

Ichthyosis FOCUS



Volume 26, No. 4

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

Winter 2008

Ichthyosis Through the Decades

We are excited to bring you a series called "Ichthyosis Through the Decades." The next three issues will introduce you to eight women from the ages of 26 to 90, whom are members of F.I.R.S.T. and are affected with ichthyosis. This issue, we are pleased to introduce you to a 26 year old living in Elmira, NY, a 33 year old living in Philadelphia, PA, and a 40 year old in Ellicott City, MD. These three women give us a candid look into their lives and share their challenges and obstacles, as well as what they have overcome throughout their lives.

See page 4

Accutane® and Dental Health

by Dr. Andrew Sonis

Dental decay, or dental caries as it's referred to by dental professionals, is a dynamic process characterized by the loss of mineral structure as a result of an environmental insult. What exactly does this mean? Most of us are familiar with the grade school science project of placing a tooth in soda pop and watching it dissolve over time. While you might think this is a result of the sugar in the pop, it is actually the result of the pop's low pH or acidity. The acid leaches or dissolves the calcium composing the tooth, resulting in its disappearance. This process occurs when the environmental pH drops below 5.5.

Normally the mouth has a neutral pH, meaning it is neither acidic nor basic. However, when dental plaque is exposed to a carbohydrate source it produces lactic acid, resulting in a precipitous drop in the pH. Should this acidic environment be maintained for greater than twenty minutes it can initiate the decay process. So foodstuffs left in contact with the teeth, i.e., trapped in the biting surfaces, or frequent snacking or "grazing" can lead to increased decay susceptibility.

The decay process typically begins with plaque adhering to the tooth surface. Dental plaque is composed of bacteria that possess the ability to produce lactic acid when exposed to a carbohydrate source. Over time, the acid leaches calcium from the dental enamel resulting in a chalky white appearance. Should this process be allowed to continue, the surface of the enamel becomes undermined and ultimately caves in, or cavitates, and thus the formation of a cavity.

Fortunately, nature has provided some help in protecting our teeth from these frequent insults. Saliva has the capability of buffering or neutralizing this acid and allowing for return to a neutral pH. The importance of saliva in protecting the teeth cannot be over emphasized. When patients with head and neck cancer receive

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The Foundation for Ichthyosis
& Related Skin Types
1364 Welsh Road, Suite G2
North Wales, PA 19454

215.619.0670 • 800.545.3286
Fax: 215.619.0780
Email: info@scalyskin.org
Web: www.scalyskin.org

Executive Director
Jean Pickford

Editor
Moureen Wenik

Medical Editor
Amy Paller, M.D.

Editorial Assistants
Louis Giuliana
Tiffany Moore

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Executive Director's Report



Dear Members & Friends of F.I.R.S.T.,

My best wishes to everyone for a wonderful
year in 2008. The promise of a new year
always brings new hope and a refreshing
outlook for the future. At F.I.R.S.T., we are
poised for another wonderful year of
educating, inspiring and connecting our
members and friends.

In this issue we are featuring a new column called
"Ichthyosis through the Decades." It will feature glimpses
of members living with ichthyosis from different age
perspectives: from twenties to people in their nineties.
We hope that these spotlights will make a connection
with you.

Also featured is a summary of our new four-year strategic
plan. I am very excited to share this plan with our members,
because it highlights our upcoming goals. I hope you
will share in this excitement and continue or renew your
support of F.I.R.S.T.

The 2008 Family Conference is just months away, and it
will be here before you know it. I hope you will consider
attending this three-day inspirational and educational
event. If you would like to meet others affected with
ichthyosis, learn about new treatment ideas, or meet
with the expert doctors, this is your opportunity.
Detailed information is on pages 9-12. I hope to see you
there.

I attended the annual Medical & Scientific Advisory
Board meeting which was held at the American Academy
Of Dermatology meeting in San Antonio. F.I.R.S.T. also
honored Dr. Eugene Van Scott and Dr. Ruey Yu at the
2008 Testimonial Dinner. On tap for the upcoming
months is the 13th bi-ennial family conference in
Chicago this summer. I am also busy preparing for
the second annual Phantom Tea national fund raiser.
I expect more members will be joining our efforts this
year.

