

One person makes a difference!

While on a business trip, Foundation member Jolie Cina, mother of Portia Cina, had a chance encounter with State Senator Richard Codey from her state of New Jersey. Through conversation, she learned of his compassion for those with skin disorders and other medical issues. She followed up on that chance meeting and invited the senator to a fundraising event that she hosted last winter. Since then, the senator introduced a bill into the New Jersey State Legislature memorializing the US Congress to increase funding for ichthyosis research. The bill was passed and is on its way to Washington! Additionally, Jolie sent the senator a lovely note to thank him for his efforts on behalf of Portia and the Foundation.



continued...

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To all Friends of FIRST,

The FIRST Board of Directors is currently in the process of implementing a four-year strategic operating plan for the Foundation. One key element of this plan is to develop and execute a marketing plan. The marketing plan will look to create awareness of, and provide connections to, FIRST's constantly improving services for internal audiences like you and others not familiar with our Foundation.

I'm very excited to report that a volunteer six-person marketing committee has developed a marketing plan. It was approved by the Board of Directors in late 2009. After identifying FIRST's core strengths and message strategies to promote it, the initial recommendation of the committee was to update our logo and incorporate a tagline within it.

We wanted the logo to communicate better who we are and the benefits FIRST provides. The logo needed to be visually impactful, warm, and contemporary, while still keeping some of the old feel we all have identified with the Foundation. The tagline needed to identify and differentiate our organization while reinforcing clear benefits. The revised logo and tagline are to the right:



As you can see, FIRST is more pronounced and is designed to gather visual attention with the full descriptive name of the organization beneath it. We've grown the "fuzzy person" into a "family" to illustrate better that FIRST serves a wide community. The Educate, Inspire, Connect tagline encompasses in a brief and impactful way three key Foundation benefits and stands as a strong visual reminder of the organization's entire mission.

Effective immediately, we will be transitioning this new logo and tagline onto all printed and electronic FIRST materials. I look forward to telling you about, and getting your feedback on, other exciting marketing plan tactics the committee is developing at the 2010 National Family Conference in Orlando.

Eric Schweighoffer

FIRST Marketing Committee Chair

ONE PERSON MAKES A DIFFERENCE...

continued

His office then sent out press releases to all of the New Jersey newspapers announcing the resolution. This is a great example of how one person can make a difference! The FIRST website has posted a sample letter that you can send to your representatives asking them to submit similar legislation in your state. Simply go to the story "New Jersey Passes Ichthyosis Research Legislation" on our website; then, click on the links provided to find the names of your representative and to print out the sample letter.

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The Foundation for Ichthyosis & Related Skin Types™ is a 501(c)3 charitable organization supported by public and private donations. All contributions to the Foundation are tax deductible to the full extent of the law.

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

Ichthyosis Focus is provided as a service to members of the Foundation as a medium for the free exchange of information. Neither the Foundation for Ichthyosis & Related Skin Types™, its Board of Directors, its Medical Advisory Board, nor the Focus Editors endorse any treatments or products in Ichthyosis Focus. Views and opinions expressed in this publication do not necessarily reflect the views of the Foundation or Foundation officials.



Correspondence Corner

My name is Kevin Young and I have Ichthyosis CIE. In 1973, the obstetrician announced to my parents that they "had a son with dry skin." As we know, the ramifications of ichthyosis are much more than just dry skin. There are medical and psychological effects as well. There's a personal story between diagnosis and where we, or our loved one(s), are today. I'm a writer by trade with a penchant for videography. I'd like to utilize my skills in film to tell a story about ichthyosis... yours and mine.

I'm in the process of outlining a documentary about ichthyosis. I want it to be informative about the disease, but with a strong focus on the personal aspects by utilizing family videos and photos. I'd like to conduct interviews with affected adults, children, and members of the medical community. My time line is flexible, but I'd like to have it coincide with the upcoming conference.

If you think you'd like to take part in this project, whether it is via an interview, family video/photo submissions, or would like to give your opinion/input, please contact me.

Any assistance on this project would be greatly appreciated.

Kevin Young

Phone: (843)762-2899

Home Address: 1415 Amanda Park Lane, Charleston, SC 29412

Email: y.kevin.young@gmail.com

In Memoriam

Frances McHugh

November 22, 1920 – July 26, 2009

It is with great sadness that we announce the passing of a pioneer in FIRST's history. Frances McHugh passed away last summer. Many members will remember that Frances was a past president of the Foundation serving from 1992 to 1994. Prior to serving as president, Frances was a member of the Board of Directors for 4 years. During her tenure as president, Frances orchestrated the hiring of the Foundation's first full-time, salaried executive director, ushering the Foundation into a phase of rapid growth and expansion. Throughout her tenure on the Board of Directors, she was a tireless advocate for ichthyosis research and a tenacious fund raiser.

