

Ichthyosis FOCUS



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Summer 2009

What Happened to the Ichthyosis Registry?

by Philip Fleckman, M.D.



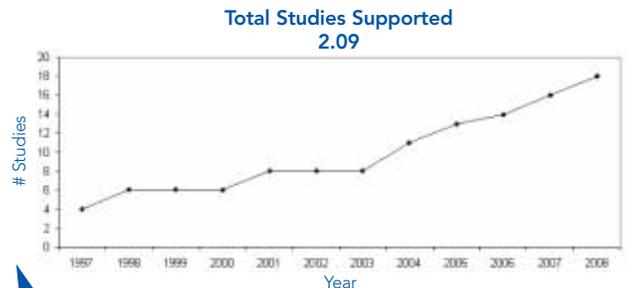
The Registry is alive and well!

The Ichthyosis Registry was funded by the National Institutes of Health (NIH) from 1994 through 2005 to enroll people with ichthyosis, to characterize their specific type of ichthyosis using defined descriptions, and to collect information about enrollees in order to advance understanding of the diagnosis, causes, and treatment of the disorders. Funding by the NIH occurred as a result of lobbying by members of F.I.R.S.T. The application for funding was a collaborative effort by the members of the Medical and Scientific Advisory Board of F.I.R.S.T.

Enrollment was a time-consuming process (those of you who participated can testify!). The process involved paperwork by enrollees and the physicians who cared for them, along with a detailed interview by the Registry Coordinator, Geoff Hamill. Geoff and Kim Pineda, the Registry secretary, established warm friendships with many of the enrollees during this long process. Geoff is now working is a Registered Nurse on the Seattle Cancer Care Alliance floor at the University of Washington Medical Center; Kim is enrolled in a PhD program in musicology at the University of Oregon while he continues to run a concert series in Seattle, the Baroque Northwest ensemble, <http://baroquenorthwest.com>.

The Registry stopped enrolling individuals when NIH funding ended in 2005. The NIH funded the Registry to enroll and describe affected people, but the goal for enrollment was to end up with a large group of well-characterized individuals with ichthyosis who were interested in contributing to knowledge about their disorders. Six hundred ten people endured this demanding process, resulting in the best set of information to be found about a large group of people with ichthyosis. At that time, we entered into the maintenance phase, taking advantage of the hard work and expense of the enrollment process.

What have we done with this valuable resource? Since its formation, the Registry has supported 18 different studies resulting in 21 publications. You can see a list of these on the Registry website at <http://www.skinregistry.org>. You can see from the chart of the studies shown below that the number of studies supported has increased as more people were enrolled and investigators have become aware of this resource. Another reason for increased use of the Registry is the research grants that F.I.R.S.T. has begun to fund.



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**Region 5
Meeting
Scheduled**
(see pg. 14)

Many of those enrolled ask why there are no studies on "their disease." Studies of rare disorders can be arbitrarily divided into 1) those where

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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.

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Correspondence Corner

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

I'm writing you because I recently learned about ichthyosis. I read an article about a baby with this skin disorder on a German newspaper website that made me think of some products that may be helpful to people with this disease. I am an independent representative with a U.S. company which operates in 49 markets. We have innovative and clinically proven products, with scientifically advanced ingredient technologies and skin beneficial formulas comprised of only the best ingredients. There are some ingredients that have been used in skin care products for years which may be detrimental to the skin; they are not used in our products, and every one of our products is dermatologist tested.

What caught my attention in the article was the mention of the baby having calluses all over her body and that her skin needs to be moisturized every few hours. To start with, we have a cream for the feet that works on the underlying cause of rough, dry, and cracked feet. It softens and exfoliates dead cell buildup and calluses for soft, smooth skin. I would think that it should work on other parts of the body as well. It has been very effective on my soles and I've already used it on my hands. In relationship to that, we have a body lufra in liquid form. It provides essential exfoliation by gently working away surface impurities and dead skin and then rinses away completely without leaving a residue that can dry and irritate skin, and is 100% soap-free. Finely ground walnut husks provide gentle exfoliation for the whole body. We also have a soap-free body cleanser available in a bar and in liquid form. In addition, we have two moisturizers that I think are excellent. The first is a lotion which I use all the time except sometimes in cold winter weather. It increases the skin's moisture retention function and provides moisturizing while helping to prevent moisture loss. The second is a cream that I love using in the winter. It delivers all—day moisture for supple, healthy looking skin. The moisturizers are not greasy at all and you need to use only a small amount. They soak into the skin and work much longer than anything else I have used in years past. We also have a tearless body and hair wash for babies to cleanse, soothe, and moisturize.