This is an exciting time to be a member of F.I.R.S.T. We
are improving our services and growing stronger every
day. On behalf of our staff, I wish everyone a healthy and
prosperous year and look forward to working together
again with you.

Sincerely,

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

Grassroots Fundraising

Making Music for F.I.R.S.T.

The Fall Focus featured the fantastic newspaper article about the Foulks family, of Midway, TN. Carlie Foulks' Kinder Musik teacher read the newspaper article and she posted it at the music school, raising \$170. This is one example of how awareness, such as a newspaper article, can make a difference!

Awareness in the Media

Gary Mills and his family were featured in the Newport News Daily Press. The Mills have four children, but only Sarah and Aubrey are affected with lamellar ichthyosis. The Mills feel that public awareness is important to having others understand this rare disease. This feature was a great way to share their story.

Pumpkin Painting Event Successful

Michelle Lott is "tickled pink" by the success of this year's pumpkin painting event. The pumpkins, which were donated by Lott's Greenhouse, were painted by 81 children! This fundraiser was held in conjunction with Ichthyosis Awareness Week. It was so much fun the Lott family has decided to make it an annual event. In addition to painting pumpkins, a bake sale was held, contributing to the \$1829.00 raised for F.I.R.S.T.



Dear F.I.R.S.T.
Our daughter has A.R.C.I. (Lamellar with CIE traits). To help raise money for F.I.R.S.T., I asked my blog readers to shop at Amazon.com. I received a commission on the sales, and have matched it dollar for dollar. I'm happy to be able to send a check for \$186.94 to F.I.R.S.T. I hope this little fund raiser grows and next year I can send an even larger amount.

Jennifer Bryson

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Ichthyosis Through The Decades

Becky Butler - Age: 26
Elmira, NY

What type of ichthyosis are you affected with? Lamellar Ichthyosis



What treatments do you use for your ichthyosis? Creams mostly, Aquaphor with 10-12% lactic acid, Vaseline around the eyes with eye pads and a sleeping mask, St.Ives with aloe lotion, baths, occasional soaks in the hot tub back home.

How have these treatments changed over your lifetime, and has your ichthyosis itself changed? Over the years, my ichthyosis has become more manageable due to my ability to increase acid percentages and care for myself better. As a child I had loving parents who helped me with this, but a child can only take so much. As a child my skin split frequently, was thicker, and I was more stiff and uncomfortable. As an adult (now using stronger creams, pumice stones, etc.), I have less restrictions in the cold, dry weather and look much clearer. I will always have restrictions though—not being able to sweat, prone to infection. The trick is figuring out to work with the restrictions not against them.

Tell us about the challenges you face, at this decade of your life dealing with ichthyosis. I think that no matter what decade of life you are in, you always face the challenge of what society wants you to look like. I will never fit into that mold (pretty, perfect skin, nice hair) and that realization is often sad and lonely. Dating is always not fun. To me it all reverts back to the society mold, men wanting a "pretty girl" a "typical girl." Sadly, I haven't dated a lot. I am a firm believer in not settling for less. I often find myself longing to find a companion to snuggle up with; however, while I wait to find Mr. Right, I've been able to build myself into a strong self-sufficient woman. I find it important to not dwell too much on the challenges; they can often overwhelm you, even consume you.

What seems important now that you are older compared with what seemed important when you were younger? During my middle school and high

school years I wanted more than anything to fit in and be truly accepted. As an adult I don't focus on that anymore. I'm unique for a reason, and I use that uniqueness and build on that uniqueness everyday. My mother says I "march to the beat of my own drum." I love my beat, as do many others. You just have to listen hard enough to yourself, your wants, your needs, your interests, your quirks, your feelings and find your beat.

If you knew "then" what you know "now" what would you do different? Lots of stuff!!!! I wouldn't have dwelled on trying to fit in so much and to follow what was considered the "norm." I would have just been myself, and who knows maybe in doing so I might have encouraged others to do the same. If I could do it all over again I would take more risks, try more new things, and meet more people. In the words of Garth Brooks, "Life is not worth living if you stand outside the fire." I tended to err on the side of caution and do just that. If I knew then what I know now I would have danced every day in the fire!

