

Ichthyosis Focus



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

Summer 2004

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 to ensure 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 try to 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 some 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; special equipment, medication, medical problems, activities or events that might affect performance, student work and grades, how to support or build upon school activities and learning at home, volunteering 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 and guidance counselor prior to the beginning of school to 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 preferential 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

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Designate Funds

through



A United Way
System Partner

or



Giving Programs

(see page 3 for more details)

Correspondence Corner

Dear Members of F.I.R.S.T.:

Our fourteen-year-old daughter, Jamie, has lamellar ichthyosis and contact dermatitis. Jamie also has extensive telangiectasia, which is broken capillaries on her face, mainly on her cheek and nose.

Jamie is very conscious of the way she looks, which is not helped by hurtful remarks made by people who pass comment without thinking. We have always encouraged Jamie and supported her, but now that she is in her teens, no amount of encouragement is enough to make her feel better.

We are exploring the possibility of Jamie having laser treatment on her face to help the broken capillaries. Has anyone with lamellar ichthyosis had experience with laser treatment for broken capillaries with a Candela V Beam Laser? The V Beam Laser is the latest available in New Zealand. Are there more recent models available in the United States that we are unaware of?

Jamie had undergone a laser patch test on her cheek with no adverse reaction, but the pain was intense. The Laser Specialist had no experience with using laser on someone with lamellar ichthyosis and was puzzled as to the level of pain Jamie felt after only 8 to 10 pulses. A total of 300 pulses would be needed to complete her whole face. I am trying to discover what kind of pain relief we could use. The specialist has never used a general anesthetic before. I am also concerned as to how many treatments would be required for improvement to be seen, if any. The test patch produced a very slight improvement. We would appreciate any information. It is very difficult here in New Zealand to access experienced help, as most have never seen anyone with ichthyosis. The Ichthyosis Focus is a lifeline for us.

Kind Regards,

Mandy Metzger
Dunedin, New Zealand
metzger.family@xtra.co.nz

Dear F.I.R.S.T.:

Thank you for the tremendous compilation of facts, insight, and research you make available via the Focus. Your quarterly newsletter has answered many questions concerning ichthyosis vulgaris, which I have had for 66 years. Rereading your newsletters, even a couple of years later, informed me of information I either missed or forgot.

One such example is your fact sheets, specifically one on earwax, which has been a perennial problem for me. I discovered that sheet after reading Jean Pickford's report again in the Fall 2002 issue.

Thank you for all you do.

Patricia Blackwell
Bokeelia, FL

Correspondence Corner

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Dear F.I.R.S.T.:

My son Ryan turned 18 in March, 2004. He was born with Harlequin ichthyosis and is believed to be one of the oldest survivors. What Ryan would truly benefit from is a computer. He has a refurbished one that someone gave him years ago, but it is constantly having problems and is not working right now. There is a 17-year-old in Canada that I would love for Ryan to be able to email. Being a loner, he needs to connect with someone who goes through the same things he does.

I am able to look at all the posts on the ichthyosis website because I do it from work, but he would then be able to read and contribute, especially to the youth issues. Ryan does not tolerate heat very well, so in the summertime when I'm at work he is mostly inside. With a computer he could play games, research things (like information on his bird "Buddy"), email, etc. This year Ryan will receive a certificate of graduation from his high school, not a diploma. He has missed way too much school over the years to get a diploma. I plan to keep him in school as much as possible, even if he has to take remedial classes at the junior college nearby. For this, a computer would be absolutely necessary.

Please let me know as soon as possible if this is a possibility, or if you can refer me to another organization.

Thank you,

Annamarie Gonzalez
San Diego, CA

Editor's Note: The Foundation is not able to help Ryan with this request. If you, or an organization you know, is interested in helping Ryan acquire a computer, please contact Maureen in the national office. For a profile of Ryan Gonzalez, see page 6.

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United Way and Combined Federal Campaign Programs

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 current mailing address and phone number, 1601 Valley Forge Road, Lansdale, PA, 19446, 215-631-1411.

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 that 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 0810, which is listed in the charitable organizations directory.

New Emollient for F.I.R.S.T. Members

(30% Urea + 10% lactic Acid)

MONEY BACK GUARANTEE

Hundreds of F.I.R.S.T. members use our odor free, non-greasy 10% urea + 10% lactic acid lotion to improve skin & scalp instead of prescription products.

\$15.99 for a 16-oz bottle

Now try our more potent
30% urea + 10% lactic acid lotion
\$12.99 for a 4-oz bottle



To order: (800) 668-8000 • www.dermaltherapy.com

A School Survival Guide for Parents of Children with Ichthyosis

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than under IDEA.