Thank you for the opportunity to let me share this with your members. For my website address and additional information anyone would like, please contact me at 732.438.0491 or monika.hermann@comcast.net. By the way, there is a Product Information Page for each product on the website that can be downloaded. There are also ways one can save money when ordering the products.

Warm regards,

Monika Hermann

Monmouth Junction, NJ

Editor's Note: Neither the Foundation, its Board of Directors, nor its Medical & Scientific Advisory Board endorse any specific products.

Correspondence Corner continued on Page 3

Donate through the United Way or Combined Federal Campaign Programs

Donating to the Foundation through the United Way or Combined Federal Campaign is an easy and convenient way to support the important work of the Foundation. A small deduction of \$5.00 per paycheck can add up to over \$200 per year for the Foundation. It's simple, convenient, and can really make a difference.

The United Way of America is the national organization dedicated to leading the United Way movement in making a measurable impact in every community across America. The United Way movement includes approximately 1,400 community-based United Way organizations. Each is independent, separately incorporated, and governed by local volunteers. The Foundation for Ichthyosis is the recipient of funds from many of the United Way community-based organizations. Through the Donor Choice Program, you can designate all or a portion of your donation to the Foundation. Simply write in "Foundation for Ichthyosis & Related Skin Types" on the Donor Choice Option form, and your gift will be sent to our office. Be sure to include our mailing address and phone number, 1364 Welsh Road, Suite G2, North Wales, PA 19454, 215-619-0670.

The Combined Federal Campaign (CFC) is the annual fund-raising drive conducted by federal employees in their workplace each fall. Federal employees and military personnel raise millions of dollars each year through the CFC to benefit thousands of non-profit charities. The Foundation is the recipient of funds from many CFC organizations throughout the country. The Foundation's CFC code is 10322, which is listed in the charitable organizations directory.

Contact your Human Resources Department to find out how you can support the Foundation using United Way or Combined Federal Campaign.



Correspondence Corner
continued from Page 2



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

My son Sama's skin seems to benefit greatly from taking the antibiotic Augmentin (125mg Amoxicillin + 31.25 mg Clavulanic Acid.) All the old scaly skin falls away. I am not sure if it will help in research. I just wanted to tell you in case it might help research.

Thank you,

Ada Mulhern

Carlow, Ireland

Editor's note: Augmentin is an oral antibiotic that is only available with a prescription from your physician. It should be taken only intermittently as prescribed for bacterial infections, and is not intended as a means to peel thickened skin.

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Executive Director's Report



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

F.I.R.S.T. is now part of the social networking phenomenon! We've created a F.I.R.S.T. Facebook page and are connecting people from all over the world. Social networking has become an integral part of many organizations' online strategy. A recent survey by Nonprofit Technology Network (NTEN) reports that nearly three-quarters of all their survey respondents have a presence on Facebook. If you are a Facebook user, go to **Foundation for Ichthyosis** and add F.I.R.S.T. as your cause and spread the word!

For the past 10 years, F.I.R.S.T.'s website has been an integral part in educating, inspiring, and connecting individuals, families, and healthcare professionals about ichthyosis. We have been very fortunate to have our website hosted at no cost by Accurate Imaging, Inc., www.aimg.com. Joe DeMicco, CEO, and his team at AIMG have been a tremendous asset to F.I.R.S.T.; we are continually grateful for their support. AIMG is a full-service website design and internet marketing agency.

To keep you updated on the progress of our strategic plan, our marketing, database, research, and fund raising initiatives are in full swing. We hope to be hiring a first-time Development Director very shortly. Our new database, DonorPerfect, is installed and has already been an amazing tool, in just a few short weeks. Our dedicated marketing committee volunteers are working hard to streamline our "look" and develop strategies to position F.I.R.S.T. in the public sector. You can look forward to more exciting updates in the coming months.



Over the past year, F.I.R.S.T. re-organized several of our staff positions and hired a new and valuable team member, Donna Wiggins, who has been with us since Thanksgiving. Donna is our new Membership Services Coordinator and a wonderful addition to F.I.R.S.T. Some of you may have received a letter from Donna recently regarding your membership renewal. If not, Donna will be contacting all our members at least once a year to renew their support of F.I.R.S.T. She is also concentrating her efforts to rejoin some of our lost or lapsed members and connect with our lost and lapsed donors.