On a personal level, Frances was also a wife, mother, and grandmother. She was married to her husband Pete for 65 years. Together they had 3 children, 5 grandchildren and 3 great-grandchildren. Their children are: Peter McHugh, Shelly Licursi, and Claire McHugh. Shelly is the mother of Ryan Licursi, who has EHK. It was the birth of Ryan that began Frances' involvement in the Foundation.

Frances loved being with her family, working at her church and traveling. She visited many great places across the United States, Europe, the Tropics, and even Cuba many years ago. On a cruise to Alaska a few years ago, she and Pete joined the family on every excursion including white water rafting. Frances truly lived life to its fullest and will be dearly missed.



FIRST Rocks the House In Orlando!



2010 National Family Conference
Friday, June 25 – Sunday, June 27
Regal Sun Resort in
Walt Disney World® Resort



Join us at FIRST's signature event. You will benefit from stimulating discussions about causes, treatments, and research updates. Share your personal connections with others who understand. Meet new and old friends to exchange ideas, support, and advice. Gain knowledge about your disease and helpful products and resources. Help expert physicians and investigators advance our understanding of the different types of ichthyoses and related disorders. Come be educated, inspired, and connected!

Workshops & Events at a glance...

Friday, June 25

10:00 – 12:00 pm	Registration
11:00—12:00 pm	Session for 1st Time Attendees
11:00—12:00 pm	RSN Volunteer Training
12:00—1:00 pm	Lunch
1:00—5:00 pm	Kids' & Teens' Camp (ages 17 -under)
1:00—1:45 pm	General Session
1:00—8:00 pm	Clinical Screening Appts.
2:00—4:00 pm	Workshops I
4:00 pm	On your own

Saturday, June 26

7:00—8:45 am	Breakfast
9:00—5:00 pm	Kids' & Teens' Camp (Field Trip)
9:00—10:00 am	General Session
10:00—12:00 pm	Ask the Experts
12:00—1:00 pm	Lunch
1:00—3:00 pm	Workshops II
3:00—5:00 pm	Workshops III
6:00—10:00 pm	Dinner & Family Social

Sunday, June 27

7:00—8:45 am	Breakfast
9:00—12:30 pm	Kids' & Teens' Camp (ages 17 -under)
9:00—11:00 am	Workshops IV
11:15—12:30 pm	General Session & Closing
12:30—2:00 pm	Farewell Lunch

Teen Field Trip

Teens and tweens, ages 11-17, will participate in an offsite field trip to *DisneyQuest*® Indoor Interactive Theme Park in Downtown Disney.

Kids' Camp



Special educational and social programs for the affected children and their siblings are an integral part of the conference. Each day, children in the kids' and

teens' camp will enjoy activities, entertainment, educational programs, and refreshments. Thanks to a very generous donation from the Vaseline® Skin Fund, FIRST is able to offer the kids' and teens' camp at no cost. Significantly reduced registration fee for children ages 1- 13 is also available.

Clinical Screening Appointments

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 25. Participation is voluntary. Sign-up is required prior to the conference by completing the Clinical Screening section on the Conference Registration Form.

Registration: Online registration will be available beginning in January on our website, www.firstskinfoundation.org. The Conference Registration Form and payment must be submitted to the national office by June 4th. Registrations without a completed form and payment will not be considered complete. *Please note: Registration does not include your hotel room. Accommodations at the Regal Sun Resort must be made separately.*

Cancellations & Refunds: Cancellations received prior to June 4th will be refunded less a \$25 per person administrative fee. No refunds issued after June 4th.

Dress Code: Conference attire is casual, including Saturday evening's dinner & family social.

Meals: The conference registration fee includes lunch on Friday, June 25; breakfast, lunch, and dinner on Saturday, June 26; and breakfast and lunch on Sunday, June 27. All registrants are on their own for dinner on Friday evening.

FIRST Idols Talent Revue: Back for its second year...this revue, which is open to children ages 5 to 18, is guaranteed 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 26, after dinner. If you wish to participate, complete the FIRST Idols Talent Revue section on the registration form.

Director of Fun: The Regal Sun Resort provides a FUN Director whose only job is to make sure kids are having a good time! The FUN Director organizes daily activities and games within the hotel property for kids to enjoy. There is also a "Kids Corner," located in the main lobby along with a daily activity schedule. Check availability and hours.

