Ichthyosis Focus

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

Volume 27, No. 1 A Quarterly Journal for Friends of F.I.R.S.T. Spring 2008

Ichthyosis Through the Decades

Second Part of the Series

The first series of "Ichthyosis Through the Decades" was well received by our members. We are excited to share the stories of Terry Melton, age 53 living in State College, PA and Mary Jones, 63 from Newton, KS. We are pleased that both of these women shared their stories with us. Their insight, past challenges, and future hopes are inspirational for everyone, young and old. We hope that you will learn from their stories and build on their strength.

Terry Melton - Age: 53
State College, PA

I am affected with epidermolytic hyperkeratosis (EHK).

As the daughter of an academic dermatologist, I have an epic history of treatments including experimental ones (from a young age): vitamin B12 shots (1960s); urea ointments, methotrexate, plasma infusions (1970s); propylene glycol under occlusion, and accutane (1980s). My treatment now consists of ammonium lactate lotion once per week followed by a late afternoon soaking, exfoliating bath. Otherwise I maintain with a daily shower with lots of suds (Dial) and Lubriderm and Eucerin. My ichthyosis is much improved over when I was younger, though it is not clear whether this is due to just getting older or just getting smarter about how to deal with it. Basically, the long flat surfaces are clear and the flexural areas are the most affected. Whereas I always seemed to be on oral antibiotics when I was younger, I now treat all infections early with Bactroban ointment. A great product!

My primary challenge with aging has been the effect of drying cold air, since I live in the Northeast. My older skin lacks flexibility, and I wish now that I had protected its elasticity with more sunscreens when I was younger. Younger F.I.R.S.T. members, take note! I love rainy, wet weather, but as soon as the temp drops below freezing, I can feel all moisture fleeing my body. It's always a challenge to find the happy balance between dry skin and greasy clothing.

The social challenges of a disfiguring condition have virtually ended for me. I have a loving husband and two adopted kids-adopted to avoid more EHK in the family and a successful career. I rarely think about my skin, and if one thing appears true, it's that the less I think about my skin, the less other people think about my skin. With the social challenges of dating, education, and career development over, my focus is on how I can remain healthy for many more years. I do believe that keeping my weight down is beneficial for my skin, as well as staying flexible with exercise. I walk on the treadmill everyday. This keeps my heart healthy, which means my feet and ankles don't swell and blister as much in hot weather.

I try to live my life so as not to regret the path not taken. I seriously doubt I would do anything different if I had to do it over again. Maybe I would have gone without long sleeves and long pants more often, because although I was always self-conscious, I've learned over time that people are not cruel so often as just curious. I've been fortunate to have a supportive family and friends all my life, and am looking forward to a healthy old age, traveling and gardening in retirement, and bouncing a few grandchildren on my knee!

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Inside Ichthyosis Focus

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

Correspondence Corner

Dear F.I.R.S.T.,

We're going on vacation soon and I just made some business cards with Harlequin Ichthyosis information on them. I made the cards because a lot of people stare and act strange around Hunter. Some people have even voiced loudly that she is sunburned. Since we are going to Key West I thought it would be good to have some business cards on hand to give out. If we notice someone staring or whispering, I send Hunter over and she introduces herself and tells them about her skin. She does so in a friendly and polite way. When an adult is involved Hunter explains she has a very rare genetic skin disorder. This is particularly useful with very rude people (if I can keep my temper in check); they get embarrassed because they know they've been caught and either apologize, get out of dodge, or end up talking with us. If we notice younger kids staring, acting scared, or asking their parent and the parent is trying to shush them, Hunter goes over and introduces herself and talks with the kid in terms they can understand about her skin. The parent usually apologizes but I tell the parent it's OK for kids to ask because they are naturally curious and that we don't mind answering questions. We'd rather people just ask. Some kids are fascinated by Hunter and they end up talking for a while. We believe the best course of action is to educate people.

Patti Steinitz

Dear F.I.R.S.T.,

Thanks for the Ichthyosis Focus magazine. I received it yesterday and I am so glad to read the stories of the women affected by this condition and how their stories are so similar to mine. I agree with what they have to say one hundred percent. It's so nice and touching, I totally feel connected to them. The magazine really lifts my spirits every time I receive it because it keeps on informing me.

God Bless,
Esther Kimani - Kenya

Dear F.I.R.S.T.,

I just read the new articles from the ladies that are 20, 30 and 40 years old! How wonderful and what a great idea! I learned a lot regarding how others handle their skin care and what they use. I am looking forward to the next set (my age bracket).

Keep up the good work!
Barb Karas

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Correspondence Corner

Dear F.I.R.S.T.

I just found out some really great news today! I called Eucerin /Beiersdorf about them discontinuing Aquaphor Original Ointment from store shelves, and the representative let me know that it can still be ordered through the pharmacist. In addition, she also told me about a program that the company offers to families that use large quantities of Aquaphor. If you send them a letter from your doctor on his/her letterhead with your contact information, diagnosis, and treatment regimen, and how much Aquaphor you use, they will send you a case of Aquaphor - free! It needs to be faxed to 203-563-5630, and you can make a new request every 3 months.

Sincerely,
Jennifer See

Dear F.I.R.S.T.

