

Ichthyosis Focus



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Growth Failure in Children with Severe Ichthyosis

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Background

It has become apparent to dermatologists who have had the opportunity to see a number of children with ichthyosis that some of these children are small for their age.

Less commonly, severe growth failure has been observed during infancy. Severe growth failure is recognized as particularly common in Netherton syndrome, but can also occur in other types of ichthyosis. The basis for this "failure to thrive" has not been previously studied, although it has been suggested that the chronic skin inflammation and increased skin cell production of ichthyosis may be the source of increased energy needs in these children. Some studies of children and adults with severe, widespread skin diseases (similar to some forms of ichthyosis) have shown that gastrointestinal dysfunction, particularly impairment in the ability to absorb fatty foods from the diet, may be a problem. Our study was undertaken to identify the cause(s) of growth failure in children with ichthyosis.

Hypothesis

We reasoned at the outset that energy losses due to impaired skin barrier function could be a previously unrecognized cause of growth failure in children with severe ichthyosis.

Impaired skin barrier function, as measured by increased rates of water evaporation from the skin surface, has been shown to be present in most people with ichthyosis, due to the abnormally formed outermost layers of skin (the stratum corneum or SC). As water evaporates, it carries with it energy in the form of heat (0.59 Calories/ml). This is why sweating results in cooling of the body. We reasoned that in some children with ichthyosis, the energy lost through their impaired skin barrier might be large enough to cause or contribute to their growth failure. This article will summarize two recent publications resulting from this study.

Methods

Ten children with ichthyosis and growth failure, i.e., with height for weight or weight for height in the third, or lower, centile for age, were admitted to the University of California San Francisco Pediatric Research Center for the study. The ages and diagnoses of the participants are given in Table 1. A nutritional evaluation was undertaken that included measuring blood levels of iron, several vitamins, essential fatty acids and other nutrients, as well as some routine blood chemistries, such as calcium, magnesium, and phosphate levels, and a blood cell count. A history of the child's caloric intake was obtained and caloric intake was recorded over five days of the study. An extensive evaluation of gastrointestinal (GI) function was obtained, including

measures of the ability of the GI tract to absorb protein and fat. Upper and lower endoscopies were performed to further evaluate GI status. Skin function was evaluated by measuring transepidermal water loss (TEWL) at multiple body sites to determine an average or "mean basal" transepidermal water loss. The patient's body surface area (BSA) could be determined from their height and weight and, when multiplied by the mean basal TEWL, we could determine daily total transepidermal water loss (TEWL). From this we could calculate daily total caloric losses from skin evaporative water losses (S-EER for Skin Estimated Energy Requirements). We then incorporated the Skin Estimated Energy Requirements into energy balance studies, as follows. The normal or expected energy requirements for each child were obtained from standard tables for children of the same size and age (Normal Expected Energy requirements, N-EER). The total daily caloric requirement (total estimated energy requirements, T-EER) was then calculated as the sum of normal estimated energy requirements (N-EER) plus skin estimated energy requirements (S-EER). Normal estimated energy requirements (N-EER) and total estimated energy requirements (T-EER) were then compared to the child's daily caloric intake, based upon the 5-day caloric counts. To determine if our children were in a hypermetabolic state

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Correspondence Corner

Dear Members and Friends:

In the last issue of the Focus, Annamarie Gonzalez made a plea for a new computer for her son, Ryan. Ryan is the oldest living known person with Harlequin ichthyosis and a remarkable young man.

Several of our members were moved by the profile of Ryan and offered their support. The donations sent are enough for Ryan and Annamarie to purchase a new Dell PC with all the whistles and bells a teenage boy could need, along with a new chair, printer, and home installation.

Ryan and Annamarie are excited and overwhelmed by this outpouring of support. Ryan is currently in a transition program that is helping with community skills and job training and placement. He is working part-time and is investigating programs at a local community college. A new computer system will certainly help Ryan as he moves toward college and young adulthood.

Ryan is also training for another Challenged Athletes Foundation event and is training with his coach and friend, Brian, for the Tour de Tucson in November. He'll be riding up to 60 miles on the back of a tandem bike. The Foundation congratulates Ryan on his incredible perseverance and accomplishments and thanks all those who reached out to help him with an important need.

Sincerely,

Maureen Tierney
Program Director
Focus Editor

Dear Jean:

This is a belated thank you for my lovely key ring. Maybe one of these years I'll be able to attend the conference. Any plans for Boston?

I'm glad I could help with fundraising. I remain hopeful that one of these days my daughter will be able to feel good in her skin.

Stephanie Sawyer-Ames
Watertown, MA

P.S. The other night I pulled out my newsletter for your address and then went through it. How excited I was to see a letter in the Correspondence Corner regarding a young girl with Sjogren Larsson Syndrome. I contacted her mom immediately. The three contacts I have made in the past 6 years have been through F.I.R.S.T.!

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In Memory of Friends

Sadly the Foundation lost a number of friends and supporters within the past year. Many of these individuals' family and friends chose to remember their loved ones with a memorial contribution to the Foundation. We are very grateful to everyone who thought of the Foundation and the ichthyosis community in their time of loss. Our sincerest thanks and sympathies go out to these families.

Noah Cobb. Beloved son of Chris and Elizabeth Cobb. Noah was born with KID syndrome and, sadly, lived for only 6 months. While Noah wasn't with his family long (he spent most of his short life in the hospital), he was a blessing and will always hold a special place in his family's hearts.

Joann Crowley. Beloved grandmother of Austin Milam, who has lamellar ichthyosis. "She was the best grandmother ever and she is deeply missed," said Jodi Milam, Joann's daughter and Austin's mother.

