



May is the time set aside to engage in national ichthyosis awareness. This is a great time to come together as a community to spread the word about what ichthyosis is and how friends and neighbors can help your family and the larger ichthyosis community. There are many ways to participate in ichthyosis awareness. Contact your local newspaper to participate in an interview, or hold an awareness event like a bake sale or a car wash. Visit FIRST's website or call the office for awareness event ideas and to ask for supplies.

## ICHTHYOSIS AND HEARING LOSS SURVEY

Please take a moment to complete an online survey to help us understand ichthyosis and its related ear symptoms. All patients with ichthyosis are welcome to participate. This anonymous survey is part of a research study and participation is voluntary. You can find the link on the FIRST website homepage, or select 'research' under the Research & Support tab. Thank you.

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## ELOVL4 Deficiency

### *A New Form of Ichthyosis Discovered by Next-Generation DNA Sequencing*

William B. Rizzo, M.D.

Recent advances in "Next-Generation" DNA sequencing technologies promise to revolutionize the ability to diagnose patients with genetic diseases and discover new forms of ichthyosis not previously recognized. These new methods, including "whole exome sequencing", allow researchers to detect alterations or mutations in the functional parts of all of the genes. A recent example of the power of these DNA sequencing methods is the identification of a new form of ichthyosis caused by mutations in the gene called ELOVL4 that codes for an enzyme with the same name.

The story behind the discovery of ELOVL4 deficiency actually goes back to a few years ago, when researchers generated a strain of mice with the equivalent ELOVL4 gene "knocked out," or inactivated. The reason for making the mutant mice was to investigate a rare form of human childhood-onset blindness with macular dystrophy that is caused by ELOVL4 mutations. Surprisingly, rather than being blind, the ELOVL4 knockout mice had severe ichthyosis at birth and died several hours later from dehydration. ELOVL4 is an enzyme that is present in the skin, eye, and brain, and is needed to make very long-chain fatty acids, a group of lipids that are important for the epidermal water barrier. The deficiency of cutaneous very long-chain fatty acids and consequent abnormal water barrier in the knockout mice accounts for the ichthyosis. Although the ELOVL4 enzyme is present in the brain, the newborn mice never had any neurologic symptoms before they died.

Now fast-forward to about 1 year ago. Dr. Fowzan Alkuraya, a geneticist in

Saudi Arabia, saw a 6-year-old boy with congenital ichthyosis, mental retardation, severe seizures, and spasticity. He thought the boy might have Sjögren-Larsson



syndrome (SLS), which is also associated with ichthyosis and neurologic symptoms, so he sent us the boy's cultured skin fibroblasts for testing. Our tests ruled out SLS and we considered that he might have another similar "pseudo-SLS" disease. Because his parents were genetically-related as cousins, which greatly facilitates genetic studies, Alkuraya investigated the boy using whole exome DNA sequencing and found that he carried a mutation in the ELOVL4 gene that is destructive to the enzyme. But mutations in this particular gene were only known to cause macular dystrophy in humans - not the ichthyosis and neurologic symptoms seen in the Saudi boy. We reasoned that if the ELOVL4 mutations actually caused his symptoms, additional patients should exist elsewhere. We and Alkuraya therefore decided to look for ELOVL4 mutations among other pseudo-SLS patients who lacked a diagnosis. After screening the gene in 15 such patients, a boy in India was found to carry a different destructive ELOVL4 mutation. This child had some of the same skin and neurologic symptoms as the Saudi boy; unfortunately he died at 2 years of age from the severe neurologic disease.

For now, we know very little about ELOVL4 deficiency. Why do some mutations cause ichthyosis with severe neurologic disease,

*Continued on page 14*



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## AWARENESS...

### *An Hour of Ichthyosis on the Radio in California*

Robyn Swan gave birth to a happy, healthy  
daughter, Geordyn Lily, on June 28, 2010. Geordyn  
was born with a collodion membrane. It was  
later determined that Geordyn has congenital  
ichthyosis. Dr. Marvin Trotter of the Ukiah  
Valley Medical Center, where Geordyn was born,  
conducts a radio show on KZXY in Mendocino  
County, California. He asked Robyn and her  
mother Lynn, a physician's assistant and midwife,  
to appear on the show to discuss ichthyosis. Lynn  
is very proactive in her community and is well-known for her fundraising and  
charitable events. Robyn, who is a Registered Nurse, and her mother spent an hour  
on the radio show *Mind, Body, & Health* on a Tuesday morning in January, and did a  
truly fantastic job speaking about ichthyosis and often promoting FIRST. The Swan  
family is planning on attending the 2012 National Family Conference in Denver with  
their beautiful little girl who is the light of their lives.