If you feel 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 needs 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. Appropriate evaluation will give you and the school a lot of information about your child. This information will help you and the school 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, dates and location, 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 0-2 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 newly-revised second edition booklet entitled, "Ichthyosis: A Guide for Teachers," see page 5.

Website Resources for Parents

http://www.nasponline.org/advocacy/pbs_resources.html

<http://www.usdoj.gov/crt/ada/adahom1.htm>

<http://www.ed.gov/index.jhtml>

<http://lone-eagles.com/virginia.htm>

<http://clerccenter2.gallaudet.edu/Ken/Impact/ieps.html>

<http://www.edlaw.net/frames.html>

http://www.ldonline.org/ld_indepth/special_education/

<http://www.asha.org/about/legislation-advocacy/federal/IDEA>

<http://www.orangeusd.k12.ca.us/specialed/resources/selaws.html>

<http://www.calvertnet.k12.md.us/schools/speced/ADAIDEA504.html>

<http://www.nod.org/education/index.cfm>

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The ABC's of Adaptations and Accommodations

Alphabet strip taped to student's desk.

Break long-range assignments and projects into smaller ones.

Calculators, checklists, and computers.

Dictate work or assignments to students.

Extended time for tests, projects, and assignments.

Flash cards.

Group cooperatively, give cues, graphic organizers.

Highlight main ideas or specific words.

Instruction given orally and in print.

Journal writing could be drawing pictures or scripted by another.

Kids use assignments books to organize work.

Large print or type for easier reading.

Manipulatives and models.

Number lines, notebooks.

Oral reports in place of written ones.

Paired reading, peer tutors.

Quiet space or work area.

Read tests, directions, and assignments.

Shorten assignments, smaller amounts, study guides.

Tape texts and stories, three-dimensional ruler.

Use a test format that requires little writing.

Verbal responses to questions and tests, vocabulary lists and visuals.

Worksheets and/or test written on a lower level.

Xerox copies of assignments for home and provide examples of projects.

Your tests could be open book or take home.

Zero in on reinforcing concepts through hands-on activities and games.

Foundation Resources

Planned Giving Brochure

Since its founding in 1981, the Foundation has been fortunate to have many friends who care about its future. Through their thoughtfulness, the Foundation has begun to receive many substantial gifts, which help to meet both current and long term needs for continuation of our mission.

The opportunities for charitable gifts to the Foundation are many and varied. Our Planned Giving Brochure will provide you with an overview of making donations in the form of securities, tangible assets, and bequests to help secure the future of the Foundation.

It is our hope that this new giving program will generate conversations between you, your family, and your financial advisors. You can become a partner in the Foundation's future through your planned gift. Please contact the national office by email at info@scalyskin.org or call directly at 1-800-545-3286 to receive the Planned Giving Brochure and other pertinent information. The Foundation's future is in your hands.

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. This is an opportunity to alleviate some of the financial burden that may be facing you or your family. It is easy to apply and you will receive the award in cash, if your application is accepted.

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, 1601 Valley Forge Road, Lansdale, PA 19446. **The deadline for applications is October 31, 2004.** The awards will be given in December 2004.

Donations to the Jane Bukaty Membership Assistance Fund are always appreciated and enable the Foundation to make this fund available to more of our members.

Second Edition Teacher's Guide is Now Available

The Foundation produces *Ichthyosis, A Guide for Teachers* as part of our resource library. The booklet is designed for parents to help ease their children's transition into the school environment. The guide is also intended to be given to school personnel to help them better understand ichthyosis and school-related issues. The teacher's guide provides information about such topics as: ichthyosis and its symptoms; relationships with teachers, parents and children; overheating; introducing ichthyosis to classmates; junior and senior high school issues; special education programs; and much more. This 40-page booklet, originally written in 1994, has recently been revised and redesigned, just in time for the beginning of the new school year. It is available to all Foundation members and to the general public for only \$5.00 plus postage. Please email the national office at info@scalyskin.org, or call 1-800-545-3286 to order your booklet(s) today.

Spotlight On ...



Ryan Gonzalez



From left, Ryan Gonzalez, Ryan's mother Annamarie Gonzalez, and his swim coach, Brian Potter.

Miracles Can Happen, Young Man Beats All Odds

By Cyril Thomas, PAC
Emergency Department, SDMC

It is early morning, November 2, at La Jolla Cove. Ryan Gonzalez has partially put on his wetsuit, leaving his chest in contact with a somewhat chilly sea breeze. "Ten minutes to start," announces the director of the race over the loudspeaker. "It is time to get ready," says Ryan's coach. I can see in his eyes pride mixed with fear and determination beyond belief. His body has to be greased up in Aquaphor to prevent his skin from drying out before completely putting on his wetsuit. His head, totally bald, is covered with a thermal cap and ultimately with the bright yellow cap displaying "Challenged Athletes Foundation" - CAF.