Joe T. LaBarbera. Beloved father of Randy LaBarbera, who has lamellar ichthyosis. Joe was a veteran of World War II, a successful businessman, an avid sportsman, and a community leader. Joe and his wife, Chris, are long-time supporters of the Foundation, as is their son Randy.

Mary Licursi. Beloved grandmother of Ryan Licursi, who has EHK. Mary has six other grandchildren and had recently become a great grandmother. Ryan spoke at her funeral, remembering how she loved to be with her family. Mary's wish was that donations be made to the Foundation at the time of her death. She would be very proud to know that a substantial sum was received in her memory to support the mission of the Foundation.

Bernard Mayer. Beloved father of Jacque Hollingsworth, whose son, Jackson, has lamellar ichthyosis.

Geneva Retzlaf Tonahill. Beloved mother of Kathy Rogers and grandmother of Angela Godby, who has lamellar ichthyosis. Kathy Rogers was a founding member of the Foundation and served on the Board of Directors. Angela Godby is the current chair of The Foundation's Advocacy Committee. Their family continues to be generous supporters of the Foundation and its mission.

Vincent Ruta. Beloved son of Amy and Sam Ruta. Vincent was born with Harlequin ichthyosis and, sadly, only survived a few days.

Rita Siegel. Beloved mother, mother-in-law, and grandmother to Dan and Lauri Siegel and their sons, Bradley and Douglas, who have X-linked ichthyosis. Dan Siegel is a member of the Foundation's Board of Directors and is our General Counsel.

Memorial donations from these families totaled over \$5,000. The Foundation is very grateful to the many family members and friends who sent memorial donations in honor of their loved ones. Honor or memorial donations are a wonderful way to remember someone or to mark an accomplishment, and to help the Foundation achieve its important mission.

For more information on honor and memorial donations, please see page 11 for our Honor/Memorial cards. Or call or email the Foundation office and ask for our Planned Giving brochure, 1-800-545-3286, info@scalyskin.org.

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(i.e., expending more energy at rest) we measured oxygen consumption and carbon dioxide generation at rest and compared the expected (E) resting energy expenditure (REE) for a child of this age and size with our measured (M) resting energy expenditure (REE).

Results

The results of our study are summarized below. For further details, the reader is referred to the original publications^{1,2}.

Nutritional Studies and Gastrointestinal Function

Three of the ten children had a mild deficiency of one or more nutrient: vitamin A (1 out of 10); vitamin D (3 out of 10); iron (1 out of 10). Two patients had mild fat malabsorption. One child had lactase deficiency. Another had peptic esophagitis. The remainder of the nutritional and gastrointestinal studies were normal, with the exception of the finding that constipation was a problem in 8 out of 10 patients. We also observed some findings that suggested chronic hypovolemia (decreased total blood volume), namely increased calcium (5 out of 10) and magnesium (4 out of 10) levels, and/or elevated hematocrits (red blood cell volume) (4 out of 10), but this study did not include tests that would have directly evaluated blood volume and hypovolemia.

Skin Barrier Function

All the children exhibited impaired skin barriers with elevated mean basal transepidermal water loss (TEWL) (Patients: 39.6 ± 20.6 ml/m²/hr vs. Normal: < 9.7 ml/m²/hr). Children with Netherton and Harlequin ichthyosis had the most severe barrier defects (mean basal TEWL > 40 ml/m²/hr). Those children with CIE and Ichthyosis en confetti had intermediate barrier defects (mean basal TEWL between 20 and 40 ml/m²/hr). And those with lamellar ichthyosis and trichothiodystrophy had the least abnormal barriers (mean basal TEWL between 15-20 ml/m²/hr). We also obtained skin biopsies for electron microscopic evaluation of the structures

of the skin that are responsible for the skin barrier; abnormalities in the quality and quantity of these structures correlated closely with the skin barrier defect (mean basal TEWL). The defective skin barriers can result in large volumes of water lost each day across the skin surface (mean 746 ± 468 ml/day).

Energy Balance Studies

All children were consuming sufficient calories each day to support growth in a normal child of the same age and size (caloric intake was greater than or equal to normal expected energy requirements, N-EER). However, daily caloric losses due to the skin barrier defect ranged from 84 to 1015 Calories/day, compared to expected rates of 41 to 132 Calories/day for children of same body surface area (BSA) with normal skin barriers. And when skin caloric requirements were added to estimated requirements based upon age and size (total estimated energy requirements, T-EER), 6 patients were in positive energy balance (i.e., consuming enough calories to support growth) and 4 were in negative balance (i.e., they were not consuming enough calories to meet their needs).

Resting energy expenditure (REE) was assessed in six patients. In 5 out of 6, measured REE exceeded expected REE based upon norms for age and size, consistent with a hypermetabolic state. Moreover, the percentage difference between M-REE (measured resting energy expenditure) and E-REE (expected resting energy expenditure) was correlated with the severity of the barrier defect (mean basal TEWL). Thus children with more severe barrier defects were more hypermetabolic (expending more energy at rest).

Summary and Conclusions

1. Nutritional deficiencies are not common and relatively mild in children with ichthyosis and growth failure.
2. Gastrointestinal function is largely normal in children with ichthyosis and growth failure, but mild fat malabsorption may be present in

some. Constipation is a common problem in this group.

3. Skin barrier function is abnormal in these children. Some forms of ichthyosis appear to have more severe barrier abnormalities; these children may lose large volumes of water each day. These children need to compensate by increasing their fluid intake. Whether they do adequately compensate for skin barrier water losses was not examined; the next phase of our research will address this question. It is possible that the chronic constipation in these children may be due in part to inadequate compensatory fluid intake.
4. Increased caloric requirements due to skin evaporative energy losses because of their ichthyosis were present in all and appear to be sufficient to account for the growth failure of most of these children.
5. While these children, at this point in their lives, were consuming sufficient calories to support growth in "normal" children, some of them did not adequately increase their intake to compensate for the calories lost due to their ichthyosis. We suspect that infancy may be a critical time for these children to receive sufficient calories to support growth.