*Robyn & Geordyn Swan  
with Robyn's mom, Lynn Meadows*

## Correspondence Corner



### WHAT WORKS FOR ME

I am a 67 year old female with lamellar ichthyosis. I recently heard about Asea, which is a  
liquid that contains redox resignaling molecules. I drink 4-6 ounces daily and also spray  
it on my body, then apply glycolic acid cream that was prescribed by my dermatologist.  
I have been amazed at how much thinner my skin feels. I have heard from a young  
woman whom I  
am in contact with  
that it also helps  
with eczema and  
psoriasis. The  
staff at my salon  
even noticed the  
difference in my  
skin during a  
recent manicure  
and pedicure!

I would be happy  
to talk to anyone  
interested in more  
information.

**Judy Brownlee**  
Dalton, Georgia  
[brownlee@optlink.us](mailto:brownlee@optlink.us)

**EDITOR'S NOTE:**  
*Neither FIRST, its  
Board of Directors, nor  
its Medical & Scientific  
Advisory Board endorse  
any products. Please  
consult your physician.*



**NEW & IMPROVED!**  
**30% Urea  
Moisturizer**  
for FIRST Members

Hundreds of FIRST members use Dermal Therapy's  
odor-free, non-greasy moisturizers to improve skin  
and scalp instead of expensive prescription products.

### MONEY BACK GUARANTEE

**Ask for FIRST Members' SPECIAL DISCOUNT!**

**30% Urea Moisturizer 4 oz.** ~~\$15.99~~ **\$14.99**  
(30% Urea, 10% Alpha Hydroxy)

**10% Urea Moisturizer 16 oz.** ~~\$23.99~~ **\$19.99**  
(10% Urea, 10% Alpha Hydroxy)

To order call: **(800) 668-8000** or visit  
**[www.dermaltherapy.com](http://www.dermaltherapy.com)**



## 17th Biennial Conference Registration Form

Complete this form and return it to the national office or register online at [www.firstskinfoundation.org](http://www.firstskinfoundation.org). The conference registration form and payment must be submitted to the national office by **June 1st**. Registrations without a completed form and payment will not be considered complete. *Please note: Registration does not include your hotel room. Accommodations at the Renaissance Denver Hotel must be made separately.* Cancellations received prior to June 1st will be refunded less a \$25 per person administrative fee. **No refunds issued after June 1st.**

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

### Kids' Camp

Social programs for all affected children and their siblings are an integral part of the conference. Children in the kids' camp (ages 1–12) will enjoy activities, entertainment, educational programs and refreshments while their parents participate in conference workshops and sessions. Be sure to indicate if your child will be attending the kids' camp on page 6. A licensed child care company will be hired to provide this service. A nominal fee is required so FIRST can be sure who is planning to use this service and the appropriate number of childcare providers will be hired for the safety of your children.

### Ichthyosis Genetics Study Update

At the 2010 family conference in Orlando, Dr. Keith Choate and his team from Yale University enrolled over sixty families in a gene discovery project to identify the genetic causes of ichthyosis. What a success! This year, the Yale team will be enrolling additional families in this study and following up with those already enrolled. People with ichthyosis who have never had genetic testing and those who have had genetic testing without identification of a disease causing mutation are invited to participate. Previous participants will be asked to meet with the Yale team and to provide additional clinical information.



### Program at a glance...

#### Friday, June 22

9:00-11:00 am Registration  
 9:00- 6:00 pm Clinical Screening  
 11:00-12:00 pm Opening/Welcome  
 12:00-1:00 pm Lunch  
 1:00-4:00 pm Kids' Camp (ages 1– 12)  
 1:00-2:30 pm Workshop 1 (teens/adults)  
 2:30-4:00 pm Workshop 2 (teens/adults)

#### Saturday, June 23

7:00-8:45 am Breakfast  
 8:45-12:00 pm Kids' Camp (ages 1– 12)  
 9:00-10:00 am Panel 1 Discussion  
 10:00-12:00 pm Teens Group  
 10:00-12:00 pm Workshop 3  
 12:00-1:00 pm Lunch  
 1:00-5:30 pm Kids' Camp (ages 1– 12)  
 1:00-5:30 pm Teens Offsite Field Trip  
 1:00-2:45 pm Panel 2 Discussion  
 3:00-5:30 pm Group Networking  
 6:00-10:00 pm Dinner/Dance

#### Sunday, June 24

7:00-8:45 am Breakfast  
 8:45-12:00 pm Kids' Camp (ages 1– 12)  
 9:00-11:30 am Workshop 4 (Focus groups)  
 11:30-12:00 pm Closing

[www.firstskinfoundation.org](http://www.firstskinfoundation.org)

**It's Time to Smile High  
 in the Mile High City of Denver  
 with FIRST!  
 Can't wait to see you!**



## Hotel Accommodations

The discounted room rate negotiated with the hotel is \$119 + tax flat rate. This rate is available from June 16 through June 26. All attendees must make their own reservations at the Renaissance Denver Hotel by calling toll-free 1.888.228.9290 or going to FIRST's website, [www.firstskinfoundation.org](http://www.firstskinfoundation.org) and clicking the link for our direct online hotel reservation page. To receive the discounted room rate, you must identify our group name as "Foundation for Ichthyosis." *Reservations must be received on or before 5 pm on May 22, 2012 to be guaranteed a room in the room block.* 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 at 303.399.7500.

