



ICHTHYOSIS FOCUS

Vol. 17, No. 3

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

Summer 1998

1998 F.I.R.S.T. Family Conference

Over 300 people gathered in the Philadelphia area in June for our family conference. The attendees represented six countries: U.S., Canada, Bermuda, England, Ireland, and Italy.

A social gathering on Friday evening kicked off a full weekend of scientific sessions and discussion groups presented by our distinguished faculty. There was time to get to know each other too, with groups gathering at the dance on Saturday night and at poolside before and after the sessions.

More than 80 children and teenagers attended. The younger ones participated in the Children's Program and teens were able to mix and mingle at scheduled and impromptu social gatherings.

Thanks to all of the volunteers whose hardwork and dedication made this meeting a huge success.

Just Enough Cooks

by Deb Vilas



Sandro & Roberta Dall'Aglio with interpreter (center).

Francis McHugh, had been working since November to line up volunteers, many of whom included their own family and friends. Shelly not only got us eight nursing students from Camden County Technical School, but she also procured donations of snacks and craft supplies for our activities. In her search for donations, she found a B.J.'s Wholesale Club sales representative, Jill, who offered to volunteer her whole day on Saturday. Jill brought supplies for friendship bracelets, which the children created with her help, and enough teddy bears so that every child received one.

Katie and Sue Getz were busy planning as well. Katie had the great idea of arranging for a small petting zoo to be set up for the Children's Program. Sue coordinated the efforts of local 4-H groups to put it all together. Between the Licursi and Getz families, Elena Levitan, Betsy Wilford, and myself, we gathered enough toys and games to supply the playroom. To our surprise, the hotel came to our assistance with a wagon load of toys that they lent to us for the weekend.

Dr. Jeff Miller, a dermatologist, brought along several volunteers and aided in the care of our young ones. With all this help, things had to go well, and they did. Registration went without a hitch. With two volunteers signing in children and logging parents' whereabouts, two volunteers writing out name tags and one

I am a lucky person. On Friday, June 19, a caravan of friends and family (eight people in four cars) headed down to Cherry Hill, NJ to assist me with the Children's Program for F.I.R.S.T.'s 1998 National Conference. With the prospect of over 60 children in my care for the weekend, I felt I needed all the help I could get. But in truth, I got more help than I ever could have imagined.

Shelly Licursi and her mom,



Shelly Licursi & Francis McHugh.

Additional conference coverage starting on page 6.

see **JUST ENOUGH** on page 8

ICHTHYOSIS FOCUS

Vol. 17, No. 3
Summer 1998

Copyright © 1998
by F.I.R.S.T.

Ichthyosis Focus
is published quarterly by the
Foundation for Ichthyosis &
Related Skin Types (F.I.R.S.T.)

Request to reprint information
contained in *Ichthyosis Focus*
should be directed to the editor.

F.I.R.S.T.
P.O. Box 669
Ardmore, Pennsylvania 19003

610-789-3995
800-545-3286
FAX: 610-789-4366

E-mail:
ICHTHYOSIS@aol.com
Web address: <http://www.libertynet.org/~ichthyos/>

Editor
Elena Levitan

Medical Editor
Amy Paller, M.D.

Science Writer
Betsy Bates-Freed

Editorial Assistant
Betsy Wilford

Layout/Graphics
Amy Bottoms

F.I.R.S.T. is a 501(c)(3) charitable
organization supported by private
donations. All contributions to
F.I.R.S.T. are tax deductible to the
fullest extent allowed by law.

The editor invites correspondence.
We welcome your comments,
observations and suggestions.
Please send your letters to us c/o
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 reported on 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

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

I am writing to you because I have read a disturbing newspaper article. While searching on the web, my husband ran across an article from the San Francisco Examiner on their web site Examiner.COM. The article was entitled "Poor Fingerprints Cost Teacher's Job." Apparently, recently passed legislation requires California teachers to give fingerprints for background checks. The article is about a qualified candidate who cannot be hired by the school system. He has no readable prints because of a chronic skin condition.

I feel this is a matter of grave concern because my daughter, who has CIE, also has no fingerprints and I believe many of the Ichthyoses lack clear fingerprints. Is there something F.I.R.S.T. can do to prevent this discrimination? What can we do? I would be happy to help if you can direct my efforts.