What hopes do you have for the future, taking your condition into consideration? I'm a dreamer and a goal setter so I've got lots of hopes. I hope to help others with special needs (particularly children). I hope to become a published children's book author. I hope to one day live on the water and open a small café. I hope to travel extensively with family and friends. I hope to fall in love. I hope to have someone fall in love with me. I hope for a society that focuses more on inner beauty than outer beauty. I hope to inspire others to find inner strength, and I hope that my parents will be around to see all of my hopes and dreams come true. Some of the hopes I'm working on to make realities. To me no hope, dream, or goal is too little or too big; they all take time and effort and change. Change is always the hardest to face because it is so uncertain, but in the end it often leads to exactly what you were hoping for...sometimes, it even leads to something better than what you could have imagined.

What advice would you have for others affected? Always remember that ichthyosis is a **PART** of who you are but it isn't **WHO** you are. Having ichthyosis doesn't define you, you define yourself. Live!

Nicole McMillian - Age: 33
Philadelphia, PA



What type of ichthyosis are you affected with? Lamellar Ichthyosis

What treatments do you use for your ichthyosis? I use the following creams /ointments, soaps in various rotations throughout the year: Eucerin, Vaseline (Lavender/Baby scented—any store brand will do), Shea butter, All Natural African Black Soap (found in most herbal shops), Dove Body Wash, Neutrogena soap (dry skin), Cetaphil Gentle Skin Cleanser, St. Ives Apricot Scrub, Extra Strength PDS Cream (by Neostрата), and Tazorac cream .1%.

How have these treatments changed over your lifetime, and has your ichthyosis itself changed? As a child and through high school/college I only used Eucerin cream. As I've gotten older, I've noticed that my skin has gotten drier and is more susceptible to changes in the environment (heat, cold, humidity, hard water, etc.) In my twenties, I started to experiment with various acidic lotions (lactic, glycolic, salicylic) to assist with exfoliation. Also, I can no longer use Eucerin by itself. I am always mixing it with other creams to help me stay moisturized during the day.

Tell us about the challenges you face, at this decade of your life dealing with ichthyosis. My job keeps me pretty busy, and I am very socially active in the evenings and weekends. I am always on the go, and the biggest challenge for me is finding and/or making the time to actually take care of my skin properly. In college, I learned the art of the 30-45 minute "prep and go" (Shower/Lotion/Dress). Although I am quite skilled and use it as part of my daily routine to get ready for work, it does not always bode well for my skin. I take longer showers on the weekends, as well as incorporate exfoliation and body scrubs. However, I would love to slow down enough to include long luxurious baths and soaking my feet as part of my weekly routine.

What seems important now that you are older compared with what seemed important when you were younger? When I was younger, my total focus was on my skin and making it look as good as possible so that I would not be teased or look different. Now my focus is on more than just skin and I don't mind being and looking different. When I turned 30, I dyed my hair light brown and last year I dyed it light blond. In summer I wear bold beautiful colors; the brighter the better. Ichthyosis is only one part of me, and it is important to me that I improve

myself physically, mentally, spiritually, and financially as well. I try to surround myself with positive people to form healthy relationships and positive colors to improve my mood.

If you knew "then" what you know "now" what would you do different? I was a very shy kid and I definitely wish that I would have been more social and outgoing. I used to try to blend in and not draw attention to myself. After college, I worked several years in retail and that forced me to interact more with people. I have learned that a friendly smile and hello can work wonders in starting a friendship. If I could do it again, I would smile more and frown less.

What hopes do you have for the future, taking your condition into consideration? I hope to stay as healthy and as limber as possible. I would like to be able to do my own bathing and skin routine as long as possible without outside assistance. When I am 93, I hope to still be able to put lotion on my back and on my feet. (I see yoga in my future!)