## Driving Directions & Free Parking

Contact the Renaissance Denver Hotel at 303.399.7500 or visit their website at [www.renaissancedenver.com](http://www.renaissancedenver.com) and click on Maps & Transportation. Their street address is 3801 Quebec Street, Denver, CO 80207. Parking will be complimentary for all conference attendees. When making your room reservation be sure to mention that you are with the Foundation for Ichthyosis group. You will use your room key to get in and out of the lot and not be charged.

## Meals & Dress Code

The conference registration fee includes lunch on Friday, June 22; breakfast, lunch and dinner on Saturday, June 23; and breakfast and lunch on Sunday, June 24. All registrants are on their own for dinner on Friday evening. Conference attire is casual, including Saturday evening's dinner & family social.

## Elitch Gardens Discount Tickets

FIRST has negotiated discounted tickets for nearby Elitch Gardens Theme & Water Park located in downtown Denver, with over 60 rides and attractions, live entertainment and plenty of shopping and dining to keep you busy for hours! The discounted ticket price is \$22.99 per person (children 3 years and younger are free)! If you are interested in visiting the park while you are in Denver, tickets can be purchased on page 6 of the registration form and will be distributed to you at registration. Visit [www.ElitchGardens.com](http://www.ElitchGardens.com) for additional info or phone 303.595.4FUN.

## Complimentary Area Shuttle

The hotel offers a complimentary shuttle to Quebec Square and the Northfield Shopping Center. Area attractions and shuttle service details are available on our website at [www.firstskinfoundation.org](http://www.firstskinfoundation.org).

## Airport & Shuttle Information

Denver International Airport (DEN) is the major airport for the Denver area. The Renaissance Denver Hotel offers a complimentary shuttle to and from the airport. From the airport to the hotel, go to Baggage Claim Level 5—Westside Doors 506/Eastside Doors 511. Proceed to the third island where you will see "Hotel Shuttle" signage. When departing the hotel to return to the airport, it is recommended to make a reservation at the front desk. More detailed information is available on the Complimentary Shuttle Service Flyer on our website.

## Air Charity Network

You may be eligible for free transportation using the Air Charity Network. To find out if you are eligible for free transportation to and from the conference, please contact Air Charity Network directly at 877.621.7177.

## Teen Field Trip

Teenagers, ages 13-17, will participate in a chaperoned offsite field trip to Denver's Museum of Nature & Science/Planetarium/IMAX Theatre ([www.dmns.org](http://www.dmns.org)) on Saturday afternoon. Be sure to check the box on page 6 if you want to participate.

## Grand Rounds

FIRST will be sponsoring Dermatology Grand Rounds at Children's Hospital of Colorado on Thursday, June 21 (the day before the conference). The purpose is to teach doctors to recognize the medical signs and symptoms of the ichthyoses and understand the common psychological aspects. Doctors attending will receive Continuing Medical Education (CME) credits. A handful of individuals affected with different types of ichthyosis will be asked to participate. *If selected*, you (or you and your affected child) will sit in an exam room. Medical students/doctors from the area will come to observe your symptoms and ask questions about how the condition affects you and your daily life. It is an incredible opportunity for doctors and future doctors to see a variety of the ichthyoses in one setting and learn firsthand. If you are interested in being considered as a patient volunteer for these Grand Rounds, please check the box on page 6. The number of patients is limited, so only a few will be selected. FIRST will provide accommodations for a Thursday night stay if you are selected to participate. You will receive an email from the FIRST office if selected.

**Conference Registration Deadline—June 1, 2012**  
**Register Online at [www.firstskinfoundation.org](http://www.firstskinfoundation.org)**  
**Hotel Room Reservation Deadline—May 22, 2012**



## Contact Information

First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_

Email: \_\_\_\_\_

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



## Registrant Information (must include all names, ages, and type of ichthyosis)

First Name	Last Name	Age	Affected by Ichthyosis	Kids Camp Participant	T-Shirt Size circle 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
_____	_____	_____	<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

Please indicate which type of ichthyosis affects your family: \_\_\_\_\_

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' camp. Therefore a nominal fee will be required to ensure we have an accurate number of participants.

## Clinical Screening Appointments

Meet privately 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 on Friday, June 22, from 9:00 am - 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
_____	_____	_____	_____
_____	_____	_____	_____

If you are planning to visit **Elitch Gardens** on Friday night, please check this box so we do not schedule your appointment after 3 pm.