Sincerely,
Gail K. Lord
Manassas, VA

Editor's Note: California Assemblywoman Barbara Alby has recently introduced a bill providing alternative methods for background checks (Assembly Bill 75).

F.I.R.S.T. has mailed several letters stating our position on this issue. If you are a California resident, please consider contacting your local state representative in support of this measure, or writing to Assemblywoman Alby at State Capital, Sacramento, CA 95814.

For Christopher,

I remember growing up at a time when the worst thing that happened to me as a child with EHK was being stared at and being made fun of. For my son, Christopher, things are not as simple. Nonetheless, no mother could be prouder. Although he doesn't think so, he's charming, brave, intelligent, kind, caring, sensitive and has an absolutely magnetic personality. All young people with ichthyosis need to understand that you have complete control of your self esteem. I'm sure you're tired of hearing "Be strong", or "Who cares what the other kids think?" But it is true. Things WILL be OK. There will be days when you think, "Why me?" I did. You may not see the light at the end of your tunnel, but trust me

when I assure you that things will get better. If you start basing your self-worth on how ignorant people treat you, you're letting them win. Show them what you're made of. But most importantly... Love yourself, because we do!

Sincerely,
Mary Stefanos
Robins AFB, GA

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

I am interested in obtaining the NeoStrata (NeoCeuticals) PDS treatment product, but am unable to order through the toll free number as I am a Canadian consumer. Would there be any way that I would be able to obtain the PDS regular cream?

Thank you very much.

Sincerely,
Mary Ann Brentnell
Canada

Editor's Note: If you live outside of the United States, you can order directly from the developer, NeoStrata Company, Inc. Contact Kathryn Snyder by phone (609-520-0715, ext. 323) or fax (609-520-0849) for ordering information.

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

My family and I would like to thank you for a very successful and informative National Family Conference. It was our first and, hopefully, not our last.

I would like to offer a suggestion for the next conference. I think it would be beneficial to offer the Mother's Group earlier in the weekend so that we all have a chance to meet first. I would also like to see one group held through the weekend for mothers and fathers. Perhaps a more informal, sharing group held later in the evening might offer an outlet to the people who need support from others who share their feelings.

If I had to choose one thing that had the greatest impact on me, it would be the awareness of the incredible need for a support network for families. Everyone had so much to offer with so little time to do so. The weekend went much too quickly for all of us. Wonderful new friendships were formed over the weekend and will, hopefully, continue for years to come.

Keeping that in mind, I'd like to propose an

idea to F.I.R.S.T. I think that a Member Directory would be an excellent idea. It would be very simple in form and strictly voluntary. Members would choose just what and how much information they would like included. I know that I, myself, came away with more names, addresses and phone numbers than I can count, but also met many other people I would love to correspond with that I did not get the opportunity to exchange information with.

Sincerely,
Joanne J. Brunetti
Brookfield, CT

Editor's Note: If you attended the National Conference and would like to be included in a telephone and address directory for attendees, please call Joanne Brunetti at (203) 775-8758.

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

Upon returning from the F.I.R.S.T. National Conference in Cherry Hill, I felt I just had to write to let you know what a heartwarming experience it was for me. This was my first conference with F.I.R.S.T. and hopefully, in the future, I will be able to participate again. It is a very important forum and a great learning experience for everyone. And it is so much nicer to be able to put the names with the faces of the people behind the scenes making F.I.R.S.T. possible. I was really inspired by all the people I came in contact with.

The mothers discussion group really hit home for me. One mother especially stands out in my mind and one of the comments she made about "being chosen" and how "God doesn't give us more than He feels we can handle." This reminded me of a newspaper article a friend passed on to me shortly after the birth of my daughter and I would like to share it with you.

*When God Seeks the Right Mother
Most women become mothers by accident, some by choice, a few by social pressures, and a couple by habit.*

This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen?

Somehow I visualize God hovering over earth selecting His instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make note in a giant ledger.

"Armstrong, Beth, son. Patron Saint Matthew."

"Forrest, Majorie, daughter. Patron Saint Cecelia."

