



Ichthyosis Focus

Vol. 19, No. 4

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

WINTER 2001

Applications Being Accepted for Membership Assistance Fund

This past October, F.I.R.S.T. received many applications for funding from the Jane Bukaty Membership Assistance Fund. The committee reviews these applications twice a year, October and March. The foundation is now accepting applications to be awarded in March. Here's an opportunity to alleviate some of the financial burden that may be facing you and your family. It's easy to apply and you will receive the award in cash! Here's what you need to do:

- Submit a letter indicating your need for funding
- State the amount of money you are requesting. Awards will generally not exceed \$100.00
- Demonstrate the financial need for this product/treatment
- Indicate what product or treatment you want the funding for

Email your request today to info@scalyskin.org or mail your letter to the attention of the Jane Bukaty Membership Assistance Fund at 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446.

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.

An Ichthyosis Update – Part I

This is adapted from a talk given by Dr. Mary L. Williams at the Academy of Dermatology Annual Meeting in San Francisco in March, 2000 and edited by Rita Tanis.

The term "ichthyosis" was coined in the 19th Century to connote the resemblance of the skin condition to fish scales – this, of course, offered no insights into cause or treatments, but provided a name around which further efforts to classify different types could be undertaken. These efforts occupied the next ~100 years. The major advances of the mid-20th century resulted in improved clinical classifications. An example being clarification of the clinical discrimination of lamellar ichthyosis from epidermolytic hyperkeratosis and of ichthyosis vulgaris from X-linked ichthyosis. In the 1970's a few inborn errors of metabolism (i.e., inherited defects due to deficiency of an enzyme) were linked to specific types of ichthyosis (i.e., steroid sulfatase deficiency was identified as the cause of X-linked ichthyosis), and some improved treatments, notably alpha hydroxy acids and retinoids became available. The genetic era began in the 80's with the identification of the steroid sulfatase gene and in the 90's every year or so, one or two new genetic causes of ichthyosis (and its relatives) were discovered. Nothing therefore prepared me for my astonishment as I researched the recent literature in preparation for this talk and discovered that in 1999 and the first 2 months of

2000 no less than 8 new genes causing these disorders had been identified.

The New Genes:

Darier's disease, although not strictly an ichthyosis, falls under the wider umbrella of F.I.R.S.T., because it is a genetic disease in which scaling skin is one of its main features. It was found to be caused by mutations involving the ATP2A2 gene¹. This gene codes for a specific enzyme which is responsible for the regulation of calcium levels within the cell. If the gene is defective, the enzyme function is altered. The calcium concentration inside skin cells is known to be important in cell-to-cell adhesion and also in regulating the process of maturation to form fully mature, outer skin cells (stratum corneum). Therefore, defects in this important enzyme can account for both the tendency to form blisters and the tendency to scale found in Darier's disease. Also in **Hailey-Hailey disease**², another gene was identified this year. ATP2C1 is another gene that also codes for an enzyme which helps regulate calcium concentrations. Patients with this condition have more problems with blistering, but fewer problems with scaly skin than patients with Darier's disease.

continued on page 14

Highlights from
Ichthyosis Awareness Week
See pages 8 & 9

*F.I.R.S.T. Celebrates
20 Years in 2001*

Look for our special 20th
Anniversary Edition of
Ichthyosis Focus in late February.

This issue of *Ichthyosis Focus* has been generously
underwritten by Merz Pharmaceuticals,
distributors of Aqua Glycolic.



Ichthyosis Focus

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

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



Correspondence Corner

Hi Everyone,

My name is Maria Tessinari, a member of F.I.R.S.T., and a Production Coordinator at ABC News 20/20. I am in the process of gathering as many stories as possible because I'm trying to get 20/20 to produce a piece on ichthyosis. I too have ichthyosis, but my case is a mild one. I don't have half the knowledge I would like to about this condition. That is why I would like to ask all of you for anything you can possibly send me, such as stories about yourself, or someone you know, photos, or anything else you might like to contribute. The stronger my case, the better shot I have of convincing the network why a story should be done. You can email me at Maria.I.Tessinari@ABC.Com or write to Maria Tessinari, 147 Columbus Avenue, 10th, New York, NY 10023 Thanks for all your help!!!

Maria Tessinari
New York, NY

Dear Jean:

I read Clem Amore's letter in the last issue of Focus with interest. In it he states, "I would like to join the National Registry but I am not seeing a dermatologist. My treatment is being overseen by my primary care physician." Please tell him and your readers that there are dermatologists who will be happy to help them enroll in the Registry, even if they are not following them actively as patients. Although the Registry is not funded to pay for physician visits, we have tried to work out arrangements with dermatologists around the country to help affected individuals enroll at minimal expense. In some cases for example, at the University of Washington Medical Center in Seattle, the institution has agreed to write off charges for such visits. Many of the participating dermatologists are writing off their charges, or charging a minimal amount.

Anyone interested in help with this should contact us. We'll do our best to help.

Regards,
Phillip Fleckman, M.D.
Registry Director
Seattle, Washington

To join the National Registry, call
800-595-1265.

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

My name is Mrs. Nancy Marie Rusin, prior name Nancy Marie Burgo. I am 43 and I was born with lamellar ichthyosis. I live in Florida, but was raised in Rochester, New York. I believe everyone who has lamellar ichthyosis belongs in Florida. I feel that God had a purpose when he created me. I feel his purpose was for me to let people who have lamellar ichthyosis see that there is hope for their future, having a spouse, having a family, but most importantly, to be able to look and feel as close to normal as possible.

Yes, I am living proof. People who have lamellar ichthyosis or have a child with it look at me and say they never would have thought that I had lamellar ichthyosis. I feel very proud to show off my before and after pictures since I work very hard at taking care of myself. I would love it if I could meet some more people down here in South Florida. I'm not a doctor, but I sure could share with doctors, as well as anyone who may have an interest, about what the Florida weather does for me. I can also share how I coped with lamellar as a child and, most importantly, how well and how far I have come...sort of like a rags to riches story. For those of you who would be interested in getting together, please contact me at: Nancy Rusin, 9647 Richmond Circle, Boca Raton, FL 33434.

Nancy Rusin
Boca Raton, FL

Kids will be Kids, especially at AAD's Camp Discovery

Water sports, campfires and just being silly with other kids are summer activities most children can take for granted. Not so for the children participating in the American Academy of Dermatology's (AAD's) Camp Discovery program, which this past summer completed its eighth successful season of offering children with severe dermatological conditions a place to just be kids.

The week long camp, designed for children ages 10-13, took place in July and August at Camp Knutson in Crosslake, Minnesota. and Camp Horizon in Millville, Pennsylvania. This year, there was also a teen camp held in June for young people ages 14-16 at Camp Knutson. Nearly 200 children attended the three camps this summer.