What advice would you have for others affected? "We can and will become what we aspire to be"—Tracy Chapman. Connect with others who have ichthyosis through F.I.R.S.T., e-mail, calls, or the AAD skin camps (Camp Horizon/Discovery). My ichthyosis friends have taught me so much about life and have given me inspiration to get through the rough times. I have learned that having ichthyosis does not have to limit me. At times I still wonder what my life would be like without this condition. However, I do know that I would not have met the truly beautiful people that I have been fortunate to meet in my life's journey. I am now 33 with a zest for life and a lot of living to do. I am not afraid when people ask me about my skin. I am willing to educate them about ichthyosis and do it with a smile. I may even bring it up before they do. People ask me, "How come you are so happy?" I tell them that a frown will only bring more frowns and negative energy; I've had enough of negative thoughts to last a lifetime. I smile because I am happy with myself. Surround yourself with positive energy, and know that life can be what you make it if you change your attitude, and create a supportive environment for yourself.



Look for more
"Ichthyosis through the decades"
in our future newsletters

Khristine "Kacy" Leach - Age: 40
Ellicott City, MD

What type of ichthyosis are you affected with? EHK- KRT palmoplantar



What treatments do you use for your ichthyosis? I have a skin regime that consists of using scouring pads, a dremel drill and over the counter lotions (Eucerin, St. Ives, Lubriderm, shea butter) supplemented with glycerin as my current treatment. For my hair I use Tea Tree and Redkin products on my scalp. I go once a month to my salon for a deep scalp cleansing. Doing this keeps my scalp looking good. I have also tried facials at the salon, but using St. Ives apricot scrub is just as effective and much more affordable.

How have these treatments changed over your lifetime, and has your ichthyosis itself changed? As a child my grandmother made salves or lotions using a variety of ingredients to give me comfort. And I spent lots of time in the bathtub, often screaming over the scrubbing I was getting. Now I shower daily and only take a bath once or twice a week. I now find I must change up what I use on my skin as most things seem to lose effectiveness if used too long. As far as my skin, it is much different now than when I was a child. As a child I had thicker, darker, more noticeable scaling. My skin was also more fragile when I was younger. Now with my regimen I am able to keep the scaling better controlled. I now seem to have more redness than when I was younger. It may just be that it is more noticeable due to less scaling. I no longer get skin tears as easily as I did as a child. That also could be due to not doing as many tomboy activities. LOL!!!

Tell us about the challenges you face, at this decade of your life dealing with ichthyosis. Lately, I have been dealing with constrictive bands on my fingers. This has caused me to have numerous surgeries to place skin grafts in order to relieve pain. Most of the other things I have been experiencing have been the same throughout my whole life. For instance, weather changes in my skin are still a nuisance, whole body peels after I have been sick, cracking on my hands and feet, and getting overheated due to not sweating well.

What seems important now that you are older compared with what seemed important when you were younger? The things that are important to me now are my marriage, raising my children, growing in my faith, and loving others. As a child I was worried about fitting in and belonging. As I have grown up I have realized that

I have ichthyosis; it doesn't have me. It's not what makes me who I am. It is a part of me that people I meet will either accept or not.

If you knew "then" what you know "now" what would you do different? For the most part, I don't think there is anything I would change. I think all the things I have been through have made me the person I am today. The main thing that comes to my mind is that as a child I was afraid of people staring at me. I would try to do as little as possible to draw attention to myself. As I have grown older I have learned that getting people's attention is what shows people I am just like them. As I have grown older I have developed a very outspoken personality. I am usually the first one to say "Hi" and I feel this makes me more approachable.

What hopes do you have for the future, taking your condition into consideration? I hope research continues for the whole ichthyosis family. I hope for better treatments and, of course, that a cure is found.

What advice would you have for others affected? Wow, where to start?? First off, be proud of who you are. You were perfectly and purposefully made as who you are. Your skin is just a part of your identity, not all of it. Take it upon yourself to teach all you meet something about your skin. Be easy on yourself because there will be days you are frustrated and just plain sick of the EXTRA we must do because of our skin. It's ok to feel this way, but try not to stay in this place long. Be creative and always be willing to try new things for your skin. And most importantly, reach out to others that are affected. Share your ideas, experiences, and personal care. It is such a great feeling to talk to someone who knows exactly what you are going through. Many of us have had periods of our live where we have felt all alone and needed someone to talk to.

*Special Thanks
to
Becky, Nicole and Kacy
for sharing their
stories with us*

Four Year Strategic Plan Adopted at Board Retreat

On November 10, F.I.R.S.T.'s Board of Directors voted unanimously to approve a new four-year Strategic Plan, effective January 1, 2008. The prior five-year strategic plan came to a close at the end of 2007. The Strategic Planning Committee worked very hard for more than eight months developing the new plan, which will provide the framework to guide the Foundation, the Board of Directors, Executive Director, and staff from January 2008 through December 2011.