The Phantom Tea Party fundraiser is a great idea. We are going to participate, but in a slightly different way.

Afternoon tea and tea parties are actually a part of the culture here in Bermuda and my family and I have tea parties to celebrate birthdays. So we've decided to hold a 'live' garden tea party and will invite many friends and family to attend and donate to FIRST. If people cannot attend in person, donations can be mailed in.

I hope this sounds good to you - we are certainly excited about our fundraising tea!

Thanks very much,
Laura Ashton - Bermuda

For tea packets, contact the Foundation office at 800.545-3286

Grassroots Fundraising

California Members Planning 3rd Annual Golf Tournament

Josh and Amie DeGarmo of Napa, CA are busy planning the 3rd Annual Golf Tournament to benefit the Foundation. This year's event will be held at the Silverado Country Club on July 9, 2008. All entries must be received by June 20, 2008. If you live in sunny California, and would like to participate, contact Josh at Diggermos@aol.com.

Last year the DeGarmos had a very successful Golf Tournament. The couple raised over $20,000. The event took place at the Napa Country Club in Napa, CA on July 9, 2007. An entry form can be found on the foundation's website at **www.scalyskin.org**

News & Notes

Dermatologists Recognized and Awarded

Congratulations to Anne W. Lucky, MD, for receiving the Practitioner of the Year Award from the AAD (American Academy of Dermatology). Dr. Lucky, a member of F.I.R.S.T.'s Medical and Scientific Advisory Board was recognized at the American Academy of Dermatology's 66th Annual Meeting in San Antonio, TX. Dr. Lucky practices pediatric dermatology in Cincinnati, OH. F.I.R.S.T. is grateful for Dr. Lucky and her dedication to the Foundation and the ichthyosis community.

Congratulations to F.I.R.S.T. Medical and Scientific Advisory Board member Dr. Anna Bruckner, for receiving a Career Development Award from the Dermatology Foundation for the project "bone mass and fracture risk in patients with epidermolysis bullosa". This award allows her the support to continue her work on this research project. Dr. Bruckner, Director of Pediatric Dermatology, practices Dermatology, Pediatric Dermatology, and Pediatrics in Palo Alto, San Francisco, and Stanford, California. Congratulations to Dr. Bruckner from F.I.R.S.T.

F.I.R.S.T. Board Member Emeritus, Peyton Weary, MD, was presented with the Environmental Protection Agency (EPA) 2007 Best of the Best Stratospheric Ozone Protection Award. Throughout Dr. Weary's career, he has continually put forth extra effort for causes that he believes in, such as the environment, tanning regulations or on behalf of the hospital where he spent many productive years teaching. The EPA noted his decades of work to deliver the message of prevention and awareness to as many people as he could reach. F.I.R.S.T. congratulates Dr. Peyton on receiving this award.

Reprinted in part from Dermatology World, Vol. 18, No 3, March 2008. Dermatology World is a publication of the American Academy of Dermatology Association.

Keith A. Choate MD, PhD has been awarded a Physician-Scientist Career Development Award from the Dermatology Foundation and will receive an NIH K08 (Mentored Clinician Scientist Career Development Award) in support of his work studying the molecular basis of Ichthyosis en Confetti. Dr. Choate has a longstanding interest in ichthyosis which began at Stanford University where, as an undergraduate in the laboratory of Paul Khavari, and in clinical collaboration with Mary Williams, he achieved the first successful correction of the genetic defect in human skin cells from patients with lamellar ichthyosis. He has been at Yale University since 1996 where he received his PhD in Cell Biology in 2001 for work characterizing epithelial ion transport pathways and his MD in 2004. As a resident and fellow in the Department of Dermatology, Dr. Choate began working with Leonard Milstone in a clinical practice dedicated to the care of patients with ichthyosis and related skin disorders. On the basis of novel observations made in a group of those patients who have ichthyosis en confetti, he began collaboration with Richard Lifton, MD, PhD in the Department of Genetics to identify the genetic basis of ichthyosis en confetti. He will join the Yale faculty in July, 2008.

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Congratulations!

News & Notes

Family Health History Web Site

Americans know that family history is important to health. A recent survey found that 96 percent of Americans believe that knowing their family history is important. Yet, the same survey found that only one-third of Americans have ever tried to gather and write down their family's health history.

Because family health history is such a powerful screening tool, the Surgeon General has created a new computerized tool to help make it fun and easy for anyone to create a sophisticated portrait of their family's health. The site guides users through a series of screens to record health data for family members. All personal information is maintained on the user's computer. No information is given to the government. Once the history is complete, it can be printed and shared with a physician. Visit the link **www.familyhistory.hhs.gov/** to get started. Those that don't want to use the online version, or without computer access, may call the Department of Health and Human Services at 1-888-Ask HRSA (275-4772).

Excerpts reprinted from the Department of Health and Human Services website.

Genetic Information Nondiscrimination Act

The Genetic Information Nondiscrimination Act (H.R. 493, S. 358) is a bill that will prohibit discrimination on the basis of genetic information with respect to health insurance and employment. It was introduced to establish basic legal protections that will enable and encourage individuals to take advantage of genetic screening, counseling, testing, and new therapies that will result from the scientific advances in the field of genetics. It will also prevent health insurers from denying coverage or adjusting premiums based on predisposition to a genetic condition, and prohibit employers from discriminating on the basis or predictive genetic discrimination. Additionally, such legislation would stop both employers and insurers from requiring applicants to submit to genetic tests, maintain strict use and disclosure requirements of genetic test information, and impose penalties against employers and insurers who violate these provisions.

