

Ichthyosis Focus



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

Summer 2007

A School Survival Guide for Parents of Children with Ichthyosis

Stephen G. Pickford, Assistant Principal, Sandy Run Middle School

Summer is almost over, and it is time to start thinking about the upcoming school year. If you are a parent with a child who has ichthyosis, there are many things to consider ensuring a successful school year for your child. If your child will be entering a school system for the first time this fall, these thoughts can be quite confusing and downright intimidating. This article will offer some suggestions on how to set your child up for success at school this year, whether it is your first foray into the educational system or your child is already attending school.

As a parent, you already know the strengths and weaknesses of your child when it comes to his or her readiness for attending school for the first time. If your child has previously been enrolled in a school system, you have celebrated your child's successes and wondered how to help with his or her areas of weakness. There are some practical steps you can take that apply to both situations.

Ichthyosis affects each individual differently. Depending on the severity of the symptoms exhibited by an individual, this may or may not have an effect on the child's ability to perform at a level consistent with his or her age group peers. If a child does exhibit some developmental delays in cognitive functioning because of how the disease has affected his or her physical and/or mental growth, these are warning signs the child will need some special accommodations in a school setting. If the child is progressing with his or her age-appropriate peers, other accommodations can be made in terms of the health issues surrounding the treatment of his or her particular variety of ichthyosis.

Communicate with teachers regarding involvement in the educational progress; such as special equipment, medication, medical problems, activities or events that might affect performance, student work and grades. Ask how to support or build upon school activities and learning at home. Volunteer to help in the classroom or school, and encouraging behavior that leads to success at school because success at school for your child is the bottom line. It is also a good idea to schedule a meeting with the principal, guidance counselor, and nurse prior to the beginning of school. Discuss your child's special interests and skills, medical treatments and privacy during school hours, the side effects from medicines and or treatments, transportation issues, what your child excels at, strengths and weaknesses,

seating arrangements, and other issues you feel are important to the success of your child at school.

Decide beforehand how to handle intrusive questions or ridicule. Do you want to present the information about ichthyosis to the class on the first day of school? How will this be handled? Who will be responsible for the special accommodations regarding overheating, medicines, and other issues? Your child may need some other special accommodations outside of the normal school rules. Clothing issues may arise from hats or sunglasses needed by your child that violate dress codes. Your child may require seating in cushioned chairs or seats away from windows and/or bright areas. Outdoor play and overheating should be discussed. Also frequent water breaks, sunscreen, cooling vests, temperature maximums and other restrictions for physical education participation without total exclusion from everyday school activities should also be reviewed prior to the start of the school year.

These special accommodations can sometimes be provided under section 504 of the Rehabilitation Act of 1973. Section 504 makes it illegal for any group receiving federal money to be unfair to a person with a disability. It applies to any school that receives federal money. Section 504 is a civil rights law, which prohibits discrimination against individuals with disabilities. Section 504 ensures that the child with a disability has equal access to an education. The child may receive accommodations and modifications. Unlike IDEA, Section 504 does not require the school to provide an individualized educational program (IEP) that is designed to meet the child's unique needs and provides the child with educational benefit. Fewer procedural safeguards are available for disabled children and their parents under Section 504 than under IDEA.

Continued on page 10

Designate Funds Through



Combined Federal Campaign

or



Giving Programs
See page 3 for details

Correspondence Corner

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

Recently, our 3-year-old son with lamellar ichthyosis, Mason Shaw, was hospitalized for an extended period of time. He had major surgery and needed IV's and PICC lines in both arms. He typically spends a lot of time soaking in a tub at home and could no longer do so for almost 2 months. The children's hospital brought us a variety of new creams to try. We loved them for Mason! Especially with his skin being extra dry and flaky from the lack of moisture from bathing!

We were given Sween 24, Sween Cream, Sween Baza Protect, Sween Actrac-Tain lotion, and Sween Xtra Care Lotion. We used them all for different reasons and on different parts of his skin. The lotion is a great moisturizer for areas like his face and scalp. It's not as thick and greasy feeling. We had to use it more frequently on other parts of his skin. The Sween Cream is thicker and is great for his whole body. His torso is his worst spot, so we would compound the cream and the Sween 24 for that area. We used the Actrac-Tain once a day in place of the others. It contains urea and really helped his skin soften to exfoliate and wipe away even during just a sponge bath! The Baza Protect is more of a diaper cream and has really helped his sore bottom! We actually mostly use it around his g-tube site. (His feeding tube that is a button coming from his tummy!)

These creams have really helped Mason stay comfortable through all of his hospital time, and we continue to use them now that he is home and still unable to bathe. Our home health agency even provides these creams with a prescription from his doctor!

Sincerely,
Kerry Shaw



Visit the Sween store at www.sweenstore.com to shop for the many products Sween offers.

