

# Ichthyosis FOCUS



Volume 28, No. 1

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

Spring 2009

## Regional Support Network to Host Region 1 Meeting in Connecticut

### *Dr. Leonard Milstone to Speak at Region 1 Meeting*

The Foundation proudly announces Dr. Leonard Milstone as the Keynote Speaker for the Region 1 meeting. This is an opportunity for families to meet the leading medical expert on ichthyosis located on the East Coast. Region 1 is comprised of the states of Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, New York, New Jersey, and Pennsylvania.

The meeting will be held on July 18, 2009 at the Hilton Mystic Hotel in Mystic, Connecticut. This is a great weekend getaway for families; the hotel is conveniently located within walking distance to the Mystic Aquarium and Mystic Seaport. The hotel has generously discounted the room rate to \$159.00 plus tax, per night. The Foundation has blocked off a limited number of rooms for the members attending the meeting and advises attendees to reserve rooms today. The registration fee for the meeting is \$35 per person for attendees 13 and older and \$16 per person for children 1-12. The registration fee includes lunch as well as a regional meeting t-shirt. To register for the conference, fill out the registration form located on page 13 or visit the website to download the form, and mail payment to the national office by June 30, 2009. We look forward to seeing you in Mystic.

### *Regional Support Network (RSN) Volunteer Update*

Thank you to everyone who has sent in an application to become a Regional Volunteer. If you are still considering volunteering for the RSN, you can fill out the application, which is located on the website at [www.scalyskin.org](http://www.scalyskin.org), call the National Office at (800) 545-3286, or email Moureen Wenik, Program Director at [mwenik@scalyskin.org](mailto:mwenik@scalyskin.org). The more volunteers we have, the stronger our 10 Regions will be. Not sure what region you are in? See the map below.



*Inside Ichthyosis Focus*  
2009 Annual Report - pgs 5 - 12  
Testimonial Dinner - pg 14  
Gold Triangle Award - pg 14



ACCURATE IMAGING  
[www.accurateimaging.com](http://www.accurateimaging.com)

*F.I.R.S.T. wishes to extend grateful appreciation to Accurate Imaging, Inc. They have generously hosted and managed our website for 9 years. We look forward to the exciting changes that will be taking place in the future.*

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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](mailto:info@scalyskin.org)  
Web: [www.scalyskin.org](http://www.scalyskin.org)

*Executive Director*  
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*Editorial Assistants*  
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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

Greetings, F.I.R.S.T.,

I am Robert Edward Tapley, Jr. I was born on September 2, 1940 in Northern Minnesota, 250 miles north of the Mayo Clinic in Rochester, Minnesota.

I was born a collodion baby with Lamellar Ichthyosis–CIE. When I was born, I could not close my eyes. My mother kept a washcloth over them. Shortly after my birth, I was taken to the Mayo Clinic. My parents were told that there was nothing that could be done for me. Take me home, make me comfortable and give me about a year to live. Fortunately for me, my mother was a Registered Nurse and did what she had to do to keep me alive. There is no family history of Lamellar Ichthyosis.

I endured the usual ridicule in elementary school and junior high school. I was called "alligator skin" and went home crying many times. I graduated from high school in 1958. After graduation, at age 18, I decided to shave my head and begin wearing a full wig. Also, at age 18, I needed to get an upper denture plate because of poor teeth. At age thirty, I was required to get a lower denture plate. It may be of interest that, contrary to current general practice, since about the age of 30, I never take baths or put any ointments on my skin other than on my face and hands. Of course, this means not wearing shorts or a short sleeve shirt in public and vacuuming the floors on a regular basis. My skin treatments are described below.

From the time I was born, Aquaphor was applied to my skin. From the age of 15 to the age of 30, I sanded my face and hands twice a week with a carpenter's belt sander. At the age of 30 (1970), my father suggested that I go to the Mayo Clinic to find out what effect the continual sanding is having on my skin. I traveled to Rochester and, when I walked through the door of the Mayo Clinic, they said, "Boy, are we glad to see you. Would you like to be the first to sign up for our research/development program for Retin-A?" I spent two-and-a-half years driving back and forth to the Clinic. I was putting on 8 tubes a month from the waist up.