To learn more about the status of this bill and the Coalition for Genetic Fairness go to **www.geneticalliance.org** and click on Public Policy, or call or email the Foundation office for more information, 1-800-545-3286 or info@scalyskin.org.

2008 Testimonial Dinner

Honoring Drs. Eugene Van Scott and Ruey Yu

On Friday evening, February 1, 2008, renowned dermatologist, Dr. Eugene Van Scott, and Dermatopharmacologist, Dr. Ruey Yu, were honored for their efforts on behalf of the Foundation. Drs. Van Scott and Yu are best known for the discovery of alpha hydroxy acids. They first discovered the unique skin care benefits of AHAs in 1974, through their research on inherited dry skin, medically termed ichthyosis. They collaborated for twenty years researching and developing AHA products prior to founding The NeoStrata Company in 1988, the medical community's recognized leader in alpha hydroxy acid formulations.

F.I.R.S.T. honored these pioneers at a Testimonial Dinner at The Spire at Historic Sunset Station in San Antonio, Texas. Both doctors have been tirelessly committed to the Foundation and its patients for decades. The dinner was a tremendous success. Poignant tributes were given by Dr. Robert Auerbach, Dr. Eric Vonderheid, and Barbara Green. The families of both men shared in their evening.

Dr. Van Scott and Dr. Yu

The Board of Directors and the Foundation staff are extremely grateful to Dr. Van Scott and Dr. Yu for having allowed the Foundation to host this successful event in their honor. The event raised more than $60,000 for the Foundation's general operating budget.

Executive Director's Report

As I work on the last minute changes to the conference activities, I am getting very excited to see many of you in Chicago. We are planning a wonderful and worthwhile program full of activities and entertainment for all ages. Our theme of *"Educate, Inspire & Connect"* will be evident throughout the weekend. Our attendance is the highest ever. There is still time for you to register if you would like to attend. The deadline is June 6. If you are unable to attend, please look forward to highlights and pictures in the next issue.

Our annual spring membership mailing will be arriving shortly, if you haven't received it already. Please be sure to renew or reactivate your membership with F.I.R.S.T. If you cannot afford the suggested membership donation, please do not hesitate to let me know by calling or emailing the office.

The 2nd annual Phantom Tea is in full swing. Donations from this national fund raiser are arriving at our office every day. We hope to double our donations from last year, from $32,000 to $64,000. It is really an easy way to get involved and make a difference for F.I.R.S.T. If you haven't sent back your postcard to participate, please send it in. It's not too late to take part.

F.I.R.S.T. is also beginning to see the benefit of members ordering flowers from Flowerpetal.com. Here is another simple way to help F.I.R.S.T. Visit www.scalyskin/flowerpetal.com and order your flowers for relatives, friends, and loved ones. Twelve percent of every sale is donated back to F.I.R.S.T.

I am extremely proud to present our yearly annual report on pages 8 -13. As you will read, F.I.R.S.T. is working tirelessly to help our members and those affected with ichthyosis and the related skin types. The Foundation is fortunate to be governed by an extremely strong and committed Board of Directors and Executive Officers. Today, we are reaching new heights that were only dreams a few years ago. Through our programs and services, we are growing stronger every day, one member at a time.

Sincerely,

Jean

The Lennox Foundation Grant

Great news and congratulations to F.I.R.S.T.! We recently were awarded a $100,000 grant from the Lennox Foundation. Many, many special thanks to Suzanne Phelps, who provided this opportunity for F.I.R.S.T. The Lennox Foundation is a family-run foundation, and only relatives can nominate organizations for funding. Suzanne's son is affected with a yet-to-be diagnosed type of ichthyosis and she recommended F.I.R.S.T. for the Lennox Foundation's large grant cycle.

The funds we received will be designated to support our new four-year strategic plan. There is the potential for two additional grants in the next two years. This year's funds are earmarked for three specific programs: 1) an Ichthyosis Clinical Scholar Program; 2) the Ichthyosis Registry; and 3) an Ichthyosis Telemedicine Project. You will be hearing more about these programs in the very near future.

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Professor of Dermatology, University of Virginia
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Annual Report President's Report

Greetings to all Members and Friends of F.I.R.S.T.:

In my previous Annual Report message, I spoke of Soaring to New Heights, a theme that was used for the Foundation's 2006 Family Conference in Atlanta, GA. For all F.I.R.S.T. Board Members, our Executive Director and our extremely talented staff, this theme has provided a continual reminder that sustaining organizational growth, providing enhanced and effective service to those affected with ichthyosis and related skin types, and developing even better ways to actively engage more people in F.I.R.S.T. are indeed lofty goals.

With these summary goals of continued growth, service and engagement, a sub-committee of the board and staff worked during much of 2007, and with great care and diligence, to reflect on our progress against the previous strategic plan. We also sought ways to leverage our past successes and programs into even more success and progress over the next four years.