Camp Discovery offers kids with conditions such as ectodermal dysplasia, ichthyosis, epidermolysis bullosa, and

alopecia areata, the opportunity to enjoy a typical summer camp experience, complete with swimming, water skiing, boating, fishing, and arts and crafts - all with medical supervision.

Perhaps most importantly, Camp Discovery gives the children a chance to interact with others and to make new friends without being defined by their condition. It provides them with the invaluable opportunity to learn that their condition does not have to be an obstacle.

Parents can rest easy knowing that the camp's volunteer staff is uniquely able to handle their children's special needs. The camp is run by volunteer dermatologists and nurses who are familiar with treating the conditions that the young campers have. Many of the counselors have skin conditions themselves, allowing them to serve as role models and mentors to their young charges.

There is no fee to attend Camp Discovery. Costs, including transportation for all the campers, are funded by donations from AAD members, industry partners, dermatologic societies, and concerned individuals. This year, the camp accepted a \$10,000 donation from the Noah Worchester Dermatological Society - the largest donation ever received from a dermatological society, as well as numerous other large donations.

Members of the AAD recommend their young patients as potential participants in Camp Discovery, so talk to your dermatologist today! Applications for next year's camp will be mailed in late February 2001. For more information on Camp Discovery, visit the AAD Web site, www.aad.org, or contact Debby Kroncke at (847) 240-1008, fax (847) 330-0050, or e-mail dkroncke@aad.org.

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ASK THE READERS: What Do You Do?

At the national office we continually receive questions from our members about all different issues. We know that many of you have your own "tried-and-true" methods for your skin care. We also know that many of you have great answers to those difficult questions that are frequently asked by the general public.

We have developed **ASK THE READERS: What Do You Do?** to share this valuable information with others. Each issue will ask a question of our readers and we will print your answers. If you have any advice you would like to share, please take a moment and send in your comments.

How do you answer, "What is wrong with you or your child's skin?"

My daughter and I have Epidermolytic Hyperkeratosis (EHK). When she was very, very young, I taught her how to clearly pronounce Congenital Epidermolytic Hyperkeratosis Ichthyosis. Imagine people's faces when these complex words were coming out of a two-year-old's mouth! Most people responded with the simple word, "Oh." **Reba B.**

I look at this as an opportunity to educate the "unknown" about ichthyosis. I reply, "Thank you so much for asking. I would love to educate you about ichthyosis and I hope you will pass on what you've learned to others." An important reason to answer these questions is so that your beautiful child feels secure in their skin, which was made especially for them. **Lisa A.**

My little boy says "I have ichthyosis skin. This is how I was born." **Lisa D.**

When a child asks me, I tell them that it's just the way my daughter was born. Just like you were born with blue eyes or brown hair, she was born with very, very dry skin. We put a lot of lotion on her. When an adult asks me, I tell them that it's a traffic jam of skin cells. Then most people say, "It will go away when she gets older right?" I have to tell them no and that it's a genetic disease. She will have this all her life. **Susan S.**

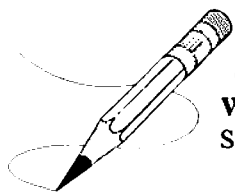
I respond by telling people that my son has rare skin condition and it's x-linked...that he got it from me, his mother. I also tell them that it's just the way God made us. **Leigh D.**

I respond by saying "My son has a genetic skin disorder and he doesn't have the ability to sweat." **Cheryl D.**

Here's our next question:

How do you keep your skin the most moist?

Send us your comments. We will print the responses in the next newsletter. Here's how to contact us:



E-mail: info@scalyskin.org

Fax: 215.631.1413

Call: 800.545.3286

Write: 650 N. Cannon Avenue,
Suite 17, Lansdale, PA 19446

My answer varies. I usually say my daughter was born with severely dry skin but it also depends on who is asking. Sometimes I give more details to people I know and explain it in technical terms. When a stranger asks me, I give fewer details. **Jean M.**

Since my son has just turned three, his classmates are becoming a little more curious about his skin. One new boy in his class recently asked the teacher why my son gets cream put on his skin. The teacher was about to answer, but looked at my son and allowed him the opportunity to answer for himself. He replied, "I have dry skin. It is ichthyosis. The cream makes my skin feel better." For that age group, it was a satisfactory answer. With adults, he's a little more shy and I might answer for him. **Denise B.**

These helpful hints are provided by our members. F.I.R.S.T. does not recommend or endorse specific products or treatments. The information presented here should not be construed as medical advice and does not replace the counsel of your physician. Individual variances in ichthyosis cases require the consultation of a physician. It is important to see your doctor before altering anything in your treatment.

Executive Director's Report

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



I want to thank everyone who donated to F.I.R.S.T. through our summer appeal campaign, distributed in the last issue of the newsletter. Donations are gratefully accepted throughout the year, so if you missed the envelope, please be sure to look in the center flap of the last issue. I also want to thank everyone who took the time to complete the Member Priorities Survey. Your responses to this survey will help set our priorities and shape our programs as we approach our 20th anniversary. The Strategic Planning Committee is hard at work setting goals for the future and your opinions are very valuable.

I am excited to report that F.I.R.S.T. was invited to participate in a film documentary about ichthyosis last month. Lisa Regina, a filmmaker from New York City, is producing and directing a film documentary about Kenny Krips, a 30-year-old man with lamellar ichthyosis. Lisa was childhood friends with Kenny and is determined to create more awareness and understanding about ichthyosis. There will be a screening of the documentary in Philadelphia and New York City by the New Year. It will also be submitted to various film festivals, including Sundance.

This year's Ichthyosis Awareness Week was very successful. Highlights and photos are printed on pages 8 and 9. I would like to thank everyone who participated this year. Even the smallest effort can make a big difference. It's not too late to help out, so call me if you need support or ideas.

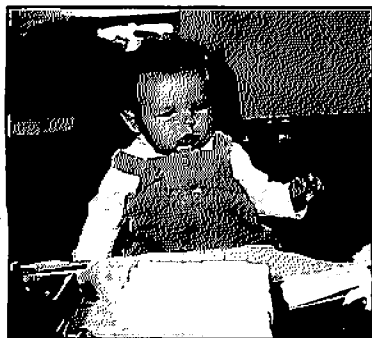
Once again, F.I.R.S.T. will be funding a research grant through the Dermatology Foundation. Special thanks to Neostrata for their generous donation which made this year's funding possible. I am also pleased to report that F.I.R.S.T. received a significant donation from Dr. Eugene Van Scott to help F.I.R.S.T. begin to build a research fund. F.I.R.S.T. looks forward to adding to this fund so we can continue to help young investigators with new ideas.

