes; and give them reliable, good information. We have provided a tear-out sheet for you to bring along on your visit and leave behind for their information.*

Be Prepared. *– Plan what you would like to discuss. You do NOT need a specific legislative agenda to discuss, but you do need to be prepared. Simply making a face-to-face connection with a member and his or her staff is vital.*

Thank Them. *– Everyone likes to hear "thank you." Over the past five years, Congress has doubled the funding for the National Institutes of Health (NIH). This meeting is the perfect time to thank your member of Congress for supporting this increased NIH funding.*

Sharing your story and your connection to ichthyosis and the Foundation will go a long way toward advancing our cause. After you meet with your representatives, contact Jean at the national office to share your experiences. Later this year, the Advocacy Committee will be forming a Legislative Action Team, who will serve as the Foundation's key contacts for getting the word out to federal representatives on issues important to the Foundation's membership.

Don't know who your member of Congress is? Call 202.224.3121 or go to www.house.gov or www.senate.gov.

Thank you!

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Ichthyosis

What Is Ichthyosis?

Ichthyosis is a family of genetic skin diseases characterized by dry, thickened or thin, scaling skin. In some forms of ichthyosis, the natural shedding process is slowed or inhibited, while in others the production of skin cells is faster than normal.

Dermatologists estimate that there are at least twenty varieties of ichthyosis, with a wide range of severity and associated symptoms.

What Causes Ichthyosis?

Ichthyosis is the result of a genetic mutation passed from parent to child. In some rare cases, the genetic mutation occurs spontaneously in the affected person. Ichthyosis is not contagious.

How Many People Have It?

Ichthyosis affects more than one million Americans. Ichthyosis comes in many forms, ranging from mildly dry skin to intense scaling, cracked, and thick skin. The more severe types are rare.

What Are The Symptoms Of Ichthyosis?

Ichthyosis is present at conception and it is obvious at birth that something is wrong with the baby's skin. However, in some cases the symptoms do not become apparent until sometime during the first year of a child's life.

Symptoms of ichthyosis range widely depending on the type of ichthyosis involved. Some symptoms include: extremely dry skin; constant build-up of scales; dehydration; itchy skin; difficulty sweating; thinning hair; protruded eyelids; and increased risk of infection.

Ichthyosis can be a disfiguring disease and has numerous social and psychological implications.

How Is Ichthyosis Treated? Is There A Cure?

There is no cure for ichthyosis, only treatments to help manage the symptoms.

What Can I Do To Help?

Research on the genetics of ichthyosis and improved treatments is vitally needed as well as educating the public about ichthyosis. Because ichthyosis is a rare condition, many people, including doctors, simply do not know what it is.

The Foundation for Ichthyosis & Related Skin Types, a 501(c)(3) organization founded in 1981, offers information, education, advocacy, and support services to persons affected with ichthyosis and their families. The Foundation serves as an important bridge between ichthyosis patients and the medical community. To receive more information about contributing to or becoming a member of the Foundation, please call 215.631.1411 or visit www.scalyskin.org.

News&Notes

... Insect Repellents

Summer sun, summer breezes, and summer insects are in the air. Insect repellents can help us enjoy being outdoors in the warm weather and can protect against West Nile virus, Lyme disease and Rocky Mountain Spotted Fever.

Product	*Active Ingredient*	*Mean Length of Protection*
OFF! Deep Woods	DEET, 23.8%	301.5 minutes
Sawyer Controlled Release	DEET, 20%	234.4 minutes
OFF! Skintastic	DEET, 6.65%	112.4 minutes
Bite Blocker for Kids	Soybean oil, 2%	94.6 minutes
OFF! Skintastic for Kids	DEET, 4.75%	88.4 minutes
Skin-so-Soft Bug Guard Plus	IR3535, 7.5%	22.9 minutes
Natrapel (Tender)	Citronella, 10%	19.7 minutes
Green Ban for People	Citronella, 10%; Peppermint oil, 2%	14.0 minutes
Buzz Away	Citronella, 5%	13.5 minutes
Skin-so-Soft Bug Guard	Citronella, 0.1%	10.3 minutes
Skin-so-Soft Bath Oil	Uncertain	9.6 minutes
Skin-so-Soft Moisturizing Suncare	Citronella, 0.05%	2.8 minutes
Gone Original Wristband	DEET, 9.5%	0.3 minutes
Repello Wristband	DEET, 9.5%	0.2 minutes
Gone Plus Repelling Wristband	Citronella, 25%	0.2 minutes

Reprinted from the American Skin Association Skin Facts, Volume 9, Issue 2, Summer 2002.

Medical Editor's Note: *The American Academy of Pediatrics recommends no more than 10% DEET for children with normal skin. Individuals with more severe forms of ichthyosis may experience increased absorption of active ingredients. Apply insect repellents to clothing rather than directly to the skin whenever possible, avoiding eyes and mouth.*

Dr. Gary Peck Recognized

Gary L. Peck, MD, received the 2002 Discovery Award from the Dermatology Foundation. Dr. Peck recognized and developed the therapeutic impact of isotretinoin, profoundly affecting clinical dermatology and the chemoprevention of cancer. Dr. Peck's landmark 1976 article in *Lancet* described the successful treatment of keratinizing dermatoses (which include ichthyosis) with the oral synthetic retinoid isotretinoin (a synthetic form of Vitamin A). Observing the same facial dermatitis seen in Retin-A-treated acne patients suggested a significant therapeutic benefit in managing severe acne, ultimately revolutionizing its treatment. Dr. Peck is now the Director of the Melanoma Center and Clinical Director of Cancer Prevention at the Washington Cancer Institute in Washington, DC, and maintains a private practice in Bethesda, Maryland.

Reprinted from Dermatology Focus, Vol. 21, No.4, Winter 2002/3.

Handling Health Insurance Disputes

Due to political pressures on state governments, forty-one states and the District of Columbia have created a mechanism to handle consumer disputes with managed care insurers. Now the Kaiser Family Foundation and Consumers Union have published a guide that provides a state-by-state rundown of insurance dispute mechanisms. You can obtain The Consumer Guide to Handling Disputes with Your Employer or Private Health Plan, 2003 Update for free by ordering it from the Kaiser Family Foundation website: www.kff.org/consumerguide or call 202-347-5270.

Reprinted from the NORD On-Line Bulletin, February 2003.

* * *

PADDOCK TOPICALS

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

12%* LAClotion™ (AMMONIUM LACTATE) LOTION

LAClotion™ 12% (ammonium lactate) Lotion

Rx only

For topical use only. Not for ophthalmic use.

Indications and Usage

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

Contraindications

Known hypersensitivity to any of the label ingredients.

Precautions

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

Carcinogenesis, Mutagenesis, Impairment of Fertility

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

Pregnancy

Teratogenic Effects. Pregnancy Category C:

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

Nursing Mothers

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

Pediatric Use

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

Adverse Reactions

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

Overdosage

The oral administration of ammonium lactate to rats and mice showed this drug to be practically non-toxic (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.

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

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

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