Acknowledgements

Dr. Melvin Heyman, a pediatric gastroenterologist, was co-investigator on this project. Dr. Peter M. Elias, assisted by Debra Crumrine, performed the skin electron microscopic studies. Drs. Ashley Fowler and David Moskowitz coordinated the study and performed the skin and energy consumption measurements. Dr. Anthony Wong assisted Dr. Heyman. Ms. Sharon Cohen was the dietician for the study. Ms. Jeannie Addis was the nurse coordinator, and was assisted by staff in the Pediatric Clinical Research Center.

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This study is ongoing. If you are interested in having your child participate, please contact me at: williamsm@derm.ucsf.edu.

¹ The lay term “calories” is in scientific terms “kilocalories.” “Calories” here refer to kilocalories.

² Fowler AF, Moskowitz DG, Wong A et al. Nutritional status and gastrointestinal structure and function in children with ichthyosis and growth failure. *J Pediatr Gastroenterol Nutr* 38(2): 164-9, 2004.

³ Moskowitz DG, Fowler AF, Heyman MB et al. Pathophysiologic basis for growth failure in children with ichthyosis: an evaluation of cutaneous ultrastructure, epidermal permeability barrier function, and energy expenditure. *J Pediatr* 145: 82-92, 2004.

⁴ TEWL rates differ normally on different body sites. Also in some forms of ichthyosis, notably Netherton syndrome, the severity of skin involvement may vary over different body sites. Therefore, to obtain a mean TEWL representative of the total body surface, we measured TEWL on multiple body sites then weighted their contribution based upon the approximate percentage of that region of the body to the total body surface area.

⁵ We used data from the literature for TEWL in normal children. The value of 9.7 represents the upper limit of normal for mean basal TEWL (i.e., plus one standard deviation).

⁶ Ichthyosis en confettis is a newly described form of ichthyosis that resembles CIE, but in which small (confetti-like) areas of normal skin develop over time. Although the genetic basis has not yet been identified, it appears to be distinct from the CIE/LI family of disorders.

⁷ The quality and quantity of epidermal lamellar bodies (the organelle that delivers lipid to the SC) and the SC intercellular lipid lamellae was assessed on a 0-4+ scale (4+ = normal). The thickness of the stratum corneum (SC) was also assessed (0-4+). Normal was 4+ and thicker than normal (i.e., most ichthyosis) was also scored as 4+. This is useful, because in Netherton syndrome the SC is typically thinner than normal.

Table 1: Summary of Patient Characteristics

Patient (n)	Age (y)	Sex (M/F)	Diagnosis
1	9.5	F	Ichthyosis en confetti
2	7.3	M	Netherton syndrome
3	10.0	M	Netherton syndrome
4	13.6	M	Netherton syndrome
5	4	M	Ichthyosis en confetti
6	7.75	F	Harlequin Ichthyosis
7	10.5	M	Psoriasis
8	12	M	Lamellar Ichthyosis
9	6	M	CIE
10	2.83	F	Trichothiodystrophy

Definitions (in order of appearance):

Endoscopy - visual examination of the stomach and upper and lower intestines with a special instrument.

Malabsorption - impaired absorption of nutrients in the intestines.

Lactase deficiency - not enough of the enzyme that breaks down a sugar, lactose, that is found in milk.

Peptic esophagitis - inflammation of the esophagus due to the reflux of acid and pepsin from the stomach.

Hematocrit - the ratio of the volume of red blood cells to plasma in the blood.

Spotlight on Tsering Choden



*Tsering Choden,
age 2 ½*

Hi, My name is Ugyen Pelden (pronounced oog-yen) and I am writing from a far away, tiny Himalayan kingdom, which many have never heard about. It is called Bhutan, in the north of India. We are a small country with just a population of approximately seven million.

On the 8th of April, 1998, my daughter Tsering Choden was born. She was called a “collodion baby” by the doctors at the hospital, and later her condition was diagnosed as lamellar ichthyosis. Probably she is the only one born with this type of skin disorder at the hospital and in Bhutan. My husband and I were both shocked out of our wits. We had never seen a baby look like that. She had very plastic looking yellowish skin. Her eyes were mere slits and she had just two tiny holes for a nose. I was so upset I couldn't bring myself to hold her and I rejected her for several hours. All I could do was cry and cry until I felt I had no more tears left in me. All around me I saw newborn babies, with their mothers holding them proudly. I felt so empty and shattered. I kept asking God, if there is one above, “Why me?” “Why is this happening?”

After a while, I was exhausted and fell asleep. When I woke up I wanted to take a look at my baby, so I walked from my room to the nursery at the end of the corridor. I could hear a child crying lustily and as I walked nearer to that room the crying got louder. When I walked inside the room, I saw a few babies sleeping peacefully, including the nurse (it was around 2 a.m. in the morning). Only one baby was crying at the top of her voice, and I instinctively knew she was my baby. I walked to her crib and was mesmerized. She had been fed with drips since I didn't nurse her even once. I could see she had kicked out the drip needle from her feet. She was kicking and her hands were clenched, as if she was trying her best to fight the world and all her problems all by herself in the best possible way. I had tears rolling down my face as I picked her up and fed her. She immediately sucked with much gusto and I felt a bonding with her.