## FIRST Idols Talent Sign-Up (ages 5–13)

*Back for its third year! This is a popular and heart-warming event for our kids to showcase their talents to our audience. Performances will take place on Saturday evening after dinner. A CD player and microphone will be provided. Please bring your own music, costume, props, etc. All performances will be limited to a maximum of 2 minutes.*

Child's Name: \_\_\_\_\_ Age: \_\_\_\_\_ Grade: \_\_\_\_\_

Type/Description of Act: \_\_\_\_\_

\_\_\_\_\_

## Teen Field Trip Permission & Release

An organized trip has been arranged for teenagers (ages 13–17) to visit the Denver Museum of Science & Nature/ Planetarium/IMAX Theatre from 1:00–5:30 pm on Saturday, June 23. Caregivers from Corporate Kids Events will chaperone your children and they will travel to/from the museum by shuttle bus. I give permission for my son/daughter to attend this trip and understand FIRST is not liable for any incident or injury while my son/daughter is not in my care.

Teen(s) Name \_\_\_\_\_

Signature of Parent/Guardian: \_\_\_\_\_ Date: \_\_\_\_\_

## Photo & 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 2012 Family conference in which I or my family may be a part.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Payment

### Registration

1. Adults (Ages 13 and up) \_\_\_\_\_ x \$ 215.00 pp USD = \$ \_\_\_\_\_  
2. Children (Ages 1– 12) \_\_\_\_\_ x \$ 90.00 pp USD = \$ \_\_\_\_\_

### Optional Add-Ons

1. Kids Camp (Ages 1–12) \_\_\_\_\_ x \$ 10.00 pp USD = \$ \_\_\_\_\_  
2. Teen Field Trip (Ages 13–17) \_\_\_\_\_ x \$ 15.00 pp USD = \$ \_\_\_\_\_  
3. Elitch Gardens Discount Tickets\* (3 & under free) \_\_\_\_\_ x \$ 22.99 = \$ \_\_\_\_\_  
4. Donation to support the conference scholarship fund = \$ \_\_\_\_\_

**Total Payment** \$ \_\_\_\_\_



### Method of Payment

Check, payable to FIRST (in US Funds)       Credit Card: Visa, Mastercard, Discover or Amex  
Credit Card # \_\_\_\_\_ Expiration Date \_\_\_\_\_ Authorized Signature: \_\_\_\_\_

### Grand Rounds

Please check here if you are interested in participating in the Grand Rounds on Thursday, June 21. The number of patients is limited, so only a few will be selected. See more details on page 2.

\*You will receive your Elitch Gardens tickets with your registration packets. Arrangements are on your own and transportation is not provided.

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 \_\_\_\_\_





## President's Report

### Greetings to all Members and Friends of FIRST:

Educate, Inspire, and Connect; these three words were first adopted at the November 2007 board of directors retreat in Philadelphia as our organizations branded "tag-line," or guiding light.

For all stakeholders of FIRST, we eye these three words as goal posts to fuel the passion and commitment for FIRST that each of us shares. These three words serve to unite all of us around our singular mission of best serving individuals and families affected by ichthyosis. In the end, these three words explain why we do - what we do.

And how we do it is important too. Our board members, Jean, and FIRST staff are challenged to invest wisely, deliver results, make a positive difference, and leverage our investments into larger, more sustainable outcomes over time. After all, precious resources are ... well, precious!

Be assured that at FIRST, your financial support is crucial and used with direction and oversight that drives our fundamental, daily operations and multiple strategic priorities. In 2011, we focused on building greater program depth with key initiatives. We will amplify and expand on those achievements during our next planning period (2012-2014) and beyond.

Good listening and strong volunteerism underpins all of FIRST's successes. What we invest in is driven largely by what we hear members say is critically important to them and most beneficial to their membership. Further, these programs don't happen on their own, they represent substantial commitments of innumerable volunteer hours by hundreds of members and an extraordinary core of expert medical professionals to achieve.

For certain, a strong investment of time, treasure, and talent is essential to our sustainability as a premier advocacy organization. Below are a few illustrations of the type of results, impact, and leverage we have all produced by supporting each other:

- **We seek a cure.** Financial commitment, exceptional researchers, and member engagement add to create hope that new scientific knowledge in skin biology, genetic mutations, and stem cells will address key questions and provide important answers. Since 2006, our peer reviewed research grant program has motivated world class scientists to submit 34 applications for funding. FIRST has made 13 awards totaling more than \$1.4 million to explore novel approaches and new therapies to find a cure for ichthyosis. We must do more research!
- **We support young clinical researchers.** Ichthyosis is rare, with around 250 births per year. Even rarer are clinical dermatology experts that focus their research on ichthyosis. Without exceptional young clinical dermatologists focused on advancing research relevant to FIRST, we will fall further behind. In 2008, we awarded our inaugural Clinical Scholar Award to Dr. Keith Choate of Yale University. Dr. Choate's research provided free genetic testing to 85 members at the 2010 Family Conference in Orlando, Florida. His laboratory ob-

tained significant funding from the National Institutes of Health (NIH) valued at \$1.86 MM over 5 years, and his major scientific article appeared in the prestigious journal called *Science* (co-authored with mentor and colleague Dr. Leonard Milstone and other scientists at major research institutions).