During an early brainstorming session, the Strategic Planning Committee was able to distill all their ideas into three simple words: educate, inspire, and connect. These three words not only became the beginning of F.I.R.S.T.'s new mission statement, but they were the heart of the Strategic Plan itself. The strategic initiatives outlined in the plan are ambitious. Attaining our goals will require a huge commitment from the Board of Directors, our staff, and our membership base.

The objective of the Strategic Planning Committee was to determine how the organization could have the greatest impact on behalf of its members during the next four years. The committee sought input from members of the Board of Directors, past leaders of the organization, and members of the Foundation. The Committee met face-to-face for a two-day planning retreat. As is typical in a strategic planning process, they reviewed and updated the Foundation's Mission Statement, developed a set of core values for the organization, reviewed trends from our constituent surveys and interviews, did a lot of brainstorming and performed a SWOT analysis (internal strengths and weaknesses, external opportunities and threats). The end result of this process was the development of eight strategic priorities which will guide the Foundation's efforts for the next four years.

F.I.R.S.T.'s new mission statement reads: "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."

The Board of Directors also approved four core values, which are defined as a set of behavioral expectations for all individuals associated with the organization. These values will help structure parameters for how the Board, the staff, and those affiliated with F.I.R.S.T. conduct business:

- *Compassion* – We are a caring organization recognizing the unique challenges faced by our community and will provide support with kindness and empathy.
- *Hope* – While celebrating today's strengths and successes, we strive to convey that the future will be filled with friendship, support, and cures.
- *Integrity* – We will conduct ourselves in a trustworthy, ethical, and reliable manner, in everything we do and say.
- *Responsiveness* – We provide accurate and timely information to meet the medical, social, and educational needs of our community.

Listed below are the eight strategic priorities, which are the primary goals that will guide the Foundation's efforts for the next four years. The priorities can be categorized into two main groups: 1) Infrastructure, which includes resources that the Foundation needs to further develop to ensure our future success, and 2) Outreach and Education, which includes programs that need to be expanded or improved to continue to meet the needs of our members.

Infrastructure Priorities
Diversified Development Strategy (Fund Raising)
Comprehensive Strategic Marketing Plan
Website Redesign
New Database Management System

Outreach & Education Priorities
Research Funding Program
Physician/Medical Resource Development
Regional Support Network
Plan for Individuals & Families

Each priority has a detailed action plan and timeline for the staff and Board to follow the necessary steps to be successful. The Board and Strategic Planning Committee will be reviewing the plan on a regular basis to determine its success or modifications. They believe that this plan is ambitious and challenging and many issues will affect its success.

The Board of Directors is very proud to present this strategic plan to our membership and friends of F.I.R.S.T., knowing the final result will strengthen the Foundation's basic guiding principle—educate, inspire and connect those touched by ichthyosis.



Correspondence Corner

Dear Ms. Pickford:

It has been quite some time since we have been a part of F.I.R.S.T. I guess when you are lucky enough to have things go well, you tend not to seek help. I am ashamed to say that I never gave a thought to the fact that our story may be helpful to someone else who has faced the challenges of Lamellar Ichthyosis. That is why I am writing to you now.

We adopted our 26-year-old daughter, Katie, when she was 14 months old with full knowledge that she had been diagnosed with moderate Lamellar Ichthyosis. In the short period of time before Katie came home, we were able to obtain a bit of medical knowledge, but certainly not enough to completely educate us. I guess that is what you call "hitting the ground running".

Our first visit to our dermatologist told us that Katie may not have much more hair than she did at that time (which was very little!), she would most likely have very poor teeth, be prone to infections, and would have to limit her physical activity due to her not being able to sweat. Bill and I looked at each other, shrugged our shoulders, said we would buy her a wig, possibly dentures when needed, and went home.