Indeed, in my short time as president, an undeniable strength of F.I.R.S.T. is our rich history of dedication and commitment of so many volunteers for over 25 years. Clearly, the wonderful people associated with our Foundation, including staff, members and volunteers, are its most important asset.

Therefore, as we conducted a nine-month strategic review and planning process, performing in-depth interviews of founders and past presidents, medical advisors, volunteers of F.I.R.S.T., members and current board and staff leadership was fundamental to our evaluation and establishing the proper future direction and actions upon which F.I.R.S.T. should embark. Additionally, we sought the outside counsel of a third party to help facilitate the effort – the Nonprofit Center at LaSalle University, a group that specializes in counseling and advising non-profit organizations in such matters.

In the end, reliance on this type of dedication from our past and current members, volunteers and the professional guidance from LaSalle, made our work gel quite nicely. From among all whom participated in the process of reviewing our past goals, brainstorming and setting the course for the next four years, our mission has never been clearer, and the effort to accomplish our mission never more resolute - everyone felt very strongly about, and emotionally embraced, the following statement:

Our mission is to educate, inspire and connect
those touched by ichthyosis and related disorders
through emotional support, information, advocacy and research funding
for better treatments and eventual cures.

Perhaps you have seen this statement already on recent newsletters. You will surely begin to see the consensus message of Educate, Inspire & Connect on future publications, informational tools, marketing pieces, and on literature and shirts at our upcoming marquee organizational event, the 2008 Family Conference in Chicago (June 27-29).

Importantly, our mission at F.I.R.S.T. is authentic, and genuinely defines who we are and what we are about. From an organization perspective, this clarity is a key to gaining the confidence and collective, yet focused, efforts of our members, staff, and volunteers. Equally important, our mission statement presents us to others in a clearly differentiated way to drive future awareness campaigns.

In acting on this mission, our goal is to continue forging bonds among us and other stakeholders that last a lifetime, and so the board is committed to the development of a solid, long-term marketing plan that takes our numerous assets and focuses them towards those that we want to reach and influence.

In this plan, we challenge ourselves to develop new and expanded approaches that continue to reach out and provide our current members of ALL AGES with continued support, much-needed information, advocacy and research funding and information about better treatments within the ichthyoses and related skin types, while also offering those new to our organization a welcome mat to meet and learn about our organization, some for the very first time. This marketing plan will be the cornerstone from which we talk about ourselves and which spurs continued interest of major benefactors in our organization.

Our updated strategic plan also calls for the aggressive development and use of technology infrastructure to enable us to "reach out" in additional, innovative ways to more people in need and prospective stakeholders. One

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example is a key investment in computer software that can efficiently be utilized to manage our ever-growing database of members and stakeholders.

An equally powerful way to leverage technology for our goals is through a tele-medicine initiative that we will try to form through collaboration with professional societies like the American Academy of Dermatology and with the use of restricted grant resources to F.I.R.S.T and/or unrestricted funds raised through grassroots and staff-driven efforts.

Your board of directors believes these infrastructural initiatives are simply too important to let them sit on the back burner for much longer! Having lived in a rural area for over 30 years, I personally believe that current and prospective members that just live too far away from those expert in treating ichthyosis, and their rural physicians, will find tremendous benefit from such an important and timely investment.

Developing internet connectivity without developing the outstanding young professionals that are so very important to better treatments and management for our members would be shortsighted. Thus, we have joined forces with our Medical and Scientific Advisory Board members and will develop a plan to jointly identify gifted, young dermatologists as clinical experts and nurture them in our direction with organizational support.

Connecting our members to the knowledge, engagement and inspirational support of research and clinical professionals represents hope to all affected by ichthyosis and the related skin types. We must do everything we can to strengthen those relationships and find new ones. Thus, be assured that F.I.R.S.T remains committed to finding sources of financial support for dedicated research, and will make every effort to get these funds into the hands of the most qualified research experts that may make for better treatments and eventually lead to cures.

From the reports of Jean (Executive Director) and John (Chief Financial Officer) included in this Newsletter, together we are accomplishing a great deal, and the organization is growing and on sound financial footing. This is strong testimony to those that have led us in the past, and provides a glimpse of what the current leadership needs to embellish.

So, I would ask you to consider providing further support of this good progress in the following two tangible ways:

- One of the best ways you can help support our mission statement is to attend our upcoming family conference in Chicago, and the fundraiser at Harry Caray's the evening before, if possible. If the number of early bird registrants is an indicator, 2008 promises to be a record attendance for our family conference. If you have not signed up yet, get on it right away – with more than ten clinicians doing consulting at the conference, Chicago will provide you the best way to become connected, educated, and inspired!
- Please join with so many other members and volunteers and get engaged in our organization – both through your continued or future financial commitment to F.I.R.S.T. and our mission, but to each other as well.

In closing, the goals of F.I.R.S.T. certainly remain lofty and our 2008 – 2011 Strategic Plan is ambitious. Nonetheless, with your continued support of our excellent staff, the Directors, and your fellow members and the many grassroots volunteers that work tirelessly throughout the year, we expect to accomplish all of our strategic goals and continue making a positive difference – please reach out and help us when you can, by answering our call when we reach out to you.