Our apologies if you have experienced some technical trouble with our website. But we've made some changes and it's fixed and working great. Please remember, there are some areas that are still under construction so bear with us. Visit our website today at www.scalyskin.org.

The restructured Ichthyosis Support Network is officially up-and-running. Lori Schreiber, our program director, along with our volunteer coordinators, are ready to help you with your questions and concerns. This network is for you, our members. You are not alone, so take advantage of the opportunity to talk with others who share similar life experiences. You will make new friends and build lifelong relationships. See pages 11 and 12 for more information.

Sincerely yours,

Jean R. Pickford



The office welcomes our newest employee, Kellie Ann Pickford, who arrived on August 14th. She is very productive and keeps us on our toes.

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Board of Directors



Donna Rice, President

Ms. Rice has been a member of F.I.R.S.T. since the 1992 birth of her daughter, Haley, who has ichthyosis. She has been a volunteer coordinator of the support network for 8 years and has served on F.I.R.S.T.'s Board of Directors for the past 5 years. Ms. Rice is in her second term as board president, has testified before congress as an advocate for F.I.R.S.T. and reports to the medical advisory board at their annual meeting. Ms. Rice is the stay-at home mother of 4 children between the ages of 22 and 7. She and her family live in a small farming community near the gulf coast of Texas.



Leonard Milstone, M.D., Vice-President

Dr. Milstone has been a member of the Medical Advisory Board of F.I.R.S.T. since 1982 and has chaired that group since 1989. He is Professor of Dermatology at Yale University School of Medicine and is Chief of the Dermatology Service, Veterans Administration Connecticut Healthcare System. In addition to his clinical and administrative duties, he actively pursues his interest in research which currently is directed toward iron metabolism in skin. Dr. Milstone is an internationally recognized expert on the diseases of ichthyosis and related skin types, and is an Associate Editor of the Journal of Investigative Dermatology.



Mary Williams, M.D., Secretary

Dr. Williams received her medical degree from the University of Chicago School of Medicine in 1969. Following an internship in pediatrics there, she moved to California to complete her pediatric and dermatology residencies at the University of California San Francisco, where she has remained as a faculty member. Currently, she is an Adjunct Professor of Dermatology and Pediatrics and Chief of the Pediatric Dermatology Service. Her interest in ichthyosis began during her dermatology residency, when she participated in the initial clinical trials of isotretinoin (Accutane) for disorders of cornification. With one of her patient's mothers, Mrs. Barbara Landwehr, she co-founded the National Ichthyosis Foundation, subsequently renamed F.I.R.S.T. In addition to her clinical activities, Dr. Williams has teamed with her husband, Dr. Peter Elias, to investigate the causes of ichthyosis in their research laboratory.



Laura J. Phillips, Chief Financial Officer

Ms. Phillips is a Senior Manager in Ernst & Young LLP's National Professional Practice group at the firm's offices in Cleveland. She is responsible for developing and interpreting auditing guidance for the firm's U.S. practice and is nationally recognized in the area of derivatives and hedging. Ms. Phillips is also a Technical Audit Advisor to the Auditing Standards Board of the A.I.C.P.A. Ms. Phillips is a Certified Public Accountant, as well as a Certified Information Systems Auditor. Ms. Phillips and her husband horseback ride together and she continues to be active in competitive show jumping and dressage.



Michael F. Dunleavy

Mr. Dunleavy is Corporate Vice President - Business Development at Crown Cork & Seal Company. Joining Crown Cork & Seal Company in 1992, Mr. Dunleavy opened their first steel and aluminum Coil Coating facility in Toledo, Ohio. During the past several years he has been responsible for Corporate Strategic and Implementation Planning and been active in corporate restructuring and organizational development. Mr. Dunleavy is active in Community, Educational, Economic Development and Charitable Organizations. He serves on the boards of the Pennsylvania Chamber of Business and Industry, PhAME Inc. (Philadelphia Area Accelerated Manufacturing Education), Pennsylvania Educational Consortium, Team Pennsylvania Foundation, Nazareth Hospital Foundation, United Cerebral Palsy, and F.I.R.S.T.



Gloria F. Graham, M.D.

Dr. Graham is in the private practice of dermatology at Grahams' Dermatology Services, P.A. in Morehead City, NC. She received her medical degree from Bowman Gray School of Medicine (AOA), Winston-Salem, NC in 1961. She took her residency training in dermatology at the University of Virginia, Charlottesville, VA from 1962 to 1965. She is the author of 50 publications. When she is not practicing dermatology, she and her husband, Dr. James H. Graham, frequently travel.



Elizabeth Gray

Ms. Gray is the full-time mother of four children, ages 1 through 14. Her son Matt, 9 years old, has lamellar ichthyosis. Ms. Gray joined F.I.R.S.T.'s Board of Directors in January 2000. She also serves as vice-president for the Clarke College Alumni Board and is a founding member of Greater Elkhorn Recreational Trails, Inc. Ms. Gray currently works as an independent consultant and adjunct professor at Bellevue University. She is an avid biker and reader.



Tiffany Karst

Ms. Karst is the mother of Jessa, 8 years old, who has lamellar ichthyosis. She has a master's degree in Social Work and is a medical social worker at the University of Kansas Hospital in Kansas City, Kansas. Ms. Karst attended her first family conference in Chicago in 1993 and has been very involved with F.I.R.S.T. since that time. She joined the board in 1996 and is in her second term as a board member. With her family, she organizes an annual fund-raiser that has become a tradition for their friends, family, co-workers and their neighborhood.



Glenn Oclassen

Mr. Oclassen founded Oclassen Pharmaceuticals, Inc. in 1985 and served as a director since the company's inception. He was President and CEO from 1975 until 1991, and became Chairman of the Board of Directors in January 1991. The company was acquired by Watson Pharmaceuticals, where he continues to serve as an advisor. Mr. Oclassen is a Special Limited Partner in Montreux Equity Partners and is founder and chairman of NextDerm, Inc., a company recently acquired by Procyte, Inc., where he serves as a member of their Board of Directors. Mr. Oclassen is a member of the Cutaneous Therapy Society and the North American Clinical Dermatological Society.



Daniel J. Siegel, Esq., General Counsel

Mr. Siegel is a partner with the Philadelphia law firm of Gay & Chacker, P.C. He received his A.B. degree from Franklin and Marshall College and his J.D. from Temple University School of Law. Mr. Siegel's practice is concentrated in the areas of workers' compensation, Social Security disability, personal injury, civil litigation and appellate practice. Mr. Siegel has been active in various capacities with many non-profit organizations, as an officer and as counsel, for many years. Mr. Siegel is married to Eileen Watts and has two sons, Bradley, 9, and Douglas, 6, both of whom have x-linked ichthyosis.