Since that morning, she and I have come a long way. When she was one year old she lost all her hair as her scalp peeled off and developed infection. She had to undergo a skin graft around her eyes on the upper eyelids at nine months as she lost partial vision in her right eye when she was seven months. Since the graft, she could close her eyes. Then again when she was two years old, her grafts no longer worked and she was back to the same condition. Her eyelids pulled back and she couldn't close them at night. So we went to another hospital in South India and they did the grafts again. This time on both upper and lower lids, taking skin from her forehead and her thighs. Her hair also grew back after application of a medicine called dipivate. Throughout all this, she remained cheerful and confident and a survivor.

I have a friend in the U.S., her name is Colleen Nicholas who lives in Maryland. She sent me the F.I.R.S.T. magazine and she enrolled me as a member and I got more F.I.R.S.T. magazines. We have realized that we are not the only ones with this problem, although I wish we had the same sort of support, research, doctors, and medicines as you have in the states. Anyway, I made friends with a few people, particularly a woman named Nancy Russin who had written to F.I.R.S.T. from Florida (her letter was printed in the Volume 19, No. 4, Winter 2000). Then, I also made friends with another woman called Mary Bellucci from PA, USA, who has a son with a milder form of ichthyosis. I have also received many different types of lotions and ointments, which my generous friends in the U.S. have sent to me.

Currently, Tsering is using Equate oatmeal bath treatment, which really helps to soften her skin. She is also using Equate daily moisturizing lotion. I cannot get any of these here, and it is all the most generous contribution of my friend Mary Bellucci. I make do with liberal application of Vaseline and at night I heat a little mustard oil (we grow it in our fields and extract the oil) and give her an oil massage from head to toe. My friend Nancy suggested wearing plastic around her feet and then socks to avoid the deep cuts on her soles. Besides that, I have taken her to all the hot springs in Bhutan. Everyone goes there and believes the water is medicated and will help a person to get cured of various illnesses. She does improve when we are there, but her skin gets dry and scaly when we get back home.

Now Tsering will be six years old on the 8th of April this year. She has been enrolled in a school nearby and the teachers are most kind and cooperative, although the children are getting used to her. I also attended school with her for two whole weeks and the teacher allowed me to sit with Tsering in class for the first week. We were subjected to much stares, and some even remarked audibly and called her “scary face” and “ghost” or “ugly face.” I have been gritting my teeth and trying to accept it, but sometimes I find myself losing my cool, like the last time a group of students came to stare at Tsering, nudged each other, and called her a ghost. I said that she is just a little girl who wants to go to school and to be accepted as one of them. I guess they too have never seen a person who looks like that and it is a normal reaction.

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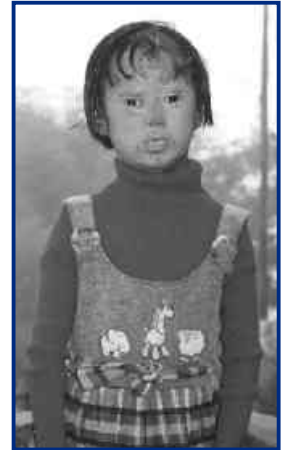
Spotlight on Tsering Choden

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Tsering sometimes asks me why she was born like that or why someone is staring at her and calling her scary. I tell her that if someone does that, to smile broadly at that person and ask if she can be their friend. I tell her that god sometimes makes us like that, with physical as well as mental drawbacks, but inside we are all the same. I tell her that both her father and mother love her very much and she can get on in life on that love, that there are some children without the love of their father or mother or both. She seems to understand and accept my explanation. Now her classmates don't pull their chairs away from her; they (one or two of them) even agreed to hold her hand during games and said they are not scared to hold her hand.

I would like F.I.R.S.T. to please publish this letter and to request anyone who wants correspond and be our friends to do so at my address:

Ugyen Pelden
P.O. Box 246
Thimphu, Bhutan
Asia
Email: uginap@hotmail.com



Tsering, age 5 ½

Camp Horizon 2004

By Nicole McMillian

Almost every August since 1997, I have made the three-hour journey to the mountains of central Pennsylvania to reach the grounds of Camp Victory. This unassuming campsite hosts Camp Horizon, a one-week overnight camp for children 8 to 13 years old with skin disorders. My first year at camp as a counselor was very overwhelming and emotional for me. It was the first time that I had ever seen anyone else with ichthyosis. Camp Horizon allowed me to be free and to be me. It is a place where children and adults are not stared at because of how they look. In fact, skin is the last thing anyone thinks about, as every child and adult's inner beauty shines through while visiting camp.



Ichthyosis doesn't stop these volunteers from helping out at Camp Horizon.

Campers are encouraged to try new activities, make new friends, and most importantly, have fun being a kid. Daily activities include arts and crafts, fishing, archery, mask making, swimming, rock climbing, and paddle boating. However, the fun does not end there. Every night there is a themed event for the campers to enjoy before bedtime. Many campers bond while delighting in casino night, a luau swim party, cabin Olympics, and making s'mores. My favorite event is always the camper talent show. The kids have an opportunity to showcase their talent in the form of singing, dancing, skits, jokes, playing instruments, and a variety of other acts. Every child is always greeted by warm and enthusiastic applause and encouragement from fellow campers, counselors, and staff. It is a fun-filled evening enjoyed by all.

The best part of camp is seeing the first-time campers develop over the course of the week. Seeing a child's first Camp Horizon experience is comparable to watching a caterpillar in a cocoon that finally bursts free to reveal a strong, radiant, and beautiful butterfly. Campers who are quiet, withdrawn, and in a cocoon of shyness upon arrival are by week's end giggling, making new friends, sharing their talents, and displaying how strong and beautiful they really are.

