



MAY is ICHTHYOSIS AWARENESS MONTH!

We are changing Ichthyosis Awareness to May and members now have an entire month for awareness and fundraising activities!

See page 20 for details for planning an awareness/fundraising event.

**Mega
Issue**

**2010
ANNUAL
REPORT
INSIDE!**

INSIDE Ichthyosis Focus...

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Meeting Report from FRONTIERS IN ICHTHYOSIS RESEARCH

Leonard M. Milstone,¹ William B. Rizzo,² and Jean R. Pickford,³
Journal of Investigative Dermatology (2011) 131, 279–282. doi:10.1038/jid.2010.338

Frontiers in Ichthyosis Research, an international meeting of investigators actively involved in research directly related to ichthyosis, was held in June 2010, immediately preceding the biannual family conference held by the Foundation for Ichthyosis and Related Skin Types, Inc. (FIRST), an ichthyosis patient-support organization.* The meeting was designed to foster collaboration among investigators and between patients and investigators. It was an opportunity for the most deeply engaged individuals to begin a dialogue about efficient and effective ways to utilize scarce resources to advance research in ichthyosis. Invited speakers were asked to present ongoing research and their perspectives on significant challenges and opportunities.

Leonard Milstone (Yale University, New Haven, CT, USA) introduced the meeting, noting that it was held on the tenth anniversary of the announced completion of the Human Genome Project. The identification of genes associated with human disease was an important spin-off from that worldwide effort and the ichthyoses were no exception. In the past 20 years we have come to recognize that the ichthyosis phenotype can be attributed to an unexpectedly large number of genes, whose coded proteins have a broad array of functions. This new perspective demonstrates that no aspect of epidermal biology can be taken for granted. This new appreciation opens the door for renewed collaboration between basic scientists interested in epidermal biology and keratinization and those interested in ichthyosis.

Despite the rarity of the condition, the study of patients with ichthyosis has had a substantial impact in two areas: (i) fundamental discoveries about critical



2010 *Frontiers in Ichthyosis Research* Participants

skin functions and (ii) development of treatments that also benefit patients with more common skin diseases. It is not unreasonable to anticipate that stimulation of research in ichthyosis will continue to impact the skin disease community in this fashion.

The meeting was organized into five sessions with a mixture of formal presentations and lively discussion.

Frontiers in genetic diagnosis

The identification of genes that cause ichthyosis has fundamentally changed the way we think about this group of diseases and about skin biology. Judith Fischer (Centre National de Genotypage, Evry, France) gave a comprehensive review of how positional cloning has been used in the past 20 years to identify disease-causing genes. She described how her group used 130 consanguineous families to identify seven new genes that cause autosomal recessive congenital ichthyosis (ARCI). When 500 additional ARCI patients were screened for those genes plus transglutaminase 1, 22% still had no identifiable mutations. She indicated that single-nucleotide polymorphism arrays and whole-exome sequencing will speed mutant gene identification

Continued on page 17

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Correspondence Corner

Dear FIRST,

I don't know how relevant this is, but I thought FIRST would like to know about this. I have EHK and I've been nationally recognized as a Shakespearean Scholar. One of the stories written about the accomplishment actually mentions the fact I have ichthyosis, which I thought was really great.

Kirstin Bone

Salt Lake City, Utah

Editors Note: Kirstin was awarded the M. Rick Smith Memorial Undergraduate Prize at the Ohio Valley Shakespeare Conference for her paper, "The Forgotten Fool: Geoffrey Chaucer," which centered on Chaucer's lesser-known contributions to politics and playwriting. FIRST congratulates Kirstin on this outstanding achievement.

Flesh Tones Photo Gallery

Black & white photographs that celebrate flesh colors and flesh decorations

Suellen Hozman from Michigan, is a dedicated photographer with a vision to celebrate everyone's skin. She has photographed many individuals with a variety of flesh decorations and is preparing for her upcoming show. FIRST member, **Nancy Osentoski**, a Michigan resident, will be featured in the upcoming Flesh Tone Photo Gallery which will open with a reception on Sunday, June 5, 2011 from noon to 5:00 PM at the Craig

Mitchell Smith Glass Gallery, in the Meridian Mall, Okemos, Michigan. The gallery dates are June 4 – June 30, 2011, and the Glass Gallery hours are Monday – Saturday from 10:00 am – 9:00 pm and Sunday from noon – 6:00 pm. For more information contact Suellen at suellenyh@yahoo.com. We encourage all of our local FIRST members to support Suellen and Nancy in this wonderful show.

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FIRST celebrates 30 years!

Here are some important milestones that have been achieved.



1980

- Children and adults with ichthyosis come to University of California Dermatology Clinic for treatment with a new drug, Accutane
- Pam Brown, Barbara Landwehr and Mary Williams, MD begin to share with each other the challenges of raising a child with ichthyosis
- Pam Brown and Barbara Landwehr publish the first newsletter
- Corporate donations are received from two pharmaceutical companies
- 1st chapter meeting held in San Francisco Bay Area on November 2nd
- 2nd chapter meeting held in Ohio at the office of Dr. Frank Yoder
- The name Ichthyosis Focus is adopted for the newsletter



Barbara Landwehr

1981

- The National Ichthyosis Foundation (NIF) is incorporated on January 2, 1981
- 3rd chapter meeting held in New York
- Ted Shackelford joins NIF Board of Directors

1982

- Medical Advisory Board is formed
- Corporate sponsor for newsletter is obtained
- Regional chapters are formed
- NIF attends its first American Academy of Dermatology Annual Meeting
- Chapters begin to raise money
- Offices move to Belmont, CA
- Jack Klugman crusades for ichthyosis. NIF involved in filming an episode of Quincy that addresses Orphan Drugs.



Jack Klugman with NIF members.

1983

- 1st National Family Conference, Chicago, IL
- Members & Ted Shackelford appear on AM San Francisco



1984

- 2nd National Family Conference, Washington, DC



1985

- 3rd National Family Conference, Las Vegas, NV



1986

- 4th National Family Conference, New Orleans, LA

1987

- NIF changes its name to Foundation for Ichthyosis & Related Skin Types, Inc. (FIRST) to include a broad spectrum of keratinizing disorders and to include "orphan" diseases



1988 • 5th National Family Conference, New Haven, CT



1989 • Offices move to Raleigh, NC



1990 • 6th National Family Conference, Orlando, FL

1991 • 7th National Family Conference, Williamsburg, VA
• Creation of the Regional Support Network (RSN)
• 1st Regional Conference at Duke University

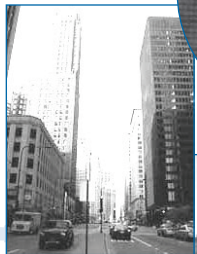


1992 • FIRST hires its first paid executive director, Susan Snyder
• More Regional Conferences in New York & Indianapolis
• Representatives from FIRST testify before Congress



Susan Snyder

1993 • 8th National Family Conference, Chicago, IL



1994 • Funding becomes available and the National Registry for Ichthyosis and Related Disorders begins