Rita Tanis

Ms. Tanis, age 44, has lamellar ichthyosis and has been involved with F.I.R.S.T. since its inception. She has a bachelor's degree in biochemistry from Boston College and attended graduate school at the University of California at San Diego. Ms. Tanis enjoys a career in real estate in Fairfield, CT where she resides. She has two wonderful boys, Tod, age 11 and David, age 9, and a new little puppy, Loki.



Peyton Weary, M.D.

Dr. Weary is a professor of Dermatology at the University of Virginia in Charlottesville where he has been teaching since 1961. He is also an active member of the American Academy of Dermatology. A former President of the Academy, he currently serves on the Cost Effectiveness Task Force as well as the Council on Research. In addition to his work with the American Academy of Dermatology, Dr. Weary is a member of the editorial advisory boards of the *Journal of the American Academy of Dermatology* and *Skin and Allergy News*.

Ichthyosis Awareness Week

October 1 – 8, 2000



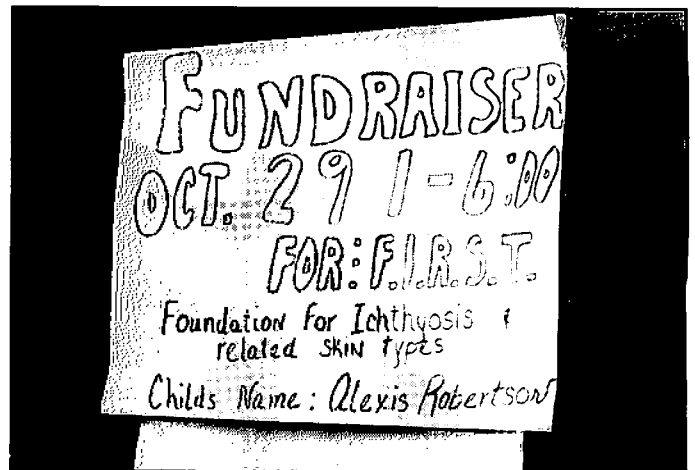
A Sacred Music Concert to Benefit F.I.R.S.T. Presented by Bailey Jones & Friends With Special Guest Kelly Walters



Jennetta Barrow and grandson, Morgan Barnes, working on Lonestar Quilt for Bell Point Quilters Guild Auction



The 1st Annual 5K Fun Run organized by Dawn Johnson.



F.I.R.S.T. fund raiser organized by Barbara Robertson.

This year's awareness week was a great success. Thanks to many of our members, we were able once again, to spread the word about ichthyosis and F.I.R.S.T. Even though we encourage everyone to promote awareness and fund raising during Ichthyosis Awareness Week, this is an ongoing project. It's not too late for you to get involved...your support is needed throughout the entire year. F.I.R.S.T. is only as strong as its membership, and we continually need your help.

Special thanks to the following volunteers for their efforts this year in helping create a better understanding of ichthyosis and raising funds for F.I.R.S.T.:

Lynne Alba...participated in a cash-back program through her local supermarket.

Jasjot Anand...collected donations from her community by placing collection cans and brochures in local businesses. Also wrote an article which was published on the internet at www.nariworld.com.

Merritt Andrews...wrote to friends and colleagues about her life and how important F.I.R.S.T. was to her. Also wrote to many television talk shows and magazines.

Lisa Austin...wrote to the Oprah Winfrey Show and other television talk shows.

Les Avakian...wrote to the Oprah Winfrey Show and other television talk shows.

Jennetta Barrow...made a gorgeous Lonestar quilt and auctioned it off in her local community (*see photo*). Spoke to colleagues at her medical center about ichthyosis. Jennetta also created a unique baby toy. All sales from this toy are being donated to F.I.R.S.T. If anyone is interested in purchasing this Hug n' Go toy, e-mail Jennetta at thingsofcloth@peoplepc.com.

Denise Benedetto...wrote to television talk shows, information news programs and magazines.

Gerri Farnworth...wrote to the Oprah Winfrey Show and wrote a very touching, personal story which will be published in her company's magazine, which is distributed around the world.

Polly Fitzgerald...wrote to television talk shows and local newspapers.

Lori Florian...organized a Santa fund raiser in her local community.

Angela Godby...wrote to the Oprah Winfrey Show.

Beth and Matt Gray...sold pumpkin suckers at their local elementary school.

Terri Hamrick-Oeschger...participated in a cash-back program through her local supermarket.

Donna Hoar...organized the "Release the Butterfly" fund raiser in her local community.

Tiffany Karst...organized annual community garage sale with all proceeds donated to F.I.R.S.T.

Dawn Johnson...organized the "Monster Dash," 1st Annual 5K Fun Run (*see photo*).

Shauna Johnson...organized the "Release the Butterfly" fund raiser and wrote to local newspapers.

Nicole McMillian...wrote to the Oprah Winfrey Show and served as a representative of F.I.R.S.T. at an awards dinner.

Frank Mele...donated funds from a local civic organization to F.I.R.S.T.

Michelle Nightengale...wrote to local newspapers.

Nancy Noe...organized the "Release the Butterfly" fund raiser in her local community.

Eustolia Perez...wrote to local newspapers, friends and relatives about ichthyosis and F.I.R.S.T., which resulted in substantial donations to F.I.R.S.T.

Tracie Pretak...originator of the "Release the Butterfly" fund raiser and organized an annual Spiritual Concert with daughter, Bailey Jones (*see photo*).

Donna Rice...participated in a cash-back program through her local supermarket.

Barbara Robertson...(*see photo*) organized a giant garage sale and fair in her local community where all proceeds were donated to F.I.R.S.T.

Dan Siegel...sold Entertainment Books with proceeds donated to F.I.R.S.T. and participated in a cash-back program through his local supermarket.

April Sproull...wrote to the Oprah Winfrey Show.

Maria Tessinari...lead singer of a rock n' roll band, donated proceeds from one evening's performance.

Paula Wetterlund...organized the "Release the Butterfly" fund raiser in her local community.

We want to thank and recognize all our members who help F.I.R.S.T., so please let us know if your name was omitted.



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outer carton and
2. Original cash register receipt for your
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What's New, What's Hot & What Works...

I have a mild to moderate case of x-linked ichthyosis. As I was growing up, summers were better because I was in the sun and sweating, but winters were often embarrassing. I've been treating myself with homemade ammonium lactate for the past ten years, which works great for me. It is odorless (a faint odor until it dries) and invisible. I shower before bed and put the lactate on my whole body, except scalp. A spray bottle, like those containing window cleaner, is a handy way to apply. The scales on my body have almost completely disappeared, although the back of my calves just above the ankle never clear up completely. Wearing shorts and short-sleeve shirts is fine now. If anyone is interested in learning how I make my homemade ammonium lactate, please contact me at Jhartley@lifetech.com.