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Grassroots



“Release the Butterfly”

Nancy Osentoski has raised nearly \$2,000 for F.I.R.S.T. with the “Release the Butterfly” campaign. Nancy, who was diagnosed at birth with lamellar ichthyosis, persuaded local store and restaurant owners to participate in this campaign. Nancy spent more than 8 hours of her day at each store, fundraising and creating awareness. In addition to the “Release the Butterfly” campaign, Nancy placed collection jars with information about ichthyosis throughout many stores. Nancy dedicated over 100 hours to her campaign. Way to go Nancy!

Nancy Osentoski at one of the many “Release the Butterfly” events

Donate through the United Way or Combined Federal Campaign Programs



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

The United Way of America is the national organization dedicated to leading the United Way movement in making a measurable impact in every community across America. The United Way movement includes approximately 1,400 community-based United Way organizations. Each is independent, separately incorporated, and governed by local volunteers. The Foundation for Ichthyosis is the recipient of funds from many of the United Way community-based organizations. Through the Donor Choice Program, you can designate all or a portion of your donation to the Foundation. Simply write in “Foundation for Ichthyosis & Related Skin Types” on the Donor Choice Option form, and your gift will be sent to our office. Be sure to include our mailing address and phone number, 1364 Welsh Road, Suite G2, North Wales, PA 19454, 215-619-0670. The Combined Federal Campaign (CFC) is the annual fund-raising drive conducted by federal employees in their workplace each fall. Federal employees and military personnel raise millions of dollars each year through the CFC to benefit thousands of non-profit charities. The Foundation is the recipient of funds from many CFC organizations throughout the country. The Foundation's CFC code is 10322, which is listed in the charitable organizations directory.

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

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Grassroots

2nd Annual 'Bid For A Cure' Raises Over \$50,000

Congratulations to Mark and Kelly Klafter on the success of "Bid For A Cure." With the endless love and support of family and friends, hundreds of items for both live and silent auctions were secured. Artwork, sports memorabilia, rounds of golf, spa packages, and home décor were just some of the items that were up for bid.

Local restaurants graciously donated food and beverages in addition to local businesses and companies donating auction items. The Klafers dedication and efforts raised over \$50,000, which will be used to support the research of EHK.

Researcher Dennis Roop, Ph.D. attended the fantastic auction and evening. Dr. Roop was a grant award recipient from F.I.R.S.T. for his project, "Testing Therapeutic Approached for Epidermolytic Hyperkeratosis Using a Preclinical Mouse Model." While visiting the Klafers, in Atlanta, GA, Dr. Roop had the opportunity to meet Adam, the Klafter's five year old son who is affected with EHK.



Pictured, L-R, Dr. Dennis Roop, Jean Pickford, Mark and Kelly Klafter, Carol and Steve Klafter.



Dr. Dennis Roop, speaks to the audience at "Bid For A Cure"



Bid for the Cure Committee Members L-R, MJ Jelleme, Gwen Levit, Kelly, Maizy Tenner, Victoria Carter

Jane Bukaty Membership Assistance Fund

The Foundation is now accepting applications to the Jane Bukaty Membership Assistance Fund for the next review period, which will end in December.

F.I.R.S.T. realizes that the fight against ichthyosis is not only a medical one but a financial one as well. As families of affected individuals maintain their daily routine of treatments, it can be complicated by the ongoing costs of medical supplies and other comforting aids and procedures. This is an opportunity to alleviate some of the financial burden that may be facing you or your family.

Awards will generally not exceed \$100.00. Applications will be awarded two times per year as determined by the Support Network & Member Assistance Committee. Applicants will be eligible to receive one award every two years.

Email a request for an application form to info@scalyskin.org, or call 1-800-545-3286. Completed forms may be mailed to the attention of the Jane Bukaty Membership Assistance Fund, 1364 Welsh Road, Suite G2, North Wales, PA 19454. **The deadline for applications is October 31, 2007.** The awards will be given in December 2007.

Donations to the Jane Bukaty Membership Assistance Fund are always appreciated and enable F.I.R.S.T. to make this fund available to more of our members.



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Dear Doctor...

We are pleased to introduce Dear Doctor. This new column features questions by our members answered by a doctor on our Medical and Scientific Advisory Board

What is Sjögren-Larsson syndrome (SLS)?

SLS is a form of ichthyosis associated with other symptoms involving the brain and nervous system. Patients are usually born with evidence of ichthyosis, but they soon show developmental delay in the first year or two of life, especially in their motor abilities such as sitting up or walking. Speech is often delayed or indistinct, and retinal (eye) abnormalities are frequently present. Some children have seizures. Unlike most other forms of ichthyosis, many SLS children are bothered by severe itchiness of their skin.