I encourage all of our members to take advantage of the regional one-day meetings that are being hosted this summer and fall in Nebraska, Texas, and Nevada. Our hope is that families will have the opportunity to connect with each other without having to travel far distances. See page 14 for details on the Region 5 meeting in Omaha or visit our website for information on other upcoming meetings.

New links have been added to our website. As you know, ichthyosis does not discriminate. People all over the world have the same issues as our members and friends in the United States and Canada. F.I.R.S.T. has provided links on our website, www.scalyskin.org, to other ichthyosis patient groups around the world for your information and networking.

Finally, new items are available to help raise funds for F.I.R.S.T. on our website. A quality baseball hat with F.I.R.S.T.'s name and logo embroidered in white stitching is a great way to protect yourself from the sun's rays and glare while supporting F.I.R.S.T. at the same time. Thanks to a F.I.R.S.T. member, we have a number of soft, cuddly, theme-dressed stuffed animal bears left over from last year's conference. It's a great gift idea and 100% of the proceeds go to F.I.R.S.T.

Sincerely,

A handwritten signature in blue ink that reads "Jean". The signature is fluid and cursive, with a long horizontal stroke at the end.

Jean R. Pickford
Executive Director

Genetic Alliance Issues Statement Applauding New NIH Therapeutics for Rare and Neglected Diseases Program

The National Institutes of Health (NIH) announced the establishment of a new initiative called the Therapeutics for Rare and Neglected Diseases (TRND) Program, a federally mandated effort to encourage and speed the development of new drugs for rare and neglected diseases. Sharon Terry, president and chief executive officer of Genetic Alliance, a nonprofit health advocacy organization, issued the following comments in response to the establishment of TRND:

"Today marks a leap forward in transforming the rare and neglected disease drug development pipeline. NIH is a crucial entity working in this space. In the United States, a rare disease is defined as a condition affecting fewer than 200,000 people, and diseases lacking substantial therapeutic development activity are considered neglected diseases. Many genetic diseases are both rare and neglected, and collectively there are more than 6,000 rare and neglected diseases affecting over 25 million Americans. Fewer than 200 of these diseases have any therapy available, and progress in this area is limited within the current system."

"Clinical trial design is a unique challenge for rare and neglected diseases for reasons such as small patient populations and the need for global recruitment. Because of these challenges, it is critical to conduct effective trials from the onset, as subsequent opportunities may not be possible. Flexible, adaptive trial design and close interaction with the U.S. Food and Drug Administration will be especially important to consider in this context. In addition, engaging disease-specific groups in preparation for clinical trials to characterize the natural history of diseases and determine clinical trial endpoints is also essential and can begin right away through the application of existing tools, technologies and networks."

"Genetic Alliance applauds the federal government for development of the TRND Program and views meaningful collaborations with external partners as a key element in the program. We have been collaborating with stakeholders in the health community including, disease-specific groups, umbrella organizations, and industry corporations while engaging in dialogue around regulatory and policy issues to bring about systems change in this area. This experience has shown us that collaborations through open and transparent processes are essential for change that will benefit health outcomes for all stakeholders."

"We are excited for the potential the TRND Program holds and hope to collaborate with the program and its partners in system transformation."

About Genetic Alliance—Genetic Alliance transforms health through genetics, promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders who create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making. For more information about Genetic Alliance, visit <http://www.geneticalliance.org>.



Discovery Health's Mystery Diagnosis Begins a New Season

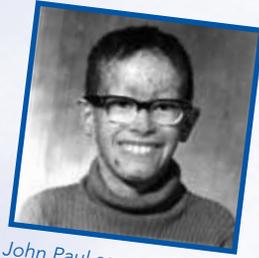
The producers of the television show *Mystery Diagnosis* are now looking for episode ideas for the upcoming season. Was diagnosis of your ichthyosis difficult? Were there circumstances that were unusual with your situation?

If you have a unique story relating to how you were diagnosed and you would like your story told on this show, please contact the Foundation office at (800)545-3286 or e-mail us at info@scalyskin.org.



Spotlight On

by Lucille Leyba



John Paul as a young boy

It was June 2, 1964. I was in labor, anticipating the birth of our fourth child. The time came and our child was born. I was half awake, semi-aware, but sensed that something was not right. I didn't hear the baby cry. I sensed a quietness, some whispers by the doctor and nurses as they moved around. Someone carried the baby out of the room and he wasn't shown to me. Some minutes later, I don't know how long, the doctor was leaning over me, talking to me. He said, "it's a boy, but he has some problems. Do you want us to call a priest, so he can be baptized?" I answered "yes." I was asked if we had a name. We didn't, but I quickly responded "John Paul." I don't know why that name popped right out of me. I wanted to see him, but was told he might live, at most, a couple of days and it would be better if I didn't. A dermatologist was called. He did a biopsy and the diagnosis was Lamellar Ichthyosis. We were told it was rare, was caused by a recessive gene and there was no cure. We found out later that most doctors had never seen it and some had never heard of it.