When the study ended, they said, "Thank you, goodbye." Obviously, I couldn't afford to buy 8 tubes a month of Retin-A. I decided to limit my treatment to my face and hands. I used Retin-A for a while, then switched to Lac-Hydrin to save money. This seemed to work fairly well. I switched to PDS Cream when I was introduced to NeoStrata products through F.I.R.S.T. Their new/improved product works well at what it is supposed to do. Be careful; putting on an excessive amount can create a major irritation reaction. I still sand my hands a couple of times a week to smooth them out.

In 1980, I decided to return to the Mayo Clinic to find out any new developments. Again, when I walked through the door of the Mayo Clinic, they said, "Boy, are we glad to see you. Would you like to be the first to sign up for our research program for Accutane (an oral medication)?" After two-and-a-half years on this program, I began developing calcium deposits on my spine (which was one of the suspected side effects), and they suggested that I leave the program, which I did.

Also, I have now, on my face, begun using Tretinoin, which is a recently released generic and much cheaper form of Retin-A. It is working very well. Be careful with this also, as excessive application will also cause irritation.



# Correspondence Corner

In an exchange for having more time to do what I want to do, I have chosen to not take baths or put moisturizers on my body. This obviously creates some minor problems. Although I don't, I do recommend soaking the feet. Major cracks in the skin, between the scales, can become a problem. The scaling on my heels is very thick and I occasionally sand my heels. Also regarding my feet, although all of my fingernails are normal, only the nails on my big toe are normal; the rest of my toenails are just blobs which I also occasionally sand down. When I describe my condition to others, I choose to say, "My skin disorder is a genetic disorder caused by the union of two recessive genes."

As when I lived in Tuscon, Arizona, living in Southern Florida requires that I be "creative" to avoid becoming overheated. I need to avoid outside temperatures over 85 degrees or my body absorbs more heat than it can eliminate. I must also avoid physical exertion that generates excess body heat.

Two years ago, my wife gave me the word that she was tired of having to turn up the television so I could hear it. A hearing exam revealed that I had a 75 % hearing loss. I purchased a pair of over-the-ear hearing aids and, now, my marriage, and life, is going much better.

I am now 68 years old. I have never been hospitalized nor have I ever had a serious or sustained illness. I do have Type 2 Diabetes, which is under control. In all other respects, I am in excellent health.

Last November, my wife and I celebrated our 48th wedding anniversary. We have 2 adopted children and 6 grandchildren. I am very active, and, with proper care, I am expecting to reach the age of 85.

My close relationship with God has sustained me throughout my life.

Thank you,

*Robert E. Tapley, Jr.*

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

After our occupational therapists encouraged us to use a soy lotion candle to help with tightness in my son, Ethan's, hands, we ordered candles from Skinny Dip Candles in Bare Naked (unscented: Ingredients: Cosmetic grade soy, avocado oil, coconut oil, shea butter, beeswax, sunflower oil, cocoa butter, vitamin E.). Ethan loved how soothing the warmth of the lotion was and his range of motion has improved since using this product. When I talked to the company about how helpful their product has been for us, they graciously offered a special F.I.R.S.T. price. The F.I.R.S.T. price is available on a private page here: <http://www.skinnydipcandle.com/first.html>. I can attest to the quality of the product, quickness of shipping, and customer service.

*Erin*

Thomasville, NC

*Editors note: In order to access the special F.I.R.S.T. page, you must type in the full address. It is not accessible from the main Skinny Dip Candle web page.*

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# Grassroots Fundraising

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](mailto:info@scalyskin.org).



## Cina Family Holds a Breakfast for F.I.R.S.T.

As you read in the last issue, Jolie Cina organized a Breakfast with Santa to raise funds for F.I.R.S.T. Recently, Jean Pickford accepted a check from the Borough of Roseland in support of this wonderful breakfast.

Jean gratefully accepted the check for \$500 from the Roseland Borough Council at their recent meeting.



## "Thank you, Kansas"

Bridget Hoover, daughter of Foundation volunteer Rod Hoover of Kansas, has participated in an event called "Thank you, Kansas." This event took place in mid-April as a way to encourage Kansans to connect those willing to lend a hand with those who need a hand.

Bridget, whose brother Brent is affected with Lamellar Ichthyosis, set up a raffle and donation booth to collect money for F.I.R.S.T. and raise awareness of ichthyosis. Although traffic was slower than expected, she managed to collect over \$170 in donations at the event. This was the start of her awareness and fundraising campaign set to last all summer and consist of many events, including a petition to mark January 30th as an official "Kansas Ichthyosis Awareness Day," as well as educational seminars. She has done extensive research and studies for inclusion as part of her senior "Exit Project" due to be completed by March 2010.