SLS is caused by alterations (mutations) in the gene for an enzyme (fatty aldehyde dehydrogenase) that is necessary for metabolism of certain unusual fats (lipids) called fatty aldehyde and fatty alcohol. It is thought that the symptoms of SLS are a direct result of accumulation of these unusual lipids in the body or possibly due to an inability to produce other lipid metabolites that are normally made by the enzyme.

How exactly is SLS diagnosed? Is there a definitive test? Will a skin biopsy give a more accurate diagnosis?

SLS is diagnosed by testing for the deficient enzyme in cultured skin fibroblasts grown from a skin biopsy or by finding mutations in the SLS gene, which can be done on a DNA sample from blood. Only about 50% of children with the typical symptoms of SLS (ichthyosis, developmental delay and spasticity) turn out to have the disease when tested. The rest have other forms of ichthyosis-some with unknown diseases. In general, the skin biopsy is not very helpful in diagnosing SLS, whereas enzyme testing and DNA analysis are definitive.

My child is scheduled for a CAT scan. What exactly will that tell them?

A CAT scan of the brain may indicate whether anatomical abnormalities are present. Kids with SLS usually have abnormalities of the lipid-rich myelin that covers the nerves and acts like an insulator to help conduct electrical impulses. This myelin defect is much better detected with MRI scans than with a CAT scan, so I do not recommend CAT scans if the primary question is SLS. Abnormal lipid accumulation in the brain can also be seen with a specialized MRI scan called MR spectroscopy.

What is the treatment for SLS?

There is no really effective treatment for SLS. The skin can respond to the usual topical lotions and keratolytic agents, but the neurologic symptoms have no specific therapy. Walking ability can often benefit from surgical procedures that improve the spasticity. The itchiness of some patients may respond to a drug called zileuton (Zyflo), but this drug is not approved by the FDA for use in children.

Currently, my child has mobility in his arms and legs; what is the likelihood of future neurological or motor inability?

This is difficult to predict for any one patient. Most children with SLS have spastic diplegia (resembles cerebral palsy) that results in impaired walking. Some children never walk, but most do walk with assistance (crutches, walkers, etc). Others with mild spasticity are able to walk independently.

Should my child see an ophthalmologist to detect early retinal abnormalities?

In some SLS children, an ophthalmologist can detect abnormalities in the retina (the part of the eye that detects vision) called "glistening white dots," which are relatively specific for this disease. The retinal findings of SLS are usually seen after about 1-2 years of age. Blindness does not occur in SLS, but slight visual impairment requiring glasses is often present. More frequent is photophobia.

My baby is six months old. Should she be on any special fat-modified diet to help with her disease?

Our experience is that the diet has no consistent effect on SLS. However, there are several reports in the medical literature of variable improvement of the skin using diets supplemented with medium-chain fatty acids, but we saw no effect of this when we studied 5 children. Nor is it clear whether special diets that limit consumption of the lipids that cannot be metabolized in SLS children are beneficial. Clearly, more research is needed on the therapeutic effects of dietary modification in this disease.

My husband and I are thinking about having additional children. What is the risk that my future children will be affected with SLS?

There is a 25% chance that future children will be affected with SLS. This risk is identical for each future pregnancy and is not reduced because you already have one SLS child. Prenatal diagnosis can be done to detect an affected fetus using DNA or enzyme tests done in the first or second trimester.

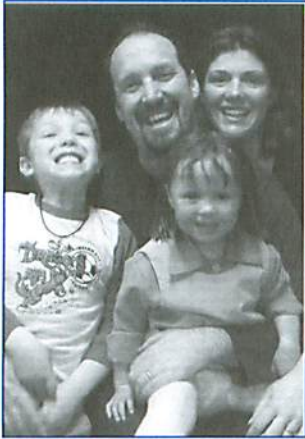
Dear Doctor has been answered by Dr. William Rizzo. Dr. Rizzo is a member of F.I.R.S.T.'s Medical and Scientific Advisory Board. He practices at the Department of Pediatrics at the University of Nebraska Medical Center in Omaha, Nebraska.

If you have a question for our next Dear Doctor send your question to info@scalyskin.org or mail to F.I.R.S.T., 1364 Welsh Rd, Suite G2, North Wales, PA, 19454.

Spotlight On

“A Lion’s Pride”

Written by Sarah Hodgkinson



Our family lives in Woodstock, Ontario, Canada, in a house that was built in 1885. Although we have not lived in our house the longest, we like to believe that we have loved here the most.

Craig and I will be celebrating our eleventh wedding anniversary this August. All good things seem to happen to us in August. Our children, Matthew and Ema, were both born in August. Matthew was born on August 2, 2001, and Ema was born on August 22, 2004. Their birthdays reveal two things—firstly, my husband and I are both teachers, thus our propensity to plan events based on school holidays and, secondly, we are both the proud parents of two beautiful Leos.