Discounted Disney Tickets: As attendees of the Ichthyosis Family Conference, you can purchase discounted tickets for all Disney Theme Parks plus other bonuses. Half day tickets are available for those who want to visit the parks after the days' meetings have ended. You can also purchase discounted full day tickets and multi-day tickets, which include one free visit to *DisneyQuest*® Indoor Interactive Theme Park, *Disney's Typhoon Lagoon*® Water Park, *Blizzard Beach*®, *Wide World of Sports*® Complex, or the *Disney's Oak Trail* Golf Course. To order tickets visit www.disneyconventionear.com/IFC or call 407.566.5600 and mention the Ichthyosis Family Conference. Orders must be placed by June 20, 2010. You may also visit our website and click on 2010 Orlando Family Conference and search for Discount Disney Ticket Program for more details.

Visit by Disney Characters: At Saturday night's dance party, you will have an opportunity to hang out and take photos with two surprise Disney characters!

Free Hotel Shuttle: The Regal Sun Resort provides a free shuttle to all the Disney parks and attractions. The shuttle departs every 1/2 hour from the hotel.

Hotel Accommodations: The discounted room rate negotiated with the hotel is \$85 for a Standard Double, \$89 for a Lakeview Double, and \$95 for a Tower Standard Double. This rate also includes the resort fee of \$15 per night per room. This rate is available from June 21 through June 30. All attendees must make their own reservations at the Regal Sun Resort by calling toll-free at 800.624.4109 or visit www.regalsunresort.com. To receive the discounted room rate, you must identify our group name as "Ichthyosis Family Conference." Internet users must enter ICFC0610 as the group code or visit the following link to be connected directly to FIRST's online reservation site:

https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=312876&hotelID=14929. *Reservations must be received on or before 5 pm on June 3, 2010.* All reservations must be accompanied by a first night room deposit guaranteed with a major credit card. Other hotel rules and restrictions may apply. For questions, contact the hotel directly.

Driving Directions to Hotel: Contact the Regal Sun Resort at 407.828.4444 or visit their website at www.regalsunresort.com. Their address is 1850 Hotel Plaza Boulevard, Lake Buena Vista, FL 32830. There is no fee for self-parking.

Air & Hotel Transportation: Orlando International Airport (MCO) is the major airport for Disney hotels. It will be approximately a 45-minute ride from the airport to the hotel. At baggage claim, you will see the ground transportation options available for your travel to the Regal Sun Resort. FIRST has made arrangements with Mears Transportation to pre-purchase your tickets at a discounted rate. Visit our website, www.firstskinfoundation.org and click on 2010 Orlando Family Conference and search for Mears Discount Coupon.

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 Orlando, Florida, 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 800.296.1217 and refer to the 2010 Foundation for Ichthyosis Family Conference Special Lift Program.

Concerned about the heat? Contact "Guest Services" at the theme park of your choice to explain ichthyosis and your heat intolerance issues. Be sure to bring a doctor's note along with FIRST's overheating fact sheet (available online). The theme park can issue a special guest pass to make accommodations for standing in lines in the heat. This is completely at the discretion of each theme park's management. Other suggestions include planning your trip to the parks in early morning or late afternoons, when the heat is less severe. You may also want to map out your visits within the park to take advantage of air-conditioned or covered attractions during the heat of the day.

SEE PAGE 13 for Conference Registration Form

President's Report

Greetings to all Members and Friends of FIRST:

From all of the staff, board members, and medical and scientific advisors of FIRST, I wish to express our deep gratitude for your continued support during the past year. Thank you for your broad interest, volunteer support, and service to our goals and mission to Educate, Inspire, and Connect those affected by ichthyosis.

Further, I hope this note finds you and your family doing well. Depending on where you live, coping with this year's "upside-down" winter weather conditions that beset much of the country may have been difficult. When the snow piled up in January and February, the driveway needed to be cleared, often in sub-freezing temperatures. So, imagining the warm weather of Florida in June seemed a pipe dream, a distant illusion.

The good news is spring and warmer weather are here, and June is not that far away. For FIRST members and our organization, that means our bi-ennial Family Conference is right around the corner. We invite all of our members, family, and friends to join us in warm and sunny Orlando, Florida. The Family Conference, our signature event, is a stellar opportunity to see folks that you may not have seen since the last conference or longer.

There is no better way to plan a family get-away than combining the FIRST Family Conference and a vacation with a famous mouse named Mickey—all in a single trip! So, please join us at the Orlando 2010 Family Conference by registering online (www.firstskinfoundation.org), by mail, or by calling the office directly. I hope you can take advantage of the opportunity to spend some extra time at Disney World, or any of the wonderful attractions and vacation spots in Florida, as part of your trip. Just thinking about the warmth and positive energy from renewing long-standing acquaintances and creating new friendships is a strong antidote for any cold weather scenario! With an expected attendance of over 450 people, we definitely plan to Rock the House in Orlando!