Jim Hartley, Frederick, MD

With my doctor's insight and support, I decided to make my own compound to try on my skin (and my children's also). We

have been greatly blessed and have seen the greatest improvement ever. I mix lactic acid (20%) in glycerin and apply to skin after shower or bath. I started with 10% and increased the amount until I saw the desired results. Please be cautious around the eyes (I don't use this on my face, but watch if children rub eyes after application to hands).

You may experiment to find the right strength for you. This formula was a Godsend during the summer months. I'm not sure of its effectiveness in winter...we'll see.

Jackie Koutsoukos, Ijamsville, MD

I am 63 years old and have congenital epidermolytic hyperkeratosis ichthyosis. My daughter who is 34 years old also has the same skin problem. My bathing regime every two days for the past several years is as follows:

Shower and wash with a good bar soap, rinse well with clear water, wash

with a body wash containing moisturizer, rinse well with clear water, apply "Jergens's Shower Active Moisturizer", rinse well with clear water, apply a good baby oil, spray body with glycerin and rose water, use NO towel and apply a good body lotion.

For about one month, I've been unable to purchase "Jergens's Shower Active Moisturizer" and my skin shows this situation. When I called Jergens, I learned it had been taken off the market. They informed me that if "enough" people called concerning this, it could possibly be brought back. Possibly some people could call for samples expressing your concern for the skin dryness that your skin condition exhibits. Please call 1-800-742-8798 for the Andrew Jergens Co.

This in-shower therapy for maximum moisturization is remarkable. Your assistance in this matter would be greatly appreciated.

Reba Benson, Owensville, IN

ISN Ichthyosis Support Network



Dear ISN Members,

As many of you are already aware, we have been spending a lot of time and energy reorganizing our Support Network. We believe it will now be much stronger and more viable than ever before! To help all the members who want to be more involved in this network, we have taken a couple of steps. First, we

distributed some membership forms to prior ISN members, to update our records. Next, we identified 15 people to be our new coordinators, based on disease type not region. You will see them introduced on the next page. Our third step involved training these volunteers. They have each been equipped with a manual that includes information on call procedures, counseling tips, and resource information. Lastly, the coordinators were given copies of those updated forms, which many of you sent in. Then, when new callers contact the national office, they can efficiently receive a referral to another trained member for support.

Two other ideas came to us when we restructured the ISN. We decided to include an ISN page in every issue of the

FOCUS. This way, everyone can be kept informed about the network, and people who have not previously joined may choose to become members at a later date. Secondly, many people who did return their membership form checked off boxes pertaining to training. Since the demand was so high, we have decided to use this ISN page of the FOCUS for some "hands-on" training, as well. So, this issue will include some information from our resource page of our training manual (see below). Future issues will cover topics such as effective listening skills, grieving a loss, and stress reduction techniques. We are definitely open to other topic ideas!

If you have decided to join the ISN, welcome. Please do not get frustrated if you are not called as a potential support person. We try to match people up with incoming callers according to many factors, and as F.I.R.S.T. continues to grow, there will be many, many opportunities to get involved.

If you have not joined but would still like to, just contact me at the national office at 800-545-3286.

Lori

Lori Schreiber

ISN Education & Training

WEBSITE RESOURCES

<http://www.scalyskin.org> – The Foundation for Ichthyosis and Related Skin Types' official website.

<http://www.ichthyosis.com> – Ichthyosis Information website which is privately owned and operated by 2 members of F.I.R.S.T. Their site offers a bulletin board, chat room, resources, helpful hints, and links to other sites.

<http://www.skinregistry.org> – The National Registry for Ichthyosis and Related Disorders is supported by the National Institutes for Health to encourage more research into diagnosis and treatment of Ichthyoses and related disorders. The Registry offers a means of empowerment for affected individuals and family members. The Registry enables scientists and investigators to share information in a confidential manner about ongoing and future research projects with the people who are most affected. This site has many good links to other helpful websites.

<http://www.rarediseases.org> – the National Organization for Rare Disorders Inc. (NORD)—provides information on more than 6000 rare diseases, including current research, publications from scientific and medical journals, completed research, ongoing studies, and patient support groups.

<http://www.geneticalliance.org> – The Alliance of Genetic Support Groups, Inc., is a nonprofit organization founded in 1986 as a national coalition of consumers, professionals and genetic support groups to voice the common concerns of children, adults and families living with, and at risk for, genetic conditions.

<http://www-hsl.mcmaster.ca/tomflem/skinp.html> – Health Care Information Resources makes information about health and disease accessible in the belief that the informed consumer is a more satisfied consumer of health-care. This service does not offer advice about health or healthcare and cannot substitute for a healthcare practitioner.

<http://www.medlib.iupui.edu/hw/derma/group.html> – Dermatology Organizations and Groups.

<http://www.kumc.edu/gec/support> – Genetic/ Rare Conditions Support Groups & Information Site.

<http://www3.ncbi.nlm.nih.gov/omim/mimlink.html> – National Center for Biotechnological Information provides online searches of a database of human genes and genetic disorders

AND INTRODUCING...Our new ISN Coordinators:

Les Avakian X-Linked Coordinator, from Fresno, CA. Les is 45 years old and an owner of an electrical contracting company. When asked, Les says his hope as a coordinator is to network with as many people as possible, and also to make lifelong friends. Les can be reached at (559) 228-4050, or emailed at lesthan@aol.com.

Denise Benedetto lives in Wantagh, NY. Her son, Marc, was born with lamellar ichthyosis in March 1997. In addition to being involved with F.I.R.S.T., Denise also teaches kindergarten. She can be reached at (516) 826-4579, or emailed at DenmarcNY@aol.com.

Debra Brodeur is from Southbridge, MA. Her 3-year-old son, Joshua, was diagnosed with a mosaic form of EHK when he was 6 months old. This is her first year of involvement with F.I.R.S.T., and she is happy to be one of the EHK coordinators. Debra can be reached at (508) 765-5263, or emailed at djb5263@aol.com.

Lisa Donovan from Medfield, MA is the mother of 6 wonderful children, ranging in age from 15 years to 2 1/2 years old. Her 5-year-old son, Derek, has Ichthyosis Bullosa of Sieman's, which is a variance of EHK. Lisa is currently in a Bachelor's program majoring in Sociology/ Anthropology, as well as working part time at Shriner's Hospital as a Child Life Specialist. Her phone number is 508-359-2455.