Ryan, now 17 years old, was among more than 600 people who participated in the 10th Annual San Diego CAF Triathlon that took place that early November morning. Among them were more than 100 chal-



Ryan, mom Annamarie, swim coach Brian Potter, and Brian's wife Gina.

lenged athletes from all over the world to participate side-by-side in a grueling half Iron-man event - 1.2 mile swim, 56 mile bike ride, 13.1 mile run - because they can... because it's not expected. Among the athletes were people who lost legs or arms in accidents or have other challenging medical conditions.

Although most are unfamiliar with most of the athletes there that morning, many Kaiser Permanente employees are familiar with Ryan. Born at San Diego Medical Center in March 1986, Ryan suffers from the rarest and most severe form of ichthyosis - Harlequin ichthyosis - a genetic disease characterized by overproduction of skin, and is considered by many a fatal disease. At 17, Ryan has reached an unbelievable milestone as the oldest living man with this disease. He has not stopped there, and recently embarked on a journey of the unthinkable.

The idea to go farther was initiated by Brian Potter, a Kaiser Permanente construction foreman, in October 2002. "You could do that," Brian said to Ryan while sitting on the beach at LaJolla Cove, staring at the buoys where Ryan's mom had been training for various triathlons. The boy was not convinced, knowing the salt water would burn his skin and make it very painful for him. That's when Brian told him about the Challenged Athletes Triathlon that would be just a year from then.

Ryan watched the race and by the end of the evening, made a deal with Brian that they

would do the 10th Annual CAF Race. From that day on Brian, an accomplished athlete, became Ryan's coach and best friend.

His mom Annamarie, also a Kaiser Permanente employee, became excited and took on the challenge by accepting to do the bicycling, and Brian's wife, Gina, would do the run. Volunteers from all over the state came to encourage Ryan and created "Team Ryan." Christine Tenconi of the Children's Skin Disease Foundation paid the \$900 race fee.

Francesca, Christine's daughter, promised to fly from North Carolina to see him race. The CAF awarded a grant for his swimming supplies and a brand new top-of-the-line



Ryan with the Foundation's 'West Coast ambassador,' Les Avakian.

Quintana Roo wetsuit. Susan Boiko, MD, Ryan's Kaiser Permanente dermatologist, and Charles Freedman, MD, Chief of Pediatrics and Ryan's Kaiser Permanente pediatrician, would also be

there to witness this special event. Even total strangers read about it on the website and flew to San Diego just to be there.

We all wondered why Ryan would do it. He surely did not do it for the glory of having his picture taken next to actor Robin Williams, a supporter and regular participant in the event, or for the medal that every participant receives regardless of their place of finish.

He did promise it to his coach, to his mom, and to his friends. On that early morning in November, Ryan Gonzalez, the longest living man with Harlequin ichthyosis, accomplished the unthinkable - finishing the first grueling leg of the half-Iron man triathlon, an open water 1.2 mile swim in salt water, in less than one hour.

Reprinted with permission from *Payday Postscript, Kaiser Permanente, San Diego, December 12, 2003.*

What's New, What's Hot & What Works

Dear F.I.R.S.T.:

Just sending this along. My six-year-old daughter, Abby, has lamellar ichthyosis. The Misty Mate product has been wonderful and easy for her to use. I thought others might find it would work well for them. Misty Mate is a manual pump style mister that uses tap water, is lightweight, and easy to use.

**Rhayne Evans
Hampstead, MD**

Editor's Note: Misty Mate and other cooling products can be found at www.misty-mate.com or by calling 1-800-233-6478.

Dear F.I.R.S.T.:

I have ichthyosis vulgaris. I have tried many products over the years to help with the buildup of scaly skin on my legs. About a year ago I began using RegenaSkin. After two months there was a dramatic reduction in the scaly skin on my legs. There is also much improved hydration and overall skin appearance. RegenaSkin is quickly absorbed, not greasy or sticky like some products I've used. I use it on my legs two or three times

a day and on my entire body after a shower. I am thrilled to be able to use just one product and have such great results. And it is very reasonably priced.

**R.B.
High Point, NC**

Editor's Note: RegenaSkin can be ordered from www.regenaskin.com, or by calling 970-484-1122.



Correspondence Corner

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Dear Jean:

We are members of F.I.R.S.T., as our daughter Kayla has been diagnosed with Sjogren-Larsson Syndrome (SLS) and has ichthyosis as part of her syndrome. In our search for products that benefit Kayla's skin, we formulated a unique product that has helped dramatically. We eventually formed a company to market and distribute this product, as well as a variety of others. Our company is Elements Home Spa, Inc. A number of our customers have commented on the benefits that they have witnessed for various skin conditions including eczema and ichthyosis. These unsolicited testimonials prompted us to share our story with you in the hope that it may help some of your members.