Two days went by and I was told I could go home the next day. I insisted I wouldn't go home until I saw him. The doctor walked out of the room. The next morning he came back and said he had decided my husband and I would be allowed to see our baby. We did. His body was covered with this thick, plastic-like covering. His eyelids were stretched outward and prevented his eyes from closing completely. (He later had surgery on his upper eyelids, but it didn't help much.) It broke our hearts to see him that way. We came home and left him, but we would go see him once a week. He lived one day at a time. I did a lot of crying and praying. I gave God two choices: "Heal him or take him." Loving him was not a problem, but I worried of what he might have to endure in this world. Eight weeks went by and we were finally told we could bring him home. We were instructed to isolate him from any germs that might be around. We already had three children and our house was very small; we didn't have any room. We were instructed the next best thing was to make drapes that would go around his crib. I started sewing the drapes and about halfway through I put them down and I told my husband, "I'm not going to hide him in that corner. If God wants to take him, we can't hide him and if He wants to save him, we can't hide him either. He will have to live in this world and the sooner we get used to it, the better." A few days later, we brought him home. We were very careful not to unnecessarily expose him to colds, etc. His siblings immediately loved him and knew we all had to be very careful. I got used to giving him his bath and applying the cream that had been prescribed.

At about six months old, we started taking him to church and other places. Yes, there were looks and questions, "Did your baby get burned?, etc." I knew their curiosity was normal and they meant no harm. I answered with patience, the best way I could. We decided we would face the world with him. A year and half later, we all welcomed his little brother into our family. They became the best of buddies and had many good times together.

The time came when he would go to Head Start. I held my breath and took him the first day. This wonderful teacher met us at the door. I explained what I could about ichthyosis ... not contagious, etc. She put her arm around his shoulders and introduced him to the little ones there. They soon accepted that he was one of them. He made friends and loved being there. Then came the first day of six years at parish school. I felt more confident since the Sister and many of the children had already seen him at church. He did encounter some problems, when a couple of children didn't want to sit by him or share a book. He went on to junior high, then high school, and each time I held my breath. In high school there was this boy who would wait for him at the door and try to trip him. Every time he had problems of that sort, we affirmed him with our love and told him not to worry, that these children just didn't know any better. I imagine he has had many difficult moments in his life that we didn't know

Spotlight On continued on Page 7

Spotlight On *continued from Page 6*



Father John Paul Leyba

about. We told him that he was to work hard and be respectful and obedient. We didn't "spoil" him. One teacher told me "He does much better than some who have everything going for them." He was an Honor Student through high school and had many true friends. He is outgoing and has grown up to be a compassionate and generous young man with a great sense of humor on top of it. His skin problems are still a daily struggle. His plans for the future according to his high school autobiography were to become a musician, an engineer, or a priest. He actually became all three.

He earned an electrical engineering degree and went on to a high paying job in the aerospace industry. He dated a fine young lady and marriage was in the picture. One day, he called us and said, "I'm entering the seminary; I just have to go find out. If I don't, I will always wonder." The desire to become a priest had never really left him, even though had had tried to push it away. The young lady was very understanding, as he had mentioned this possibility to her before. After one year in seminary, he told us he would go back. He said to us, "Without any pressure from anyone, now I know that is where I belong. I've never had such peace and joy in my heart as I do now." After five years, he was ordained a Roman Catholic Priest. He is also a very good musician and music is part of his ministry. He is very happy serving the people of God. Some people have told us, "You have a wonderful son and we love him." We acknowledge that God is the giver of all gifts and we are very grateful.



Edward and Lucille Leyba with John Paul (center)

What Happened to the Ichthyosis Registry? *continued from Page 1*

detailed examination of a specific question occurs, for example, "What gene is mutated in Darier Disease?" and 2) studies of a larger group of individuals with a disorder, for example, "Can one predict how severely a person with Darier Disease will be affected based on the specific mutation that person has?" The first type of study is often very difficult and focuses on a few affected individuals, so most investigators restrict their studies to individuals whom they know and have taken care of personally. The Registry is much better suited for the latter type of study. For example, the recent studies by Dr. Jorge Toro and his group of those people in the Registry with transglutaminase 1 mutations have resulted in better understanding of the "lamellar" presentation of ARCI.