"Rudledge, Carrie, twins. Patron Saint ... give her Gerard. He's used to profanity."

Finally, He passes a name to an angel and smiles, "Give her a handicapped child." The angel is curious, "Why this one, God? She's so happy."

"Exactly," smiles God. "Could I give a handicapped child a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel. "I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she'll handle it."

"I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I'm going to give her has his own world. She has to make it live in her world and that's not going to be easy."

"But Lord, I don't think she even believes in you."

God smiles. "No matter. I can fix that. This one is perfect. She has just enough selfishness."

The angel gasps, "Selfishness? Is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a 'spoken word.' She will never consider a 'step' ordinary. When her child says 'Momma' for the first time she will be present at a miracle and know it! When she describes a tree or a sunset to her blind child, she will see it as few people ever see my creations."

"I will permit her to see clearly the things I see... ignorance, cruelty, prejudice... and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life because she is doing my work as surely as she is here by my side."

"And what about her patron saint?" asks the angel, his pen poised in mid-air.

God smiles, "A mirror will suffice."

Author Unknown.

I felt the conference was a huge success and picked up a few pointers too. There was only one drawback, I felt that the mothers discussion group session was so short and at the end of the conference. I hope the contacts I've made will thrive. I look forward to the next conference.

Sincerely,
Ann Marie O'Reilly
Newburgh, NY



BOARD OF DIRECTORS

Donna Rice
President
Katy, Texas
(12/98)

Michelle Petersen
Vice President
Metuchen, New Jersey
(12/99)

Laura J. Phillips
Chief Financial Officer
New York, New York
(12/99)

Elise Johnson
Secretary
Lynnewood, Washington
(12/00)



Michael F. Dunleavy
Blue Bell, Pennsylvania
(12/00)

Gloria Flippin Graham, M.D.
Atlantic Beach, North Carolina
(12/99)

Lewis Horowitz
New York, New York
(12/00)

Tiffany Karst
Shawnee, Kansas
(12/99)

Leonard Milstone, M.D.
Chairman
Medical Advisory Board
New Haven, Connecticut
(12/99)

Rita Tanis
Fairfield, Connecticut
(12/98)

Deb Vilas
New York, New York
(12/00)

Janet Weary
Charlottesville, Virginia
(12/98)

Mary L. Williams, M.D.
San Francisco, California
(12/00)



Share Your Strength...

Like all small organizations with limited resources, F.I.R.S.T. must often make difficult decisions about which programs to pursue. There are many things that we know we could do more effectively, if only we had the right mix of resources at the right time.



Usually, talk of expanding resources really means one thing - raising money. But, I think that we can achieve greater goals if we can focus on an even more important resource, the commitment of our members. Today, please consider making an even greater contribution to F.I.R.S.T., a donation of your talent and your time. I'd like to ask that each and every one of you take a few moments to evaluate your strengths in terms of your skills, special talents, experience, time and money...

...and share that strength!

Do you have business experience in management, organizational development, finance, marketing, legal or related areas? Do you have good communication skills and enjoy sharing your experiences with others? Would you like to use your creative and organization skills to help us plan a regional meeting, special event, or fundraiser? Do you have a little bit of time throughout the year, or perhaps a slower season when you may be able to help with a special project? There are many ways to become more involved.

We are always seeking new volunteers to get involved in our **telephone network**. If you've benefited from being part of the network, please consider sharing your knowledge. If you haven't (some geographic regions and types of ichthyosis are not well represented) your involvement could make a difference for others. We'd like to sponsor a number of **regional conferences** and local gatherings next year, but we need the participation of local coordinators to help with the planning process. If you are interested in the workings of our political system, you may want to participate in our **political advocacy** efforts. You may choose to participate in our ongoing efforts to **increase awareness** of ichthyosis by talking to school or community groups or promoting media coverage. And, of course, sponsoring a local **fundraising event** is a good way to increase awareness for ichthyosis and raise money to support F.I.R.S.T. Our volunteers who have successfully raised funds in the past would be more than happy to share their ideas for simple, successful events. We are fortunate to have a dedicated and talented Board of Directors, and we're always looking for new individuals with strong business skills to replace departing **board and committee** members, and help lead F.I.R.S.T. into the next century.