Since the organization's inception 27 years ago, the bi-ennial Family Conference has clearly served as an incredibly valuable vehicle to Educate, Inspire, and Connect. This year in Orlando, however, we are going one strategic and very exciting step further!

FIRST is convening an important, two-day scientific and medical research mini-conference in Orlando prior to the start of the 2010 Family Conference. The mini conference was the brain-child of our extremely dedicated Medical and Scientific Advisory Board. With partial funding awarded to FIRST through a grant application submitted by our talented leadership and staff, "The Frontiers in Ichthyosis Research Conference" represents a first-of-its-kind, seminal opportunity to gather an exclusive group of select experts from around the world to discuss openly and communicate the most recent research findings and clinical knowledge about the ichthyoses.

Beyond the exchange of critical knowledge, this scientific meeting will serve to further promote the dire need for more research funds targeting ichthyosis. We also expect to inspire greater awareness and participation of FIRST members in various research-related activities that will ultimately make clinical research studies more numerous and productive. I believe that the benefits from connecting the scientific community with our organization and member's needs will be extraordinary. We look forward to sharing the key findings discussed at the Frontiers Conference during a summary presentation by Dr. Leonard Milstone to attendees of the Family Conference.

Supporting research dedicated to ichthyosis has been a major goal of our strategic plan and a focus for the past several years. The progress is impressive! In 2009, several FIRST-sponsored research projects were underway in laboratories around the world, and have continued to make good progress towards meeting their goals. Additionally, FIRST received a greater number of grant applications requesting financial support than ever before. And lastly, the upcoming Frontiers Conference in Orlando will surely bring greater awareness about our keen interest in driving more research activity, and greater leverage within the basic and clinical research community.



With such outstanding progress on building the Research Program from scratch, and with other key strategic initiatives to support financially, FIRST welcomed its first dedicated development director in 2009. **Greg Wilson** brings a strong track record in creating, supporting, and managing successful fundraising activities for similar non-profits. We are extremely excited to have this critical strategic need met through the addition of Greg, and we look forward to your meeting him in Orlando! Please feel free to send Greg a note of welcome at gwilson@firstskinfoundation.org.

Additionally, the decision and commitment to add a full-time development director at FIRST provided our Executive Director, **Jean Pickford**, the opening to grow our current staff and organizational capability. In consultation with the board and in planning exercises with all staff members, Jean re-organized the focus of her very talented staff to provide more dedicated effort and support to key operational areas—a decision primarily motivated by our goal to provide our members with a more personalized and fulfilling FIRST experience, and not just the first time!

As configured now, the organization is much better positioned to serve our members with strong, sustainable support and program effectiveness via dedicated programmatic responsibility to key strategic initiatives.

The Regional Support Network, a new Ambassadors Program, and the Research Program, all managed by **Moureen Wenik**, have placed FIRST as a front runner in ichthyosis support. Thanks to **Lisa Breuning**, our outreach initiatives of website management/redesign, and public information dissemination, are on the cutting-edge of using the latest technology and reporting the most up-to-date information about FIRST and ichthyosis. Just as important is connecting with our members and making sure FIRST's services are provided to each and every member. Thanks to **Donna Wiggins**, our Membership Services Coordinator, we continue to reach out to our current members and welcome new members on a regular basis.

Through this approach, we believe you will find engagement with our organization easier to do, support from our staff plentiful when needed, and the experience more meaningful.

I wish to wrap-up this year's annual letter by recognizing the tremendous volunteerism displayed by so many members of FIRST. The strength of any organization is resident in the amount of time, passion, and financial support people place on the importance of achieving the mission of the organization. The organization's development success, and one's involvement in it, has to matter to gain the strongest commitment and engagement from its volunteers.

At FIRST, you find very strong evidence of people making it happen through volunteerism in all forms, including offering of professional talents, time commitment, and financial support, that displays a fundamental passion for our organization and its members.

Just a few examples of the many I could cite are:

- Numerous grassroots fundraising efforts by our members which are the basic staple of any Foundation
- Medical talent donated to the development and recent launch of our telemedicine project, to provide clinical consults at our Family Conferences, and be guest speakers at our regional meetings
- Technology talent that assisted us with making the right choice for our new database management system
- Professional marketing talent that formulated our new marketing plan
- A creative team that is directing our new branding campaign to give our organization a fresh new look intended to extend a compelling message of warmth, caring, and support for those members and families affected by ichthyosis
- Substantial gifting program that underpins the Research Program commitment and serves as the focal point of our future research endowment campaign

What an impressive list! For all of those volunteers that were engaged in the past and in 2009, I wish to extend a sincere and hearty thank you. Because of your service to FIRST, we have accomplished a great deal in 2009, and the future looks very bright.