One cannot think of Camp Horizon without also being touched by the spirit of dedication that is seen in the all volunteer medical, counseling, and support staff. This great group of individuals is made up of doctors, nurses, dermatology residents, adults and teens with skin disorders, and local volunteers. They provide the leadership, warmth, caring, and smiles that are the backbone of the Camp Horizon experience. This year, I had the wonderful opportunity to be on the activities staff and I loved every minute of the time that I spent with the campers and volunteers.

Camp Horizon is an inspirational place for both children and adults. Each camp experience that I have gives me the opportunity to learn more about myself and about the courage and beauty that is within others. Friends, family, and co-workers occasionally ask me, "Why do you volunteer at camp every year?" I always reply, "Because camp has given me so much." I can't wait until next year!!!

Executive Director's Report



Dear Members and Friends of the Foundation:

Thank you to everyone who supported the Foundation during our most recent fundraising campaign this past August. Once again, our members responded in grand fashion. Your donations are what keep this Foundation growing and serving the ichthyosis community.

Enclosed in the August mailing was a brochure about the Foundation's new Planned Giving Program. Please use this brochure to generate conversations between you, your family, and your financial advisors. You can become a partner in the Foundation's future through a planned gift. The opportunities for charitable gifts to the Foundation are many and varied.

In our last issue (Summer 2004), we spotlighted Ryan Gonzalez, a teen with Harlequin ichthyosis. Ryan was in need of a new computer to begin his first year of college. Thanks to some very generous members of our Foundation, Ryan's need has been fulfilled. Both Ryan and his mother are extremely grateful for the generosity and genuine support from people who care about seeing him succeed.

Our website, www.scalyskin.org, continues to provide accurate, reliable, and up-to-date information and resources on ichthyosis and the related skin types. Thanks to the generosity of Accurate Imaging, Inc., our website was launched in the spring of 2000. Matthew Vecera and Joseph DeMicco have been long-time supporters of the Foundation and have been graciously hosting our website since its inception. Their donation has changed the lives of many people. Affected families and individuals are finding answers to questions about their skin, learning about available resources, and closing the gap of isolation and loneliness. Our most recent statistics report that during a monthly period, over 6,000 people visit our website, or 203 visitors per day. This represents people who "go into" our website, not just view the home page and leave. The average length of time each visitor spends is seven and a half minutes.

The Foundation's Fund Raising Committee has been brainstorming over recent months about new ideas to raise funds for our programs and services. The committee is comprised of volunteers of varied backgrounds and experiences. The common factor that draws everyone together is that his or her lives have been affected by ichthyosis. The committee is dedicated to helping the Foundation grow stronger and raising more money for research. The committee would like to invite more volunteers to join our efforts. We hold monthly meetings to discuss new ideas and report on current projects. Please consider joining our group. Please send an email to the office, info@scalyskin.org, if you are interested in getting involved. I am always available to answer any questions you may have.

In February 2005, the American Academy of Dermatology (AAD) will hold its annual convention in New Orleans, LA. I will be attending as a partner in the Coalition of Skin Diseases. Our group exhibits in the convention hall where more than 10,000 dermatologists from the United States and other countries have access to our information. In conjunction with the annual AAD meeting, the Foundation's Medical & Scientific Advisory Board comes together every year for a breakfast meeting. This meeting is an amazing collaboration of the country's medical experts on ichthyosis.

Planning for the 2006 family conference is starting now. Together with the Board of Directors, we have decided to host the next conference in Atlanta, GA. This area of the country was chosen for many reasons. In particular, we have never hosted a national event in the southeastern part of the United States. We move the event to different parts of the country to allow members who cannot travel long distances to have the opportunity to experience a conference. The event is two years away, but it is not too early to start saving and making plans to attend. You can look forward to seeing more information about the 2006 conference in future issues of the newsletter.

Sincerely yours,

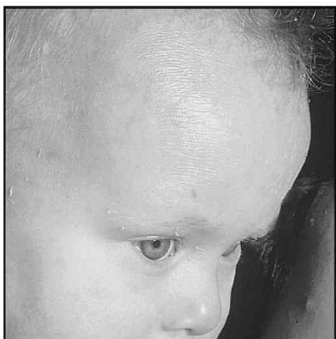
A handwritten signature in cursive script that reads "Jean".

Jean Pickford
Executive Director

When Timothy* grows up, his parents want him to be ordinary. Just ordinary.

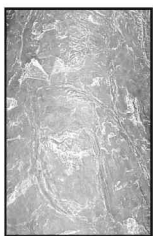


Problem Dry Skin (PDS) Symptoms
of Lamellar Ichthyosis
BEFORE



AFTER 4 WEEKS

PDS Symptoms of Lamellar Ichthyosis



BEFORE



AFTER 4 WEEKS
(outer, lower leg)



THE
NEOSTRATA
COMPANY



Now, thanks to *NeoStrata*, he can be so much more.

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* Fictitious name. Consult a physician before using on children.

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Ichthyosis and the Workplace

Ichthyosis and the related skin types can raise difficult issues in the workplace. Communication is the key: whether it is letting co-workers and managers know about the disease, or preparing the work environment to ease your disability and increase your productivity.

Like friend and family relationships, work relationships require a certain amount of communication and honesty. Co-workers may be curious about your skin, and employers may wonder how your ichthyosis might affect your work. Because of this, it is important for people with ichthyosis to understand their disease, their employment rights, and the resources available in the workplace.

The law with which people are most familiar is the Americans With Disabilities Act of 1990 (ADA). Title I of the ADA covers employment. Since 1994, it has required that employers of more than 15 people must make reasonable accommodations that allow a qualified job applicant with a disability to complete the application process or a disabled employee to carry out the duties of his or her job. According to the American with Disabilities Act, "an individual is considered to have a disability if s/he has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment."