Kayla's dermatologist, Dr. Gary Bellus, has been very impressed with the condition of her skin since we started using our body butter in lieu of Lac-Hydrin. She no longer uses these harsh treatments as she is much more comfortable using the body butter. It has reduced the flakiness and itchiness of her skin. It is not medicinal in any way and is all-natural, which we feel is better for her skin.

We offer the body butter in an almond scent,

a vanilla scent, and unscented varieties in both 4-ounce and 8-ounce sizes. The 4-ounce containers sell for \$15.00 and the 8-ounce sell for \$28.00. They are available on our website at www.elementshomespa.com or by calling 303-781-2715.

Thank you for including this in the newsletter. We are happy to answer any questions. Call us at 303-781-2715

Best Regards,

**Peter and Christy Kopp
Englewood, CO**

Editor's Note: FIRST members can purchase any number of eight oz. body butters for a discounted price of \$23 dollars each. Members must enter discount code 336 when checking out at our online store.

Dear Maureen:

My name is Monique Broekman and I have a six-year-old son, Zak, who was diagnosed with Netherton's syndrome when he was six months old. As far as we know, he is the only one in Western Australia with this condition. He has a wonderful dermatologist

named Anne Halbert, who has been a blessing since his birth. These days we have the condition pretty much in control using the basics: Lucas Pow Pow cream, Sorbolene for washing and moisturizing, Avon Hand Therapy when really dry, and Eulaetol for very dry skin on the hands and feet. For his scalp, I have come across a product called Del Lorenzo Scalp Relief, which works wonders. I am a great believer in natural products, as cortisone and steroids have never worked on Zak.

Netherton's is unknown territory in this country, and I would love to hear from or meet others with this condition, as we never know what to expect next. Zak has gone against everything they have on Netherton's. He thrives, has a huge appetite, does not suffer from asthma, and the sun and salt water are the best thing for him.

I would love to hear from others and also become a member. I look forward to hearing from you.

**Monique and Zak Broekman
P.O. Box 158
Goomalling 6460
Western Australia**

Conference Chatter

2004 National Family Conference



Conference Highlights



- 316 members attended, the most ever for a family conference!
- International members traveled to Kansas City from as far away as Belgium and Bermuda.
- Every guest received a bag full of lotions, creams, and other goodies, including a conference T-shirt.
- A general session on the latest in ichthyosis research was a great way to start the weekend.
- Top dermatologists and experts in ichthyosis led breakout groups on specific disease types and the latest treatment options.
- Discussion groups for men, women, moms, and dads provided the opportunity to talk about fears, anxieties, and successes.
- A panel discussion with local doctors provided extremely helpful information about eyes, ears, and nutrition issues.
- Support for unaffected siblings was an added bonus in the weekend activities. Parents and unaffected sisters and brothers learned skills and gained helpful insight about living with someone affected by ichthyosis.
- Psychologists, professors of behavioral pediatrics, and nutritionists guided sessions with the teens and pre-teens and encouraged them to talk about coping skills, fears, making good choices, and self-esteem.
- A field trip to Science City, an interactive hands-on museum, was a great way for the teens and preteens to socialize with one another.
- Saturday evening's entertainment was perfect for the entire family. Armed with popular dance music, the DJ also offered a game show format, including contestant booths, buzzers, and fancy lights.
- Breakouts about retinoids treatment, working with your government, school issues, and social security insurance provided valuable information and supportive insight to many of our members.
- Patients with ichthyosis had access to private sessions with the country's leading experts in ichthyosis. These clinical screening appointments were very popular and, for some, it was the first time individuals had been given an accurate diagnosis.
- Our closing speaker, John Foppe, reinforced the message that "Our only real handicaps are those mental and emotional ones that prevent us from participating fully in life."
- Our conference members departed from Kansas City with an overwhelming feeling of belonging, caring, and an armful of knowledge. To have the opportunity to spend the weekend with people who look, feel, and struggle with the same experience is priceless.

Volunteers fill the gift bags.



Drs. Scott Olitsky, Julie Wei, and Mary Williams answer questions about eyes, ears, and nutrition.



Drs. Susan Mallory and Phil Fleckman share an opinion on types and treatments.



Conference Chatter

2004 National Family Conference



Volunteer Recognition



The following awards were presented at the 2004 National Family Conference:

Volunteer of the Year Award

Presented to members whose leadership and heartfelt dedication to the Foundation best exemplify the spirit of giving.