1995 • National Registry for Ichthyosis hires professional coordinator
• 9th National Family Conference, San Diego, CA

1996 • FIRST offices move to Philadelphia
• Regional Conference, Indianapolis

1997 • First 100 patients are enrolled in the National Registry for Ichthyosis
• FIRST's website goes live on the Internet



1998 • 10th National Family Conference, Cherry Hill, NJ

1999 • FIRST funds its first research grant through the Dermatology Foundation
• Jane Bukaty Membership Assistance Fund is established

2000 • FIRST receives funding to hire a professional coordinator for the Ichthyosis Support Network (ISN)



• 11th National Family Conference, Philadelphia, PA

• FIRST funds its second research grant through the Dermatology Foundation

• Molecular diagnosis is made possible through the Registry

• Website is professionally updated, hosting services donated, inquiries increase significantly

2001 • Regional Conference in Bloomingdale, GA
• FIRST funds its third research grant through the Dermatology Foundation
• Two personal major gifts are received



2002

- 12th National Family Conference, Seattle, WA
- Five-year strategic plan adopted, top priority is research
- FIRST receives first Gold Triangle Award from American Academy of Dermatology for its new website www.scalyskin.org



2003

- FIRST secures funding to update its resource library
- Major fundraising campaign is launched for research money



2004

- 13th National Family Conference, Kansas City, MO highest attendance to date
- National headquarters moves to a larger office space
- FIRST receives first bequest
- FIRST achieves \$100,000 in the first year of a fundraising campaign for research

2005

- Online educational modules are donated and published on the website
- New DVD is produced featuring teens living with ichthyosis
- FIRST receives 2nd & 3rd Gold Triangle Awards from the American Academy of Dermatology for the Education Modules for Healthcare Professionals on its website and for Teen DVD, "Living with Ichthyosis"



2006

- FIRST launches its own research grant program
- Founders, Mary Williams & Peter Elias, are honored at testimonial dinner
- 14th National Family Conference, Atlanta GA



2007

- Four-year strategic plan is adopted, top priorities include: research, new data-base management system, new website, expanding RSN, marketing, and physician resource development

2008

- 15th National Family Conference, Chicago, IL
- FIRST receives 4th Gold Triangle Award from the American Academy of Dermatology for the 2008 National Family Conference
- FIRST produces new DVD, The FIRST Story



2009

- FIRST launches a Facebook page



2010

- FIRST launches new logo and new color scheme
- Website redesigned and URL changed to firstskinfoundation.org
- FIRST launches a YouTube page
- FIRST launches Tele-Ichthyosis Website
- 16th National Family Conference, Orlando, FL
- FIRST hosts International Frontiers in Ichthyosis Research Meeting



A Message from the Executive Director...

Dear Members and Friends of FIRST,

Hello. For our regular readers, yes, this is an unusually large newsletter. We've made a few changes just for this issue. We are combining the winter and spring issues into one "mega" issue to coincide with our spring marketing efforts. I hope you enjoy all the announcements, articles and informative content. We have been very busy and are excited to share the latest news and highlights!



30th Anniversary... On January 2, 1981, FIRST officially became incorporated in the state of California. Over these past thirty years, we have grown from an idea by two doctors and a few families to a strong, vibrant, patient advocacy organization respected and recognized in the dermatology industry. Boasting more than 2,000 members, FIRST is proud of its history! Please see pages 3 thru 5 for a snapshot of our major accomplishments along the way.

May is Ichthyosis Awareness Month... For many years, FIRST has celebrated Ichthyosis Awareness Week (IAW) during the first week of October. Unfortunately, there is major competition for media attention during October and we often go unnoticed. It has also been suggested that we expand our timeframe from one week to a full month so families have more time to spread awareness or host a grassroots event. So alas! We have moved it to the month of May. In fact, years ago IAW was in May, so we are keeping with our early tradition.

It Makes Cents to Help FIRST... To make it easier for families to raise awareness and funds for FIRST, we are launching a new initiative called, "It Makes Cents to Help FIRST." During Ichthyosis Awareness Month (May), everyone is asked to collect change (or bills). Encourage your family, friends, co-workers to help you. Tell people why you are collecting so they can learn about ichthyosis and our Foundation. Whenever you find loose change in your car, on the ground, or in a vending machine, add it to your pot. At the end of May, convert your donations into a check or money order and send it to FIRST. See page 23 for more details. Even if you only collect a few dollars in change, it will add to our grand total. In addition, each participant that raises \$100 or more will have their name entered in a drawing to win \$300 toward next year's conference. We are hoping to raise \$50,000, so send it in!



New Development Coordinator... FIRST recently hired Christine Shea Wassel as our new Development Coordinator. Chris will be helping FIRST in all areas of fund raising and other special projects. This new part time position replaces our full time Development Director position. Chris began working at the office in November and already has had a positive impact in our fund raising programs. For the past 10 years, Chris' full-time job has been mother to five girls. Prior to that, Chris was a manager at IMS Health. She brings a lot of passion to FIRST and her managerial skills will be a huge asset.

Dr. Leonard Milstone to be honored by FIRST... Dr. Leonard Milstone, one of the original dermatologists who founded FIRST, will be honored on Friday, July 8 at the Top of the World in Baltimore, MD. Dr. Milstone is so deserving of this honor. He has held many leadership positions within our organization over the past thirty years. More importantly, he has devoted a major part of his career to studying and treating patients affected with all forms of ichthyosis. If you are member of FIRST, Dr. Milstone has touched your life in some way. FIRST is very proud to be able to honor his passion and commitment to our Foundation. If you are interested in showing your support of Dr. Milstone, please visit our website or contact the office directly. All donors will be recognized in the event's program book.

2012 Conference Location....drumroll, please! After surveying a focus group from our membership and making a visit to the city myself, Denver has been selected as the 2012 location for the next family conference. This city is amazing and promises to be a great location for everyone. **Mark your calendars for June 22, 23, and 24th.** More details to come! Check our website in the near future.



Best regards,

Jean R. Pickford

Executive Director

Regional Meetings Bring Support

FIRST members appreciate the support they receive from each other, which is why the one day Regional Meetings are so well received. Members do not have to live in the region which a meeting is hosted, and are welcome to attend any meeting. Regional meetings are facilitated by a member of the Medical & Scientific Advisory Board.

Registration for each meeting will be available on the website or by contacting Moureen Wenik, Program Director at mwenik@firstskinfoundation.org or call the National office at 800.545.3286. The schedule for the 2011 regional dates and cities are:

REGION 2 - April 30, 2011 - Richmond, Virginia - Drs. Jorge Toro & Gabriele Richard
Delaware, Maryland, West Virginia, Virginia, North Carolina, South Carolina

REGION 7 - June 11, 2011 - Seattle, Washington - Dr. Philip Fleckman
Washington, Montana, Oregon, Idaho, Wyoming, Alaska

REGION 3 - July 16, 2011 - Atlanta, Georgia - Drs. Mary Spraker and Leslie Lawley
Tennessee, Georgia, Alabama, Mississippi, Florida, Louisiana, Arkansas

REGION 4 - September 10, 2011 - Chicago, Illinois - Dr. Amy Paller
Missouri, Illinois, Indiana, Ohio, Michigan, Kentucky

Register
online!