For those of you who are not familiar with the qualities of the different astrological signs, allow me to explain a few characteristics of the Leo, the lion of the zodiac symbols.

It is said they are born leaders, and they know it. They are blessed with many talents and a destiny for greatness. They are generally optimistic and cheerful. If something gets in their way, they conquer it, the way a lion will defeat virtually any foe in the jungle. And like the lion, they do so

with dignity (taken from www.Astrology-Love-Horoscope.com).

Matthew and Ema are Leos. They're lions. Or cubs, if you will.

When Ema came home from the hospital, Matthew insisted that he had to give her a present—a small, stuffed lion.

Matthew has demonstrated an instinctively protective nature with Ema. He immediately informs others that she is his little sister and that she's two and three quarter years old. He'll hold her hand, help her brush her teeth and even escort her to bed after reading her a book. Unfortunately, Matthew's protective nature with his little sister does not end there. He is also protective of his toys. She knows this, counts on this, and sees this as his weakness. For example, after Matthew is delivered to kindergarten each morning, she "pounces". Ema seizes this, opportunity to make Matthew's toys her own. She rides his Big Wheel, reads his books, plays with his Lego, and so on. On a number of occasions, Toy Story's Woody has been transformed into a baby doll and strapped into a stroller for walks throughout the house. Upon Matthew's return, great battles have ensued over the ownership rights of Woody. In Ema's eyes, possession is nine-tenths the law and is made binding by roaring, "It's very, very mine!" The perpetual gnashing of teeth and slashing of claws could not be properly resolved until a Jessie doll was finally purchased for Ema on e-bay.

The one characteristic that we are hoping to see develop further in our children is generosity—a trait that Leos are traditionally known for. They both prefer to have the "lion's share" of toys. In an effort to give back to a few organizations that have helped our family in the last few years, I established a charity to raise money for our local children's hospitals through a nation-wide scrapbooking event planned for this October, www.csc4k.com. In a discussion with Matthew about the concept of being "charitable", I mentioned that there were many children at the hospital that would love to play with some of the toys that he no longer wants. His response was, "Don't worry about them, Mom. Santa knows where to find them." Ema also keeps a tight inventory on her belongings. She frequently hides them under her bed, in kitchen cupboards, and even in the refrigerator, so that her big brother can't get his "paws" on them.

Matthew and Ema's "lion-like" behavior can also be seen in their interaction with other, visiting children. Much like the timid antelope that wander through the savannah, many children flee to the shelter of their parents when faced with the energy and charisma of our two cubs. Matthew and Ema are very social. They play hard, love to dress-up, hoot and holler, explore, make things, and have a fun time. Inside or outside, they skip, run, and jump, pausing only for snacks and the inconvenience of lunch or dinner. They also sleep close to twelve hours each night, a solitude that is abruptly halted by seven o'clock wake-up calls of hard cover children's books knocking on our heads. Of course, they are now recharged.

Continued on page 7

Conference Chatter

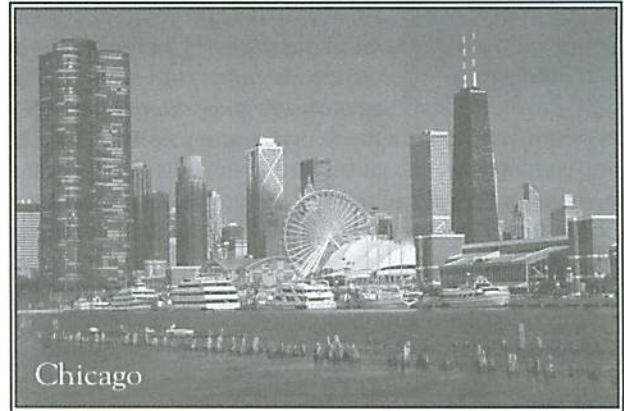
2008 National Family Conference June 26-27-28, 2008

Windy City here we come! Mark your calendar for *Friday, June 26, Saturday, June 27 and Sunday, June 28, 2008*. The Family Conference will be held at the **Chicago Marriott O'Hare in Chicago, Illinois**. The hotel is located minutes from the airport, making your travel easy and convenient. Downtown Chicago is only 15 miles away and can be easily reached using El-train service which is located just one block from the hotel. The hotel has a beautiful connecting indoor and outdoor pool for families to enjoy pool side time.

Past-conference attendees know first-hand how much is gained from meeting with other families and talking with knowledgeable dermatologists. That is why we see so many of you return to each conference year after year. If you have never experienced a family conference, this is your chance! Since the conference is one year away, you will have plenty of time to make plans to attend!