From the very beginning Katie showed a spirit that we knew would

be both challenging and empowering. Little did we know it was only the beginning. People would stare and make rude comments. We stared back, commented back, and taught Katie how to stick our her tongue at a very early age! We told her every single day (usually in the morning when her skin was the driest and her hair was standing on end) how beautiful she was and if people did not like what they saw it was their problem. We also tried to educate people, when we thought they were capable of being educated.

Katie started dancing lessons at 3 years old. She continued to dance, taking as many as nine classes a week until she was 12 years old. She was chosen to be on her dance school's competition dance team and earned gold and silver trophies. She played basketball, field hockey, and was the ONLY girl on the all-boys high school lacrosse team. Mind you she is all of 5 feet tall and 110 lbs!

Academically, Katie excelled. She took French from 3rd grade through graduation and earned a spot on the National French Honor Society. She graduated from high school and took a year off to decide what she wanted to do in her future. Her love of animals started her in the direction of becoming a veterinarian, but her heart told her that she could not pursue that field.

Today, Katie is a college student (on

the dean's list). She will graduate next spring with a Bachelor's in Physical Education and Exercise Science and wants to be a physical therapist. She works at a kennel, where she is able to still pursue her love of animals. She is a member of the Connecticut Roller Girls, which is one of three roller derby teams in the state. Their team won the 2007 Championship, and Katie was voted MVP and High Scorer for the season. She was also recently elected captain of their newly formed travel roller derby team and we cannot be prouder of her.

Yes, Katie gets overheated, but she knows her limits. She knows how to cool down quickly and takes the best possible care of her health.

My only recommendation is never limit your child. We always let Katie do anything she wanted. If she couldn't do it, she knew that long before any of us did.

If there is anyone you know with a newly diagnosed child or perhaps someone who has fears of the unknown, please give them my name and ask them to contact me. I would be more than happy to share our story with anyone.

Sincerely,

Joanne Brunetti

jbrun77@yahoo.com

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

About a year ago, I saw Kevin Bacon on a talk show. He was discussing an organization that he started called Six Degrees. It was an organization where you could go to support your favorite charities or you could add your own charity. I was interested, so I logged on to www.sixdegrees.org. Of course no one had added F.I.R.S.T. to the charity list, so I decided to do so. I created my own charity badge for F.I.R.S.T. which included a picture of my son Marc who has lamellar ichthyosis. Then I was able to send the link of my charity badge to everyone on my e-mail list. Once they received the link, with a brief message from me, they were able to use their credit card to send a donation to F.I.R.S.T. on Marc's behalf. By doing this, I was actually able to raise \$1025 for the Foundation! So next time you are on the computer, go to www.sixdegrees.org and create your own charity badge for the Foundation. Send it on to your friends and see how much money you can raise for ichthyosis by just pushing a button!

Denise Benedetto, New York - DenMarcNY@aol.com



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
3:15—5:30 pm	Adult Workshops IV
6:30—8:00 pm	Dinner
8:00—11:00	Dance Party/Talent Revue

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.

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

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
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>

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 \$ _____

Method of Payment

_____ Make checks payable to F.I.R.S.T. in US Funds.

_____ Credit Card Payments: Visa, Mastercard, or American Express \$ _____

_____ Credit Card # _____ Expiration Date _____

Authorized Signature: _____

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.

Name _____ Date _____

For Office Use Only

Date Posted _____

Check Amex Visa Mastercard Paypal

Authorization # _____ Amount _____

**Experience the friendliness and generosity
of the Windy City**

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

Your Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: _____
Email: _____

For office use only:
Amount: _____
Date Posted: _____
Authorization#: _____

Number of Adults Attending _____ x \$20.00 USD \$ _____
(Registration fee includes light buffet, beverages and transportation)
Please list names: _____

Method of Payment
 Make checks payable to F.I.R.S.T. in US Funds.
 Credit Card: Visa, Mastercard or AMEX
Credit Card # _____
Expiration Date _____
Authorized Signature: _____

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.

News & Notes

Camp Discovery 2008

The American Academy of Dermatology (Academy) is proud to offer four camping sessions this year for young people with skin conditions who are between the ages of 8 and 16. Under the expert care of dermatologists and nurses, Camp Discovery gives campers the opportunity to spend a week with other young people with similar skin conditions, while participating in activities such as swimming, boating, fishing, arts, and crafts and lots of other camp games and activities. Many of the counselors also have skin conditions and can provide support and advice to the campers.