Thanks to the support of F.I.R.S.T. and several other sources, the Registry has successfully pursued the goals of better understanding of the ichthyoses. As long as we continue to provide a resource for investigators, we will persevere.

Thank you to all of those who have enrolled and who respond to our annual mailing. If you have been "lost," please contact us by phone, email, or snail mail to re-establish contact. We value your participation. If you missed the opportunity for enrollment, it is our loss; we regret that we are unable to enroll new participants.

“Now is the time to think about getting involved in an awareness week activity for this year.”



One week out of the year, our members host awareness campaigns and fund raising events to raise money and educate the public about ichthyosis. Ichthyosis Awareness Week will be officially celebrated *October 4 - 11, 2009*. In actuality, Ichthyosis Awareness can occur anytime during the year—when you can devote your energy to raising awareness or funds for the Foundation.



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

Ichthyosis Awareness Week

October 4 - 11, 2009



Fundraising ideas:

- Auction
- Bake Sale
- Bingo
- Book Sale
- Candy Sale
- Car Wash
- Dance
- Donations in lieu of birthday gifts
- Dress Down Day at Work or School
- Garage Sale
- Golf Tournament
- Halloween Costume Contest
- Raffle
- Skate-a-thon
- Submit a personal story to local newspaper, radio or TV stations
- Walk-a-thon

How you can help...

The possibilities are endless. Start by contacting your local newspaper to let them know about Ichthyosis Awareness Week. Share your personal story with them, or let them know that you will be hosting a fundraising event.

For those of you who have always wanted to do something to help raise awareness and money for the Foundation, but have little experience...we have the answer. The Foundation staff has created an easy-to-follow manual on how to organize a grassroots fundraiser. It is available free of charge to anyone who requests it. It contains great information about how to contact your local media and the essential steps to create a successful event, plus much more. Please call the office at 1-800-545-3286 or email us at info@scalyskin.org with your mailing address to receive a copy.



In Memoriam ~ Barbara Landwehr

November 9, 1944 – March 14, 2009

It is with great sadness that we announce the passing of Barbara Landwehr, mother of member Deatra Loomer (known as Dee Dee Landwehr to many) who is affected with Lamellar Ichthyosis. Barbara was diagnosed with stage 4 liver cancer and passed away on March 14, 2009.



Many of you may know that Barbara was one of the original founders of our Foundation. Barbara's daughter, Dee Dee, was a patient of Dr. Mary Williams. She met Rita Tanis, and subsequently Pam Brown, through Dr. Williams, and they formed a connection helping each other with issues that arose on treating their children affected with ichthyosis. They began hearing from other parents and decided the time was right to form a support group to help each other with questions, concerns, and skin care ideas.

Drs. Mary Williams and Peter Elias helped spread the word to colleagues that this group was forming. Within weeks, other parents started mailing in letters for the group. Very quickly they put together a newsletter and asked medical experts for story contributions. Within the first few months, over 800 people contacted them. This small group exploded into the National Ichthyosis Foundation, which chartered as a non-profit charitable organization on January 2, 1981.

Barbara Landwehr was instrumental in beginning what is now the Foundation for Ichthyosis and Related Skin Types. Our heartfelt sympathy is extended to her family and friends.



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Grassroots Fundraising



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J.R. Drouhard loves basketball. Last year, he turned that passion into a way to raise money for F.I.R.S.T. This year, he organized another tournament on May 2 in his home town of Viola, Kansas with 86 players signing up to play.



Winning adult team.

Each paid \$10 to participate in the day and received a benefit t-shirt. Concessions were donated by local community members and additional donations were accepted. A display, complete with a TV playing the F.I.R.S.T. Teen DVD, was set up providing information about F.I.R.S.T., its mission, background, and research updates.

The event was a tremendous success, raising over \$500 for Lamellar Ichthyosis Research. With such a wonderful turn out, J.R. would like to make this an annual event. Thank you to J.R. for all of your hard work.



Winners in the 8-10 year age group.



Napa Golf Tournament Another Success

Foundation members Josh and Amie DeGarmo held their **4th Annual Golf Tournament** to raise money for F.I.R.S.T. Josh and Amie are parents to six-year-old Carson and Jaydn, three years old. Both boys are affected with mild to moderate lamellar ichthyosis. The outing was held at the Eagle Vines Golf Course in Napa, CA and included dinner and a silent auction. This year's outing was another tremendous success raising more than \$10,000 for F.I.R.S.T.