Don't
Miss It!

FIRST Welcomes New Ambassadors

FIRST has added new Ambassadors to the following regions

REGION 1

Christine & Guy Mason – Cheshire, Connecticut

Christine: crlmason@cox.net

Guy: guy.mason@cox.net

Sean & Jolie Cina – West Caldwell, New Jersey

Jolie: zoliej@yahoo.com

Sean: sean_cina@toyota.com

Denise Benedetto – Wantagh, New York

Denise: denmarcny@aol.com

REGION 4

Mark Dunkin – Kokomo, Indiana

Mark: dunkin6@comcast.net

REGION 10

Samiha Chowdhury – Bangladesh

Samiha: aquakebanaichthyosis@yahoo.com



Please feel free to contact your local Ambassador!

A complete list of Ambassadors can be found on our website under Support. If you would like to become an Ambassador in your region, email Moureen Wenik at mwenik@firstskinfoundation.org or call the National office at 800.545.3286.

Calling all Celebrities...

FIRST's Marketing Committee is looking for connections with people in the media industry. If you know someone who works in radio, TV, newspaper, magazines, or any form of media in your area, please let us know.

Even the most remote connection may lead us to something great! We want to create greater exposure in the media, so we're reaching out to our members for their support.

Please call Jean at the office at 800.545.3286 or email at jpickford@firstskinfoundation.org.



Are you the *FIRST* to Know?

The national office is hosting topical conference calls for FIRST members. The past “FIRST to Know” calls were well attended, and received great reviews. Read below for some of the feedback from our members!

Thanks again for setting up the conference call. The information was very helpful and exciting on where they stand on EHK research. It is farther along than I was aware of. —Chris C.

We want to thank FIRST for all the work and energy it took to put this call together, along with the doctors that so graciously gave of their already busy schedules. We are excited for what the future holds for EHK, and thankful for all those who have given so much of their time and energy over the years to bring the research to this stage of success! The research looks like it is going to provide much hope in the years to come. Again, thank you for all the work you put in to make this journey as hopeful and informative as possible for many of us.

—Bob, Jo Ann, and Lisa K.

The words and conversations with Dr. Fleckman and Dr. Roop were music to my ears. We are soon approaching the 30th anniversary of our beginning, and in the old days of N.I.F., you couldn't mention the misguided four letter word “CURE” because it would give false hope and it was generations away. I remember back in '82 and '83 our ichthyosis doctors gingerly dancing around the subject. Now we have doctors who are

telling us they can take our skin, reprogram the chromosomes, and can see a future without ichthyosis. This was a mind boggling conversation last night when you look back at all the work and lifetime commitments our doctors have put in. What was nice also is that we all knew one another. Steve, Mark, Teri, Amanda, Lani, Dr. Fleckman; and it was very special to listen to Dr. Roop. These FIRST conference calls elevate us to a level I like to paraphrase: WE HAVE JUST ENTERED THE DIMENSION: HYPER FIRST MODE! Good work Moureen and thank you again for everything. —Les A.

Future calls will be:

Empowering Preadolescents to Care for Their Skin

Transitioning from High School to College

Building Confidence in the Workplace

Aging Skin – What Works...

Check www.firstskinfoundation.org for the dates and times, and to register for the calls, or call the national office at 800.545.3286. Do you have an idea for a “FIRST to Know” topic? Email Moureen Wenik at mwenik@firstskinfoundation.org with your suggestion.

Thanks to the Lennox Foundation for making these calls possible.

In Memoriam

Wilmer Conrad Betts, MD

October 14, 1925 – November 7, 2010

It is with great sadness that we announce the passing of Wilmer Conrad Betts, MD., a long-time FIRST member, and father of long-time FIRST member and former Board President, Ellen Betts (Rowe) Clemmer.

The son of Elizabeth Moultrie Drake and Wilmer Zadoc Betts, Dr. Betts was born in Raleigh, North Carolina. He began practicing psychiatry in 1955 and was the second psychiatrist in practice in Raleigh. Wilmer touched many lives during his years as a physician and continued helping people well into retirement.

Wilmer and his wife Georg'Ellen, who passed away in June 2010, had 4 children, three of whom are affected with Lamellar Ichthyosis. Dr. Betts was involved with the Foundation in its early days, and contributed articles about parenting and coping to the *Focus*. Dr. Betts was also a keynote speaker and moderator at the 1986 Family Conference held in New Orleans. The Bettses raised their children to be confident and recognize that what matters most in a person is character. Wilmer often told his children “Skin is like an envelope. The letter inside the envelope is what really matters.”

The Betts family generously included FIRST as a recipient of donations in Wilmer's memory.



President's Report

Greetings to all Members and Friends of FIRST:

In spite of the challenging economic environment beginning in October 2008, FIRST has continued to sustain the absolute highest level of service and attention to all of its strategic and operational goals. This is very good news indeed, and remains possible in only one way; through the continued and committed generosity of time, talents, and financial support by so many who care about FIRST and its growth.

On behalf of the staff, board members, and medical and scientific advisors of FIRST, I wish to sincerely recognize all of our members, friends of FIRST, and the many corporate and charitable foundation sponsors who favor our organization. The combined and continued confidence in **YOUR** organization, and strong support and engagement with FIRST throughout 2010, was much-needed, and I request you stay the course with us for 2011, and beyond.

Fulfillment of the FIRST mission and goals to *Educate, Inspire, and Connect* those affected by ichthyosis never ends. From the board of director's perspective, we periodically identify activities that we believe will matter the most. We then make the investment of time and resources to drive them to successful completion.

As my fifth year as president of FIRST gets started, and we are celebrating our 30th anniversary, it is my honor and privilege to extol the highest level of respect, regard, and praise on a truly exceptional leader, our executive director Jean Pickford, and her equally driven, dedicated, and highly motivated staff comprised of Moureen Wenik (Program Director), Lisa Breuning (Public Relations Coordinator), Donna Wiggins (Membership Services Coordinator), and our newest member, Chris Wassel (Development Coordinator).

Moe, Lisa and Donna are very skilled, compassionate, and knowledgeable, and they provide personalized support and service to our members second to none in the non-profit world. For certain, their professionalism and work ethic would allow them to excel in the commercial world. But for board members, Jean, and you, they provide consistency, familiarity, and a relationship quality that our stakeholders can count on each and every time. To all three of you, a heartfelt thank you for all that you do in service at every level within FIRST!

I would be remiss if I failed to mention the recent addition of Chris Wassel to our staff as our new Development Coordinator. She has already demonstrated a commitment to our mission and a very strong work ethic. Chris, welcome to the organization; we wish you the best as you begin to get to know our members, and you build on the successes of your fellow FIRST colleagues.

What type of leadership does Jean provide FIRST? She displays a tremendous energy and vibrancy. In June 2010, Jean celebrated her 11th anniversary with FIRST, an astounding sign of loyalty to any organization. Jean is always focused on advocating for our members and FIRST's mission. Her leadership role with the Coalition of Skin Diseases (of which, FIRST is a member), her participation on the expert panel of the NIAMS Advisory Council, articulating the needs of our organization to benefactors and foundations, and her interactions with renowned dermatologists and scientists from around the world to request their active engagement in FIRST, are just a few examples of her commitment and dedication.