The 2008 Family Conference is currently being planned and is guaranteed to be a great event for everyone in attendance. Conference details will be published in the Fall 2007 Newsletter as well as on the website. The 2008 Family Conference will allow more opportunity to attend workshops and network with other families. The children will be able to attend kid's camp while the tweens and teens have a great few days to learn, network, and tour the fabulous Chicago sights.

New this year! A scholarship fund will be available for families to apply for financial assistance to attend the Chicago conference. The *Family Conference Scholarship Fund*, funded by the Jean Giroux Charitable Trust, will provide funds for registration, travel, and accommodations. Funding is limited; all applications will be evaluated based on scholarship guidelines. A scholarship application can be found on page 12. A scholarship application can also be accessed at www.sealyskin.org or by calling the office at 1-800-545-3286.



Jean Pickford meets with F.I.R.S.T. member and Chicago resident Frank Osowski during a visit to Chicago.

Spotlight on "A Lion's Pride" *Continued from page 6*



The Hodgkinson Cubs, Mathew and Emma

It's also said that Leos know they will reach the top, it's just a question of when. Along the way, they are organized, frank and out-spoken, qualities which focus on their target of being a leader. Nothing could be more true of our youngest, Ema. While turning only three this summer, she feels that she is ready for school. Each morning, she routinely packs toys and snacks in her Dora the Explorer backpack, eagerly anticipating our walk to Matthew's school. Upon our arrival, she graciously greets several of her fans (various mothers, fathers and grandparents that are dropping off their loved ones), shows off her outfit-of-the-day ("Peoples like Ema's shoes!"), and then leads a line of marching children across the field and through the playground equipment, while waiting for the bell to ring. The only reason she does not cause a scene each day when she is not allowed into the school is the knowledge that Matthew's toys are laying unprotected back at the den.

Both of our children are intelligent, compassionate, strong-willed, and happy. It stands to reason that Matthew and Ema are the pride of our family. They are, after all, our beautiful lion cubs.

Ema just happens to have been born with ichthyosis.

Executive Director's Report



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

Each spring, I travel to Washington, DC to meet with colleagues from the Skin Disease Coalition (CSD) and to speak with our congressmen and senators about skin disease research. I was also hoping to see the famous cherry blossoms in bloom that surround the capitol but wasn't so lucky. The first item on my agenda was to participate in a development day with

leaders from various patient advocacy groups, like F.I.R.S.T. We spent quality time discussing how we can improve our visibility among the dermatologists at the annual meeting and throughout the year. A solid strategy was developed and action items were equally divided among the advocacy groups.

A great benefit to this development day is the opportunity to learn and share ideas with other skin group directors. It is interesting and valuable to hear what other groups do to fundraise, develop strong boards, and support their



Jean Pickford meets with colleagues from the Coalition of Skin Disease.

patients. I am always so proud to share our successes with them and hope they gain as much as I do from our conversations.

The second agenda item was to meet with our congressmen and senators on Capitol Hill. Collectively, the American Academy of Dermatology Association (AADA), the Coalition for Skin Diseases (CSD), and the Society for Investigative Dermatology (SID), urged Congress to provide a 6.7 percent increase to the National Institutes of Health (NIH) for fiscal year 2008 and to all institutes that have skin disease research portfolios.



Outside the Capital building, Washington, DC, during Skin Disease Research Day 2007. Picture L-R, Rick Megargell, CSD Patient Advocate, Luis Garza, MD, Jennifer Motil, MD, Angela Godby F.I.R.S.T board member, and Jean Pickford



Jean Pickford with Diane Baker, MD, President of the American Academy of Dermatology

The Burden of Skin Disease

Skin disease is one of the top 15 groups of medical conditions that showed dramatic increases on both prevalence and health care costs between 1987 and 2000. Despite this fact, no data on skin disease has been compiled since 1979. In order to close the gap, the American Academy of Dermatology Association and the SID co-sponsored a study, "The Burden of Skin Disease".

The report shed light on the impact that skin disease has on the United States population. Prevalence, economic burden and quality-of-life figures reveal aspects of the tangible burden. There are also intangible dimensions of the burden of skin disease that arise from the visible nature of many of the diseases. Skin conditions affect an individual's ability to interact with others and compromise the self-confidence of those inflicted. The following are some facts from the Burden Report about skin disease.

- At any given time, one in three people suffers from a skin disease.
- There are approximately 3,000 diseases that affect the skin.
- Skin diseases cost our nation approximately \$39 billion dollars each year, including medical costs and the costs associated with lost productivity.
- Over 65 million Americans see physicians annually due to skin conditions, including skin cancer. Skin disease is responsible for a significant portion of all occupational disease claims.