2003

Peter Steinert, PhD
Bethesda, MD
Awarded posthumously

2004

Kelly & Mark Klafter
Alpharetta, GA

Frances Bernstiel Memorial Award

Presented to member(s) whose outstanding grassroots fundraising efforts help to contribute to the financial strength of the Foundation.

Denise & Marc Merritt
Commack, NY

Past Board Member Award

Michael Dunleavy
Blue Bell, PA
Recognizing nine years of service on the Board of Directors

Distinguished Service Awards

Presented to a member(s) for their extraordinary contribution or service to the Foundation by helping us grow in strength, membership, or recognition.

Anita Adams

Joti Anand

Les Avakian

Jennetta Barrow

Denise Benedetto

Lee Ann Bruno

Raj Dosanjh

Lori Florian

Terri Hamrich-Oeschger

Chris & Randy LaBarbera

Ann Pokalsky

Tracie Pretak & Bailey Jones

Paula Rivers

Stephanie Sawyer-Ames

Liza Santamina

Meslissa Tierney-Osterloth



Corporate Sponsorship



The Foundation for Ichthyosis & Related Skin Types wishes to express its sincere thanks to our 2004 National Family Conference Corporate Sponsors. Their financial contributions ensured the success of the conference.



Merz Pharmaceuticals - Reception Sponsor.



Johnson & Johnson - Audio Visual Sponsor



Dermik - Children's Program Sponsor



GlaxoSmithKline

GlaxoSmithKline - T-shirt Sponsor

Verizon - General sponsor • Ortho Neutrogena - General Sponsor • Sir Speedy - Program Book Sponsor

Gift Bag & Other Donors

Atsko, Inc. • Avon, Inc. • Beiersdorf, Inc. • Cooper Labs • Del Ray Dermatologies • Dermal Therapy • DermaSystems, Inc. • Doak Dermatologies • Ecco Bella • Galderma Labs • Johnson & Johnson CPC • LaRoche-Posay • Merino Skin Care USA • Nail Tek • OrthoNeutrogena • Pharmaceuticals Specialties, Inc. • Pierre Fabre • Procyte Laboratories • RegenaSkin, Inc. • Stiefel Labs • Summers Labs • Swiss American

A Fountain of Knowledge logo designed and donated by ShiftClick, LLC.

The Foundation is extremely grateful to our generous corporate donors who supported the conference.

Conference Chatter

2004 National Family Conference



Conference Comments



Dear Jean:

Wow, the conference was a great event! I have to say I learned so much, met wonderful people, and was so very impressed. Your event was so well thought out and organized. The kids truly loved the DJ, and it was so fun to watch them! In addition, I was so amazed by the dedication and commitment of your doctors. They gave so much of their time – even on a holiday weekend. They were also so friendly and available throughout the entire conference. I was so moved by their dedication that I sent each of them a thank you card.

I am now sifting through my many notes and am looking forward to meeting with my medical team here, sharing all of the new information I have obtained.

Maureen and Laura worked so hard; please give them a special thank you from me. I

loved the door prize that Maureen made; we already have a special place for it!

Thank you again.

**Kara Stadt
Fairport, NY**

Dear Jean:

Zebulun and I wanted to let you know that we enjoyed the conference this past weekend so much. It was good to be there again and to renew old friendships and make new friends. We had a great time and appreciate all the hard work you put into the Foundation. Zebulun is already talking about the next conference.

Thanks,

**Cathy Register and Zebulun Sipper
Montgomery, AL**

Dear Jean:

Hi! I wanted to write you and express my gratitude for everything you have done. Attending my first F.I.R.S.T. conference was quite a memorable experience. Not only did I meet an extremely intelligent doctor (Dr. Milstone), with whom I will be following up, but oddly enough I met my cousin! Kevin Young and I are related and our mothers are trying to “trace the gene.”

At any rate, thank you so much for your dedication and effort. I look forward to seeing you in two years (maybe Hawaii!). Keep in touch.
Sincerely,

**Holly Benton
Walterboro, SC**



Conference Feedback



- The conference was wonderful. I hope I can come back!
- The conference was great, but there was something missing. I think there should be some sort of one-on-one group for preteens and teens to talk about their skin. They keep too much inside.
- I would like it if the teens were given time to break out with the adults. One of the most special parts of the conference is talking to older people with my condition.
- The closing keynote speaker I think was picked for my son. Thank you!
- I really liked meeting my friends and making new ones. I really liked the closing keynote speaker.