Conratulations and thanks to Josh & Amie for organizing this successful event. The Foundation truly appreciates your hard work on our behalf.



If you would like information on holding a grassroots fundraiser, please contact the Foundation office at (215) 619-0670 or e-mail us at info@scalyskin.org.

The Foundation is very thankful to all of our wonderful members for their hard work. Grassroots fundraisers are a great way not only to raise money for F.I.R.S.T, but also to raise awareness about ichthyosis in your community.

A Scrapbooking Birthday Party

Foundation member Sarah Hodgkinson is an avid scrapbooker and has many friends who also enjoy this hobby. She is also mother to 4-year-old Ema, who is affected with CIE. Sarah decided to put her talent to use and raise money for F.I.R.S.T. On Saturday, May 6, Sarah invited 18 friends and family members to join her and celebrate her birthday at a scrapbooking party. Sarah has celebrated her birthday in this way many times. The party was held at the local scrapbooking store, and the owner donated the crop room (a large room with tables and chairs). Instead of gifts, Sarah asked her guests to bring a donation to F.I.R.S.T. Sarah's husband, Craig, supplied pizza, garlic bread, salad, and drinks for the dinner. This festive event raised more than \$200 which was donated to F.I.R.S.T. Thank you to Sarah and your friends and family for your unending support!



Participants at one of Sarah's parties

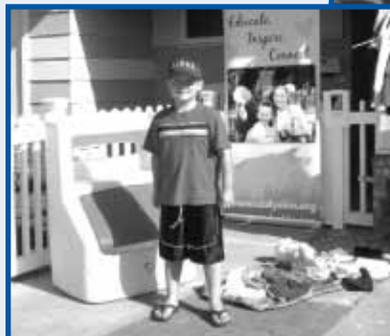


Teapots are a Triumph for Ten Year Old

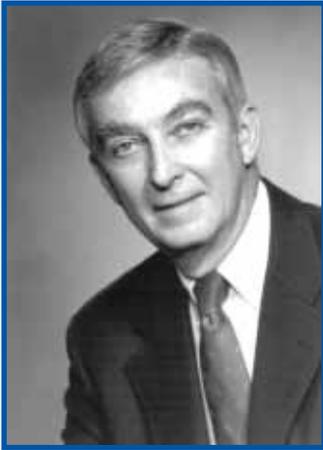
Even the youngest of our members find ways to help F.I.R.S.T. Ten-year-old Emelia Gregor, affected with NCIE, turned our Phantom Tea Fundraiser into a way to bring awareness to her community and raise money at the same time. Emy placed teapots in her school and in businesses around her community and earned \$400 for F.I.R.S.T. Next year, she plans to host an actual "tea party." Many thanks to Emy and her family for their efforts on our behalf!

Creative Kids Hold Yard Sale

Cade and Chandler Phelps organized and manned a yard sale to help raise money in honor of their younger brother, Dane Christian Phelps, who passed away one year ago. All proceeds raised from the yard sale were donated to F.I.R.S.T. They made it a big event, including a lemonade stand and even wearing the new F.I.R.S.T baseball caps available on our website! Their efforts raised over \$400 for the Foundation. Many thanks to Cade and Chandler for their devotion to their family's cause.



In Memoriam



Peyton Edwin Weary

It is with great sadness that we announce the passing of long-time F.I.R.S.T. member and Board Member Emeritus, Peyton Edwin Weary, 79. Doctor Weary died suddenly of cardiac arrest on Friday, June 26, 2009, at his home in Charlottesville, Virginia.

Doctor Weary was born in Evanston, Illinois, and was a graduate of Phillips Exeter Academy, to which he gave credit for establishing his life's values, Princeton University, and the University of Virginia School of Medicine.

He served in the United States Army as a Captain from 1956 until 1958. Doctor Weary was a Professor of Dermatology at the University of Virginia, serving from 1958 until 1999; he was Chairman of the Department of Dermatology from 1976 until 1993, and retired with the title of Emeritus Professor of Dermatology. He held the Edward P. Cawley Chair in Dermatology from the University of Virginia.

Doctor Weary served on the Foundation's Board of Directors from 2000 to 2008 and was appointed as Board Member Emeritus this past January. Along with his beloved wife, Janet, they were an integral part of growing F.I.R.S.T. to where it is today. They were both involved in the early days of our organization in spreading awareness and raising funds to help serve the ichthyosis community. Of most recent note, the Weary's were honored and recognized for their important work, along with Drs. Gloria and James Graham, at F.I.R.S.T.'s 2007 Testimonial Dinner in Washington, DC.