- **We help our members.** Members cope best with ichthyosis through a strong support system. Ours is truly a difference maker. Since 2011, our office staff has provided much needed information and network support to 160 new contacts. Further, seven regional conferences have brought 30 dermatologists directly to 248 individuals and 118 families at a cost of ~\$160 per person. Direct interaction by skilled, knowledgeable professionals, or face-to-face engagement, has changed the lives of more than 400 people, an estimated 75% of whom are new to FIRST and its services and programs! We do not stop there. Through the Jane & Henry Bukaty Skin Care Fund, we provided 11 grants for members to purchase much-needed skin care products to vastly improve their skin condition; 42 individuals received travel scholarships to attend the 2012 Family Conference; and 7 young students became UFIRST Scholars via our partial scholarship program to attend a four year college/university of their choice.
- **We make technology work for us.** Our website undergoes constant review, and our tele-medicine program, launched in 2009, promises to link rural physicians with ichthyosis experts. We have successfully registered 60 physicians and 22 cases have been submitted and reviewed by 11 experts through tele-medicine. Not surprisingly, a smart phone "app" is being piloted in Texas as part of our involvement with the Coalition of Skin Diseases (CSD), a consortium of skin disease non-profit organizations.

Our aggregate investments and volunteerism embody each of the words **Educate, Inspire and Connect** in clear and substantive ways.

So how do we accomplish more? We must secure greater funding from a wider variety of sources, continue to invest in research, provide a stronger network of support by building leadership groups within our Ambassador Program, extend the skin care assistance program to more individuals, and use internet technology and social media in savvy ways to broadcast our story wider, promote stronger connections with members, and do so cost-effectively.

Such an aggressive agenda requires strong leadership. You will soon see evidence of our Board-level succession planning. Mike Briggs will transition to president of FIRST starting in 2013 as I complete my sixth year as president. Many of you know Mike. For those who do not, we

*Continued on page 13*

# Chief Financial Officer's Report

Fiscal Year End 09/30/11

*Dear Members and Friends:*

Well, I hope everyone has begun to see some shining light at the end of that dark, dark tunnel most of us have been looking down for much too long. From an overall standpoint, FIRST held its own financially compared to prior years, with additional tightening of the belt on expenses while continuing to maintain our level of fundraising. After much effort and involvement by the Finance Committee and the Board, we have a sound investment policy in place and are hiring an asset manager to implement it.

Looking at the numbers, like you hear me say every year, our current year Statements of Financial Position, included in this issue, illustrates Net Assets decreasing slightly by \$19,843 or 1.0% under last year. This is more attributable to decreased donations from corporations and this year's special event fundraiser rather than from the expense side. Also, even though our new investment policy won't kick into place until April, we were very fortunate that the value of our investment portfolio increased by \$7,235 or 2.0%.

On the Revenue side, we maintained the same overall revenue stream as last year, not counting restricted donations, and actually increased member donations by \$19,000 or 20.0%. Restricted donations for research were down \$97,000 but that does not necessarily denote a trend. These kinds of donations are most always driven by specific donors with specific focus on types of research. Many areas of revenue more in our control increased.

On the Operating expense side, we were able to reduce the cost of operations by over \$30,000. Spending levels also continue to be very much in line with national standards for program, fundraising, and administrative categories. Jean Pickford has done an outstanding job of balancing needs verses value, especially during the last few years. In addition, our investment in donor tracking software continues to pay off. The information it provides giving better direction on how to focus our fundraising efforts.

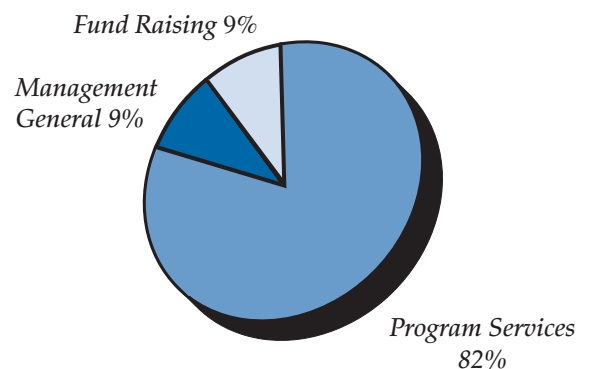
In closing, I want to thank everyone for continuing to help our fundraising efforts and I hope that you are pleased with the services we provide our stakeholders and the affected. I look forward to seeing many of you at the Family Conference in Denver this summer. Please feel comfortable in approaching me with any questions you may have regarding our finances.