Continued on page 9

Executive Director's Report

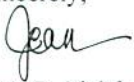
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Easing the Burden: Investment in skin disease research has improved the health of Americans

The NIH has played an instrumental role in the revolution of cell biology, genetics, immunology, information, and laser technologies that provide unprecedented opportunities for achieving advances in basic research and medical treatment for conditions of the skin. The research pipeline must continue to be funded in order to gain an understanding of the underlying causes of skin disease to ease the burden of the millions of Americans suffering from skin diseases.

In closing, I also encourage each of you to contact your local congressmen and senators to help us in our efforts. The Foundation hosts an advocacy page on our website to help guide you through this process. Please take a moment to visit the page at www.scalyskin.org and click on "Advocacy" in the top box on the upper left hand corner. Learn how you can get involved! If you have any questions, please contact me directly at 215.619.0670 or email me at jpickford@scalyskin.org.

Sincerely,



Jean R. Pickford
Executive Director

Advocacy for F.I.R.S.T.



The Foundation's Advocacy Committee has been mapping out a focused plan to make ichthyosis more known in Congress. The first initiative is to educate congressmen about ichthyosis and let them know that constituents in their districts are affected by the disease and more research funding is needed.

What is Advocacy? Advocacy is the act of pleading or arguing in favor of something, such as a cause, idea, or policy; active support.

- Increasing ichthyosis awareness
- Increasing medical research funding
- Working toward improved treatments, genetic testing abilities and a cure

Who do we want to contact? Contact the members of the U.S. House of Representatives and your two U.S. Senators. To access this information for your specific location, visit: House of Representatives at www.house.gov
United States Senate at www.senate.gov

How should I contact them? You can email your member by visiting www.house.gov/writerep. Other ways are:

- Sending a faxed letter (regular mail may be slow)
- Setting up a personal meeting
- Talking over the telephone
- Submitting written testimony to the House Appropriations Committee on Labor, Health and Human Services

What do we want to ask for?

- Ask to support increased funding for medical research at the National Institutes of Health

- Encourage NIH to increase skin disease research, specifically, ichthyosis research

When do we do this? Now is the time to get to know your member and staff. The Budget process takes place during February 1-April 15 and the Appropriations process typically works like this:

- February -May: Hearings and discussion
- May -September: Real numbers come out
- Oct. 1: Beginning of new fiscal year

Where does all this take place? If you are in Washington, D.C., you can make an appointment to visit your members' office on Capitol Hill. If not, you can meet with your member and/or their staff at their local district offices in your area.

Here are the basics when contacting a Congressional member:

- Introduction-state your name and address, reinforce that you are a voting constituent
- Be prompt, be quick, and be prepared
- Clearly state the "ask" which is an increase in medical research funding
- Personalize your story
- Bring visuals (pictures of those affected with as well as the ichthyosis fact sheet)
- Follow up

A printable fact sheet on ichthyosis and a sample letter written to Congress are available (on the website at www.scalyskin.org or) from the F.I.R.S.T. office, either email info@scalyskin.org or call 1-800-545-3286. Please contact the Foundation's national office if you have any questions, or are planning to contact your congressional member on behalf of increased ichthyosis research.

A School Survival Guide for Parents of Children with Ichthyosis

Continued from page 1

If you believe your child will need some academic accommodations in school, schedule a meeting with the school guidance counselor and principal prior to the beginning of the school year. Find out about the special services and programs your school district offers to individuals with special needs. Learn more about the Individuals with Disabilities Education Act (IDEA). This federal law gives your child the right to receive special accommodations in an academic setting. This is instruction specially designed to meet the unique needs of children with disabilities. Over five million children ages six to 21 receive special education and related services each year in the U.S. at no cost to parents. IDEA was designed to meet the child's unique needs that result from having a disability and to help the child learn the information and skills that other children are learning.

How do you know if your child is eligible for special services? IDEA provides a definition of a child with a disability. The disability must affect the child's educational performance. The child must fit into one of the 13 disability categories established by IDEA, and the disability must cause the child to need special education and related services.

The 13 disability categories established by IDEA are autism, deafness, deaf-blindness, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, serious emotional disturbance, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment.

How can you be sure your child has a special need? Write to the school district's Director of Special Education or local principal requesting that your child be evaluated for special education services. Written notification will start the timelines for evaluation if the school district agrees to an evaluation. Always keep a copy for your records.

What happens during an evaluation? The school must evaluate your child in all the areas where your child may be affected by the possible disability: health, vision, hearing, social and emotional well-being, general intelligence, performance in school, and how well your child communicates with others and uses his or her body. The evaluation must be complete enough to identify all of your child's needs for special education and related services. An appropriate evaluation will give you and the school a lot of information about your child. This information will help you and the school to determine if your child has a disability and then design instruction based on your child's special needs.