There is no fee to attend this very special camp. Full scholarships, including transportation, are provided by the Academy through generous donations from its members, outside organizations, and individuals.

2008 Dates:

- July 6 – 11, Teen Camp in Crosslake, Minnesota (ages 15 – 16)
- July 12 – 18, Junior Camp in Crosslake, Minnesota (ages 10 – 14)
- August 9 – 16, Camp Horizon, Millville, Pennsylvania (ages 8 – 13)
- August 10 – 15, Camp Dermadillo, Burton, Texas (ages 9 – 16)

For information about volunteering at one of the camps or referring a child to Camp Discovery, visit their Web site at campdiscovery.org or contact Janine Mueller at 847-240-1737 or jmueller@aad.org.

Camp Wonder 2008

The Children's Skin Disease Foundation is now accepting applications for Camp Wonder 2008, an incredible experience being offered to children with skin disease, ages 7-16, at no cost to the child or family. Camp Wonder is a medically-staffed summer camp for children with all skin diseases. At camp, children with skin disease forget about their illness and have fun doing many activities such as arts and crafts, ropes course, swimming, boating, horseback riding, or theatre. To register your child for camp, please visit www.csdf.org or e-mail Christine at ctenconi@hotmail.com, or call 925-351-7225. We hope to see you this summer!!!

Camp Wonder 2008 - Livermore, California
June 22 - June 30, 2008

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high levels of radiotherapy that include the salivary glands in the field they frequently experience a marked reduction in salivary production. The effects of this on the integrity of the teeth can be devastating. The decay process, that typically requires about three years from initiation to cavity formation, is condensed to about six months. Figure 1 shows the dentition



Fig. 1

of a cancer patient with little saliva production and the effects six months after receiving radiotherapy.

Radiation is not the only cause of poor saliva production. Many medications also have this effect to varying degrees. Included in the laundry list of medications is Accutane® (isotretinoin). Several studies have shown patients taking Accutane may experience a gradual decrease in saliva production with increases in dental decay.[1-3] While not as dramatic as the cancer patient example, one can certainly manifest the initial symptoms of this problem within several months of taking Accutane (see Figures 2 and 3).



Fig. 2



Fig. 3

Is there anything the patient taking Accutane can do to prevent or minimize these adverse effects of the medication?

The answer is a resounding YES!

First, remove the source of the acid production, namely dental plaque. Meticulous oral hygiene including brushing and flossing is imperative. Orthodontic appliances compound this problem of dental plaque retention by providing roughened surfaces for increased plaque adherence. So orthodontic patients need to be

that much more diligent! Second, restrict exposure to foods that tend to promote dental decay. This is not just candy and sugary snacks. The bacteria composing dental plaque are capable of using almost any foods containing refined carbohydrates or starches. Additionally, try to avoid foods that tend to adhere to the teeth and avoid frequent snacking. Third, make the teeth more resistant to the acid exposure by utilizing a fluoride supplement. Ask your dentist for a prescription for one of the high fluoride containing gels and use it as instructed. These are extremely beneficial even to patients residing in communities with a fluoridated water supply. Fourth, keep yourself well hydrated by drinking plenty of water and, should you experience a dry mouth, use sugar-free lemon drops or saliva stimulating gum (Biotene®) to stimulate saliva. Lastly, see your dentist more frequently. Rather than the typical six month visitation schedule, consider every three months. Lastly, should you find your dental health deteriorating or experience a dry mouth, discuss with your physician potential alternatives to Accutane. Studies have shown that salivary function typically returns to normal several months after stopping the Accutane.

1. Lupi-Pegurier, L., et al., Reduced salivary flow induced by systemic isotretinoin may lead to dental decay. A prospective clinical study. *Dermatology*, 2007. 214(3): p. 221-6.
2. Oikarinen, K., et al., Systemic oral isotretinoin therapy and flow rate, pH, and matrix metalloproteinase-9 activity of stimulated saliva. *Acta Odontol Scand*, 1995. 53(6): p. 369-71.
3. Reynolds, N.J., et al., Effect of oral isotretinoin therapy on saliva volume and composition. *Br J Dermatol*, 1991. 125(2): p. 189-90.