Every year, we enclose a contribution envelope in the summer issue of *Ichthyosis Focus*. This year, the envelope is different. On it, we've asked that you indicate ways in which you would be interested in getting more involved with F.I.R.S.T. Please take a moment to review the information on the envelope and fill it out *even if you choose not to make an additional donation at this time*. Please feel free to enclose a note describing your interests, skills, and ideas.

I'm looking forward to hearing from you.

Elena Levitan
Executive Director

Third Annual Ichthyosis Awareness Week October 4-10, 1998

Ichthyosis Awareness Week (IAW) is a full week dedicated to making the general public aware of ichthyosis and its impact on individuals and families.

A number of families throughout the country have used Ichthyosis Awareness Week as an opportunity to raise funds for F.I.R.S.T., and at the same time to raise awareness in their communities. There are many other ways to get involved, such as speaking at a school or community group, meeting with your local office, or arranging for local media coverage.

Please consider getting involved this year. The Foundation can provide suggestions for events, press packets, educational materials, and even door prizes! Contact Tiffany Karst, 1998 Ichthyosis Awareness Week Coordinator (913-268-3692 or e-mail at tkarst@kumc.edu), or Elena Levitan at the National Office (1-800-545-3286) for more information.

AN EASY WAY TO HELP

by Donna Rice

Many grocers throughout the country are providing an easy way to support charitable organizations through their "percentage back" programs. While each grocer or supermarket chain may call the program something different and have specific ways to receive the refunds, they work in basically the same way.

A percentage of your grocery purchase is refunded back to the organization at regular intervals. Some grocers require that you save and submit tallied receipts, others supply you with a card to be scanned prior to each grocery purchase that automatically records the purchase amount for your organization, while still others allow refunds only for designated days. An application form to be completed by the organization is usually required.

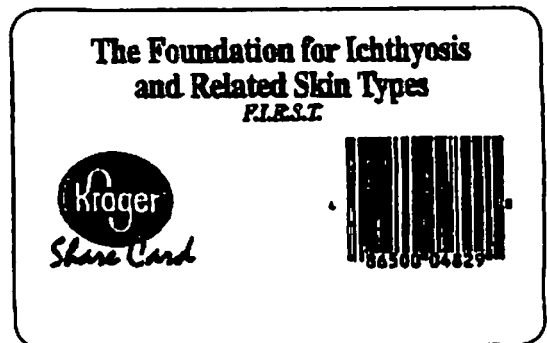
F.I.R.S.T. currently participates in two programs with hopes to add more in the coming months. In the Philadelphia area, Genuardi's has been refunding 1% of submitted grocery store receipts for several years. Our participation in this program was started by Francis Bernsteil. Her daughter, Lynne Alba, continues to collect and tally receipts, with the help of her family and friends. Genuardi's contribution generated close to \$500 this past year. More recently, we began participating in Kroger's "Share" program in Houston and Dallas, which requires a scan card and also refunds 1% of purchases.

One percent may not sound like much, but a grocery bill of just \$50 a week comes to \$2,600 a year with a refund to F.I.R.S.T. of \$26. Multiply that by 5 participants (\$130) or 10 (\$260) and it quickly adds up. F.I.R.S.T. is an organization that has learned to do a lot with a little and even 1% back allows us to continue our mission.

How can you help?

- * Residents of the Houston and Dallas areas should contact Donna Rice (281-391-4407) to obtain a Kroger Share Card.
- * Members in the Philadelphia area can save their Genuardi's receipts and periodically mail them in to the National office.
- * Members in other areas can contact their local grocers to find out about their "percentage back" programs and get an application form. Call Elena at the National Office. She will provide the paperwork required for the program to be established.

If you would like more information about an easy way to support F.I.R.S.T., call Elena at the National Office or Donna Rice in Texas at 281-391-4407.



“Do You Have Ichthyosis?” by Christina Cayuela

“Do you have ichthyosis?” This was a question asked of me, one year ago, as I was watching my five year old son play at a McDonald’s Play Place in LaCanada, California. My heart began to race. How could this woman know about ichthyosis?