The evaluation has been completed, now what? If your child is found not to be eligible for special education, it must be in writing, an explanation given, and you must be given information about what to do if you disagree with the evaluation and want to challenge district's decision. Most states also have a Parent Training and Information Center (PTI) you can access on the web for more specific answers to your questions. If your child is found eligible for an Individualized Education Plan (IEP), that plan must be developed within 30 days of that finding. An IEP sets reasonable learning goals for the student and also states the specific services the district will provide. Other information found in an IEP includes present levels of educational performance, annual goals, special education and related services to be provided, participation with non-disabled children, participation in state and district-wide assessments, transition services, and measuring progress.

Who develops the IEP for your youngster? The parents and child (when appropriate), the regular education teacher, a special education teacher, a district representative (LEA), the school psychologist to interpret the evaluation results, and other individuals such as a speech therapist or occupational therapist.

What happens during the IEP meeting? The child's strengths and needs are discussed by the IEP Team to decide the educational and other appropriate goals for your child, the type of special services your child needs, and the related services your child may require to benefit from his or her special education plan.

What are the "related services" for which your child may be eligible? Transportation, speech and language pathology, audiology services, physical therapy, occupational therapy, recreation, counseling services, orientation and mobility services, medical evaluation or diagnostic services, school health services, social work services, psychological services, parent counseling and training, and other related services. Each state will vary in the services offered to IEP students.

Infants and toddlers also can receive services under the IDEA umbrella. These services are called early intervention services for children up to 2 years old and preschool services for children ages 3-5. Contact your local state agency for more information.

Hopefully, this article has answered many of your questions about the special services your child may require in order to have a successful school year. I encourage you to contact your child's school to start to lay the groundwork for a rewarding, enriching, and exciting school year for you and your child.



Editor's Note: To access a copy of the second edition booklet entitled, "Ichthyosis: A Guide for Teachers," visit the website at www.scalyskin.org or contact the F.I.R.S.T. office at 1-800-545-3286. Website resource on page 16

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



One week out of the year our members host awareness campaigns and fund raising events to raise money and educate the public about ichthyosis. Ichthyosis Awareness Week will be officially celebrated during September 30–October 7, 2007. In actuality, Ichthyosis Awareness Week can occur anytime during the year—when you can devote your energy to raising awareness or funds for the Foundation.

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

Ichthyosis Awareness Week



September 30 through October 7, 2007

Fundraising ideas:

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

How you can help...

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

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

Conference Chatter

❖❖❖ *New For 2008* ❖❖❖

2008 Family Conference Scholarship Fund Guidelines & Criteria

(Funded by the Jean Giroux Charitable Trust)

A scholarship fund is available for families to apply for financial assistance to attend the Chicago conference. The Family Conference Scholarship Fund, funded by the Jean Giroux Charitable Trust, will provide funds for registration, travel, and accommodations. Funding is limited; all applications will be evaluated based on scholarship guidelines.

Scholarships Available

- Scholarships are available for registration fees for two people, with one person being affected
- Scholarships are available for one hotel room for three nights
- Scholarships are available for transportation for two people, with one person being affected (includes travel from the airport to the hotel)

Eligibility for Applicants

- Each applicant must have a membership application on file at the national office. You can download a membership application form on our website at www.scalyskin.org or contact our office.
- Based upon availability of funds, priority will be given to applicants who clearly demonstrate a need for financial assistance based upon income and family circumstances.
- Each applicant must commit to volunteer at the conference for period of time and attend all conference workshops.

Disbursement of Funds

- The award recipients will be reimbursed for the conference, on the last day or by mail immediately after the event.
- The award recipients must bring receipts for reimbursement; no costs will be reimbursed without written proof.

Application

- Completed applications must be submitted by February 1, 2008. They can be faxed to 215.619.0780 or mailed to 1364 Welsh Road, G2, North Wales, PA 19454, Attn: Family Conference Scholarship Fund.
- Applications must be submitted with:
 1. Confirmation of hotel reservation (if applying for hotel costs)
 2. Confirmation of transportation arrangements (if applying for travel reimbursement)
 3. Copy of most recent IRS Form 1040

All applications will be strictly confidential.



Foundation for Ichthyosis & Related Skin Types

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

2008 Family Conference Scholarship Application Application Deadline: February 2, 2008

Name _____

Address _____

City _____ State _____ Postal Code _____

Province _____ Country _____

Home Phone _____ Work Phone _____

Cell Phone _____ Email _____

How many people will be attending the conference? _____

Name: _____ Age _____ Type of Ichthyosis: _____

Name: _____ Age _____ Type of Ichthyosis: _____

Name: _____ Age _____ Type of Ichthyosis: _____

Name: _____ Age _____ Type of Ichthyosis: _____

Have you attended a family conference before? Yes No

If yes, how many conferences and when? _____

Why do you need a scholarship to attend?