Bridget is a junior at Rock Creek High School in St. George, Kansas, will graduate in 2010, and is currently exploring her college options.



The Foundation is very thankful to all of our wonderful members for their hard work.

# Can You Recognize This Skin Disease?



The Coalition of Skin Diseases (CSD) recently produced a 4-color poster which was mailed to more than 4,000 U.S. dermatologists for their examining room walls. The poster has photos from the 16 different skin diseases that the CSD represents, including ichthyosis. Bullet points describing ichthyosis, with a photo of an affected person, and the Foundation's Web site, are on the poster.

This poster is a great awareness tool on ichthyosis for both the general public and the dermatology community. F.I.R.S.T. is grateful to the Vaseline Skin Fund for financially supporting this project.





# President's Report

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



When preparing comments for the President's Annual Report message for the Foundation's spring newsletter, I do something dangerous: look back to review my comments from previous years to remember where we were, what we thought was important and relevant at the time, and measure how we are doing together on our journey as a group of dedicated and supportive members.

In the 2007 newsletter, I spoke of our Soaring to New Heights, a theme that was used for a very successful 2006 Family Conference in Atlanta, Georgia.

The following year, I described how the Board of Directors better defined our organizational mission: to Educate, Inspire, and Connect those touched by ichthyosis and related disorders; and set in motion multiple, specific strategic initiatives intended to sustain the "soaring momentum" of F.I.R.S.T.

Having a strategic plan is important to all successful organizations, for without one an organization is rudderless. A good strategic plan sets in motion a consistent, shared vision that along with the necessary commitment to its execution allows an organization to "steer" how it will "soar." You want the plan to provide focus and you want it to be simple and easy to measure yourself against its aims. And when special challenges arise, our collective belief and motivation as a board was that a good strategic plan for F.I.R.S.T. would define what is most important to our members and what must get done to advance our mission!

Clarity of purpose has never been greater, and a focus on what matters never more required. In spite of the unprecedented challenges of a broad economic downturn, F.I.R.S.T. remains committed to operating at peak efficiency through our exceptional staff in Philadelphia. Moreover, we are successfully implementing eight (8) key initiatives by 2011 that represent real opportunities to grow our organization to the benefit of all its members, friends and benefactors.

Not all of the projects have a wow factor to them. For example, the continued growth of F.I.R.S.T. has created a need for our relatively small staff to cost-effectively serve more people, and thus we needed to improve our infrastructural capacity. Characterized somewhat like air and water for our organization, the following two strategic projects represent vital contact tools that will be utilized for improved communication with, service to, and programming for our members well into the future.

-  New Database Management System – after significant research and diligence being done on multiple vendor software products, management decided on a system with full training and implementation to occur by 2009. This new software will enable us to maintain better connection with our members and donors, and communicate frequently on many levels with more of a personalized touch than possible in the past.
-  Website Re-design – Accurate Imaging has been selected as the vendor to update and re-build our website, a process that will continue through most of 2009. Clearly, the website is the major portal of entry to F.I.R.S.T. and used to obtain electronic copies of accurate information about the ichthyoses. As such, it is essential that our website be designed so it is more manageable by our internal staff to keep content and news announcements "current" and "up-to-date," its overall utility be upgraded to meet current standards, and that our website be found easily navigable by all that visit it.

Throughout 2009, you will see signs of these fundamental improvements as they become fully implemented.

There are certainly strategic projects that do have wow factors to them and have potential outcomes that the board believes are game-changers for current and future members of F.I.R.S.T. Four of these projects aim to:

-  Continue our focus on grass-roots fundraising projects by providing training and support and to diversify our fundraising efforts to raise a dedicated \$3 million endowment to fund new and ongoing research. We are actively recruiting a development director to lead this activity.
-  Aggressively market foundation activities to educate and reach more prospective members, clinicians and donors about our programs, services and benefits of membership – we have completed the development of

*continued on Page 6*

## Foundation for Ichthyosis & Related Skin Types 2008 ANNUAL REPORT

our first major piece, i.e. a 12 minute video production from our very successful 2008 National Family Conference in Chicago, and will utilize the complete or targeted versions at multiple venues throughout the upcoming years.

 Strengthen our regional support network by developing eight (8) specific geographic regions that interact and communicate regularly and meet "locally" during the off-year of the National Family Conference - locations have already been determined for four regional meetings, coordinators and volunteers are being recruited, and the date has been determined for Region 1 conference.