Most sincerely,

David R. Scholl, Ph.D.
President

Chief Financial Officer's Report

Dear Members and Friends:

Our audited financial statements illustrate yet another banner year for the Foundation. Our auditors, McGladrey & Pullen, LLP, issued another unqualified opinion and graciously kept fees down to a reasonable amount for which we are most thankful. Increasing donations to our restricted funds challenged us to develop a more effective reporting system. The new system allows us to track each funding source, from when money comes in, to when and how it is spent. This also allows us to allocate interest earned on monies not yet spent for each restricted amount. My other good news is our available cash and short term investments have grown to a point that I am now researching an asset management firm to improve our returns. Previously, our cash and short term securities were not sufficiently large enough to attract a credible asset manager.

Our current year Statements of Activities shows our Change in Net Assets increasing by an impressive $706,085 or 304% over last year. Total equity increased by 105% and unrestricted equity increased by 165%. The real significance of this is that if the economy, which we are all worried about, causes lower contributions, we have unrestricted reserves to cover almost three years of operating expenses.

On the revenue side, we had an increase of 71% in contributions primarily due to a major non-member donor. We also increased our interest income by just over $25,000 from the $5,000 we had been averaging the past few years. In addition, the Board of Directors came through again with $24,000 in direct solicitations. On the expense side, expenses were pretty much contained and in line with budget; we made reductions in some areas and spent more on others. The most notable increase was in the area of staffing, where I believe this was money well spent. Jean Pickford is now better able to focus on key areas requiring her attention and the results have been impressive, not only in improvements in providing our services, but in our fundraising efforts as well. Overall, not counting grants funded, expenses even decreased by $10,000.

Foundation for Ichthyosis and Related Skin Types, Inc.

Statements of Financial Position
September 30, 2007 and 2006

	2007	2006
Assets		
Current Assets		
Cash	$ 1,085,428	$ 420,972
Marketable securities	277,471	244,883
Pledges receivable	-	150,000
Prepaids and other assets	2,840	4,350
Total current assets	1,365,739	820,205
Cash, permanently restricted	10,000	10,000
Furniture and Equipment, net	4,430	2,891
Total assets	$ 1,380,169	$ 833,096
Liabilities and Net Assets		
Current Liabilities		
Grants payable	$ -	$ 150,000
Accounts payable and accrued expenses	2,395	11,407
Total current liabilities	2,395	161,407
Net Assets		
Unrestricted	1,167,163	439,142
Temporarily restricted	200,611	222,547
Permanently restricted	10,000	10,000
	1,377,774	671,689
Total liabilities and net assets	$ 1,380,169	$ 833,096

See Notes to Financial Statements.

After last year I threw out my crystal ball so I will not try to forecast the financial future for the Foundation. However, it does seem that we have begun a new phase of our growth, helping more and more people than we could have ever imagined. As I said last year, the Board is not resting on its past success. During our retreat this past November, we made strategic plans for the future that have the potential of helping us sustain the tremendous growth path we have been on over the past few years. Oh and by the way, some of those fundraising ideas you never thought would bring *in* money, have really panned out very well, so keep them coming in to Jean.

Sincerely,

John J. Schoendorf
CFO, Board of Directors

*The Statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2007. A complete copy of the audited financial statements and the independent auditor's report are available and can be obtained by calling the national office at 215-619-0670 or 1-800-545-3286.

Fiscal Year 2007 Contributors List

October 1, 2006 thru September 30, 2007

$100 - $249

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Contributions received between October 1, 2006 – September 30, 2007 are listed in this years annual report.

Ichthyosis Through The Decades

Mary K. Jones - Age: 63
Newton, Kansas

What type of ichthyosis are you affected with? Severe Lamellar Ichthyosis

What treatments do you use for your ichthyosis? I alternate between 2 topical prescription medications: Tazorac gel 0.1% and 8% more lactic acid added to the 12% Lac-Hydrin. They seem to make the skin peel better for me that way instead of using just one product. I also like to use Dermal Therapy on my hands. To keep my skin moist after each time I bath or wash my hands, I use Neutrogena Norwegian Body Moisturizer, which I learned about and was a free sample from the manufacturer at the F.I.R.S.T. Conference in Kansas City.

I use a Bath Seltzer that is created just for me by a gal in Wichita that has a bath and body shop. She was willing to experiment with different ingredients until it worked for me. It contains several oils that I believe soften the skin so I can rub it off easier in the bath. I spend at least 3 times a week in the bath for longer periods of time trying to rub the skin off. For more info about her product, just email me.

Skin grows rapidly in my ears also and attaches to the eardrums so at times my hearing is limited. Usually I can clean them out myself but I have broken my eardrums many times over the years. (But, as you all well know, with our rapid skin growth it doesn't take long for them to repair.) I have struggled the last 2 years with limited hearing and fluid in the Eustachian tubes. I just found a new ENT that understands my problem because he has some experience with patients with ichthyosis. I now use DermOtic Oil that contains a small amount of a steroid. It thins out the skin in the ear canal and he thinks it will keep the eardrum clean so he will not have to peel the skin from the eardrum. He also suggested that I use Zinc Sulfate because it should help with a certain enzyme (metalloproteinase) in the skin. I haven't used it long enough to know whether it works yet.