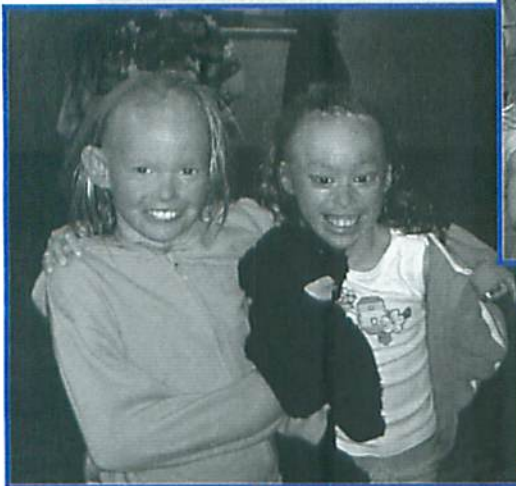
- Fantastic conference. We learned so much again. I can't wait for the next one!
- I enjoyed this weekend. It was great to feel like we fit in and not to have to worry about being singled out. My daughter made several friends and really had fun. John Foppe was awesome!
- This was our first time attending the conference. Really enjoyed it. Our daughter met several girls close to her age and hung out with them. They really had a great time at Science City and the dance after dinner. Jean and everyone did a great job!
- I enjoyed meeting new people and I liked how everyone treated everyone as an

- equal. I feel that there should be group activities that would bring us closer together. Because we know the friends we make here will be lifelong friends.
- Thanks for all the great effort. The conferences keep getting better and so does F.I.R.S.T. Many lives have been improved by your work, and I hope that brings you much happiness and satisfaction.
- Thanks to all who have planned, pulled together, volunteered and made this conference. If not for my mom, I would never have heard of this program or organization. Thanks for everything.
- My first conference and I've left with many blessings.

Conference Chatter

2004 National Family Conference

THE FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES
 A FOUNTAIN OF KNOWLEDGE
FAMILY CONFERENCE • KANSAS CITY • 2004



Friends reunited.



There was a lot to smile about in childcare.



The teens pose for a group shot.



Preteens get a lesson in self defense.



Mothers and daughters.

Conference Chatter

2004 National Family Conference

THE FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES
A FOUNTAIN OF KNOWLEDGE
FAMILY CONFERENCE • KANSAS CITY • 2004



Teens and dads.



A quick pose for the camera.



Volunteer friends.



Young adults take a moment to bond.



Everybody on the dance floor!



Take care. See you in 2006!

Executive Director's Report



July 2004

Dear Members and Friends of the Foundation:

The past few months have been very busy for the Foundation staff and me. Since my last report in the Spring 2004 newsletter, many exciting things have occurred. For one, I celebrated my fifth year anniversary with the Foundation in June. The past five years have been an amazing journey for me, both personally and professionally. I look forward to continuing my service to the Foundation, its board, and our countless volunteers and donors.

The 2004 membership campaign took place this spring. During this campaign everyone recorded in our database is asked to renew their membership in the Foundation. The membership campaign is our biggest in-house fundraiser each year and, once again, this year was no exception. To date, our membership campaign has raised 11% over our projected goal. Over the past year and a half, I have been communicating the importance of maintaining membership in the Foundation. I'm glad to see many of you who let your membership lapse have renewed with generous donations. Thank you for supporting the Foundation's important work. All members in good standing will con-

tinue to receive all the benefits of membership.

The Foundation's office moved to a new location in April. It was a welcome event since our new office is much larger and in a better location. Over the years as the Foundation resources and staff grew, we began to outgrow our space. A desk, filing cabinet, box, or table took up every inch of open area. Our new office is twice the size for only a few dollars more per month. It is less than a mile from our old office, which has allowed us to keep the same phone number, fax number, and email address. Please be sure to note our new address: 1601 Valley Forge Road, Lansdale, PA 19446.

Our fundraising campaign for ichthyosis research has been doing very well. Thanks to donations from our generous membership and successful grassroots fundraisers, the campaign has raised over \$130,000 for ichthyosis-related research to date. Raising money for research is a never-ending process and we are continually working to raise more. The next time you send a donation to the Foundation, please consider giving a little extra to support this initiative.

The 2004 Family Conference was held earlier this month, on July 2 - 4 in Kansas City, Missouri. It was our best-attended conference

with more than 334 people registered. The event was an amazing experience for everyone, especially the families who had never attended a conference before or met others with ichthyosis. Many new friendships were forged and old ones were renewed. The opportunity to have more than 300 people together in one place to learn and talk about ichthyosis and its related issues is remarkable. See pages 9 to 11 for highlights and pictures from the conference. A date and location has not yet been determined for the 2006 conference. Stay tuned for more information in an upcoming newsletter or the Foundation's website, www.scalyskin.org.