You see, I was born 34 years ago with CIE/Lamellar Ichthyosis. During the first 14 years of my life, my parents took us (my only and younger brother was also born with ichthyosis) to all of the BIG Medical Centers in California and also to doctors in Germany and Mexico. Like so many parents, they were looking for a miracle, but to no avail. For the last twenty years, my brother and I have just been living with ichthyosis - not treating it in any way except moisturizing with Eucerin. And so, when this woman who

obviously did not have ichthyosis asked me if I did, I was shocked. Up until that day, I had never seen anybody like myself nor even heard of anyone with the same condition. And so I answered, “Yes I do. But, how do you know about ichthyosis?” She proceeded to tell me about a friend who has ichthyosis. She also told me a little about F.I.R.S.T. and their conference. We exchanged phone numbers and soon I was in touch with her friend - Elise Johnson.

During the last week of May, I started to make phone calls regarding the upcoming Conference that I thought was to be in September. Well, much to my surprise, the Conference was June 19-21 in New Jersey. HELP! I had less than three weeks to schedule this trip. Well, it all worked out. Within three days I had my flight booked, my room reserved, registration mailed, a babysitter for my son and an approved vacation day from work. The only problem now was, “How do I pay for all this?” You see, I am a divorced single mother, on a very tight budget. So, I started to make phone calls again and sure enough, between my family and people at work, my trip was fully funded.

On Saturday morning at the Opening Meeting, sitting in my chair feeling like it was a mistake that I came, I listened to a woman talk about her life with

ichthyosis. She began to talk about her crazy friend in California who had met a lady, in a McDonald’s, with ichthyosis. As I sat in my chair, with my heart once again racing like it was a year ago, I listened to the speaker recount my whole story, word for word. And so, I stood up and let everyone know that I was that woman from McDonald’s. The audience laughed and applauded. For those of you who were at the conference, I think you’ll agree when I say, “It was quite a moment!” I, one lost soul with ichthyosis, had been found and introduced to many



Donna Rice with her children Adam & Andrew.



Lynne Alba with her children Matthew & Brittany.



Tom Alba (left) with Sandro Dall'Aglio and Harry Abia.

Family Conference

Others like myself because one crazy and bold woman spoke to me.

My main purpose for going to the conference was to finally see people like myself. So, you can only imagine the disappointment and anger I felt when I arrived Friday evening to see that no one looked like me. As a matter of fact, throughout the whole weekend, I saw no one who resembled me. But, as I was to find out later, no one looked like me because I didn't have to look like me. As I sat and listened to people and saw their pictures, I realized that many of them used to look like I do but have found a treatment program that clears their condition tremendously.

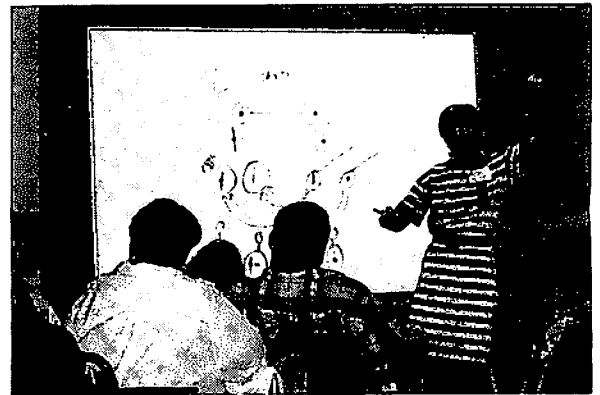


Janet & Dr. Peyton Weary.

The conference was incredible! So many nice people to talk to and learn from. As I headed back to California on Sunday, I took lots of new medical information to help me find my treatment program, product samples, and hopes that when I return to the next conference, I too will look just like everyone else - BEAUTIFUL!!!

We Learned So Much... ...From Our Faculty & Each Other!

The highlight of the National Conference is the day and a half of General and Breakout sessions devoted to a wide range of topics related to ichthyosis. Our faculty and moderators led sessions in three areas: 1) gene therapy and genetic research, 2) the latest in treatment, including retinoid therapy, topical treatments, and common problems such as infection and ear complications, and 3) discussion groups for individuals with ichthyosis and their families.



Dr. Sherri Bale discussing about the Genetics of Ichthyosis.