For members who are considering a more active role in FIRST, I would strongly encourage you to reach out to Jean, her staff, a board member, and members to ask how you can help. The organization needs and welcomes your energy, your talents, and your engagement. The timing has never been better to have a positive impact on YOUR organization and start friendships and new relationships—for life!

Let's join together to make 2010 the best year ever. See you soon in Orlando!

Warmly,
David R. Scholl, Ph.D.
President

Board of Directors



David R. Scholl, Ph. D.
President
Grandfather of affected child, CIE
President & CEO,
Diagnostic Hybrids, Inc.,
Athens, OH



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Partner, Berenfeld, Spritzer,
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Miami, FL



Jennifer F. Hillman, Esq.
Affected, Lamellar
Ichthyosis
Attorney at Law
New Hyde Park, NY



P. Brian See, Esq.
Affected and father of
affected children,
Ichthyosis en confetti
Partner, Williams Mullen
Richmond, VA



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Secretary
Mother of affected child, CIE
Director, HR Corporate
Reporting,
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District Supervisor, UniFirst
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Terry Melton, PhD
Affected, EHK
CEO, Mitotyping
Technologies, LLC
State College, PA



Mary Williams, MD
Founding Member
Adjunct Professor of
Dermatology & Pediatrics,
Dermatology Service
University of California
San Francisco, CA

Chief Financial Officer's Report

Fiscal Year End 09/30/09



Dear Members and Friends:

I believe this past year's financial statements, audited by McGladrey & Pullen, LLP, illustrate the foundation's ability to withstand all the negative impacts of our economy. Unlike many not-for-profit organizations, we seem to have a donor base that is very stable and dedicated, and have, therefore, continued to raise funds above national statistics and with virtually no deterioration. In addition, when comparing our expense spending with other similar organizations, our numbers are right in line. Approximately 82% is spent on programs including research grants, 9% on fund raising, and 9% on management and general expenses.

With the hope of recovery, it has become more important than ever to finish a modernized investment policy to take advantage of any hoped for upswing in the economy. Although I have not been able to move as quickly as anticipated in that direction, we have increased the number of members of our finance committee to assist in this important task. We have been meeting regularly now to discuss various alternatives and are doing research into how other organizations have changed their policies to accommodate the changing financial environment to reduce the risk of loss in their financial investments. Fortunately, we were able to minimize our investment losses this year, so that the actual value of our investments only deteriorated by \$7,600.

Looking at the numbers, our current year Statements of Financial Position, included in this issue, illustrates Net Assets increasing by \$19,995 or 1.3% over last year. Although not an exciting number, you may have read that, nationally, most not-for-profit organizations experienced an erosion of their assets due to inadequate or improper asset management.

On the Revenue side, we had a decrease of 11% in contributions mostly due to not having the ability to have an extremely successful grassroots fundraiser, like at the family conference in Chicago in 2008, and the family conference itself. Interest income also decreased by \$19,000 after experiencing the full impact of rate adjustments during the prior year.

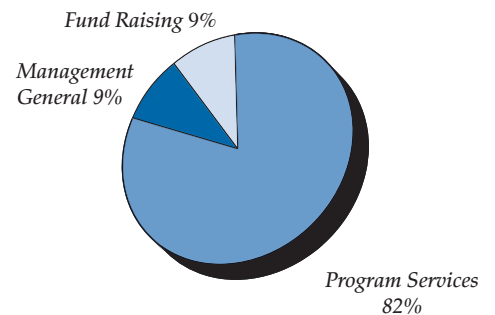
On the operating expense side, expenses continued to be relatively in line with prior years and budget. Payroll and related expenses did increase, but that was offset by using staff and executive director time to focus more on raising money and being able to perform more tasks and duties aimed at providing better service to members.

From a management standpoint, our not-for-profit donor/member management software program has turned out to be every bit as valuable as hoped. Rather than war tales about implementation or user problems, our executive director and staff have only kudos on how it is helping them perform better.

In closing, I hope all of you have been successful in coping with our changed financial world and look forward to seeing many of you at the family conference in June.