 Launch a HIPAA-compliant telemedicine program that would be one of the first in the world to connect members and families in need, and their clinical support, to a team of dermatology experts recruited by F.I.R.S.T. to review their case history and communicate to the attending physician – select members of our Medical and Scientific Advisory Board are spear-heading this activity and once our partnership with the University of Missouri to host the technology infrastructure is completed, our organization is well along the path to accomplishing this goal of connecting members needs with expert medical consultation.

Just imagine for a moment.....

Imagine an organization that is retaining and growing its membership, physician, friends and donor base every year by double digits, has operational access to the most efficient tools for communicating on a timely and regular basis, produces the highest quality medical and vendor informational pieces to emphasize its mission and capability to positively impact people's lives, drives a thriving network of interaction across the world through its website portal, educational literature, physician resource network, telemedicine initiative, regional support networks and bi-annual national family conferences, provides funds for research that are directed by a world class scientific review committee and applied to disease areas that matter most to our members, and is managed by a highly energized staff of professionals under the extraordinary leadership of an executive director like Jean Pickford!

Now that's a WOW - Welcome to F.I.R.S.T.!

The overall health of any organization is often judged by whether first, it has the financial resources to carry out its mission, and second, does it have the full and active engagement of its members. As you can tell from our CFO Report, the financial assets of F.I.R.S.T. have grown steadily in recent years, both in non-restricted and restricted funds. Plain and simple, this has been due to the hard work of our members as they are involved each and every month in critical and various grass-roots fundraising projects, through the generosity of several large donors that have committed funds for focused activities during the past several years, and the grant writing of our internal staff. Working together, F.I.R.S.T. has experienced a steady expansion of its operating potential and reserves for key initiatives.

Full and active engagement of our members, and the depth of their emotional commitment to F.I.R.S.T., can be measured in so many ways. Every issue of our newsletter, the letter from our Executive Director and every article and note conveys substantial engagement at multiple levels of our membership. However, the most evident for me is your attendance at the national family conference every two years. That is where you will find all of the physical and emotional assets of the organization on full display for everyone to tap into and gain benefit. Chicago was the best attended conference yet, with a record-breaking 400 individuals present. Now that's a sign of engagement! We look forward to the June 2010 Family Conference in Orlando with great anticipation to see old friends, make new acquaintances and see the "focus" on children's faces when they spot Mickey for the first time.

In closing, I wish to thank all members for your dedication to F.I.R.S.T., your continued generous donation of time and resources to helping us achieve our unique mission and strategic objectives, and trust that you and your family will continue to find our organization as the best resource available to provide emotional support, information, advocacy and research funding for better treatments and an eventual cure for those affected with ichthyosis or a related skin disorder. Together, we continue to make a big difference and a very positive impact!

Most sincerely,

*David R. Scholl, Ph.D.*

President

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## Foundation for Ichthyosis & Related Skin Types

# 2008 ANNUAL REPORT

# Chief Financial Officer's Report

Fiscal Year End 09/30/08

Dear Members and Friends:



As I had noted in my last update, our financial statements audited by McGladrey & Pullen, LLP, continue to illustrate our improving financial stability. Following up on my comment last issue about engaging an asset manager to improve our returns, I have now met with an organization from Texas and one from Miami. Both have been very successful in maintaining value for their clients during the past year. My next step is to finish a draft investment policy and submit it to the board for approval. Once approved, the Finance Committee will make a decision on which firm might be right for F.I.R.S.T.

Our current year Statements of Financial Position, included in this issue, reports our net assets increasing by \$173,269 or 12.6% over last year. This lower increase over last year was due primarily to normalization of contributions and grant expenditures, which have been unusually high the last couple of years. We continue to have a healthy unrestricted equity balance that enables F.I.R.S.T. to cover just under two years of operating expenses, in case of unusual circumstances.

On the revenue side, we had a decrease of 34% in contributions, compared to last year. Keep in mind that last year F.I.R.S.T. was fortunate to receive a generous bequest, which accounts for the higher revenue. In perspective, 2008's number is still almost 200% increase over pre-2006 contributions! Clearly the bar has been raised. Our interest income decreased by \$7,000, down from the \$27,000 we had been averaging over the past couple of years. The real loss was from the reduction in our marketable securities portfolio, which luckily was converted to cash securities before the market tanked. The Board of Directors was also not as successful with its own individual fundraising compared to last year; they raised \$7,000 compared to their record high last year of \$24,000.