Jean, we all wish to thank you for your excellent leadership of FIRST for one-third of its life, and look forward to supporting your team's efforts to continue to exceed our goals and grow our organization for years to come. To all members and friends of the organization, please join me and my fellow board members in congratulating Jean on reaching her 11th anniversary, and taking us into 2011 with great momentum and vision for further growth of FIRST!

A connection with FIRST often starts with a concerned, anxious phone call. The questions include, What is happening? How can I learn about ichthyosis? What materials are available? Where can I find an expert clinician? FIRST provides a vast library of educationally sound literature to answer these questions. Substantial resources have been invested to develop a new infrastructure that allows broader and easier access to our resources electronically.

Continued on page 10



Execution of our key strategic initiatives continued along several veins in 2010, and included the following examples of progress:

- Re-design of our marketing materials and website to make our message clearer, materials more attractive, and our website robust, informative and navigable
- Development of a FIRST Fanpage on Facebook, and Twitter feed to enhance connections to our organization through the new phenomenon of social networking
- Selection and implementation of computer software that more efficiently allows our executive director and staff to keep pace and stay in-touch with our growing list of members/friends
- Initiation of a tele-medicine offering that has grown in utility for clinicians who wish to be linked to our panel of dermatologists who are clinical and/or research experts in the field of ichthyosis. This program effectively assures that anyone in the US can find expert help, and we look forward to broadening access to this important program beyond the US in the future.
- Continued funding of select research projects administered through the FIRST Research Program
- Development of the FIRST Ambassador Program
- Establishment of a new educational scholarship program for college-bound members

What is your role in our organization? Multi-dimensional, I hope. The number one thing to consider is to get involved. It has never been easier. Also, it would be great to see you and your family at our bi-ennial National Family Conference in June 2012 in Denver, Colorado, or attending one of the several Regional Meetings that are planned for 2011, better yet **COME TO BOTH!** Please strongly consider making the commitment to attend at least one of these functions, you will see first-hand how valuable these “get together” opportunities are for you and your family.

Orlando was a blast! If you can visualize a Conga line of children, parents, FIRST staff members and expert, world class dermatologists all led by Mickey Mouse dancing, weaving, stepping and laughing through the ballroom of a resort hotel in Orlando – then you get the picture. Each FIRST conference has its own aura of fun and enjoyment, but one element that never changes is the sense of “common bond and caring” that by the end of the conference is emotionally overwhelming.

We also are forging bonds through our newly developed Ambassadors Program. FIRST coordinates a team of ambassadors, who reach out to physicians and clinicians in their area to ensure that information is readily available at medical institutions about ichthyosis and FIRST. To each individual that has committed to being a FIRST Ambassador, thank you! Your dedication of time and talents to your organization is having a measureable impact on the growth of programs and the benefits to our members.

Of course, a meaningful way to show your support and confidence in our organization is to contribute what you can financially. Your donations go a long way to make the programs and commitments to our members meaningful and helpful. They are absolutely essential to the strength and vitality of any non-profit organization. In advance, thank you for your collective generosity to FIRST.

Lastly, I wish to recognize three truly outstanding board members that have left our Board of Directors after many years of service. All have been staunch advocates and tireless workers for FIRST; **Dr. Phil Fleckman** and **Elena Levitan** for over a 9 year period of dedicated service to the board membership, and **Dr. Terry Melton** after two terms during which she headed up our Board Development Committee. All promise to stay involved going forward, and Dr. Fleckman will continue working directly with the FIRST board as an emeritus member. To all three, we wish only the very best, and bravo for a job well done!

In closing, please continue to help FIRST in any way you can and consider increasing your financial support to FIRST. Your funds will be used wisely. I wish each and every one of you and your families the very best in 2011.

Warm regards,

David R. Scholl, Ph.D.

President

Chief Financial Officer's Report

Fiscal Year End 09/30/10

Dear Members and Friends:

We seem to have been fortunate once again in yet another turmoil filled economic year. I must thank everyone for doing your best to keep your level of donations and efforts up and helping FIRST during the past year with virtually no deterioration.

Looking at the numbers, our current year Statements of Financial Position included in this issue, illustrates Net Assets increasing by \$76,902 or 4.9% over last year. Fortunately we were able to minimize our investment losses this year so that the actual value of our investment portfolio increased by \$27,100. We hope to continue this trend by engaging an asset manager in the very near future. I have interviewed numerous candidates and have narrowed them down to three choices. We are in the final stages of review.

On the Revenue side (not counting National Conference revenue), we had a slight decrease of 1.2% in overall contributions mostly due to a slightly lower level of restricted donations for research. Many areas of revenue actually increased. Interest income unfortunately decreased by \$9,000 but this trend should be rectified with the addition of an asset manager.

On the operating expense side (not counting National Conference or Grant Expenditures), expenses continued to be relatively in line with prior years and budget. We also continue to be very much in line with national spending levels for Program Expenses (81.9%), Fundraising Expenses (11.0%) and Management & General Expenses (7.1%) which actually decreased just over 2%. Payroll and related expenses

increased due to adding a senior staff person dedicated solely to fundraising. Additional budgeted spending included a one-time increase this year for updating our website design and funding the Frontier's Conference just prior to our Family Conference. Based on our experience with the senior development position, the position has been reformatted and a less-senior, part-time person has been added to assist Jean in her efforts.

In closing, I hope all of you have been fortunate in dealing with the continued economic issues facing us each day. It was most wonderful to see so many of you at the Family Conference in Orlando, and I hope to see more of you at the next one.

Sincerely,

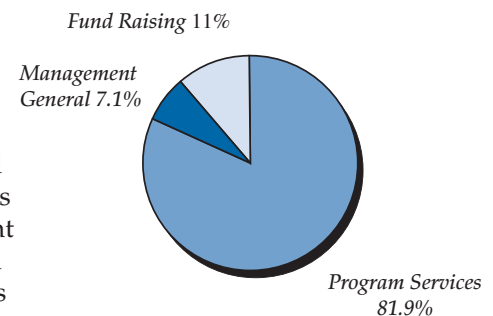
John J. Schoendorf (EHK member)

CFO, Board of Directors

The statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2010. 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 215.997.9400 or 800.545.3286.



Fiscal Year 2010 Expense Allocation



Foundation for Ichthyosis and Related Skin Types, Inc.