It is illegal to require a job candidate to take a medical examination prior to a job offering. The employer cannot try to ascertain whether a job candidate has a disability. Therefore it is sometimes up to the employee to decide whether to disclose his or her disability to the employer. If your ichthyosis is mild and not readily apparent, it is your choice if you want to disclose it. However, while one may have reasons for keeping a disability a secret from an employer, revealing it may require the employer to provide certain accommodations that will allow you to perform better at your job.

Tips for Workplace Communication

- 1. Plan ahead.** Plan carefully how and when to discuss your ichthyosis with co-workers and supervisors. Education about ichthyosis and its symptoms can help change their perceptions and expectations of people with ichthyosis. Begin by researching all the changes that could make your job as productive as possible.
- 2. Meet with your supervisor.** Schedule a meeting with your supervisor at a time when neither of you is under pressure. Describe simply and plainly the ways your ichthyosis may affect your work (stiffness, dry eyes, overheating, etc.). The goal is not to generate sympathy, but to find ways to solve the problem that will benefit the company, your co-workers, and yourself.
- 3. Offer alternatives.** Be prepared to offer suggestions for possible changes, such as using assistive devices or accommodations (air conditioner, private area to apply lotions, hand-held vacuum to remove skin scales, etc). These assistive devices and accommodations are items you may need to help you do your job more easily. Chances are any changes you may need will not cost much. Tax deductions and/or tax credit may be available to certain employers who provide accommodations and/or jobs for people with disabilities.
- 4. Communicate with your co-workers.** Understand that co-workers can become resentful if they feel you are not doing your share of the work. Explain to them how ichthyosis affects your body and may, at times, affect your ability to work, but that you are making reasonable accommodations.
- 5. Listen to your body.** You may be tempted to "work through the pain" of ichthyosis, but overdoing it may cause exhaustion, overheating, increased risk of infection, and dehydration. Instead, set your priorities and pace yourself. List your tasks in order of importance and do the most important ones while you feel strongest and most energetic.
- 6. Create a healthy work environment.** Arrange your workday or work area to limit the amount of lifting, carrying, holding, or walking. Vary activities to avoid sitting in one position or repeating one action too long. Go to bed at a regular time and get enough rest to carry you through the next day.
- 7. Develop a support network.** Other people in the workplace may have physical disabilities and can offer support and understanding. Establish friendships with co-workers whom you can trust. If you are not feeling well or are having a difficult time with a particular issue or co-worker, take a break and talk it out with a trusted co-worker. Just having someone to listen can make you feel better and change your perspective on the situation.
- 8. Maintain a positive attitude.** Remember that you are allowed to have low-energy days, but that you're in control of how you relate to the disease. Share your thoughts with other people with ichthyosis through the Foundation's Ichthyosis Support Network. Contact the national office at 800.545.3286 or email at info@scalyskin.org.

Honor & Memorial Cards

Tired of going to the card store and spending lots of money? Here's a great way to send out honor or memorial cards to your family and friends while supporting the Foundation. F.I.R.S.T. has created two very special cards, one for memorial acknowledgements and the other to honor someone's life event (i.e. birthday, engagement, marriage, religious milestone, new home, etc.). It's simple and easy to do and provides a thoughtful way to recognize your family and friends. Here's how to send a card:

Complete the form below and return it to the F.I.R.S.T. office at 1601 Valley Forge Road, Lansdale, PA 19446, with your check or credit card information. Order a packet of six cards and envelopes, three of each kind. Keep your cards on hand and use them as needed.

OR

Contact the office via email, phone, or mail with the necessary information including the type of occasion, name & address of recipient and name & address of sender. We'll send the card for you! Your card will be sent on the very same day we receive your request.



_____ Please send me _____ packets of six cards @ \$25.00 each. Total \$ _____

_____ Please send me _____ individual memorial cards @ \$5.00 each. Total \$ _____

_____ Please send me _____ individual honor cards @ \$5.00 each. Total \$ _____

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

Payment Method:

___ check ___ credit card (Visa, Mastercard and American Express)

Account # _____ Expiration Date _____

Thank you for supporting the important work of the
Foundation for Ichthyosis & Related Skin Types, Inc.

Grassroots Fundraising and Awareness

BRADLEY PHARMACEUTICALS, INC.

Bradley Pharmaceutical, the parent company of Doak Dermatologics and makers of the Carmol® products, continually shows its support for the Foundation's important work, particularly during this year's Ichthyosis Awareness Week. In 2003, the company created, produced, and mailed a full-color brochure to all practicing dermatologists in the country. This year, executives from Bradley decided to send a second mailing to coincide with Ichthyosis Awareness Week. Their marketing department also sent a press release over the PR News Wire for distribution to the New York metro area for medical and editorial markets, promoting education about ichthyosis.



The hard working committee: (from left) Jack & Paulette Gale, Mark Pederson, Donna Kober, Denise Melhorn, and Glenn Jordan.

First Time Golf Outing Raises \$16,000 for Foundation

Foundation members Donna and Fred Kober organized their first-ever grassroots fundraiser during Ichthyosis Awareness Week, October 3 to 9. The event was a Golf Outing and Dinner at Cool Creek Golf Course in Wrightsville, PA, held on October 8. More than 60 golfers attended the outing and \$16,000 was raised for the Foundation. Congratulations to the Kober family for their outstanding efforts!

The Kobers are the parents of Derek, age 6, and Alec, age 2, who is affected with lamellar ichthyosis. After meeting families at the conference this summer in Kansas City, Donna and Fred decided they wanted to raise money to help the ichthyosis community. Along with several friends and relatives, the Kobers planned the event from scratch.