Request for Funding

- Registration Fees for _____ adult(s) at \$150 and/or _____ child(ren) at \$115.
- Hotel Accommodations for _____ nights (up to three nights will be reimbursed).
- Travel (Please include transportation to and from hotel)
Train \$ _____ Plane \$ _____ Automobile \$ _____ Other \$ _____
- Monthly family combined income: \$ _____
(Please include a copy of your most recent IRS Form 1040)
- Monthly family combined expense: \$ _____

** All dollar amounts must be included in order to evaluate your application.*

Please tell us in your own words why you would like to attend and what you expect to learn from the Family Conference? (Use additional paper if necessary.)

Please feel free to include any additional information that you would like to share with us:

I acknowledge that:

- ✓ All receipts for approved funding must be submitted at the conference registration for funds to be reimbursed at the conclusion of the conference.
- ✓ I am required to volunteer for a few hours at the conference and attend all workshops.
- ✓ The information I provided on my application, as well as my financial information, is accurate and truthful.

Signature of Applicant: _____ Date: _____

F.I.R.S.T. and its officials reserve the right to disqualify any application that is incomplete. Please be sure to check all appropriate boxes. Applications received after February 1 will not be considered.

Thank you for your confidential information.

News & Notes



The Foundation for Ichthyosis & Related Skin Types has teamed up with the Oreck Corporation, home of the world famous 8-lb. vacuum, to offer our membership a simple and easy to do National Fundraiser. It's called Oreck Party and is held at your local Oreck store. We're looking for volunteers who would be interested in hosting a "fun-raising" party. It's as easy as 1-2-3.

How the host program works:

- 1) Become a host or hostess simply by contacting the national office. (215) 619-0670 or via email at info@scalyskin.org. You will be given the Oreck contact for the store in your area.
- 2) Call your local store to set the date and then mail your invitations to a minimum of 6 people. (Oreck will provide you with the invitations.)
- 3) On the day of your party, simply bring a snack for your guests. Oreck will do the rest. (Oreck will provide beverages, plates and napkins for you and your guests.)

Your party will last about 1 hour, and consist of product demonstrations and fun things like door prizes, games and most of all – fun! The best part is,

Oreck will donate a minimum of 10% of the party proceeds to support F.I.R.S.T.

Oreck offers a variety of solutions so you can create a clean home environment. For your daily floor cleanings, their upright vacuums are light weight, easy to use, and offer superior filtration including HEPA filtration. All of the Oreck XL[®] uprights have fantastic warranties ranging from 3 years all the way up to 21 years. In addition to daily cleaning with your vacuum, Oreck also suggests that you deep clean your floor surfaces for maximum clean. The multi-purpose floor machine, when combined with their Oreck Dry Carpet Cleaner, can deep clean your carpets and remove up to 70% more allergens than vacuuming alone. The final piece to consider essential for a totally clean home are the Oreck XL[®] Professional Air Purifiers. They clean your air 24 hours a day removing dust and allergens from your home without expensive replacement filters. The result is a simply amazing clean home!

So please don't delay, contact our office to book your party today!

Make Everyday a GoodSearch Day!



Please join us in supporting F.I.R.S.T. and the important work we do. By using www.goodsearch.com each time you search the internet, F.I.R.S.T. will receive a penny. Simply go to the GoodSearch homepage and select the Foundation for Ichthyosis and Related Skin Types from the drop down box to designate us as your selected charity. The site is powered by Yahoo!, so you'll get the same quality search results that you're used to. What's unique is that they have developed a way to direct money to our Foundation with every click. So hurry don't delay, make everyday a Good Search Day.

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Cūtemol is formulated to be rich and thick,
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Mention this ad and we'll send you a 2 oz. tube
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Phantom Tea Fundraiser Update

We are excited and pleased to announce that the Phantom Tea fund raiser has just passed \$30,000 in donations and they keep coming in everyday! Congratulations to all of our members that participated in this new fundraising effort! We had 81 families participating in this first-ever national event. We are so proud of our members and their efforts.

If you who have not yet sent out your invitations, now is the time to get them out to your family and friends! Remember, each donor will be specially thanked by the Foundation shortly after their donation is received, and a list will be provided to you so you can personally thank them as well.

A School Survival Guide

continued from page 10

Website Resources for Parents

www.nasponline.org/advocacy
www.usdoj.gov/crt/ada/adahom1.htm
www.ed.gov/index.jhtml
www.1donline.org/1d_indepth/special_education/
www.orangeusd.k12.ca.us
www.calvertnet.k12.md.us/schools/specced/ADAIDEA504.html
www.nod.org/education
www.asha.org/about/Legislation-Advocacy/
lone-eagles.com/virginia.htm
clercenter1.gallaudet.edu

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Have you moved recently or are planning on moving soon? Please let us know your change of address so you can continue to receive the Focus. Postage for the newsletter does not include forwarding.



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Suite G2
North Wales, PA 19454