Leigh Dry is one of our x-linked coordinators. Her father, age 75, has ichthyosis, as do her two sons, Steven, 12, and Matthew, 8. Currently her family is relocating from Houston to Boston, for her husband's career. Leigh has completed half of her M.Div. at Southern Methodist University, and hopes to finish her degree at Boston University.

Lori Florian lives in Boulder City, NV, outside of Las Vegas. She has a 5 year old daughter, Shelby, with CIE. Lori can be reached at 702-294-2915, or reached by email at lfo456@aol.com

Tom Frost and his wife, Carol, live in Herndon, VA, which is near Washington, D.C. Their daughter, Margaret, now age 13, was diagnosed with Nethertons Syndrome at age 2. She

has attended Camp Horizon for 5 consecutive years and the family has been in contact with F.I.R.S.T. for several years. Tom can be reached at 703-318-9440 or tfrost@aol.com.

Deidra Long and her husband, Dan, have 2 boys, Ethan who is 10 and Evan who is 8. Evan was diagnosed with EHK at age 2 weeks. Dee became involved with F.I.R.S.T. when Evan was 2, finding the organization through the National Organization for Rare Diseases. Dee feels that being able to talk to other parents has made a big difference in her life, and would like to provide that same support to others. She also feels that Evan's condition led her to her career, teaching children with disabilities. She can be reached at (419) 947 -5933 or DANDEE@Redbird.net.

Jean Meeker has been a member of F.I.R.S.T for 3 1/2 years. She lives in New Jersey, near Atlantic City, with her husband and 2 daughters, Amanda age 5, who has CIE and Danielle, age 3. She can be reached at 609-272-8871, or email her at Jmeeker81@hotmail.com

Patrice Russell has been involved with F.I.R.S.T. for about 3 years. Her darling daughter, Roni, who is now 3 1/2 years old, has lamellar ichthyosis. Patrice is one of two lamellar coordinators, and has really enjoyed the contact with other parents. She can be reached at (912) 748-8396 or emailed at Tressey5@juno.com

Marie Schuster has been a member of F.I.R.S.T. since 1993. She has been diagnosed with both ichthyosis vulgaris and eczema. She is the only member of her family to have ichthyosis. She is single, without children, but does have a pet iguana. She can be reached at 608-833-4381 or mschuster@aomad.com

Patti Steinitz has been very involved with F.I.R.S.T. and advocating for children with special needs since her daughter, Hunter, age 7, was born. Through this advocacy, Patti feels she has become well educated on Medicaid, insurance companies, and education law. As the Harlequin support coordinator, Patti has enjoyed communicating with many families dealing with Harlequin and other forms of ichthyosis.

Maria Tessinari is 26 years old and lives in Dumont, NJ. She is currently working for ABC News in New York. She has ichthyosis vulgaris and says she is glad to be a coordinator. She wishes that there had been a support network like this when she was growing up!

Deb Vilas has CIE. She has been a member of F.I.R.S.T. for almost 10 years, and has served in various capacities on the Board and with the support network. She is a child development specialist, and is currently pursuing a master's degree in Social work at NYU. Deb lives in NYC with her significant other, Jeff Krauss, and her three cats, Babe, Max, and Mojo.

Bette Winkel has a 19-year-old son with Darier's Disease, who handles all the flares well, and copes with all of the social ramifications. Her son was diagnosed at age 15 and is being seen by doctors at the Mayo Clinic in Rochester. Bette is a nurse who is currently working at a clinic near her home.

REGIONAL CONFERENCES

Please watch for upcoming information about regional meetings, planned for the Spring/Summer 2001. The first of these one-day events will take place in Houston, Texas. Subsequent meetings will take place in other cities around the country. We are looking into the Chicago area as a possibility for the second site. If you would like to be involved in the planning of a regional event, please contact us at the national office, 1-800-545-3286.

In general, the goal in taking care of ichthyosis is to hydrate (moisturize) the skin, hold in the moisture, and keep scale thickness to a minimum.

**Foundation for Ichthyosis & Related Skin Types, <http://www.scalyskin.org>*



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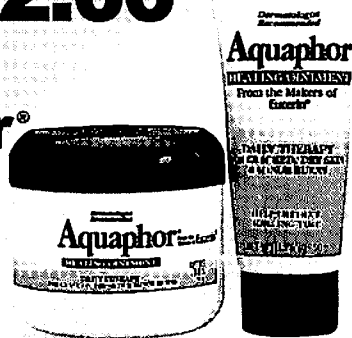
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An Ichthyosis Update - Part I

continued from page 1

Cholesterol is an essential component of the plasma membrane that surrounds each cell, and also of the membranes lying between the cells of the stratum corneum. In these outer skin layers, cholesterol acts to prevent too much evaporative loss of water from the interior of the body to the drier atmosphere. Several genes encode specific enzymes that are responsible for the synthesis of cholesterol. A mutation in two of these genes has been linked to rare ichthyosis syndromes (i.e., **Conradi-Hunerman-Happle syndrome** and **CHILD syndrome**). Cholesterol and other by products play many other roles in cellular functions, hence the effects of these enzymatic defects may be quite complex. We do know that skin is particularly vulnerable to defects involving cholesterol synthesis, because, unlike other parts of the body, the cells of the outer skin layers (epidermis) are unable to take up cholesterol from the blood stream, and, there-

fore, cannot bypass problems in cholesterol synthesis by using preformed cholesterol from the diet.

Several new genes have also been characterized in which mutations can cause **palmoplantar keratoderma (PPK)** where the thickened outer skin is restricted mostly to palms and soles. These genetic defects involve structural protein systems, i.e. one of the proteins of desmosomes and one of the keratins which form elaborate cellular networks within the epidermis to ensure stability and integrity of the epidermal cell layer.

Tracing the link from genetic cause to effect becomes more complex in a disorder such as **Dyskeratosis congenita**. Most commonly an X-linked recessive disorder that, similar to X-linked ichthyosis, affects primarily males, there are many clinical abnormalities associated with this disease. The gene affected in this syndrome, **DKC1**, codes for a protein involved in synthesis of ribosomes¹.

Ribosomes are the site in the cell where the information from the DNA in the nucleus is translated into protein via messenger RNA. Because all genetic information from the nucleus passes this way, it is perhaps not surprising that there are so many diverse effects from a mutation involving this gene.

Finally, other genetic breakthroughs of this past year were the identification of connexin gene mutations in two scaling skin disorders (i.e., **Erythrokeratoderma variabilis** and **Vohwinkel's syndrome with deafness**). Connexins are also specialized structural proteins and when these proteins are altered, the cell to cell communication network is adversely affected.