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

Fiscal Year 2009 Expense Allocation



Foundation for Ichthyosis and Related Skin Types, Inc.			
Statements of Financial Position			
September 30, 2009 and 2008			
	2009	2008	
Assets			
Current Assets			
Cash	\$ 1,266,212	\$ 1,395,448	
Marketable securities	232,636	233,361	
Prepays and other assets	3,248	1,100	
Total current assets	1,502,096	1,629,909	
Cash, permanently restricted	70,203	70,203	
Furniture and Equipment, net	12,435	3,242	
Total assets	\$ 1,584,734	\$ 1,703,354	
Liabilities and Net Assets			
Current Liabilities			
Grants payable	\$ -	\$ 150,000	
Accounts payable and accrued expenses	13,696	2,311	
Total current liabilities	13,696	152,311	
Commitments (Note 9)			
Net Assets			
Unrestricted	995,824	1,035,228	
Temporarily restricted	505,011	445,612	
Permanently restricted	70,203	70,203	
Total net assets	1,571,038	1,551,043	
Total liabilities and net assets	\$ 1,584,734	\$ 1,703,354	

See Notes to Financial Statements.

The statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2009. Complete copies 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.

2009 Donor Listing

This listing includes all donations made during the 2009 Calendar Year.

\$100 - \$249

Ms. Nancy Abrams
Accenture Supply Chain Management
Mr. & Mrs. A. J. Adam
Mr. & Mrs. B. Stephen Adams
Mr. & Mrs. John Adams
Adaptive Driving Access, Inc.
Dr. Rolena Adorno
Mr. & Mrs. J.R. Aguila
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Mr. & Mrs. John Bratton, Jr.
Mr. & Mrs. James Brennan
Mr. & Mrs. Charles G. Brown
Mr. & Mrs. James L. Brown
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Ann-Margaret Burke
Dr. and Mrs. Patrick Burkhardt
Mr. John Burton
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Mr. Thomas J. Clark
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Classic Designs & Printing
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of Chicago
Construction & General
Laborers' Union #152
Construction & General
Laborers' Union #25
Construction Laborers'
Union Local #1
Ms. Donna J. Corbin
Mr. & Mrs. Matt Crain
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Executive Director's Report



Dear Members, Donors, and Friends of FIRST:

This past year has been one of many accomplishments for FIRST. I am privileged to be working with such a talented group of committed board members and volunteers, along with our dedicated staff who work tirelessly to advance our mission. As we continue moving forward with our four-year strategic plan, 2009 added another year of tremendous growth for the ichthyosis community:

Regional meetings

By creating smaller, geographically diverse meetings, in addition to the national biennial conference, more affected individuals and families were provided the opportunity to connect with one another in person and to learn about the latest ichthyosis news, treatments, and research updates.

Tele-Ichthyosis Website

This site provides dermatologists and primary care physicians access to a panel of leading experts in ichthyosis to assist them with the care of their patients by working with the doctors to determine the proper diagnosis and to suggest possible treatments.

Marketing Plan

The volunteer and hard-working marketing committee developed and is executing a comprehensive marketing plan to (1) create and grow awareness of ichthyosis and FIRST, (2) re-energize active and inactive FIRST members to participate in our cause and be ambassadors for the Foundation, and (3) engage both current and new donors that their contributions are a worthwhile "investment" for them and FIRST.

The old adage, "Success breeds success", certainly applies to FIRST, particularly over the past five years. Our membership and donors are part of a successful organization whose careful stewardship of donated funds and thoughtful planning of current needs and future goals set us on a winning course. Some of the most notable accomplishments over these past five years include:

FIRST's Research Program—In 2005, FIRST developed its own research funding program and has been accepting grant applications since its inception, funding a total of 13 worthy projects to date, focused on Lamellar/CIE, EHK, and ichthyosis-related research.

Strengthening our membership and donor base—Our membership is the lifeline of FIRST. It's how and why we exist. With increased attention to member's needs and a more sophisticated donor management system, FIRST is serving more members every day and reaching out to new families to join our special community.

Staff, Board of Directors, Medical & Scientific Advisory Board, and key volunteers—Under the governance of our board and guided by our medical board, FIRST continues to recruit the most talented people who volunteer countless hours and who want to make a difference. With our expanding programs and services, adding two additional staff members to manage and implement these programs has taken our effectiveness to new heights and helps us reach even higher goals.

Information Dissemination—With the use of new technologies, FIRST continues to expand our website, www.firstskinfoundation.org, and will be making even more impactful changes this summer. Over the past five years, we have also added several new resources to our arsenal of information, including two online educational modules for the diagnosis and management of ichthyosis in newborns, a video featuring affected teenagers and how ichthyosis impacts their life, and an even newer video that features everything you need to know about FIRST, ichthyosis, the family conference, and why you should invest in our future.

These important highlights are just a few of the many services we have achieved to educate, inspire, and connect those affected by ichthyosis. As I enter my 11th year of service to the organization, I am proud of what we have accomplished and look forward to even greater accomplishments in the future.