Statements of Financial Position
September 30, 2010 and 2009

	2010	2009
Assets		
Current Assets		
Cash	\$ 1,378,260	\$ 1,266,212
Investments	258,348	232,636
Prepaid and other assets	10,747	3,248
Total current assets	1,647,355	1,502,096
Cash, permanently restricted	70,203	70,203
Furniture and Equipment, net	10,169	12,435
Total assets	\$ 1,727,727	\$ 1,584,734
Liabilities and Net Assets		
Current Liabilities		
Grants payable	\$ 75,000	\$
Accounts payable and accrued expenses	4,787	13,696
Total current liabilities	79,787	13,696
Commitment		
Net Assets		
Unrestricted		
Undesignated	800,861	769,757
Board designated	257,269	226,067
Total unrestricted net assets	1,058,130	995,824
Temporarily restricted	519,607	505,011
Permanently restricted	70,203	70,203
Total net assets	1,647,940	1,571,038
Total liabilities and net assets	\$ 1,727,727	\$ 1,584,734



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Executive Director's Report

Dear Members, Donors, and Friends of FIRST:

Our current four-year strategic plan is almost complete. Working with the Board of Directors, staff and several key volunteers, we have successfully accomplished and are currently implementing the plan's key initiatives since 2008.

Our new website provides cutting-edge information and resources at your fingertips. New materials are being developed to ensure FIRST provides support through all stages of an affected person's lifecycle. Our Support Network has been regionalized to better serve member's needs. Regional meetings, topical conference calls and community outreach initiatives have been implemented. We are engaging more dermatologists and other healthcare providers through our tele-ichthyosis website. Our new database has improved our membership tracking system, which enables us to better meet your needs. And, we've developed a diversified fund raising program to improve our financial stability and ensure the continuation of our services.

Currently, we are implementing a comprehensive marketing plan to engage new members, strengthen our relationships with current members, increase our arsenal of knowledgeable physicians, and reach new audiences for greater awareness.

Funding research is our top priority. We are grateful to all our generous benefactors who contribute to our research fund, allowing FIRST to continue to fund vital research.

Hosting the international Frontiers in Ichthyosis Research meeting this past summer took us one step closer to advancing a collective effort to find a cure.

Our Board of Directors will meet for its annual face-to-face retreat this November to adopt a new four-year strategic plan. You can be confident that your investment in FIRST is extremely valued and will be used for the most worthwhile and beneficial programs for the ichthyosis community.

FIRST proudly celebrates its thirtieth anniversary this year. Our history is marked with many accomplishments. Supported by our members, donors and friends, FIRST will continue to educate, inspire, and connect those touched by ichthyosis and related disorders through emotional support, information, advocacy and research funding for better treatments and eventual cures.

Sincerely,

Jean R. Pickford

Jean R. Pickford
Executive Director



Jean Pickford meets with FIRST-funded researchers, Dr. Dennis Roop and Dr. Jiang Chen, in their lab at the University of Colorado



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How to make Ichthyosis (Fish Scale Disease) in Fish

*Qiaoli Li, Ph.D., Assistant Professor of Dermatology ~ Jouni Uitto, M.D., Ph.D., Professor and Chair
Department of Dermatology and Cutaneous Biology, Jefferson Medical College, Philadelphia, PA*

Ichthyosis (derived from the ancient Greek word meaning “fish”) refers to a group of disorders in which skin is dry and scaly often from birth. There is quite a lot of variability in the severity of this skin condition. In the milder forms skin is just dry, especially during winter months, while in the most severe cases, large scales are present which can affect the individual’s well being and survival. Through the work of several investigators, it is now clear that alterations in many different genes can cause ichthyosis in patients, and the types of mutations and the genes harboring such mutations can explain the tremendous variability in the disease severity.

For many forms of ichthyosis, there is no effective treatment, and different animal models have been developed so as to allow testing of new treatments. The “gold standard” of such models is mouse which can be manipulated at birth so that they develop ichthyosis, and these mice can then serve as a target for different testing protocols. However, the drawbacks of the mouse model include the long time that it takes to develop a mouse with the disease, small number of pups being born to each mother, and the cost of maintaining the mouse colonies for testing. In an attempt to create an alternative, more expedient, model system to study ichthyosis, we have recently turned our attention to zebrafish which has several benefits over the mouse systems (Figure 1A). For example, the zebrafish develop very rapidly so that all major organs, including the skin, develop in 5-6 days after fertilization. Zebrafish also produce a large number of embryos, approximately 50-

100 per female each day, and maintaining these zebrafish colonies is very cost efficient.

One of the advantages of zebrafish is that we can change their genetic makeup at one-cell stage by easy manipulation in the laboratory. We have recently made efforts to prevent the synthesis of protein known as ABCA12 which is missing in patients with Harlequin Ichthyosis, the most severe form of the disease. Examination of the top layer of the skin in normally developing zebrafish reveals well developed structures, so-called microridges, which look like fingerprints in humans (Figure 1B). If the synthesis of the ABCA12 protein is inhibited, the microridge development is perturbed, and instead, the top layer of the fish skin shows abnormal scale-like structures, somewhat similar to patients with different forms of ichthyosis (Figure 1C). Thus, the zebrafish provides an expedient model system, which develops abnormalities in the top layer of the skin. These animals now serve as a platform to study the mechanisms of the skin changes and to test different treatment modalities for use in patients with ichthyosis.

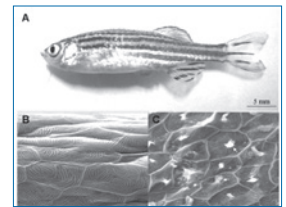


Figure Legend

Figure 1. An adult zebrafish can grow up to about 2 inches in length (A). Examination of the outer layer of the skin in a normally developing zebrafish reveals the presence of microridges (like fingerprints) pointed out by arrows (B). In the skin of a fish in which ABCA12 protein expression is inhibited, the microridges are poorly developed, and there are scale-like structures similar to patients with ichthyosis (C).

Meeting Report from Frontiers in Ichthyosis Research *Continued from page 1*

and reduce cost. Eli Sprecher (Sourasky Medical Center, Tel Aviv, Israel) spoke about the identification of genes causing syndromic ichthyoses—*CEDNIK* (cerebral dysgenesis, neuropathy, ichthyosis, and keratoderma caused by mutation in *SNAP29*) and *ANE* (alopecia, neurologic defect, and endocrinopathies caused by mutation in *RBM28*). He indicated that “rare is common” when looking for new disease genes in geographically, ethnically, or politically isolated populations and suggested that this approach will continue to be important in identifying proteins with critical functions in epidermis.

Keith Choate (Yale University) reported on a group of patients with ichthyosis for whom he and Leonard Milstone collected data; the key question for this group was not what caused the ichthyosis but what caused the areas of normal-appearing skin. He demonstrated that the normal skin resulted from frequent, unique, somatic recombination events in keratinocytes and indicated how those independent somatic cell events were used to localize and identify the gene for ichthyosis with confetti.

Amy Paller (Northwestern University, Chicago, IL, USA) concluded with a provocative review of the pros and cons of giving all patients with ichthyosis a genetic diagnosis. She noted that genetic diagnosis will change the way we think about classification, pathogenesis, prognosis, and therapy. Currently, the cost for making genetic diagnosis widely available in the United States is prohibitive.