In addition to his involvement at F.I.R.S.T., Doctor Weary has a long history of professional and personal accomplishments. Between 1964 and 1976, he organized and served as Chairman of the first year-long Senior Medical Student Elective Program in the United States. Between 1969 and 1994, he conducted 35 local and regional skin cancer screening clinics which were the first to be held in the United States. He was instrumental in establishing the American Academy of Dermatology (AAD) sponsorship of nationwide screening clinics that have occurred yearly since 1985 with over one million individuals seen since inception of the program.

From 1972 until 1975, he served as Chairman of the Council of the National Program for Dermatology which helped restructure the American Academy of Dermatology, create a central office, establish a governmental liaison function, and lay the foundation for Academy activities.

From 1975 until 1982, Doctor Weary chaired the American Academy of Dermatology Council on Government Liaison and presented testimony before various Congressional and Agency committees on more than 50 occasions. In 1978 until 1979, he served as a member of a Food and Drug Administration Interagency Task Force and was instrumental in the creation of The Orphan Drug Legislation of 1983. From 1982 until 1990, Doctor Weary served as a trustee of the Educational Commission for Foreign Medical Graduates and served on the organizing committee for the International Medical Scholarship Program. In 1984, he created the Academic Medical Center Preceptorship Program for Congressional Health Legislative Assistants and other governmental agency personnel, to orient them to the structure and function of academic medical centers. From 1985 until 1990, he assisted in the creation of the Coalition of Patient Advocates for Skin Disease Research.

Doctor Weary held many high offices in his profession and received numerous awards for his public service. Among other things, he served as President of the American Board of Medical Specialties from 1990 until 1992, which during his tenure promulgated standards for all medical specialties; President of

Peyton Edwin Weary continued on Page 13

the American Dermatological Association from 1992 until 1993; President of the American Academy of Dermatology from 1994 until 1995; and President of the National Association of Physicians for the Environment from 1994 until 1997. He was awarded the American Academy of Dermatology Gold Medal in 1990, the Academy's highest award. He also received the Stratospheric Ozone Protection Award from the EPA in 1995, the Walter Reed Distinguished Achievement Award in 2001, University of Virginia Medical Alumni Association Community Service Award in 2001, Medical Society of Virginia, The Emily Couric Community Advocacy Award in 2004, and The Elizabeth Scott Leadership Award in 2005, The Miller Center for Public Affairs.

Although Doctor Weary was an outstanding contributor nationally and internationally during his professional career, he was most proud of activities he engaged in during his retirement. In particular, he helped to enroll children in the Children's Medical Insurance Program, helped to establish the Community Children's Dental Center, and volunteered as a care provider in the Charlottesville Free Clinic. He enjoyed his involvement with the Miller Center for Public Affairs. He spent many happy and productive hours helping to educate the public about the impact of the environment on health.

Doctor Weary enjoyed the love and caring support of myriad friends and, of course, his family. He will be remembered for his courage, especially toward the end of his life—when he never failed to see the glass as "half full," his soft heart for anyone in need, his care of his family, his quirky sense of humor, and his desire to leave the world a much better place than he found it. His passionate hope was that medical care will continue to be practiced faithfully and responsibly, and that those who follow will protect the earth and the skies above it for future generations.

Consistent with their unwavering support of F.I.R.S.T., the family requested all charitable contributions in Doctor Weary's memory be donated to our Foundation. He will be sadly missed by all those at F.I.R.S.T. who had the great pleasure of knowing him.

Conference Chatter...

VASELINE SKIN FUND PROVIDES 2010 CONFERENCE SCHOLARSHIP FUNDS FOR F.I.R.S.T. MEMBERS

Thinking about heading to Disney in Orlando for the next family conference? Through a generous grant from the Vaseline Skin Fund, F.I.R.S.T. is able to offer scholarship funds for families with an affected child(ren) to attend our 2010 national family conference in Orlando. These scholarships can include registration fees, travel expenses, and hotel reimbursement. All applications must be submitted by **February 1, 2010**. Applicants will be notified by February 15 if scholarship funds will be made available to your family. To download the application, visit our website at www.scalyskin.org, and click on "2010 Family Conference Scholarship Funds." The full application will also be available in the Fall 2009 issue of Ichthyosis Focus.



News on the Hill

News on the Hill is a column to keep members current with the legislation in Washington, DC. This column is written by Angela Godby, Assistant Vice Chancellor for Federal Relations for the University of Texas System. She is affected with Lamellar/CIE.