Dr. Sonis is Clinical Professor of Developmental Biology, Harvard School of Dental Medicine, and Senior Associate in Dentistry at Children's Hospital, Boston.



News & Notes Continued from page 13

Raising money with flowerpetals.com!

F.I.R.S.T. is pleased to announce that we have begun an association with flowerpetal.com.

When you order flowers, flowerpetal.com will donate 12% of the total sale price back to F.I.R.S.T.



- There will be a link on the Foundation website, www.scalyskin.org
- Click on the link and order your flowers from the arrangements shown.
- The price listed with the arrangement is the completed, shipped price.
- There are no additional charges.
- At checkout, there will be an option to make an additional donation, if you choose.

What a terrific way to help further the Foundation. You don't have to spend any additional money and F.I.R.S.T. will receive additional donations. Spread the word to your friends and family members who may be ordering flower arrangements.

Jane Bukaty Membership Assistance Fund

F.I.R.S.T. realizes that the fight against ichthyosis is not only a medical one but a financial one as well. As families of affected individuals maintain their daily routine of treatments, it can be complicated by the ongoing costs of medical supplies & other comforting aids and procedures.

Here's your opportunity to apply for some financial assistance for ichthyosis treatment. The following criteria must be met by the applicant in order to be eligible for MAF aid.

- The applicant must be a member in good standing.

- The applicant is required to submit an application indicating the need for funding.
- The application must include the amount of funding requested, the specific product/treatment for which funds are required, and a demonstration of the financial need for this product/treatment.

Awards will generally not exceed \$100.00. Applications will be awarded two times per year as determined by the Support Network & Member Assistance Committee. Applicants will be eligible to receive one award every two years. **The deadline for applications is May 30, 2008.**

Contact the national office for an application and guidelines.

Jane Bukaty Membership Assistance Fund
1364 Welsh Rd. Suite G2
North Wales, PA 19454-1913
Email: info@scalyskin.org
or
Fax: 215-619-0780

Donations to the Jane Bukaty Membership Assistance Fund are always appreciated and enable F.I.R.S.T. to make this fund available to more of our members.

Direct Money to F.I.R.S.T. with Every Click

F.I.R.S.T. is thrilled to receive a check for \$99.05 from GoodSearch. By using www.goodsearch.com, each time you search the internet, F.I.R.S.T. will receive a penny. Simply go to the GoodSearch homepage and select the Foundation for Ichthyosis and Related Skin Types from the drop down box to designate us as your selected charity. The site is powered by Yahoo!, so you'll get the same quality search results that you're used to receiving.

F.I.R.S.T. Benefits from Technology Donations

F.I.R.S.T. is fortunate to be the recipient of some very generous computer and technology service donations. For the seventh year, Accurate Imaging, Inc., (www.aimg.com) in Teaneck, NJ, donated the hosting and maintenance of the Foundation's website, www.scalyskin.org. Our website is the portal to the ichthyosis community, caregivers, doctors and the general public. We have grown and connected with so many new members during recent years, which is a direct result of our presence on the web.

iBeast Business Solutions (www.ibeast.com), located in Wayne, PA, has been donating their computer maintenance and support services to F.I.R.S.T. for the past four years. When the computer malfunctions, the server acts funny, or we do something that we shouldn't, we call our friends at iBeast. Their staff is so kind to F.I.R.S.T., and we are grateful to have them on our side.

Last year, Integrated Technology Services, LLC (www.itsllc.com) of Havertown, PA, performed a Technology Needs Analysis for our office to make recommendations for the further integration of user-friendly technology that will increase our office's efficiency. As a result of this analysis, F.I.R.S.T. purchased a server to increase our productivity and to unify our office computer system.

Last, but certainly not least, two Board members, Mark Klafter and Daniel Siegel, graciously donated much-needed equipment to enhance our office computer system. Mark donated a fully-equipped laptop for use at off-site locations. Dan donated a new high-tech scanner, which is helping the office staff be more efficient and aids us in reducing unnecessary papers.

F.I.R.S.T. and its staff are extremely grateful for these very generous donations.



Foundation for Ichthyosis & Related Skin Types
1364 Welsh Road, Suite G2
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