(To be continued next issue)

1 Sakuntabhal, et al, Nature Genetics 21:275, '99.

2 Hu, et al, Nature Genetics 24, 61, '00.

3 Knight, et al, Am J Hum Genet 65: 50, '99.

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Spotlight On... Merritt Andrews

Once upon a time, 30 years ago, I was born with lamellar ichthyosis...

My name is Merritt Andrews and I start off my story as a fairy tale because like many fairy tales, my story has a happy ending.

I was born in Salisbury, MD to Joe and Marjorie, two very loving parents. When I entered this world I looked like a glazed donut, I was covered in a thin layer of shiny skin. I was officially diagnosed when I was a year old, after a core of skin removed from my back revealed that I had the genetic skin disorder ichthyosis, meaning "fish skin." No one else in my family had it until my brother Joe Jr. was born 2 and a half years later.

Lamellar ichthyosis is characterized by broad, dark plate-like scales separated by deep cracks. Our skin is constantly dry, flaky, itchy and on many occasions would crack and bleed. Thick scales can block pores making it difficult to sweat, putting us at risk of overheating. Joe and I were never able to sweat so we had to limit our outdoor activity during the summer when we were growing up for fear that we would pass out due to heat exhaustion.

My parents tried every "cure" out there

to make us feel more comfortable. When I was 4, on the recommendation from a friend, my mother coated me with a sticky ointment and began wrapping me in Saran Wrap. She recalled that I looked up her sadly and asked "Why Mommy?" Holding back tears, she replied "I don't know, honey, but it's not necessary." She removed the wrap never to put me through that again.

As much as my skin was a curse it has also been a blessing.

In 1977, Joe and I went to Temple Skin and Cancer Hospital and had 12 circles drawn on our torsos to which my mother applied 12 different lotions to see what worked best. What seemed to show improvement on my brother did not work for me and vice-versa. The lotions that worked great on both of us smelled so bad if applied all over, no one would want to be around us. If a lotion burned, Mom would blow on our skin until it cooled. We settled on Lubriderm unscented, which we use to this day, and Retin A.

The dry, flaky appearance of lamellar ichthyosis made us vulnerable to the igno-

rance of society. I had a darker complexion than my brother so my skin looked worse. Many strangers or school bullies ridiculed, stared at and ostracized me. I got called every reptilian name; mostly "alligator" or "crud-neck", "scabies", "leper", "flaky", etc. People even thought I was contagious or dirty, because of the dark patches of skin, and would be afraid to touch me or come near me. Some would ask if I was burned in a fire or badly sunburned. Most would just stare in disgust.

I did my best to fit in by wearing turtle-necks and long pants to hide my condition but when the weather got warm it was "open season" for the ridicule. My parents would tell us that the people teasing us had low self esteem and picked on us to make themselves feel better. I expected it from children but when adults would make rude remarks, it really hurt. As I got older, I would get clever with my responses. If someone asked "What's that on your neck?" I responded, "Oh my gosh, it's my head!" If they stared for too long I'd retaliate and stare back even harder and longer.

When I looked in the mirror I didn't see my dry skin, I saw "me" and never



15 Months



9 Years



12 Years

thought of myself as different until someone would point it out to me in a cruel and intentional way. It took days to feel human again, instead of a freak of nature. I tried to ignore it for a while but as many of us know, words and actions leave emotional scars that take a lifetime to heal. Mom was strong and comforted us when the insults made us cry, but then she'd go behind closed doors and sob. She later revealed that she would ask God to take it from us and give it to her. I suppose all parents want their kids to enjoy an easy life.

I spent a lot of my childhood playing indoors by myself. In the summer, it was too hot and in the winter, the cold air made my skin crack and hurt. I was blessed with a creative imagination and artistic talent. I made up stories with my toys or drew constantly. Most of my stories and drawings were about beautiful princesses who were admired and loved by millions of people. They were perfect and the world accepted them. In school, it was hard to be accepted looking the way I did, so I would do drawings for my classmates to get them to talk to me and be my friend. I used my artistic ability as a way of getting that admiration that I could not get in the physical sense.

As much as my skin was a curse it has also been a blessing. I am very lucky. I was not born blind or deaf and I can walk and talk and I have full function of my mind and body. All I have is dry skin, nothing else. I learned compassion towards others with disabilities because I knew

what it was like to be different. There are so many people less fortunate than me.

In 1986, my dermatologist, Dr. Howard Hines, prescribed LacHydrin 12% to use on my face and neck and the results were incredible. My face became smoother and I didn't have to hide my neck behind turtlenecks. The lotion was too greasy and expensive to use all over and I had to be careful when I went out in the sun, but from the neck up, I looked normal.

I pursued my art and went to college at Ringling School of Art and Design in Sarasota, FL. I worried about the hot climate all year round but the high humidity actually helped my skin stay moisturized. In 1993, my dream of becoming a Walt Disney animator became a reality and I moved to Orlando to work on "Pocahontas", "Mulan", "Tarzan" and our current project, "Lilo and Stitch".

1993 was also the year I discovered F.I.R.S.T. Before moving away from Salisbury, Dr. Hines asked me to try a new non-prescription lotion called Aqua Glycolic Hand and Body. I could use it all over because it wasn't greasy and it soaked in fast. It burned a little at first but within a month my body was no longer flaky. My skin would peel like a sunburn and stay smoother for longer periods of time. I loved the product so much that I wanted to purchase it in bulk so I called the company. They informed me that through F.I.R.S.T. I could buy Aqua Glycolic at half price, so I joined the

foundation immediately and attended my first conference last July where I made many lasting friendships.

Now, no one notices my skin, I look like everyone else but I work hard on keeping my skin smooth. Every morning I shower using Safeguard anti-bacterial soap (I find I'm allergic to Ivory or scented soaps) and any type of shampoo. After towel drying, I use Sea Breeze Toner for sensitive skin to clean my face (because I will get the occasional pimple) and wash that off. I apply Lubriderm unscented as a base coat to my face and then LacHydrin 12%, avoiding my eyes and mouth, to my neck and face. The Aqua Glycolic lotion goes everywhere else. I will use Retin A on my neck when it feels a little dry to help it peel faster.

Being born different has taught me so much compassion for others and made me realize how fortunate I truly am.

Once a week, usually on a Saturday, I will take a long, warm bath adding glycerin and a generic aloe vera bubblebath to it. When my skin softens I begin exfoliating with my fingernails or one of those meshy scrunchies. My skin is a bit red and tender afterward but that soon goes away. I also go to a tanning bed about once a week because I find that helps get my skin to dry and peel quicker. Since moving to Florida 7 years ago, I can tolerate the heat better, and even sweat a lot when I'm outdoors. It is hard to say what is the major factor in my skin's improvement; the weather or the Aqua Glycolic, or both. I know I am not cured – but I have come such a long way. I am so grateful that I have found things that work for me.