How have these treatments changed over your lifetime, and has your ichthyosis itself changed? Although a cure is getting closer each year, we are still only able to ineffectively treat the symptoms and not the cause. As a child, the only thing that we knew to use was thick and greasy, pure lanolin to try to keep the skin from constantly cracking and bleeding. The skin was often 1/8" thick. Then much later, when I was in high school, it was suggested that I put Aveeno in the bath water to help soften the skin. But we didn't have a bathroom, only an out-house. Our round metal tub was too small, I thought. So I would go to the milk barn and get into the vat for washing up the milking equipment. I believe that it was after I graduated from college that I started using LacHydrin. Then sometime in the 70's, I believe, they came out with Retin A. That was the first significant product for me. Everything that I have used has been topical. I tried Accutane once but didn't like the side effects and was scared of it. That brings me to what I am using now which I probably started about 9 or 10 years ago. I feel that my ichthyosis is getting worse as I age, probably due to the hormonal changes that have occurred.

Tell us about the challenges you face, at this decade of your life dealing with ichthyosis. As always, summer and winter in Kansas are very difficult. In winter I deal with the dry, cracking, and bleeding skin. In the summer heat, activities are limited. There are so many things that I want to do that I can't. I exercise by riding my bike but I must ride early in the morning or nearly dark when the heat is tolerable. We limit any traveling to spring or fall because one time we were traveling across Kansas in the summer, our air conditioner went out and I landed in a hospital from overheating.

Over the years, because of the limited products that worked for me, I would spend many hours in the bathtub scrubbing as hard as I could to get some of the skin off. Over the years I have damaged my spine and neck from pushing my body so hard against the hard surface of the tub. I would spend anywhere from 8 to 11 hours at one time scrubbing on weekends. I can no longer do that physically since I have aged. So, now I usually spend less than an hour each time, 3 times a week. As I continue to age, what happens when I am no longer physically able to take care of my skin at all?

I will always hate the fact that I'm constantly shedding big flakes of skin. It is extremely bothersome and embarrassing. I can never have a clean house. We can vacuum the floors but as soon I walk where it has been

Continued on Page 19

LAST CHANCE TO REGISTER

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

Educate, Inspire & Connect

2008 National Family Conference
Friday, June 27—Sunday, June 29, 2008
Chicago Marriott O'Hare
Chicago, Illinois

Join us for another life-changing experience. The conference features the latest medical and research updates, a better understanding of how to manage your ichthyosis, and, most importantly, a wealth of support from other individuals and families.
Come be *educated, inspired and connected*!

Workshops & Events *at a glance....*

Friday, June 27

7—9 am	Registration/Breakfast
9—5 pm	Clinical Screening Appointments
9:15—11:45 am	General Session
11:45—1:15 pm	Lunch
1:15—5:30 pm	Child Care Camp (ages 1—10)
1:15—5:30 pm	Tween Camp (ages 11—13)
1:15—5:30 pm	Teen Camp (ages 14—17)
1:15—3:00 pm	Adult Workshops I
3:00—3:15 pm	Refreshment Break
3:15—5:30 pm	Adult Workshops II
5:30 pm	On Your Own

Saturday, June 28

7—9 am	Breakfast
9:00—11:45 am	Child Care Camp (ages 1—10)
9:00— 10:30 am	Product Demo (adults/teens/tweens)
10:30—5:30 pm	Offsite Field Trip (teens/tweens)
10:45—11:45 am	Research Update
11:45—1:15 pm	Lunch
1:15—5:30 pm	Child Care Camp (ages 1—10)
1:15—3:00 pm	Adult Workshops III
3:00—3:15 pm	Refreshment Break
3:1 5—5:30 pm	Adult Workshops IV
6:30 - 8:00 pm	Dinner
8:00—11:00	Dance Party/Talent Revue

Sunday, June 29

7—9 am	Breakfast
9:00—11:45 am	Child Care Camp (ages 1—10)
9:00—11:45 am	Tween Camp (ages 11—13)
9:00—11:45 am	Teen Camp (ages 14—17)
9:00—10:15 am	Adult Workshops V
10:30—11:45 am	Adult Workshops VI
11:45—12:15 pm	Closing Remarks
12:30—2:00 pm	Farewell Lunch

Bonus Event!

Experience Downtown Chicago by Night!
Thursday Evening, June 26

Harry Caray's, world famous Italian steakhouse in downtown Chicago, is hosting a charity fund raiser on behalf of F.I.R.S.T. Plan to arrive early! See details on next page.

Educate, Inspire & Connect—Chicago—June 27-29, 2008— F.I.R.S.T., 1364 Welsh Road G2, North Wales, PA 19454— 1.800.545.3286— www.scalyskin.org

CONFERENCE INFORMATION & HIGHLIGHTS

Registration: To register for the conference, complete the Conference Registration Form and submit payment to the national office by June 6th. Registrations will not be accepted without a completed Registration Form and payment. *Please note*: Registration does not include your hotel room. Accommodations at the Chicago Marriott O'Hare must be made separately.

Cancellations & Refunds: Cancellations received prior to June 6th will be refunded less a $25 per person administrative fee. No refunds issued after June 6th.