On the expense side, expenses were pretty much contained and in line with F.I.R.S.T.'s budget. We made net reductions from the prior year of approximately 2%, not counting grant expense or National Conference expenses.

Looking to the future, I am very excited about the implementation of two initiatives originating from our four-year Strategic Plan. We have purchased an excellent not-for-profit Constituent Relationship Management software program that will really help to manage our donor base and membership records more efficiently. Even more important, we are hiring a dedicated fund raising manager who will focus on using the bells and whistles this new program affords not-for-profit organizations. The software's key strengths include donor analysis functions, which will enable our staff to focus on donor giving so valuable time will be used effectively in matching donors to F.I.R.S.T.'s programs. Once again, let us know of any new creative ideas you may have about fundraising.

In closing, I hope all of you survive this stressful economic time in one piece and with not too many painful memories of how you were financially affected.

Sincerely,  
*John J. Schoendorf (EJK member)*  
 CFO, Board of Directors

The statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2008. A complete copy of the audited financial statements and the independent auditor's report are available and can be obtained by calling the national office at (215) 619-0670 or 1 (800) 545-3286.

### Foundation for Ichthyosis and Related Skin Types, Inc.

#### Statements of Financial Position September 30, 2008 and 2007

	2008	2007
<b>Assets</b>		
<b>Current Assets</b>		
Cash	\$ 1,395,448	\$ 1,085,428
Marketable Securities	233,361	277,471
Prepays and other assets	1,100	2,840
<b>Total Current assets</b>	<b>1,629,909</b>	<b>1,365,739</b>
Cash permanently restricted	70,203	10,000
Furniture and Equipment, net	3,242	4,430
<b>Total Assets</b>	<b>\$ 1,703,354</b>	<b>\$ 1,380,169</b>
<b>Liabilities and Net Assets</b>		
<b>Current Liabilities</b>		
Grants payable	\$ 150,000	\$ -
Accounts payable and accrued expenses	2,311	2,395
<b>Total current liabilities</b>	<b>152,311</b>	<b>2,395</b>
Commitments (Note7)		
<b>Net Assets</b>		
Unrestricted	1,035,228	1,167,163
Temporarily restricted	445,612	200,611
Permanently restricted	70,203	10,000
	1,551,043	1,377,774
<b>Total liabilities and net assets</b>	<b>\$ 1,703,354</b>	<b>\$ 1,380,169</b>

See notes to Financial Statements.

# 2008 Donor Listing

*F.I.R.S.T. has revised the date parameters for this listing. For years, we have listed the giving period to reflect our fiscal year, October 1 through September 30. Many of our donors have been confused by this date parameter, so we have revised the listing to reflect the calendar year, January 1 through December 31, 2008. Please note: this listing also includes donors from October 1 through December 31, 2007, for this issue only, so that we acknowledge donors from the last quarter of 2007.*

## \$100 - \$249

Rolena Adorno	William Clendenning	Joseph Galluccio	Laurel Isicoff
Tom & Jennifer Alba	Bob & Diana Clifton	Mariah Garner	Patricia Jacklitch
Chris & Diane Alexander	Roland Coates	Margaret Garner	Kenneth & Joan Johnson
John & Evonne Allen	Richard & Mary Jo Codey	Peter & Laura Gass	Marie-Louise Johnson
John Allison	Kendall Coffey	Brenda & Steve George	Johnsonburg Rotary Club
George & Marilyn Allison	Pamela & Lawrence Cohan	Christian George	Brian Jones
Joan Alnor	Virginia Cortez	Charles & Lee Ann Germany	Richard Jones
American Sheetfed, Inc.	Cosgrove Middle School	Diana Gilbert	Robert & Patricia Jones
Carl & Shirley Anderson	Vicky Couch	Shari Gilevich	Daryl Joyce
Joseph & Majorie Andrews	Biagio Cozza	Eugene & Martha Ginn	Edward Kaier
Eduardo & Maria	Laura Crozier	Glen Falls Toyota & Scion	Anne Kaier
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Robert & Nancy Ash	Todd & Michelle Currie	Samantha Gonzalez	Lenore Kakita
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Thomas & Lisa Bachand	Tarasa Davis	Nancy Goodman	John & Dorothy Keenan
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### 2008 ANNUAL REPORT