In the next few months, my attention will focus on the next steps in our strategic plan, working with our Fund Raising Committee, assisting with grassroots fundraisers for Ichthyosis Awareness Week (see page 14), updating our website, and our annual summer appeal mailing. There is always plenty to do here at the Foundation. It is a pleasure and a privilege to work for you, our members, and all those affected by ichthyosis and related skin types.

Sincerely,



Jean R. Pickford
Executive Director

News & Notes

Researcher Paul Khavari Lectures on Gene Therapy

The 2004 Marion B. Sulzberger Memorial Award Lectureship was delivered by Paul A. Khavari, MD, PhD, at the American Academy of Dermatology's 62nd. Annual Meeting, in Washington, D.C. Dr. Khavari is the Carl J. Herzog professor of dermatology at the Stanford University School of Medicine. His lecture was titled, "Developing Genetic Medicines for Inherited Skin Disease."

Dr. Khavari described the recent research into genetic therapies for severe skin disease. "This is a story of gradual progress and hope for the future," he said. He detailed some of the obstacles he and his fellow researchers have encountered in working to

develop genetic therapies and walked the audience through three generations of research using in vivo and ex vivo methods to deliver genes that, hopefully, will correct defects that lead to severe skin diseases such as epidermolysis bullosa.

The most recent advances, according to Dr. Khavari, uses "non viral gene transfers of primary fibroblasts that can be cloned and have an integration site determined safe, and then directly injected back into the skin of the patient." Although this method appears to avoid some of the hazards of previous generations of research, more work needs to be done. "With each step we take, we become more capable and versatile at achieving our goals," he said.

continued on page 15

Ichthyosis Awareness Week

National Ichthyosis Awareness Week

The Foundation relies on its many members to help educate our local communities about ichthyosis. Now is the time to think about getting involved in an awareness week activity for this year.

October 3
through
October 9
2004

Who: This national awareness campaign has been created for you, our members, and all those who are affected by ichthyosis. It is for all the beautiful children who journey through childhood with different-looking skin, adults who enjoy life despite the relentless hours of skin care, and the seniors who see hope through the eyes of their family.

What: One week out of the year in which our members host awareness campaigns and fund raising events to raise money and educate the public about ichthyosis.

When: Ichthyosis Awareness Week will be officially celebrated during October 3 – 9, 2004. 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.

Where: The possibilities are limitless! Awareness and fund raising can take place anywhere in your local community, such as your yard, a local park, a supermarket parking lot, your child's school, the YMCA, your church, etc.

Why: 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.

How: For those of you who have experience putting together fundraisers or creating publicity for an event, we encourage you to use your skills. Be creative and organize something that interests you and your family, or is popular within your community. As always, the Foundation staff is available to help you in any way or provide literature for distribution to your audience.

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 created an easy-to-follow manual of 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 creating 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.

Here are some ideas to help get your creative juices flowing:

- Auction
- Bake Sale
- Bingo
- Book Sale
- Bowl-a-thon
- Candy Sale
- Car Wash
- Collection Cans
- Dance
- Distribute brochures to your community
- Dog Wash
- Donations in lieu of birthday gifts
- Dress Down Day at Work or School
- Garage Sale
- Golf Tournament
- Halloween Costume Contest
- Punt, Pass & Kick Contest
- Raffle
- Skate-a-thon
- Submit a personal story to local newspaper, radio or TV stations
- Submit a personal story to your company's newsletter
- Walk-a-thon
- *Release the Butterfly* Fundraiser – This fundraiser is easy to do and has been very successful in previous years. Order a batch of colorful butterfly shapes from Tracie Pretak and place them in your local community businesses for sale at \$1.00 each. Community members can have their names written on the butterfly and posted in the store. You can contact Tracie directly at 814-929-5970 to order your butterflies. ✨

TV Production Interested in Ichthyosis

"Medical Marvels and Mysteries" is a new documentary series that will air on Discovery Health in the U.S. The series follows the stories of people who have rare and unique medical conditions, and also highlights amazing medical survival stories.

"Medical Marvels and Mysteries" seeks to educate and inform viewers about various medical conditions, the causes, treatments, and technological advances.

The series is being made by Australia's leading independent television producer – *Beyond Productions* (www.beyond.com.au). We will be filming in the U.S., England, and Australia.

We are interested in talking with individuals about ichthyosis, its characteristics, and the difficulties that they have faced both medically and socially.

Please contact:

Belinda Seaman – Beyond Productions

belinda_seaman@beyond.com.au

Tel: +61 2 9437 2114

Fax: +61 2 9437 2002

AADA Takes Steps to Advance Skin Disease Research

The Board of Directors of the American Academy of Dermatology Association (AADA) recently voted in favor of collaborating with the Society for Investigative Dermatology (SID) on a project to evaluate and quantify the burden of skin disease in the United States. This project will likely have broad implications for the specialty in terms of advocacy with legislators, regulatory bodies, the National Institutes of Health, and third party payers. The decision to support the study is the latest action undertaken by the AADA over the past year that will improve dermatology's ability to press lawmakers for a strong skin disease research agenda in the United States.