Hotel Accommodations: The discounted room rate negotiated with the hotel is $104.00 per night, flat occupancy. This rate is available from June 24 through July 6. All attendees must make their own reservations at the Chicago Marriott O'Hare by calling toll-free at 800.228.9290 or 773.693.4444. To ensure you receive the discounted conference room rate, you must identify our group name of "Foundation for Ichthyosis & Related Skin Types." Reservations must be received on or before *June 5, 2008*. All reservations must be accompanied by a first night room deposit guaranteed with a major credit card.

Air & Hotel Transportation: O'Hare International (ORD) and Midway (MDW) are the two major airports in Chicago. There is a free shuttle service from the O'Hare International Airport to the hotel, located one level below baggage claim at door #2. The shuttle runs every 15—20 minutes between 5 am and 12:00 midnight.

Air Charity Network: You may be eligible for free transportation using the Air Charity Network, formerly the Angel Flight America Program. If you live within 1000 miles of Chicago, Illinois, Air Charity Network will fly a family in a 4-seater or 6-seater plane to and from the conference at no cost. Contact the National Patient Travel Center at 888.675.1405 and refer to the 2008 Foundation for Ichthyosis Family Conference Special Lift Program.

Driving Directions to Hotel: Contact the Chicago Marriott O'Hare at 773.693.4444 or visit their website at www.marriott.com and click on Chicago Marriott O'Hare. Their address is 8535 West Higgins Road, Chicago, IL 60631. There is a fee for parking.

Public Transportation: Chicago's "L" train system has many convenient stops. The "blue line" services the airport and hotel. For more information, visit http://www.transitchicago.com/maps/rail/rail.html.

Clinical Screening: All affected individuals and their families have the opportunity to meet with leading expert physicians for a free, private 15-minute consultation on Friday, June 27. Participation is voluntary. Sign-up is required prior to the conference. If you are interested, you must complete the Clinical Screening section on the Conference Registration Form.

Dress Code: Conference attire is casual, including Saturday evening's dinner/dance.

Meals: Additional meals added this year!!! The conference registration fee includes a continental breakfast and lunch on Friday, June 27, breakfast, lunch and dinner on Saturday, June 28, and breakfast and lunch on Sunday, June 29. All registrants are on their own for dinner on Friday evening.

F.I.R.S.T. Idols Talent Revue: This revue, which is open to children ages 5 to 18, is new to the conference. It promises to be a popular and heartwarming event for children to showcase their talents to our audience. The Talent Revue will take place on Saturday evening, June 28 at 8:00 pm in the Nikko Room at the Hawaiian Dance Party. If you want to participate, complete the F.I.R.S.T. Idols Talent Revue section on the registration form.

Experience Downtown Chicago by Night: Charity Benefit at Harry Caray's — Thursday June 26: Harry Caray's, world famous Italian steakhouse in downtown Chicago, is hosting a charity benefit to raise money for F.I.R.S.T. Open to the public, it is expected to gather a large crowd of local Chicagoans. It will feature a live auction, dinner buffet, cocktails, local celebrity entertainment, and comedians. Conference attendees are invited to attend at a reduced admission price of $20 per adult. This fee includes dinner buffet, beverages, and transportation to and from the hotel. Keep in mind, the entertainment may not be suitable for families with young children. Transportation will be provided, leaving the hotel at 6:30 pm and returning from Harry Caray's at 10:00 pm.

If you are interested in attending, you must register online at our website (www.scalyskin.org) or complete the registration form available on page 12. If you have any questions, please contact Frank Osowski, F.I.R.S.T. member, at frankieo@harrycarays.com.

F.I.R.S.T. is grateful to be the recipient of the funds raised from this event. Please note that this event is not sponsored by the Foundation and is wholly independent of other conference-related events.

CONFERENCE REGISTRATION FORM

Contact Information

(please print clearly)

Name: ______________________________

Address: ______________________________

City: ______________ State: ________ Zip: __________ Country: __________

Phone (Day): ______________ Phone (Night): ______________

Cell Phone: ______________ Email: ______________

☐ I give permission to F.I.R.S.T. to publish my name, contact information and type of ichthyosis in the conference roster, which will be distributed to all attendees.

Registrant Information

This section must be completed with registrant's complete name, age, and type of ichthyosis (if appropriate). There are four tracks of programs: Adult (age 18+), Teen (ages 14-17), Tween (ages 11-13), and Child (ages 1-10). Based upon ages provided, each registrant will be assigned to the appropriate program.

First Name	Last Name	Age	Will Need Child Care*	Affected by Ichthyosis
____________	________________	____	☐	☐
____________	________________	____	☐	☐
____________	________________	____	☐	☐
____________	________________	____	☐	☐
____________	________________	____	☐	☐

Please indicate which type of ichthyosis affects your family: ______________________________

*The Foundation has hired a professional child care company to entertain and supervise children, ages 1-10, while parents/guardians are participating in the adult program. There is a nominal, one-time fee of $15 per child to guarantee placement in the program and to hire the appropriate number of caregivers for the safety of your children.

Clinical Screening

Meet with expert dermatologists who are extremely knowledgeable about ichthyosis to answer any questions or concerns that you may have. These 15-minute appointments will take place throughout the day on Friday, June 27, from 9:00 am - 5:30 pm. You will receive an email prior to the conference with your appointment time. *Please note*: There may be physician residents in-training observing during your appointment. This will help educate future leaders in dermatology about ichthyosis.