Frontiers in understanding pathogenesis

As important and satisfying as it has been to learn about the genes and proteins associated with ichthyosis, we are still quite ignorant, in many cases, about normal protein functions or what precisely goes wrong in a

Continued on page 18

cell with a mutant protein. William Rizzo (University of Nebraska, Omaha, NE, USA) gave a critical overview of lipid synthetic pathways in epidermis. For each enzyme defect known to be associated with ichthyosis, he revealed our inability to explain adequately all the clinical manifestations or to understand whether pathogenesis moved through substrate accumulation or product deficiency. In the mouse model of Sjögren–Larsson syndrome that he created, he unexpectedly identified enzyme redundancy in mice but not in humans. Equally unexpected was the observation that the deleted gene resulted in substantially different phenotypes depending on the mouse strain—providing an opportunity to identify disease-modifying genes. Mason Freeman and Michael Fitzgerald (Harvard University, Boston, MA, USA) have created mouse models of mutant ATP-binding cassette A3 and A12 (ABCA3 and ABCA12). Fitzgerald explained the ways in which these mouse models of deficiencies in related lipid transporters differ from each other and how they have been useful in understanding the respective human deficiencies—neonatal respiratory distress syndrome and Harlequin ichthyosis—but also why they have been disappointing in elucidating disease pathogenesis completely. He suggested that mass spectroscopic analysis of lipids in this and similar monogenic epidermal diseases could lead to new therapeutic strategies.

Peter Elias (University of California, San Francisco, CA, USA) noted that ichthyosis therapy had often simply focused on scale removal. He urged the audience to consider pathogenesis-based therapy for ichthyotic epidermis caused by defects in lipid synthesis and delivery pathways. Such an approach might employ both pathway inhibitors to reduce toxic lipid metabolites and lipid replacement to restore deficient products. Hiroshi Shimizu (Hokkaido University, Sapporo, Japan) spoke about his experience with skin cancer occurring in unusual anatomic locations in patients with ichthyosis. He noted that increased risk for skin cancer is accepted in Kindler syndrome, xeroderma pigmentosum, and recessive dystrophic epidermolysis bullosa, but that there are only a few anecdotal reports of cancer in ichthyosis. In general, we know little about the natural history of patients with ichthyosis, their relative lifetime risk for cancer or, if the risk is greater than normal, how the mutant gene might increase risk.

Alain Hovnanian (University of Paris, France) spoke about multiple effects of mutations in the gene for the serine protease inhibitor, Kazal-type 5 (SPINK5), the cause of Netherton syndrome. The protein product of SPINK5—lymphoepithelial Kazal-type 5, or LEKTI—inhibits protease activity in the epidermis, and he described molecular pathways by which LEKTI deficiency could lead to allergy and inflammation, as well as to its more obvious role in desquamation. Identifying the specific enzyme(s) inhibited by LEKTI could lead to development of small-molecule enzyme inhibitors, an area of active

research in his lab. Pierre Coulombe (Johns Hopkins University, Baltimore, MD, USA) reviewed the well-accepted structural function of keratins in resisting shear stress and then provided less well-appreciated examples of keratin's roles in signaling activity. As examples he mentioned the roles of K5 and K14 in pigment transfer from melanocytes to keratinocytes and of K17 in modulating patched pathway-mediated tumorigenesis and in Th1/Th2 immune balance in epidermis.

Frontiers in shared reagents and resources

Investigative communities are dependent on widely accepted tools, valid measures of events, and outcomes that interest them. Few such tools exist or have been widely applied to research in ichthyosis. If translational research in ichthyosis is to move forward, such tools must be devised and validated. Mary Williams (University of California, San Francisco) introduced this session by noting the major issues faced by those with ichthyosis: impaired barrier function and increased scale. She reviewed and critiqued the various physical and chemical methods currently employed to assess these issues. She described capabilities of additional physical measurements, such as ultrasound, confocal microscopy, Raman spectroscopy, and optical coherence tomography, which have yet to be applied to ichthyosis. Transepidermal water loss, hydration, and pH are measurements commonly employed in clinical and laboratory studies, but they have not been widely used in patients with well-characterized ichthyosis.

Roger Kaspar (Transderm, Inc., Santa Cruz, CA, USA) spoke about his recent experience developing a small interfering RNA (siRNA) to treat pachyonychia congenita. Severe pain upon intralesional delivery of the siRNA to a single patient precluded its continued use in that manner. However, that problematic experience spawned a collaborative effort to develop relevant, reproducible, widely available test systems to identify and optimize “patient-friendly” delivery of therapeutic nucleic acids to human epidermis. Dr. Kaspar acknowledged the key role played by the patient support group, PC Project, in pushing the clinical trial forward and promoting a collaborative atmosphere. Robert Rice (University of California, Davis, CA, USA) posited that the cornified envelope could be viewed as a snapshot of the health of the upper layer of epidermis at the time it is formed and that different diseases of epidermis might have distinct peptide signatures retained in the cornified envelope. He showed preliminary mass spectroscopic data demonstrating reproducibility of peptide signatures from cornified envelopes collected from normal skin, and he showed some differences in envelopes collected from patients with ichthyosis, emphasizing that further work is needed to understand the significance of the findings.

Dennis Roop (University of Colorado, Aurora, CO, USA) spoke about the promise and practicality of using a patient's keratinocytes to produce induced pluripotent

stem (iPS) cells that might be used to treat genetic skin disease. He described his recent success in generating iPS cells from a patient with Epidermolytic ichthyosis, which was supported by a grant from FIRST. He then explained that his future goal was to correct the genetic defect in these iPS cells and then differentiate them back into keratinocytes that could ultimately be returned to the patient as an autograft. A frank discussion of obstacles impeding translation of this technology into patient treatment ensued. Suephy Chen (Emory University, Atlanta, GA, USA) presented recent work creating and validating an ichthyosis clinical severity index for several types of ichthyosis. She indicated that some of the measures that clinicians have used routinely to rate severity of ichthyosis are not necessarily the measures that ichthyosis patients feel have the greatest impact on quality of life, hair loss being a specific example. She explained how improvements can be made in the tool she devised.

Frontiers in preparing for clinical trials

Embarking on a clinical trial is not for the faint of heart or thin skinned. Few of the investigators or patient participants in clinical trials in rare diseases are prepared for negotiating the complexities of local and national regulatory agencies, reporting and monitoring expectations, and fundraising. Heiko Traupe (University Hospital, Muenster, Germany) spoke about the long journey from molecular insights to therapeutic innovation, using three examples. First, he outlined recommendations for an internationally consistent classification and nomenclature made by last year's ichthyosis consensus conference in Soreze, France. Second, he used his group's interest in transglutaminase 1 mutations and delivery of active enzyme to deficient epidermis as an example of preclinical challenges that are faced by investigators trying to develop new approaches

to therapy. Third, he used the demise of liarozole, a new oral agent to treat ichthyosis, as an example of how great effort and some promise can be extinguished by business, not medical decisions.