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Cort DeHart  
Richard & Carol DeLoughary  
James & Mary Beth Dinulos  
J.R. Drouhard Basketball  
Tournament  
Schuyler & Denise Eastin  
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Sharon Enting Dress Down  
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Foundation for Ichthyosis & Related Skin Types  
2008 ANNUAL REPORT

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In Memory of John O. Thoele  
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Jalsa Urubshurow  
Benjamin & Liz Waldshan  
Gayla Weinert  
Edwin & Tiffany White  
Mary Williams, MD-Calendar  
Sales Fundraiser

### \$1000 - \$4999

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Laura Ashton Tea Party  
Fundraiser  
Sherri Bale  
Barrier Therapeutics  
William & Jacquelyn Beck  
Frances & Rudolph Blankis  
David & Jennifer Bryson  
Jared Cantanucci  
John & Jamie J. Casey  
Dermal Therapy  
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Jake Horowitz  
Iott Family Pumpkin &  
Bake Sale  
John & Mary Jessiman  
Herman & Joyce Karst  
Robert Kraybill & Durreen  
Shahnaz  
Kenneth & Elena Levitan  
In Memory of Gaetano Licursi  
Edd & Jennifer Loftis  
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Henry Bukaty  
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Jean Giroux Trust  
Martina Cheung Running for  
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Merz Pharmaceuticals  
Christopher & Laura J. Phillips  
David & Valerie Scholl  
Sovereign Bank Foundation  
April Sproull Country  
Music Benefit  
St. Mary Land &  
Exploration Co.  
Unilever

### \$10,000 - \$99,999

DeGarmo Family Golf Outing  
Harry Caray Night  
Cumberland Community  
Foundation  
Edna & Myron Curl  
Endowment  
In Memory of Dane  
Christian Phelps  
NeoStrata  
Project SOS  
EugeneVan Scott  
RueyYu

### \$100,000+

Mike & Lynn Briggs  
The Lennox Foundation

## Executive Director's Report

*Dear Friends and Members of F.I.R.S.T.,*



Over the past twelve months, F.I.R.S.T. has been continually fulfilling its mission to educate, connect, and inspire our members and donors in a variety of ways. Our four-year strategic plan has provided direction for key initiatives to better serve the needs of our constituency and improve the organization.

One of our major highlights this past year was the family conference in Chicago in June. This conference was our most successful conference in our 28-year history. Almost a year later, F.I.R.S.T. still receives comments and accolades from attendees who learned so much and connected with so many. The conference is our signature event, and I highly encourage those who have never attended to try to get to at least one conference in your lifetime.

F.I.R.S.T. is taking a proactive role in connecting our members on a more frequent basis. The most common theme we hear at the close of every family conference is, "I wish we could connect with other ichthyosis families more often." We heard you and have put things in motion to make it a reality. F.I.R.S.T. will be hosting four regional conferences in various areas of the country over the next six to nine months. Although F.I.R.S.T. hosted regional meetings many years back, this new emphasis will refocus our goal of keeping our members and their families connected. Our first regional meeting will take place on July 18 in Mystic Seaport, Connecticut. (See page 1 for more information or page 13 to register.)

For the fourth consecutive year, F.I.R.S.T. has successfully continued its own in-house grant program, receiving nine new grant requests this year for funding. The careful review of these grants by the Research Review Committee determines the most promising projects deserving of F.I.R.S.T.'s limited research dollars. As the research fund grows, we hope to be able to fund many more investigators and their projects in the future.

From an infrastructure perspective, F.I.R.S.T. has purchased a new Constituent Relationship Management System. This database will help our staff to better track our members, donors, and friends. The new system will streamline data on each family's relationship to the organization and their needs and wants from F.I.R.S.T.. This will, ultimately, help us better serve the ichthyosis community.

A comprehensive marketing plan is currently being developed to determine our business and communication objectives. Once determined, F.I.R.S.T. will allocate resources and develop strategies and communication channels to achieve these objectives. A small committee of dedicated board members and members-at-large will be working on this initiative over the next year. Our website, [www.scalyskin.org](http://www.scalyskin.org), will be receiving an "overhaul" in conjunction with the new marketing plan as well.