As I look back on my life, I would not change a thing because through my experiences of having ichthyosis, I have become a much stronger person. I developed a sense of humor to get through the hard times and made lots of "true" friendships. Being born different has taught me so much compassion for others and made me realize how fortunate I truly am. We are all born unique, it is in accepting ourselves and others – just as we are – that we become whole people.



14 Years



26 Years

In Loving Memory of Judy Ahrens...

Because of the perseverance of her sister, last year Judy Ahrens was finally able to learn the name of the skin disorder she was affected with all her life. It was truly an enlightening experience for Laverne Schwartz, Judy's only sibling, when she received a call from a member of F.I.R.S.T. who lives in South Dakota. It was then that Laverne learned other people were affected with ichthyosis like her sister and there was a foundation out there to help them. For almost 59 years Judy battled ichthyosis, which went untreated for almost all of her life. Unfortunately Judy had to battle cancer in the last part of her life too. Laverne's determination to help in that fight against cancer started the search to find out more about Judy's skin disease. Sadly, Judy passed away this past June from various infections caused by the vulnerability of her skin. Her family requested donations be sent to F.I.R.S.T. in her memory. Our heartfelt condolences and sympathy go out to Laverne Schwartz and Judy's entire family, for she was a wife, mother, grandmother, aunt and dear friend.



Italian Corner



In 1999, Felice, Gianfranco and Piergiorgio (three members of F.I.R.S.T.) created the "Italian Ichthyosis Group" for people affected with ichthyosis living in Italy. This group is constantly growing, and at present

they group together over 25 patients. On May 21st their first conference was held in Milan. On July 9th, several members had a meeting in Arezzo, which is located near Florence, Italy. Pictured from left to right: Serafino, Elisabetta, little Valerio, Gianfranco, Felice, Gianni.

Italian readers can contact:

1 - Felice Geppert (the spokesman of the group)

Via D.A. Vassalli, 3 - 84128 SALERNO

Tel.: 089 753100

e-mail: geppert.asnpv@mail.com

2 - ANSPV - Via Bergognone, 43 - 20144 MILANO -

Tel./Fax: 02 8321834

Website: <http://web.tiscalinet.it/asnpv/ittiosi>

e-mail: asnpv@tiscalinet.it

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News & Notes

Face Facts - A Group for the Facially Different

Face Facts is a group dedicated to promoting the safety and well-being of the facially different through awareness and political action. This organization advocates for all people living with facial difference from any cause, including but not limited to skin disorders, burns, craniofacial disorders or trauma. They document hate crimes, harassment and abuse suffered by people that are facially different, and they work to alleviate dangerous conditions. One of its members is filing a brief with the Supreme Court regarding protections for the facially different under the ADA. They have hundreds of members and associations with organizations such as Aboutfaces and Guide for the Disfigured. Membership is open to all individuals interested in the well-being and safety of the facially different. Please contact them at facefacts@today@yahoo.com or 703-360-8109 if you have a story you would like to share or you would like more information. You can also visit their website at www.geocities.com/facefactstoday.

How to Find Medical Information

Confused about where to look for reliable medical information? Want to know more about your prescription? Searching for the meaning of a medical term?

With the National Institute of Arthritis and Musculoskeletal and Skin Diseases' (NIAMS) new booklet, *How To Find Medical Information*, you can learn how to use the Internet, libraries, phone or fax services, and many other sources to get answers to your questions. All you need is a little old-fashioned perseverance!

If you want to make informed decisions about health care for yourself and your loved ones, this free, 20-page booklet can help you gather information that will assist you in working with medical professionals. The more you can learn about your health, the better you will understand how to prevent illness, maintain optimal health and address your specific health concerns.

For your copy of *How To Find Medical Information*, and for more information on arthritis and musculoskeletal and skin diseases, write to: National Institute of Arthritis and

Musculoskeletal and Skin Disease Information Clearinghouse, 1 AMS Circle, Bethesda, Md., 20892-3675; call: (877) 22-NIAMS (free call); fax (301) 718.6366; TTY (301) 565-2966; or e-mail: niamsinfo@mail.nih.gov. You can find the booklet on the Internet at: <http://www.nih.gov/niams/healthinfo/howto.htm>. You can also call NIAMS Fast Facts at (301) 881-2731 from your fax machine telephone to receive information on arthritis and musculoskeletal and skin diseases.

National Information Center for Children and Youth with Disabilities (NICHCY)

NICHCY is a clearinghouse that provides information on disabilities and disability-related issues. Children and youth with disabilities (birth to age 22) are their special focus. They are pleased to respond to your questions, and have much information to share.

Anyone may contact NICHCY for information. Please call today or visit their website. All their publications, and many other resources, are available on-line. NICHCY, PO Box 1492, Washington, DC 20013-1492, 800-695-0285 Voice/TTY, 202-884-8200 Voice/TTY, 202-884-8441 Fax, nichcy@aed.org E-mail or www.nichcy.org Web.

Adoption Opportunity

World Association for Children and Parents (WACAP) adoption agency is representing a nine month old girl from an Asian country who has an ichthyosis diagnosis with eye opacity. For more information about adopting this child, please contact: Tim Meagher, Waiting Child Advocate, 206.575-4550, waitingchildrenadoption@wacap.org or www.wacap.org.

F.I.R.S.T. Collects Genuardi's Receipts

For those of you who grocery shop at Genuardi's Supermarkets, save your receipts and send them in to the national office. F.I.R.S.T. receives a small percentage of sales from these receipts. Every little bit helps.

National REGISTRY for ICHTHYOSIS and Related Disorders

1-800-595-1265 ■ www.skinregistry.org ■ info@skinregistry.org

The Registry for Ichthyosis and Related Disorders has been funded to continue its work through 2004! We can now offer molecular diagnosis for specific types of ichthyosis, which can clearly identify the specific change in a gene for many individuals. In some cases this will help confirm a clinical diagnosis, and may eventually lead to improved treatment. We have over 600 people participating in the Registry enrollment process, and now is the time for you to join us! Call us! Send an email! Visit our website! We are only as effective as you help us to be, so get involved!

Geoffrey Hamill, RN, Registry Coordinator • Kim Pineda, Registry Secretary
The National Registry for Ichthyosis & Related Disorders

E-mail: info@skinregistry.org • Web: www.skinregistry.org • Phone: 1-800-595-1265
Fax: 206-616-4302 • Mail: UW Derm., Room BB1353, 1959 NE Pacific St. Seattle, WA 98195

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