Sancy Leachman (University of Utah, Salt Lake City, UT, USA) briefly reviewed her successful clinical trial of intralesional allele-specific siRNA to reduce hyperkeratosis in the callus of pachyonychia congenita. She then outlined her views of the critical components in the path toward a successful clinical trial. Because such trials in rare disease usually include representatives of academia, industry, and patient advocate groups, she emphasized that each needed to understand how the others operate. Although academics are often creative, expert in the area, and adhere to scientific rigor, they also can be slow-moving, bureaucratic, and independent (noncollegial). Industry is goal oriented, outcome driven, and flexible—but can lack informational depth and have a strong financial bias. Patient advocacy groups bring a sense of urgency, financial support, and effective advocacy; however, they often need education in scientific rigor and the complexities of drug development, they can lack focus, and they are relatively more susceptible to whims of personal bias. Philip Fleckman (University of Washington, Seattle, USA) reviewed the design and accomplishments of the existing Ichthyosis Registry that was supported for 10 years by the National Institutes of Health (NIH), but has not enrolled new patients in the past 6 years since NIH funding terminated. He then presented his goals for a new registry and raised the issues of who might support it, who would “own” the data, and potential rules for data sharing.

Frontiers in physician–scientist–patient collaboration

This session brought together research investigators with “Ambassadors” identified by FIRST, individuals affected

Continued on page 20

Keith Choate, MD, PhD Honored at the Annual AAD Meeting



At its 69th Annual Meeting, the American Academy of Dermatology (Academy) presented one of the 2011 Young Investigators in Dermatology Awards to Keith Choate, MD, PhD, FAAD.

Given each year to recognize outstanding research, the Young Investigators in Dermatology Awards recognizes dermatologists-in-training in the United States and Canada for their contributions to research in the field of dermatology. The award criteria are: originality of research concept; soundness of research design; quality/clarity of research report; and perceived value of the research to dermatology.

Dr. Choate is currently an assistant professor of dermatology at Yale University School of Medicine, New Haven, Connecticut. He received his medical degree and doctorate in cell biology from Yale, where he also completed an internal medicine internship, dermatology residency, and post-doctoral fellowship in genetics. Dr. Choate is being recognized for his research in identifying the genetic basis of revertant mosaicism in the self-correcting skin disease ichthyosis with confetti and characterization of the pathophysiology of mutations causing this disorder. Dr. Choate's work could serve as a model for therapy of other disease-causing mutations. Dr. Choate also received FIRST's Clinical Scholar Award in 2008 and serves on FIRST's Medical & Scientific Advisory Board.

by a specific type of ichthyosis, or their parents. Six small groups representing specific genotypes and a group representing those who remain “undiagnosed” met separately, reflecting the belief that progress in research would increasingly require a focus on specific genotypes. Each group was asked to identify short- and long-term research objectives and ways in which the different constituencies—basic scientists, clinical investigators and patients—could help each other. Virtually all supported the idea that future research should focus on specific genotypes. Other recurrent themes included (i) access to genetic diagnosis at a reasonable cost, (ii) an active patient registry, (iii) more clinical information about natural histories of each type of ichthyosis and long-term outcomes, (iv) support for centers of research and clinical excellence in ichthyosis, and (v) one recurring clinical concern: itch and how to treat it.

In the final open discussion, there was enthusiasm for convening meetings of this kind in the future, possibly in different countries. Two working groups were established. One group will explore the feasibility and parameters of a collaborative international effort to establish a registry of patients with ichthyosis. The second will consider practical and efficient ways to provide genetic diagnoses to patients with ichthyosis. It was recognized that vigorous advocacy by patient support groups in many countries might be necessary to generate requisite governmental, insurance-industry, or private support

to make genetic diagnosis widely available. There was broad agreement that standardized, clinical evaluation tools would be highly desirable for future investigations into the natural history or response to therapy for each type of ichthyosis. It was suggested that patient support groups could assist in the development of visual analog, validated, widely available, genotype-specific clinical severity scales. Finally, it was recognized that in the face of scarce resources—limited numbers of patients, limited numbers of knowledgeable clinicians, limited numbers of preclinical scientists working on ichthyosis, and limited funding—progress in translating new approaches to therapy might likely require agreement to establish and coordinate centers of research/translation excellence.

ACKNOWLEDGMENTS

The conference was sponsored by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institutes of Health (NIH) Office of Rare Diseases (1R13AR059533-01) and by FIRST. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIAMS or the NIH. Nine of the 18 speakers have received research support from FIRST. We thank Ellen B. Milstone for assistance in preparing this summary. Ambassadors from FIRST who participated in the final day of discussion included Joe Andrews; Wendy, Mark, and Tyler Breen; Mark and Cora Dunkin; Holly Friddle; Diana Gilbert; Angela Godby; John, Shannon, and Lauren Hamill; Mark, Kelly, and Adam Klaffer; Randy LaBarbera; Ryan Licursi; Janet and Maggie McCoy; Laura Phillips; John Schoendorf; David Scholl; Brian See; and Hunter Steinitz.

*Frontiers in Ichthyosis Research was held at the Regal Sun Resort in Lake Buena Vista, Orlando, Florida, USA, 23–25 June 2010.

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May is Ichthyosis Awareness Month!

May was originally the time of the year set for Ichthyosis Awareness.

It was changed to October over time, but with so much attention on other awareness campaigns during October, the leadership of FIRST has moved it back to May to provide an entire month to reach out to your community and create awareness about ichthyosis and FIRST.

Educating your local community is very important as it can make day-to-day life much easier for those affected. The simple knowledge that ichthyosis is a genetic skin disease and not contagious, a bad sunburn, or the result of poor bathing habits, can help the public understand the disease and its symptoms.

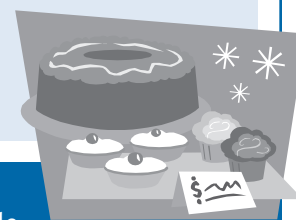
The possibilities are endless ... One of the easiest ways to spread the word in your community is to do an interview for your local newspaper and share your personal story. You can also join others in our **It Makes Cents to Help FIRST** campaign (see page 23).

Events can take any form, from a car wash, to a bake sale, to a golf tournament. Grassroots events offer not only the opportunity to increase awareness, but also raise funds for FIRST. The FIRST office has a complete **Grassroots Fundraising Guide** available to assist you with your event. It provides step-by-step information in planning and organizing your event and is available free of charge to anyone who requests it.



Fundraising Ideas:

- Auction • Bingo
- Book Sale • Bake Sale
- Candy Sale • Car Wash
- Dance • Garage Sale
- Dress Down Day at work or school
- Golf Tournament
- Raffle • Skate-a-thon
- Walk-a-thon



Please contact the national office at 800.545.3286 or e-mail Development Coordinator, Chris Wassel at cwassel@firstskinfoundation.org to receive the Grassroots Fundraising Guide.

Grassroots Fundraising

Our members across the nation have been very busy holding Grassroots Fundraisers for FIRST!



A Marathon Birthday Celebration in California

Most people celebrate their birthday with a special dinner, but **Paula Medina** decided to celebrate her birthday with a 6-mile marathon. Paula, whose 9-year-old son, Jesse has X-Linked Ichthyosis, participated in the Lake Chabot Trail Marathon in Castro Valley, California on November 6 and used the opportunity to generate awareness about ichthyosis in her community and raise funds for FIRST. Her family came out to support her on the trail and they even made t-shirts with FIRST's 'fuzzy family'! What a great way to enjoy your birthday. Thank you Paula for your efforts on our behalf.