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

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.			
STATEMENT OF FINANCIAL POSITION			
SEPTEMBER 30, 2011			
(WITH COMPARATIVE TOTALS FOR 2010)			
	2011	2010	
<b>ASSETS</b>			
Current			
Cash	\$ 1,279,085	\$ 1,378,260	
Investments	285,583	258,348	
Prepaid expenses and other assets	10,930	10,747	
Total current assets	1,555,598	1,647,355	
Cash, permanently restricted	70,203	70,203	
Furniture and equipment, net	7,083	10,169	
Total assets	\$ 1,632,884	\$ 1,727,727	
<b>LIABILITIES</b>			
Current			
Grants payable	\$ -	\$ 75,000	
Accounts payable and accrued expenses	4,787	4,787	
Total current liabilities	4,787	79,787	
<b>NET ASSETS</b>			
Unrestricted			
Unrestricted	778,689	800,861	
Board designated	223,947	222,049	
Total unrestricted	1,002,636	1,022,910	
Temporarily restricted	555,258	554,827	
Permanently restricted	70,203	70,203	
Total net assets	1,628,097	1,647,940	
Total liabilities and net assets	\$ 1,632,884	\$ 1,727,727	

## Fiscal Year 2011 Expense Allocation



The statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2011. 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.



# Executive Director's Report



*To all our wonderful members, family and friends,*

You may already know that FIRST is a very fortunate organization. Over 30 years ago, the founders had a vision—to create a network of affected families to help each other by providing emotional and practical support along with a network of caring physicians who would help FIRST's members as they journeyed down the medical path of treating ichthyosis.

Three decades later, those goals have been achieved and surpassed! FIRST proudly has grown to a vibrant, solvent, and well-respected patient advocacy organization in the world of skin diseases. Our membership of affected individuals and their families is who we serve. Friends, relatives, physicians, teachers, healthcare professionals, businesses, and many others are all those who care to make a difference. Our success is the direct result of the generosity of everyone who invests their time, expertise, and financial support in an organization that stewards their donations for the best possible purpose.

FIRST is governed by a 16-member Board of Directors. We are guided by a Medical & Scientific Advisory Board, comprised of 29 dermatologists, investigators and geneticists who specialize in the care, treatment and science of ichthyosis. Our exemplary leadership is all voluntary, which speaks volumes about their level of commitment and respect for FIRST.

A few months ago, the leaders of FIRST met to review our progress and determine our future steps for the next three years. We re-affirmed our mission of educating, inspiring, and connecting those touched by ichthyosis and related disorders through emotional support, information, advocacy, and research funding for better treatments and eventual cures. We also renewed our commitment to the core values that guide our business:

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

In the world of rare diseases, know that FIRST is working hard to make a difference for all those affected with ichthyosis or a related skin type. We are grateful to everyone who supports our important work. We are grateful to those who study these diseases to find a cure. We are sincerely grateful to be able to continue our mission and improve our members' lives every day.

Educate, inspire, and connect,

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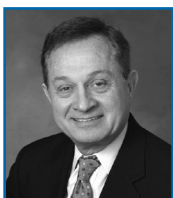
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Chris McClean  
Mr. Alan Milstone  
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Mr. Mike Nakagawa  
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Beiersdorf, Inc.  
Mrs. Sarah Dombeck Block  
Mr. and Mrs. David Bryson  
Ms. Janet Burns  
Ms. Jovita Carranza  
Mr. Etahn Cohen &  
Dr. Amy Paller  
DBG Services, LP  
Dermal Therapy Research, Inc.  
Deutsche Bank Americas  
Foundation  
Dr. and Mrs. James Stark Draper  
Mr. and Mrs. Bob Dubanski  
Dr. and Mrs. Jon Dyer  
GeneDx Inc.  
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Health & Medical  
Research Charities  
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Jed's Air Conditioning  
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Mr. and Mrs. Mark Klafter  
Mr. and Mrs. Kenneth Levitan  
Dr. and Mrs. Moise Levy  
Mr. and Mrs. Paul Licursi  
Mr. and Mrs. John McCoy  
Mr. and Mrs. Michael Miller  
Drs. Leonard and Ellen Milstone  
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Monster Dash Fun Run  
NeoStrata Company  
Northwestern University  
Phelps & Cohen  
Orthodontics Practice  
The Philadelphia Phillies  
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Night Out  
William Rizzo MD  
Mr. and Mrs. Charles Schaffer  
Ms. Ramona Schiller  
Mr. John Schoendorf  
Mr. and Mrs. Aaron Scholl  
Mrs. Janet Showers-Patterson  
& Mr. Day Lewis Patterson  
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Dr. Mary Williams &  
Dr. Peter Elias  
Ms. Edie Wohlgang  
Yale University  
Ms. Denise Yong  
Dr. and Mrs. Ruey Yu

#### \$5000 - \$9999

Mr. Qazi Fazal  
Find A Cure  
General Motors Foundation  
Mr. and Mrs. Alex Howard  
Madison Hoffman Foundation  
Stiefel, A GSK Company  
Dr. and Mrs. Eugene Van Scott

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

Accurate Imaging  
Mr. and Mrs. Michael Briggs  
The Gaffney Foundation  
Mr. and Mrs. Jeffrey Hoerle  
Merz Pharmaceuticals LLC  
Ms. Laura Phillips  
Dr. and Mrs. David Scholl  
UPS Foundation

#### \$100,000 +

Lennox Foundation

*Thank you to all our generous donors.*

## PRESIDENT'S REPORT *Continued from page 7*

could not have found a more passionate, competent, and generous individual with his time and resources to lead FIRST. Mike, congratulations on assuming this leadership position; thank you!