The Burden of Skin Disease Project follows on the heels of a number of other actions taken by the AADA to improve its ability to advocate for skin disease research. Last year the Board of Directors approved a reorganization of the Academy's Research Committee. The reorganization has enhanced the AADA's ability to consider research issues efficiently. Following the reorganization, the Research Committee has made reenergizing the NIAMS Coalition a top priority. Advocacy for skin disease research will now be a yearlong endeavor for the Coalition. In the past, the Coalition, which is made up of professional and voluntary organizations, including the AADA, with an interest in the programs of the National Institute of Arthritis, Musculoskeletal, and Skin Diseases (NIAMS), has confined its activities to a sin-

gle day of advocacy meetings on Capitol Hill each year. As part of efforts to expand on these activities, the Coalition is currently planning an event to bring legislative staff members to NIAMS to witness first-hand the work done there and learn about the latest NIAMS-funded research.

Another result of the Research Committee's reorganization was the first ever Skin Disease Research Day on Feb. 5, 2004 on Capitol Hill. The event, which was co-sponsored by the AADA, SID, and the NIAMS Coalition, brought more than 50 dermatologists to Washington, D.C. to educate members of the Senate, the House of Representatives, and their staffs, about the need to increase funding for skin disease research.

In addition to the efforts of the Academy's Research Committee and the Burden of Skin Disease Project, the AADA is collaborating with SID on a second project to identify current funding levels for skin disease research across the various institutes that comprise the National Institutes of Health. The AADA and SID are currently seeking proposals from firms interested in undertaking this project on dermatology's behalf. The information gathered through this effort and the Burden of Skin Disease Project will greatly augment the specialty's efforts to educate lawmakers in the importance of skin disease and to argue persuasively for increased funding for skin disease research.

Reprinted from Dermatology World, Volume 14, Number 7, July 2004.

Editor's Note: The Foundation is a partner in the NIAMS Coalition and participated in the Skin Disease Research Day.

Dr. Eugene Van Scott Receives Distinguished Service Award

Dr. Eugene Van Scott received the Distinguished Service Award from the Dermatology Foundation in 2003. Dr. Van Scott was one of ten visionary founders of the Dermatology Foundation. He has been a member of and generous friend to the Foundation for Ichthyosis & Related Skin Types for many years. Dr. Van Scott also served on the Foundation for Ichthyosis Medical Advisory Board for many years. His concern for people with ichthyosis led him to develop the formula for NeoCeuticals Problem Dry Skin Cream (PDS).

The Dermatology Foundation bestows the Distinguished Service Award – the highest honor the Foundation can present – upon a colleague in recognition for the highest level of dedicated and insightful leadership and service to the dermatology specialty. Dr. Van Scott is only the fourth individual to receive this honor in the past fourteen years.

Excerpted from Dermatology Focus, Vol.22, No.1. Dermatology Focus is a publication of the Dermatology Foundation.

Seniors Speaking

Dear Jean:

Yes! Please continue with the Seniors Speaking column. I think it will just take time for seniors to get connected. Being one of that elite group, I know it is not easy for us to talk about personal problems. We were raised in an age where you never mentioned you had dry skin, much less discussed it with anyone, including family. So give us some more time please, to get comfortable with this column.

I just wrote to one of the authors of a note in Seniors Speaking and hope this starts some sharing of information. Aging with ichthyosis has its own set of problems, as I am just finding out! Most doctors don't understand, or are not concerned when asked questions about the effects of dry skin inside and out. It will be up to the seniors out there to share their experiences and success stories that we can learn from.

Does your conference have a "Senior" session? Is there a dermatologist who would have insight into this area, who could speak or write an article? As the baby boomers age, is this a growing problem? As I can't attend your conferences, I would be

interested in a column/article regarding aging with dry skin problems.

A question for the Seniors Speaking column – I have dry eyes which tear all the time. I also love photography, and the two don't mix well at all! Has anyone found an eye drop that works? I have tried natural tears, lubricants, and drops for allergies, but find nothing works really well. How about ears? I get mine professionally cleaned every year and put a little Vaseline on a Q-tip around the outer edge after my bath. Any other ideas for keeping the dry skin out of the ear canal?

I have found an idea that works. If you wear tights or nylons after putting on your cream, it seems to keep the cream where it does the most good and it doesn't wear off on your clothes.

Thanks for listening, and keep up the good work!

Barb Karas
Gladstone, MI

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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