Jesse joins his mother for part of the run



The Medina Family

South Dakota Pumpkin Paint and Bake Sale

The Iott Family has once again organized their annual Pumpkin Paint and Bake Sale. With 125 people joining in at the Flandreau Aquatic Center, many painted pumpkins and many purchased baked goods. The day was fun for all and raised more than \$1,600 for FIRST.



Participants show off their artwork



Rylee Iott works on her pumpkin



Baby Evan Fasciano

Dress Down Day in Connecticut

Richard Fasciano, is a 7th grade science teacher at Torrington Middle School in Torrington, Connecticut. In June, his grandson Evan was born with Harlequin Ichthyosis. Richard decided to organize a dress down day in Torrington Public Schools. The middle school, the high school, and several elementary schools participated. Almost \$1,400 was raised for FIRST. Thank you to Richard and the Torrington Public Schools for their efforts.

Another Beading Bonanza in Maine

Kim Mayone, is the mother of 5-year-old Evan, who is affected with EHK. Several years ago, she began a fundraiser with Caravan Beads in Portland, Maine. She likes this fundraiser because it's easy for her and doesn't require a lot of time and effort. The Caravan Beads store donates 30% of all sales to FIRST and opens exclusively for Kim's event. This year was her best year yet, raising more than \$600 for FIRST!



Evan Mayone

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.

Grassroots Fundraising

Handmade Items Sold on the Internet



Ana Bryson

Jennifer Bryson is the mother of a 7-year-old daughter, Ana, affected with Lamellar/CIE. Jennifer is an extremely talented seamstress. She has used her talent to make items such as aprons, potholders, and dolls and then sells them on etsy.com, an online site that provides an opportunity for people to sell their handmade wares. Jennifer's efforts have raised more than \$300 for FIRST!



The Bryson sisters showing off shark mittens made by mom, Jennifer

Dress Down Day in Florida

FIRST member and CFO, *John Schoendorf* arranged a dress down day at his accounting firm, Berenfeld, Spritzer, Shechter, and Scheer, LLP. All proceeds from the day were donated to FIRST.



Employees participate in jeans day

Another Jeans Day Success in Ohio

FIRST member, *Lisa Klima* organized a Jeans Day at her Wells Fargo Advisors Pepper Pike Office. Lisa's daughter, 6-year-old Emma, is affected with EHK. Lisa has been organizing this event for the past several years. With a donation of 5 dozen bagels from Breugger's Bakery, and Teresa's Pizza donating pizza for lunch, a great time was had by everyone and more than \$1,000 was raised for FIRST!



Emma Klima

Denim Days Continue in Virginia

Scott Zailer, uncle of 3-year-old Portia Cina, who is affected with CIE, has once again organized a denim day at his office. For the third time, employees at Accenture Supply Chain in Reston, Virginia answered the call every Friday during January and donated money to FIRST to wear jeans to work. Thank you to Scott and the employees at Accenture for your efforts.



FIND A CURE event to be held in Atlanta, Georgia

Mike & Lynn Briggs and *Mark & Kelly Klafter* are once again hosting an evening at the Olde Blind Dog Irish Pub. The date is April 21, 2011 at 6:00 pm. Please plan to join in this evening of entertainment, refreshments and hors d'oeuvres.

One of the highlights of the evening will be a raffle of a trip to Costa Rica, as well as a week in beautiful Big Sky Montana! The evening will also feature a silent auction. For additional information, or to purchase tickets, contact the Foundation office at 800.545.3286 or email Development Coordinator Chris Wassel at cwassel@firstskinfoundation.org.



It Makes Cents
to Help

FIRST!

Whole families can get involved! Set a goal!

May is Ichthyosis Awareness Month. Help raise awareness and funds for FIRST by collecting change beginning May 1 through May 31. At the end of the month, convert your collected change into a check or money order and send it in to the FIRST office! (Due date: June 15)

There are so many creative ways to find change —look in vending machines, furniture, your pockets or your car!

Be creative to find ways to solicit change! Some ideas include:

- Decorate canisters and place them in local businesses, community or sporting events, church functions, and other places where people gather
- Hand out decorated baggies to your relatives and friends and ask them to save change for FIRST
- Work with your school to host a change collection contest between classrooms
- Collect change at your workplace
- Hold a garage, candy, or bake sale and send your proceeds to FIRST

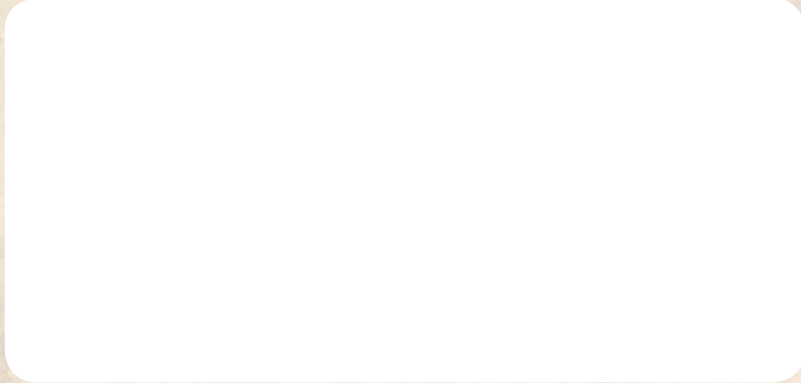
It Makes Cents to Help FIRST materials are available on our website at www.firstskinfoundation.org and click on *It Makes Cents to Help FIRST*. The site provides a print-out for canisters, a fact sheet, a sample request letter, etc.

You'll be surprised how quickly your change will add up! Have fun and be creative! Every piece of change counts and will benefit our important mission to educate, inspire and connect those touched by ichthyosis and related disorders through emotional support, information, advocacy and research funding for better treatments and eventual cures.



Win A Trip to the Family Conference!

The participant collecting the most change will win a Family Conference voucher for \$300 to be used for the 2012 conference. FIRST will also draw one name from any participant raising \$100 or more, awarding the lucky winner an additional \$300 Family Conference voucher to be used for the 2012 conference.



2011 Dates:

JUNE 26 – JULY 1

Camp Little Pine in Crosslake, Minnesota (ages 10 – 14)

JULY 10 – 15

Camp Big Trout in Crosslake, Minnesota (ages 14 – 16)

AUGUST 14 – 19

Camp Liberty in Hebron, Connecticut (ages 10-16)

AUGUST 6 – 12

Camp Dermadillo, Burton, Texas (ages 9 – 15)

AUGUST 13 – 19

Camp Horizon, Millville, Pennsylvania (ages 8 – 13)

*For more information about attending or volunteering
please visit their Web site at campdiscovery.org or
contact Janine Mueller at 847.240.1737 or jmueller@aad.org.*

**Philadelphia
Area Members!**

*Celebrate Ichthyosis
Awareness Month*

**FIRST is going
to a *Phillies* game!**



WEDNESDAY, MAY 4, 2011

Check out our website
for details and ticket
information.