I wish to close this year's letter with a story that reflects well on why what we do matters.

Called *The Story of Emma Klima and Bassett Elementary School*, you will read later in this issue about the wonderful staff and students at Bassett Elementary school. You will be left inspired by how Bassett Elementary School planned a month-long awareness and fundraising campaign for FIRST, by the generous commitment of school staff and parents alike with their time, talents, and resources, and how they ultimately connected FIRST to Westlake, Ohio, a very generous and caring community. Imagine my distinct pleasure of attending their school assembly on Valentine's Day, seeing the excitement of over 300 students from K-4 celebrating their hard work at fundraising, and recognizing Emma with huge cheers for over 20 minutes.

All of the activities at Bassett Elementary School created a sense of love and caring that was quite powerful. This type of story is "told" repeatedly throughout the year by so many dedicated and active members. *Emma's Story* is a great example of how FIRST transforms ideas into a vision, weaves a broader dream of what can be for our members, and educates, inspires and connects skillful participation and support from all stakeholders that will take those dreams and make them real.

Please keep FIRST uppermost in your mind – as the premier advocacy group for those affected by ichthyosis. And see you soon in Denver. We have an awesome set of events planned for you!

*Dave*



# 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.

## Horseshoe Tournament & Barbeque in New Jersey

**Kasey Williams**, of Audubon, New Jersey once again planned a benefit in honor of her nephew **Chad**, who is affected with x-linked ichthyosis and additional medical conditions. For the 3rd year, Barrington Rod n Reel in Barrington, New Jersey hosted this event which took place on Saturday, August 6. While attendance may have been a little lower than in years past, the enthusiasm and fun were unmatched! With a live performance by the band, *Virtigo*, participants also enjoyed a horseshoe tournament, games, a water slide, raffles, and great food. FIRST was one of the recipients of the funds raised. Kasey is enthusiastic about continuing this event next year.



*Kasey Williams*

## Zumba Classes in Florida

**Cara Tundidor** is the mother of 6-year-old **Teo**, who is affected with CIE. Cara has participated in FIRST's Phantom Tea events throughout recent years and was ready to move to the next level. Since Cara is a Zumba instructor, the logical idea for her was to hold a Zumba party as a fundraiser. She recruited international Zumba superstars George Iu and Peter Wang from China, who were on a US tour, to lead the fun. Tickets were sold, items were donated for a silent auction, and area businesses were asked to sponsor the event. The class, which was held in January was a tremendous success! 147 participants were groovin' to the music, having fun, getting fit, and helping raise awareness about ichthyosis! More than \$2,000 was raised to benefit the efforts of FIRST. Many thanks to Cara and her husband, Teofilo, her mother Carla, and sister Amber for their hard work on our behalf.



*Teo and Cara  
address the crowd*



*George Iu and Peter Wang with Teofilo*

## Volunteering Creates Cash for FIRST

**Quinn DeLoughary** is a 31 year old member of FIRST affected with lamellar ichthyosis. Quinn currently works for Dell and participated in a unique program that they offer. Dell initiated a "Make a Difference" program where if an employee volunteers more than 10 hours per quarter, the volunteer time is documented and then Dell sends a donation of \$150 to the charity of the employee's choice. Quinn volunteers regularly at her local animal shelter. Quinn then logs her volunteer time into an online portal run by YourCause LLC, which then forwards the donation to the charity of Quinn's choice, in this case, FIRST.

### **ELOVL4 Deficiency: A New Form of Ichthyosis Discovered by Next-Generation DNA Sequencing** *Continued from page 1*

whereas other mutations only cause childhood blindness? Neither boy had macular dystrophy, but they may have been too young to show it. However, this genetic defect raises the potential for treating the ichthyosis with topical application of very long-chain fatty acids (and related lipids) and lends an urgency to identifying additional ELOVL4-deficient patients.

The discovery of ELOVL4 deficiency as a new form of ichthyosis is a testament to the power of next generation DNA sequencing and the collaborative efforts of researchers worldwide (who, in the case of ELOVL4 deficiency by the way, have yet to meet each other!). Even more remarkable is that the discovery involved a *single affected patient* - not a family with many affected members, as previously required for gene identification. Like ELOVL4 deficiency, we can expect that additional new forms of ichthyosis will be revealed in the near future as next generation DNA sequencing is applied to more and more patients. These DNA advances will undoubtedly lead to more specific and effective therapies for many patients with ichthyosis, which should be a cause for hope and anticipation.