Healthcare Reform Debate Heats Up In Washington

This summer is even hotter than usual in Washington as Congress and the Administration take on the enormous task of healthcare reform. During last year's campaign, President Obama put healthcare reform high on his priority list. Congressional leaders intend to move a bill this summer, but hopes are fading on that becoming reality.

The debate is clearly a contentious one and one fraught with procedural hurdles.

The Senate has two committees developing separate bills. The Senate plans to combine those bills during the debate on the Senate floor. The House of Representatives has three relevant committees drafting legislation. Those committees have produced a single piece of legislation. Once bills are passed by the House and the Senate, then the real work begins as members work to produce a final product to send to the President.

At the heart of the discussion is the debate over developing a so-called "public plan"—one in which the government would develop a government-run insurance option to compete with private plans. Opponents fear that this option would lead to a completely government-run health system in the United States. Proponents believe the public plan is key to insuring more Americans.

Various drafts from both the House and the Senate would also increase Medicaid coverage. In addition, the bills address the problem of health workforce shortages by providing incentives to train health professionals like primary care physicians. Finally, most proposals include provisions to prohibit insurance companies from denying coverage based on pre-existing conditions.

Perhaps the biggest hot button issue is how much each proposal will cost and how it will be paid for. An early estimate gave the Senate Finance Committee proposal a price tag of \$1.6 trillion. Republicans counter that the actual cost of the Democrats' plan would top \$3.5 trillion. Democrats are considering paying for the plans by taxing employer health insurance benefits and altering Medicare payments to doctors and hospitals. Republicans would finance a plan by providing tax cuts and incentives.

It is hard to say what the final health reform package will look like, but it is definitely time to pull out your fans and brace for the heat.

Regional Support Network to Host Region 5 Meeting in Omaha, Nebraska

Dr. William Rizzo to speak at the Region 5 Meeting

The Foundation announces Dr. William Rizzo as the speaker of the Region 5 meeting. Dr. Rizzo is a Professor of Pediatrics at the University of Nebraska Medical Center. He serves on the Board of Directors at F.I.R.S.T. Dr. Rizzo is a member of the Foundation's Medical & Scientific Advisory Board. Region 5 is comprised of the states of North Dakota, South Dakota, Minnesota, Nebraska, Iowa, and Wisconsin.

The meeting will be held on **August 15, 2009** at the Henry Doorly Zoo, 3701 South 10th Street, Omaha, NE 68107-2200. This is a great weekend getaway for families; the conference registration fee includes admission to the zoo. The zoo is conveniently located within blocks of Old Market in downtown Omaha. The registration fee for the meeting is \$30 per person for attendees 1 year and older. Members in Good Standing receive a 10% discount on the registration fee. The registration fee includes a continental breakfast, lunch, and a regional meeting t-shirt. To register for the conference fill out the registration form located on page 15 and mail payment to the national office by **August 3, 2009**. Visit our website at www.scalyskin.org to download the registration form and pay online. For hotel and lodging information in Omaha, please see the Greater Omaha Convention and Visitors Bureau webpage at www.visitomaha.com. We look forward to seeing you at the zoo. Please contact Moureen Wenik at the Foundation office with any questions, mwenik@scalyskin.org or call 1.800.545.3286.

Region 5 Meeting - Registration Form
Saturday, August 15, 2009 - 9:00 AM to 3:00 PM

Contact Information

(please print clearly)

Name: _____

Address: _____
Street City State Zip

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 regional meeting roster, which will be distributed to all attendees.

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 regional meeting in which I or my family may be a part.

Registrant Information

This section must be completed with registrant's complete name, age, and type of ichthyosis if appropriate.

First Name	Last Name	Age	Affected by Ichthyosis
_____	_____	_____	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>

Please indicate which type of ichthyosis affects your family: _____

Payment

Registration Fees

Henry Doorly Zoo Admission is included with Registration Fee.

*Members in Good Standing**

Number Attending _____ x \$27.00 USD \$ _____

Non-Members

Number Attending _____ x \$30.00 USD \$ _____

*Members in good standing receive a 10% discount on registration fees.

No registration fee for children under 1 year of age (all names must be listed under registration).

I am unable to attend the meeting, but would like to make a donation. \$ _____

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 meeting. 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

Foundation for Ichthyosis & Related Skin Types

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Testimonial Dinner Sponsors...

F.I.R.S.T. wishes to thank the following very generous sponsorships of our 2009 Testimonial Dinner honoring Michael Briggs.

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