As always, I encourage you to contact our office with any questions, concerns, or ideas you may have. We are a strong and successful organization because of you, our members, friends, and donors. Thank you for all you do to make us FIRST!

Sincerely yours,
Jean R. Pickford
Executive Director



FIRST Rocks the House in Orlando!

Contact Information (please print clearly)

Family Name: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Phone (Day): _____ Phone (Night): _____

Cell Phone: _____ Email: _____

I give permission to FIRST to publish all names on this registration, contact information and type of ichthyosis in the conference roster, which will be distributed to all attendees.

Registrant Information - (must be completed with each registrant's complete name, age, and type of ichthyosis (if affected)).

First Name	Last Name	Age	Child Care*	Affected by Ichthyosis	T-Shirt Size
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL
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Please indicate which type of ichthyosis affects your family: _____

*The Vaseline® Skin Fund has generously provided a grant to sponsor the costs of our professional child care company, who will entertain and supervise all children, ages 17 and under while parents/guardians are participating in the program. For the safety of your children, the appropriate number of caregivers will be hired based upon the number of children signed up for the kids' & teens' camp. Please be confident that your child will participate in the camp so we don't over-hire caregivers, which will increase our costs.

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 during the afternoon of Friday, June 25, from 1:00 pm-6:00 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



FIRST Rocks the House in Orlando!

Volunteers Needed: Please check if you would be willing to:

- Assemble Gift Bags on Thursday afternoon, June 24
- Help with registration on Friday morning, June 25
- Help at FIRST's Kiosk Table
- Manage the FIRST Idols Talent Revue show

Name: _____ Phone: _____ Email: _____

FIRST Idols Talent Sign-Up (Ages 5-18)

Child's Name: _____ Age: _____ Grade: _____ Hometown: _____

Type/Description of Act: _____

Performances will take place on Saturday evening after dinner. A compact disc 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 FIRST 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 2010 Family conference in which I or my family may be a part.

Signature: _____ Date: _____

Tween & Teen Field Trip—Saturday, June 26 Permission Release

An organized field trip has been arranged for tweens (ages 11–13) and teens (ages 14–17) to visit Disney Quest from 1:00–5:00 pm on Saturday, June 26. Caregivers from Corporate Kids Events will chaperone each field trip.

- The following teens will be participating in the off-site field trip to DisneyQuest® in Downtown Disney®:

Signature: _____ Date: _____

Payment

Number of Adults (Ages 14 and up) _____ x \$185.00 USD = \$ _____

Number of Children (Ages 1–13) _____ x \$25.00 USD* = \$ _____

I/We are registered members of FIRST; please apply a 10% discount = \$ _____

Additional donation to support the conference scholarship fund = \$ _____

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Total Payment:
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*This significantly reduced registration fee has been made possible by a generous grant from the Vaseline® Skin Fund (VSF). FIRST will thank the VSF and confirm the use of the grant by providing the first name, last initial, and state of residence of all beneficiaries. Any identifying information will remain confidential.

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.

Signature _____ Name _____ Date _____

Grassroots Fundraising

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 FIRST, but also to raise awareness about ichthyosis in your community.

Caravan Beads Fundraiser

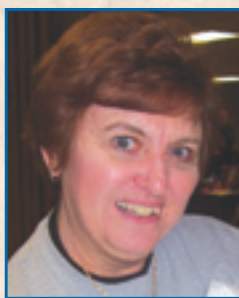
Kim Mayone, mother of 4-year-old Evan who is affected with EHK, has been organizing a fund raising event at Caravan Beads in Portland, Maine for several years. She invites friends and family members to participate in a night of beading and socializing. Many pretty necklaces, earrings, and bracelets were made, and a table was set up with brochures and information about FIRST. Caravan Beads has been very supportive of this event and closes the store for the evening for Kim's group. Caravan Beads then donates 30% of the proceeds directly to FIRST. Anyone who wanted to contribute, but could not attend the event, made donations through the website. This year's event raised more than \$360 for the Foundation. We are very thankful to Kim for her continuing work to benefit FIRST.



Evan and Kim with Caravan Beads employees, Caitlin Carbonneau, Joycelyn Kahn, Store Manager; Elizabeth Miller, and Monica Clark



Evan having fun with the beads



Sharon Enting

Dress Down Day Another Success

Sharon Enting is the grandmother of Emma Klima, 5 years old and affected with EHK. Over the years, Sharon has asked her company, Braden Sutphin Ink to sponsor a dress down day for its employees with the proceeds going to FIRST. The employees of the company have generously embraced dress down day with donations and Braden Sutphin also makes a contribution. This year's dress down day has raised a total of \$500 for the Foundation. FIRST is very appreciative to Sharon and Braden Sutphin for their commitment over the years.