# Grassroots Fundraising

## A Marathon Run in Singapore

**Durreen Shahnaz**, of Singapore, is the mother of 6-year-old **Aliya**, who is affected with CIE. Durreen runs regularly, but is not an avid marathoner. However, she decided to participate in races as a way to raise money for FIRST. Ms. Shahnaz participated in a race in August, and this past December, participated in the Standard Chartered Marathon Singapore 2011 half marathon. More than 14,000 runners participated in this event. Durreen thinks of running as a form of meditation, so this was a perfect way to combine something she loves with helping the Foundation. She advertised her run on her facebook page to secure help from her family and friends. Durreen's efforts raised \$10,000 for the Foundation. FIRST is very appreciative to Durreen and her friends and family for their efforts.



*Durreen crossing the finish line*

## Jeans Day in Indianapolis

The last Friday of every month, **Crowe Horwath** holds a Jeans Day in their Indianapolis office. The goal is two-fold - to provide an opportunity for a more relaxed work environment once a month and to support a local charity or a charity of choice from an employee. When the practice began a couple of years ago, the charity was selected by the office manager to support a local community charity. This year, it was opened up to employees to provide suggested foundations. Last summer, **Aaron Scholl** provided his suggestion of FIRST and provided information about the Foundation and how his family is involved and affected. Aaron's niece, **Payton**, is 8 years old and affected with CIE. Aaron is the son of FIRST President, Dave Scholl. FIRST was then selected as the January jeans day charity. For a \$5 donation, an employee can wear jeans for the day. The employees at Crowe Horwath raised more than \$200.



*Bassett Elementary School presents their donation to FIRST President Dave Scholl. Pictured with Dave is the Klima family.*

## Elementary Community Joins Together in Ohio

**Mark and Lisa Klima**, of Westlake, Ohio, are the parents of adorable 7-year-old **Emma**, who is affected with epidermolytic ichthyosis (formerly called epidermolytic hyperkeratosis.) Emma is lucky enough to go to school at Bassett Elementary School. The dedicated faculty and wonderful families of Bassett organized a series of fundraisers in honor of Emma and designated FIRST as the recipient. Last November, the Bassett faculty organized an evening at Applebee's Restaurant. Friends and family members of the Klima family turned out on a cold fall evening to enjoy great food and friends. Applebee's donated a portion of the evening's receipts to FIRST, generating more than \$470 for the Foundation.



*Emma with her teacher Miss Leah Burke*

More recently, the entire Bassett Elementary community, where Emma is in 2nd grade, participated in a week-long awareness and fund raising campaign for FIRST. Each year the school, headed by Principal Ben Hodge and counselor Sandee Erdman, holds a Family Game Night event and chooses a worthwhile cause to receive the money raised. This year FIRST was selected. The school held a month of activities leading up to Family Game Night on February 10. There was an assembly for the students, featuring a slideshow presentation, which provided information about ichthyosis and FIRST. One family that owns a local crafting store donated beads that were then available for purchase. Many teachers baked tasty treats for a bake sale. Snacks, drinks, and raffle items were donated by area merchants. These efforts raised more than \$4,300 for FIRST! After the game night, the school held an assembly and showed a slide show presentation of photos from the evening and presented a check to FIRST president, Dave Scholl. The Foundation greatly appreciates the hard work of all of the staff, students, and parent volunteers on our behalf.



*Emma draws a winning name in the raffle as Mrs. Erdman and Mr. Hodge look on*





## UPCOMING EVENTS

It is great to have the chance to meet other families affected by ichthyosis, and to not have to travel far to do so! Thank you to the following FIRST members for offering to host a local casual event.

### APRIL 21, 2012

A gathering in Piscataway, NJ from 1:00 PM to 3:30 PM.

Hosted by Suzanne Getz

RSVP directly to Suzanne by email at [segetz01@aol.com](mailto:segetz01@aol.com)  
or by calling 732.463.8103.

### JUNE 30, 2012

Members Jennifer See, Erin Edwards and Ellen Clemmer will be hosting a pot luck afternoon in Raleigh, NC from 12-5:00 PM.

RSVP to Jennifer See by email [jennifersee@briansee.com](mailto:jennifersee@briansee.com)  
or by phone at 804.716.2696.



The Foundation proudly announces that *Dennis Roop, PhD* will be the honoree at an event to be held on Thursday, June 21, 2012, the eve of the National Family Conference at the Denver Country Club. Dr. Roop has been affiliated with the University of Colorado for the past five years and has made significant advances with his research on epidermolytic

ichthyosis. The entire university community is enthusiastically supporting Dr. Roop and this evening promises to be a deserving tribute to him.

## FIRST *Night at the Ballpark!*



### MONDAY, MAY 7, 2012

Citizens Bank Park • Philadelphia, PA

[www.phillies.com/first](http://www.phillies.com/first)

*Deadline for tickets is April 9, 2012*



### WEDNESDAY, MAY 30, 2012

Citifield • New York, NY

[www.mets.com/first](http://www.mets.com/first)

Visit FIRST's website at [firstskinfoundation.org](http://firstskinfoundation.org)  
or call the office at 215.997.9400 for details.