Having never done a fundraiser like this, the Kobers were unaware of how many community members would pitch in to help.

First, Modern Landfill of York, PA, Donna's employer and title sponsor of the event, donated the cost of the greens fees and carts for all the golfers. Next, Big Bob's BBQ donated the entire dinner of grilled steaks, shrimp, scalloped potatoes, vegetables, and dessert. Finally, local businesses donated 104 items to be raffled as door prizes. Gold sponsors include Cleveland Brothers Equipment Co., Inc, County Line Quarry, Inc., Miller's Paving, Inc., National Earth Services, Inc., and York Waste Disposal.

With sunny, 65-degree weather, the shotgun scramble started at noon and the day ended in the ballroom with dinner, trophies, and prizes. Jean Pickford, Executive Director, spoke to the golfers about ichthyosis and thanked them for supporting the important work of the Foundation. Jean extended a special thank you to Donna, Fred, Derek, and Alec Kober for opening their hearts to the ichthyosis community and organizing such a successful event. The Kobers have definite plans to host the outing again next year.

If you would like more information about how to host a golf outing, Donna and Fred would be happy to talk with you. You may contact them at (717) 246-4612. They would love to share their first experience with others and encourage more members to get involved. It was an amazing and rewarding experience.

Pint Size Fundraiser

Rachel McDougall, age 6, and her brother Andrew, age 4, took to their driveway and a homemade lemonade stand to have their own grassroots fundraiser in support of their cousin who is affected by ichthyosis.

Dr. Peyton Weary Donates Honorarium

Dr. Peyton Weary was nominated to present the 2005 Clarence S. Livingood Lecture at the 63rd Annual Meeting of the American Academy of Dermatology. Dr. Weary will present his lecture, entitled "Impact of Global Climate Change, Biodiversity, and Population on Human Health." This is a particularly important honor as Dr. Livingood was a close friend and mentor to Dr. Weary.

Dr. Weary chose to donate the substantial honorarium accompanying this lectureship to the Foundation. Dr. Weary is a member of the Foundation's Board of Directors, a former member of the Medical Advisory Board, and has long been a generous supporter of the Foundation and its mission.



Donna, Alec, and Fred Kober present a token of thanks to Big Bob, owner of Big Bob's BBQ for donating the entire dinner.



Rachel and Andrew McDougall sell lemonade to their neighbors in Ontario, Canada, in support of the Foundation and ichthyosis awareness.

Genetic Alliance Backs “Open Access” to NIH-Funded Medical Research Disease and Patients Advocates “Must Be the Bridge to New Knowledge”

Washington DC (July 21, 2004) The Genetic Alliance, a coalition of 600 member organizations that advocate for patient families across America, has urged Congress to support a National Institutes of Health (NIH) policy requiring that biomedical research funded through NIH grants or contracts be available at no extra cost to the public.

Sharon Terry, President and CEO of the Genetic Alliance, noted, “This consumer-centered measure is a long overdue means by which to enhance public health education, speed the translation of genetic advances into quality, affordable health care, and inform and empower patients in their health care decisions.”

In the text of her letter to Representative Ralph Regula (R-OH), Chairman of the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee, Terry also argued: “Today, the Internet brings access to millions of pages of information yet most American taxpayers do not have access to the reports on biomedical research conducted with U.S. government funds.

“It is sometimes suggested that this information is not available to the 'homemaker in Nebraska' because she is ill equipped to deal with this information. We know from our 600 member disease-specific advocacy organizations that the homemaker has many resources to help her use that information. This access is critical for thousands of rare diseases; clinicians are unable to keep up with the information on 6000 rare diseases, and patients *must be the bridge to new knowledge.*”

Terry's letter supports a provision developed by Regula's subcommittee and approved by the House Appropriations Committee to remove barriers to open access by requiring that the results of research funded by the National Institutes of Health (NIH) be made available online, upon or shortly following publication, for no extra charge to the American people.

The Genetic Alliance is a nonprofit international coalition comprised of millions of individuals with genetic conditions and more than 600 advocacy, research and health care organizations that represent their interests. The Genetic Alliance promotes healthy lives by working to speed the translation of genetic advances into quality and affordable health care, public awareness, and consumer-centered public policies. More information on the Alliance may be found at www.geneticalliance.org.

Genetic Alliance Press Release, July 21, 2004

Editor's Note: The Foundation for Ichthyosis & Related Skin Types is a member of the Genetic Alliance.

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In a vehicle containing Vitamin E, Lactic Acid and Zinc

Effective, Well-Tolerated, 35% Urea-Based Moisturizer

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Please see full Prescribing Information.

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For external use only.
Not for ophthalmic use.

In a vehicle containing Vitamin E, Lactic Acid and Zinc

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Urea is a diamide of carbonic acid with the following chemical structure:



CLINICAL PHARMACOLOGY: Urea gently softens the intercellular matrix, which results in loosening the horny layer of skin and shading scaly skin at regular intervals, thereby softening hyperkeratotic areas.

PHARMACOKINETICS: The mechanism of action of topically applied Urea is not yet known.

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CONTRAINDICATIONS: Known hypersensitivity to any of the listed ingredients.

WARNINGS: For external use only. Avoid contact with eyes, lips or mucous membranes.

PRECAUTIONS: This medication is to be used as directed by a physician and should not be used to treat any condition other than that for which it was prescribed. If redness or irritation occurs, discontinue use.

PREGNANCY: Pregnancy Category B. Animal reproduction studies have revealed no evidence of harm to the fetus, however, there are no adequate and well-controlled studies in pregnant women. Because a fetal reproductive studies are not always predictive of human response, Keralac™ (35% Urea) LOTION should be given to a pregnant woman only if clearly needed.