Name of person for appointment	Age	Male/Female	Type of Ichthyosis
________________	____	________	______________
________________	____	________	______________

Has your ichthyosis been medically confirmed by a dermatologist? Yes or No

CONFERENCE REGISTRATION FORM

Volunteering

Please check if you would be willing to volunteer with:

☐ Assembling Gift Bags on Thursday, June 26
☐ Helping at the Registration Table
☐ Helping at F.I.R.S.T.'s Kiosk Table
☐ Assisting with Teen/Tweens & Field Trip
☐ Organizing a Texas Hold 'Em Game
☐ Assist in managing the F.I.R.S.T. Idols Talent Revue

Name: ____________________

Phone: ____________________

Email: ____________________

F.I.R.S.T. Idols Talent Sign-Up (Ages 5-18)

Child's Name: ____________________

Age: _____ Grade: _____ Hometown: __________

Type/Description of Act: ____________________

____

____

Performances will take place on Saturday evening at 8:00 pm. A compact disk player and microphone will be provided. You must bring your own music, costume, props, etc. All performances will be limited to a maximum of 2 minutes.

Photo and Video Permission Release

I hereby give my permission to F.I.R.S.T. to use and distribute, including but not limited to use in newsletters, guides, documentaries, appeals, website and reports at their discretion, any photos or video tapes taken at the 2008 Family Conference in which I or my family may be a part.

Signature: ____________________ Date: __________

Payment

☐ Registration Fees

Number of Adults (Ages 14 and up) __________ x $165.00 USD $__________
Number of Children (Ages 5—13) __________ x $115.00 USD $__________
No registration fee for children 4 and under (all names must be listed under registration)

☐ Child Care

Number for Child Care (Ages 1—10) __________ x $15.00 USD $__________

☐ I have enclosed a donation to support the conference scholarship fund $__________

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_____ Make checks payable to F.I.R.S.T. in US Funds.
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In consideration of the acceptance of this registration entry, I/we the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters, and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by the negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

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vacuumed, it is dirty again — even while I'm still vacuuming! Going anywhere: a friend's house, offices, restaurant, etc. — I leave a trail of skin everywhere I go. Just like Hansel and Gretel.

What seems important now that you are older compared with what seemed important when you were younger? I don't know if there is any difference. The goal has always been to find the best treatment for my skin. (I probably could have started my own store with all the products I bought through the years, thinking that I would find some cream, lotion, or potion that would help.) But as I grew older I became more pro-active in my own health instead of just relying on doctors. I have been studying herbs and supplements for the last 10+ years in search of treatments. Some things I've found I think have helped. For example: MSM Liposome Lotion coupled with MSM capsule/powder taken internally seems to help keep the skin softer and perhaps lessen buildup.

Also as we know, prescription medicines also have bad side effects. The Tazorac that I use on my skin can elevate the triglycerides in the blood. So I take cod liver oil to keep the triglycerides under control. Cod liver oil contains Vit. A which is also a benefit to the skin. Because of these medications I use and because I am not able to sweat (except on my face) to help remove toxins from my body, I use Milk Thistle to help cleanse the liver.

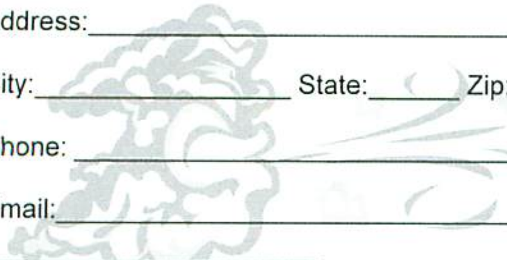
Perhaps I have more worries now that I am getting nearer to the end of my life than earlier: How to physically take care of my skin as I age and how to pay for the medication. The Tazorac alone is $1,452.00 every time I buy it. Insurance pays most of it now but what will happen when I retire and am on Medicare? There is a donut hole where they pay nothing for medications.

What hopes do you have for the future, taking your condition into consideration? Of course, my greatest hope for the future is the "cure" — the enzyme replacement therapy — in my lifetime! They are getting much closer and I want so much to see it while I'm still alive. Not only for myself but also for all the children and young adults so they don't have to go through the abuse and hurt that I did. I was teased and called "fish skin." All the rude questions of whether I was burned, fell in a mud puddle; all the laughing, pointing, and staring. I was asked to leave a swimming pool and was refused service in a restaurant, too. But the worst of all: the owner of a carnival that came to the county fair offered my mother money to let him take me on the road and put me in a "freak show." She quickly took me away from the fair because she was afraid that they would try to kidnap me. I owe my stable mental health to the presence of Yahweh (God) in my life, a loving family, steadfast friends throughout my life, and an understanding and loving husband.

What advice would you have for others affected? Live each day to the fullest. Persevere with **HOPE**. Any efforts to change our "lot in life" are important.

Experience the friendliness and generosity of the Windy City

Charity Benefit at Harry Caray's
Thursday, June 26
7:00–10:00 pm



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Number of Adults Attending ____ x $20.00 USD $______
(Registration fee includes light buffet, beverages and transportation)
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Bus transportation will depart the hotel lobby at 6:30 pm and return from Harry Caray's at 10:00 pm.
Pre-registration and payment are required.

Have you moved recently or 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.

F.I.R.S.T.
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