Despite this challenging economy, F.I.R.S.T. has fared remarkably well over the past year. Although we have all felt the effect of the economic downturn, rest assured that F.I.R.S.T. continues to offer the same programs and services as before. All non-profits feel vulnerable in this economy and this holds true for F.I.R.S.T.. However, I am confident with the leadership of our CFO, John Schoendorf, and our board's careful stewardship of our donor dollars, F.I.R.S.T. has and will continue to "weather the storm." See John's report on page 8. Please continue to give to F.I.R.S.T., as every dollar counts in our organization.

As you have read, F.I.R.S.T. has a very bright future. Our committed staff and Board of Directors will be meeting in November to evaluate our progress with the four-year strategic plan, review our policies and procedures, and develop new ideas to take us to the next level.

But most of all, F.I.R.S.T. would not be successful without our members and donors. On behalf of our board, I am grateful for your dedication to our mission and your constant, generous, financial support. In a world of rare diseases, belonging to a community that serves your educational, social, and medical needs and connects you to new friends is an irreplaceable and exceptional service. Thank you.

Sincerely yours,  
*Jean R. Pickford*  
Executive Director

# RSN Regional Meeting

Region One Meeting - Registration Form  
 Saturday, July 18, 2009 - 10:00 AM to 4:00 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

*Members in Good Standing\**

Number of Adults (Ages 13 and up ) \_\_\_\_\_ x \$31.50 USD \$ \_\_\_\_\_

Number of Children (Ages 1-12) \_\_\_\_\_ x \$14.00 USD \$ \_\_\_\_\_

*Non-Members*

Number of Adults (Ages 13 and up ) \_\_\_\_\_ x \$35.00 USD \$ \_\_\_\_\_

Number of Children (Ages 1-12) \_\_\_\_\_ x \$16.00 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

1364 Welsh Road G2 • North Wales, PA 19454 • Ph (215) 619-0670 • (800) 545-3286 • Fax (215) 619-0780  
 Web Address: www.scalyskin.org • Email: info@scalyskin.org

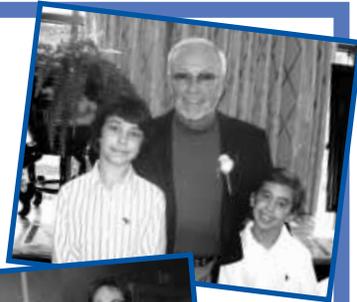
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## 3rd Annual Testimonial Dinner

Michael W. Briggs was honored at the 3rd Annual F.I.R.S.T. Testimonial Dinner held on April 17, 2009 at the Alpharetta Marriott in Alpharetta, Georgia. Mike has been a true pioneer for F.I.R.S.T. Armed with the passion to find a cure for his grandson, who was born with Epidermolytic Hyperkeratosis (EHK), Mike provided the flame to ignite F.I.R.S.T.'s own in-house research program.

This very successful dinner raised \$53,000 for F.I.R.S.T. It was attended by 100 of Mike's family, friends, former UPS co-workers, and F.I.R.S.T. board members. In addition to the touching tribute by his close friends and family, a silent auction complemented the evening's festivities. Highlighted items to bid on included a weekend getaway to a ranch in Montana, golf packages at world-class golf courses, high-end jewelry, and autographed sports memorabilia.

The Foundation is grateful for the opportunity to honor Mike and his commitment to our members. Although Mike was humbled by this honor, in his speech that evening he shared this thought, "This fund raiser was all about F.I.R.S.T., my grandson Adam, and the thousands of children born with ichthyosis."



## F.I.R.S.T. Receives 2nd Grant from the Lennox Foundation

Great news and congratulations to F.I.R.S.T.! For the second year in a row, F.I.R.S.T. was awarded a \$100,000 grant from the Lennox Foundation. Thanks to member Suzanne Phelps for providing the opportunity for F.I.R.S.T. to submit an application for the second time. The Lennox Foundation is a family-run foundation, and only relatives can recommend organizations to apply. Suzanne and her husband, Eric, lost their beloved son, Dane Christian Phelps, last June at the tender age of three. Dane had some form of ichthyosis, which was never officially diagnosed. Along with the ichthyosis, Dane struggled with other medical complications, which ultimately took his life. This grant means a lot to F.I.R.S.T. and Dane's family. We are most grateful.

The funds we received will be designated to continue to support our four-year strategic plan. The areas of focus include our new Constituent Relationship Management System, costs associated with regionalizing the Support Network, and growing our staff to better serve our members needs.