Texas-Sized Barbeque

When Madison Emily Hoffman was born in February 2008, her parents, Jeremy and Emily, did not know anything about ichthyosis or FIRST. Maddy was diagnosed with EHK and spent one month in the hospital before coming home. Emily and Jeremy took great pride in the strength that Maddy has displayed and decided to turn that strength into an opportunity to raise awareness and funds for FIRST. The Hoffman family organized a barbeque at the Rafter 7 ranch near their home in Crowley, Texas. With carriage rides, live music, and dancing, the event was very successful and raised \$1,000 for FIRST. The Hoffmans hope that this will become an annual event. The Foundation is very grateful for their efforts on our behalf.



Madison Hoffman



Bartending Contest in Pennsylvania

Lisa Kass, mother of fourteen-year-old Casey Short who is affected with Lamellar Ichthyosis, organized a terrific event to benefit FIRST. A bartending competition was held at the Irish Rover Tavern in Pennel, Pennsylvania. Over a period of six weeks, 6 teams of 2 bartenders would try to raise as much money as they could in 3 hours for the charity of their choice. Lisa's group sold tickets to encourage friends and family members to attend. They sold 50/50 raffles and auctioned baskets off to raise as much as possible. Lisa's husband, Richard Kass, and his friend Jeff, played the piano and sang for tips. It was a fun evening for everyone and raised more than \$2,700 for FIRST. Thank you to the Kass family for a terrific event.

Trojanowski's Triumph for FIRST

During Ichthyosis Awareness Week, members across the country engage in awareness and fund raising activities to benefit FIRST. The Trojanowski family continued those efforts over several months and made FIRST a household name in Hillside, Illinois. Shelley Trojanowski and her children Quincey and Lucas spent their time mailing letters and e-mailing friends and business associates to raise awareness about FIRST. They even cooked a "Lunch for Lucas" at which people made donations and had lunch. The combined efforts of the Trojanowski family raised more than \$5,600 for FIRST! We are so appreciative of their hard work and dedication.

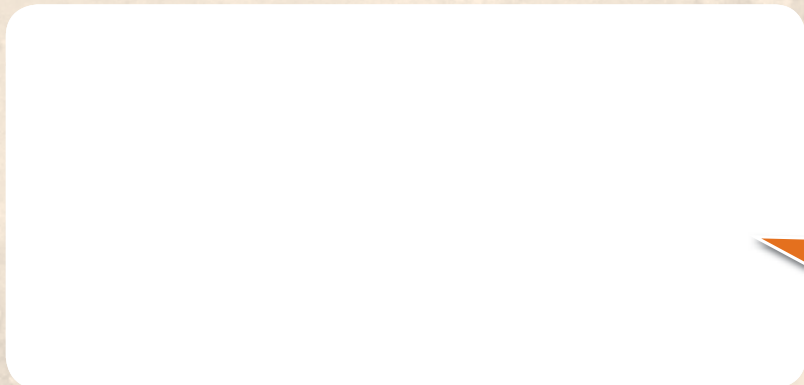


Quincey and Lucas Trojanowski



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PARTICIPANTS NEEDED FOR EHK RESEARCH STUDY

Research Title – Generating immortalized cell lines and induced pluripotent stem cell lines from patients with Inherited Skin Diseases

Description – The purpose of the project is to develop safe and effective methods to correct Epidermolytic Hyperkeratosis (EHK). Patients with other congenital and inheritable skin diseases such as Epidermolysis Bullosa Simplex (EBS) and Pachyonychia Congenita (PC) may also be eligible. Novel technologies in the field of stem cell research allow conditional immortalization of human stem cells and reprogramming skin cells into induced pluripotent stem cells. These cells will provide researchers with unique therapy development opportunities. Participants will have one visit to the study site. This visit will last approximately two hours. During this visit a sample of skin will be taken (called a punch biopsy). This skin tissue sample will then be processed in the laboratory for future investigation.

Participation is for research only. Except for research-related procedures, no treatment nor any form of compensation will be provided. Non-local patients will be responsible to arrange travel and lodging.

Eligibility Criteria – Subjects 7-60 years of age. Clinically diagnosed with the above diseases with confirmed genetic and laboratory testing. Unaffected family member (sibling) may be eligible as control subject.

Institution – University of Colorado Denver.

Protocol – COMIRB #09-0192

Principal Investigator – Dennis R. Roop, Ph.D.

Enrollment Information – For further information about enrolling as a subject in this study please email us at: yvonne.berg@ucdenver.edu or call Yvonne Berg at (303) 724-3500.