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KEEP THIS AND ALL MEDICATIONS OUT OF THE REACH OF CHILDREN.

ADVERSE REACTIONS: Transient stinging, burning, itching or irritation may occur and normally disappear on discontinuing the medication.

DOSAGE AND ADMINISTRATION: Apply Keralac™ (35% Urea) LOTION to affected skin twice per day, or as directed by a physician. Rub in until completely absorbed.

HOW SUPPLIED:
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Foundation Resources

The Foundation staff is always working to bring our members the most accurate and up-to-date information on ichthyosis, its treatment, and related issues. Our current offerings include:

Publications

Ichthyosis: An Overview

An overview of ichthyosis; descriptions of primary types of ichthyosis.

Also available in Spanish.

Ichthyosis: The Genetics of Its Inheritance

A description of the genetic inheritance patterns for the different forms of ichthyosis. (Illustrated)

Release the Butterfly: A Handbook for Parents & Caregivers of Children with Ichthyosis

A comprehensive care giving guide for anyone caring for a young child with ichthyosis. Also available in Spanish.

Ichthyosis: A Guide for Teachers and School Personnel

A tool for parents to help make the transition to the school environment for children with ichthyosis. Key information for the teacher, school nurse, and other personnel.

New Second edition.

First edition available in Spanish.

Fact Sheets

Ichthyosis Disease Fact Sheets

General descriptions of the primary types of ichthyosis.

Ichthyosis Overview

Collodion Baby

CIE

EHK

Harlequin

Vulgaris

Lamellar

Netherton

X-linked

Resource Fact Sheets

Fact Sheets dealing with physical issues related to ichthyosis.

Chicken Pox (new!)

Ear Wax and Scale

Itching

Overheating

Retinoids

Scalp Scale

Video

Butterflies: The Children of Ichthyosis

A natural adjunct to our publications, "Release the Butterfly: A Handbook for Parents & Caregivers..." and "Ichthyosis: A guide for Teachers..."

Guidelines for using the video as a tool to spark discussion and understanding are included.

Other Items

Ichthyosis Awareness Cards

Business size cards that offer a brief explanation of what ichthyosis is and how to contact the Foundation for more information or to offer support. Perfect to hand to curious strangers.

Honor/Memorial Cards

Greeting cards for any occasion. Honor a loved one with a donation to the Foundation.

Royal Blue Ceramic 11 oz. Mug

With F.I.R.S.T. logo in white.

Royal Blue Canvas Bag

With F.I.R.S.T. logo in white. 10.5 x 14 x 5

Please contact the Foundation office if you are interested in any of these items. We can mail or email you an order form, or take your order over the phone.

info@scalyskin.org

215-631-1411

1-800-545-3286

The Foundation offers other resources to help keep our members and friends connected and to support our important mission.

The Ichthyosis Support Network connects individuals with the same disease types so they can share information and support each other. The support network reaches out to parents of children with ichthyosis in particular to address their fears and concerns and to offer practical advice.

The Australia/New Zealand support contact list offers our friends in that area of the world the opportunity to connect to other people with ichthyosis in those countries.

The International Ichthyosis Groups list allows us to refer our international members to support networks closer to their homes.

The Physicians Referral List allows us to refer people with ichthyosis to a knowledgeable caring dermatologist as close to their homes as possible. The list has expanded to include some doctors in other countries.

The Foundation Brochure is a four-color brochure that helps our members educate their families, friends, school systems, workplace, and community about ichthyosis and the mission of the Foundation.

The Planned Giving Brochure provides an overview of opportunities for charitable giving to The Foundation. See page 3 for examples of how one of these opportunities, memorial gifts, can benefit the Foundation.

The Grass Roots Fundraising Guide is an easy-to-follow manual for grass roots fundraising events. It contains great information about the essential steps to creating a successful event, and more. See page 12 for recent grassroots fundraising efforts conducted by some of our members.

News & Notes

CarePages Website Helps Keep Friends and Families Informed

The website www.CarePages.com offers the families of hospitalized individuals the ability to set up a personal, customized, and private website to communicate with family members and friends during pregnancy and delivery, hospitalization, and long-term care. Daily postings and updates about the patient's status can be emailed to family and friends, so the immediate caregiver is not faced with a long list of phone calls to make at the end of the day.

The CarePage is created online by the patient or a loved one and can be used to build a support community around the patient. Your personal web page can:

Post news and updates about the patient.

Exchange messages of support without intrusion.

Keep children connected to classmates and friends.

Post visiting hours and contact information.

Share photos with friends and family.

To ensure privacy, all CarePages are protected by a CarePage name, chosen by the person creating the page. Family members and friends register on the website with a member name and password. They then have the freedom to check on a patient's progress without intruding on the family. And, the family is not faced with a long "to call" list at the end of a trying day.

CarePages instructions are available in Spanish. Go to www.CarePages.com for more information and to review sample pages.



eScrip Fundraising

The Foundation extends its thanks to our members who support the Foundation through the eScrip fundraising program. eScrip registers merchants and shoppers through its website and returns a portion of your shopping dollars to the Foundation. If you are interested in supporting the Foundation by redirecting your shopping dollars through eScrip, learn how by calling Maureen in the national office, 1-800-545-3286, or by emailing info@scalyskin.org. Or go to www.eScrip.com. Genuardi Markets and Safeway stores participate, as well as national merchants, such as Budget Rent-A-Car, Eddie Bauer, Office Max, Payless Shoe Source, and Spiegel. Many regional merchants are also registered with eScrip.

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

Have you moved recently or are planning on moving soon? Please let us know your change of address so you can continue to receive the Focus. Postage for the newsletter does not include forwarding.



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