## 2009 Gold Triangle Award

The American Academy of Dermatology's Gold Triangle Awards recognize and honor media, industry, health community organizations, public service and individual efforts that further understanding of dermatologic issues and encourage healthy behaviors in the care of the skin, hair and nails.

This year, F.I.R.S.T. received the Gold Triangle Award for the outstanding success of our national family conference. For the past 27 years, F.I.R.S.T. has been hosting a biennial family conference for our members; affected patients and their families. The conference is a life-changing experience, affording many individuals the opportunity to meet others who experience the same issues.

The Gold Triangle Award was presented in San Francisco during the 2009 Annual AAD Meeting in March. Moureen Wenik, F.I.R.S.T. Program Director, attended the dinner and accepted the award on behalf of the Foundation.



*F.I.R.S.T. Program Director Moureen Wenik receives the Gold Triangle Award on behalf of the Foundation from AAD President, C. William Hanke MD, FAAD.*

# MSAB Meeting

The Annual meeting of the American Academy of Dermatology was held in San Francisco this past March. F.I.R.S.T. staff and board members take part in these events to gain knowledge and share information. The Foundation's Medical & Scientific Advisory Board gathered for breakfast and took this opportunity to discuss topics relevant to F.I.R.S.T., its members, and ichthyosis research.



*Members of the F.I.R.S.T. Medical & Scientific Advisory Board gather at their annual meeting.*



The American Academy of Dermatology (Academy) is proud to offer four camping sessions this year for young people with chronic 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 skin conditions, while participating in everything from swimming and fishing to horseback riding to lots of camp games and activities. All campers must be referred by their dermatologist.

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.

## *2009 Dates:*

- July 5-10, Camp Knutson-Teen Camp in Crosslake, Minnesota (ages 15-16)
- July 11-14, Camp Knutson-Junior Camp in Crosslake, Minnesota (ages 10-14)
- August 9-14, Camp Dermadillo, Burton, Texas (ages 9-16)
- August 15-22, Camp Horizon, Millville, Pennsylvania (ages 8-13)

For more information about attending or volunteering, please visit their web site at [www.campdiscovery.org](http://www.campdiscovery.org) or contact Janine Mueller at (847) 240-1737 or [jmueller@aad.org](mailto:jmueller@aad.org).

## Camp Wonder 2009



**Children's Skin Disease Foundation**  
a 501(c)3 non-profit corporation

Summer is right around the corner and with that comes CAMP WONDER 2009. With the economic situation we are facing, we think that it is more important than ever to have as many children as we can attend camp this summer. Please help us to reach out to our communities and spread the word.

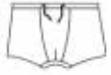
The Children's Skin Disease Foundation is now accepting applications for CAMP WONDER 2009, an incredible camping experience being offered to children with skin disease, ages 6-16, at no cost to the referring organization, children or their families. Transportation is included. The week offers the opportunity to participate in exciting activities, form lasting friendships and ultimately develop a stronger sense of self-esteem while under the careful and loving supervision of an excellent professional medical staff and cool counselors. The session will run from June 22 to June 27 in Livermore, CA.

For more information, please contact Christine Tenconi, (925) 947-3825 or e-mail: [ctenconi@hotmail.com](mailto:ctenconi@hotmail.com). Applications accepted on a first come basis.

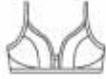
100% Natural Cotton | Chemical-free | Dye-free / Bleach-free | Formaldehyde-free | Latex-free / Spandex-free | Inverted Seam Technology | PH Balanced



Cottonique | 100% natural cotton allergy-free apparel



Mens



Womens



Kids



Infants

## What is Cottonique?

Cottonique is an innovative apparel company that offers a wide range of 100% natural cotton products designed especially for people who are sensitive to common allergens found in materials and chemicals. The company uses only 100% organically grown cotton that makes the fabric highly absorbent and breathable.

Cottonique's unique development process eliminates the need for bleaching compounds, color dyes and textile resins that can pose a threat to sensitive skin. Unlike other garments in the market, Cottonique products are free from formaldehyde, a chemical that is often used to control the shrinkage of clothing. To ensure the customer's utmost abrasion-free comfort, Cottonique uses inverse-seam technology that places the rough edges of seams on the outside of the garment rather than in direct contact with the skin.

## Benefits of Cottonique

- 100% Natural Cotton
- Chemical-free
- Dye-free / Bleach-free
- Formaldehyde-free
- Latex-free / Spandex-free
- Inverted Seam Technology
- PH Balanced
- Highly Absorbent & Breathable

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