Our faculty was composed of top clinicians and researchers in the field, including the Director of our National Registry, leading skin biology researchers at the National Institutes of Health, and members of our Medical Advisory Board.



Exhibitor Gerard Kalie (Glaxo Dermatology).

We are truly fortunate to have the participation of such dedicated individuals, who were willing to spend a weekend away from their families, often travelling at their own expense, to share their knowledge with us.

We also learned a lot from each other in the discussion groups. We're already planning for our next conference in the year 2000, where we hope to schedule more discussion time earlier in the program.

Two exhibitors, Glaxo Dermatology and Pierre Fabre Dermatology, helped to support our meeting and shared products and information with us. Several other companies also participated in our sampling program.

Just Enough Cooks

by Deb Vilas

JUST ENOUGH from page 1

slapping name tags on bottles, strollers, dolls and blankets, the line moved quickly.

Once we were all gathered together, we started the morning with two active get-to-know-you games. These involved the whole group of children, ages 3-13, while the 1-2 year olds settled down in the "quiet room". The first group activity involved a hand-holding game, something that any child with ichthyosis welcomes in a supportive environment. We all stood in a circle holding hands, and the challenge was to pass two hula hoops in opposite directions around the circle without letting go of your neighbor's hand.

The second activity was based on a game supplied to me by Elise Johnson, and it's called, "Where do you stand?" I stood at one end of the large room, with my friend, Isabel, on the other. I would yell out one phrase, such as "I live in the country!", and she would yell out the opposite, "I live in the city!" Kids were instructed to run to either side, or stand in the middle to literally show where they stood. We formed a human scale that kept changing with each new statement. "I listen to CDs!" "I play an instrument!" In this way, we found out our similarities and differences, and got to know each other a bit.

Snacks followed (my favorite part of any day), and then children had a choice of outdoor play or the friendship bracelet craft.

The morning flew, and lunch brought a break for us all. After lunch,



Story time with Dr. Jeff Miller.



Jaylene Eastin with Amneet & Puneet Jasjot.

we took two consecutive groups of the older children to a miniature golf course across the street. The children who stayed behind made Father's Day cards, played games and watched videos. In the late afternoon, we took children in small groups to the petting zoo, where they met two rabbits, a hamster and a rat. I would like to add here that none of the outdoor activities would have been safe or possible if it were not for the number of adult volunteers we had assisting us.

It was hard to believe when the first day was over. I fell into bed before 9:00 p.m. for the first time in years. Sunday morning felt a little calmer to those of us who'd helped the day before. The activities on Sunday were fun and self-esteem promoting. Chuck Sides set up a mural entitled, "I Made A Friend At F.I.R.S.T..." Children wrote and drew about the good friends they'd made that weekend.

We were blessed by the presence of Nathaniel Murray, a talented movement specialist who had even the most physically limited children bouncing off a giant, rubber ball as if it were a trampoline. Nathaniel worked out with the children for over two hours and involved over twenty children.

A table was set up with a pile of empty lotion and cream bottles. The children's creativity positively burst forth as they created a museum of three dimensional dolls, using the containers, glue, paper, yarn and scraps of material.

I was busy with a Polaroid camera loaned to us by Geoff Hamill of the National Ichthyosis Registry. He also donated three



Deb Vilas



April Sproul

Family

Conference

packs of film, and I used them to photograph as many children as I could. I glued each photo on a piece of construction paper and wrote, "I Like Me Because..." I helped the children finish the sentence with their own words. In the end, we had a beautiful book which each child is receiving a copy of after the conference.

All in all, it was a fun filled, action packed weekend. But nothing can measure the most important aspect of the program : Children meeting others like themselves. Friendships forming. Self esteem growing. The words of the children say it all:

"I like me because I am unique."

"I am a good friend."

"I am me and me is very special."

"I like my skin."

"I love to use my imagination."

And last but not least:

"This was my first time
but not my last. I had a good time.
Thank you!"

Aren't kids great?



Nathaniel Murray gets the kids rolling.

Lost & Found!



This doll was left in the children's room at the National Conference. Do you know who she belongs to?

Regional Support Network (RSN)

PROGRAM DIRECTOR

Elise Johnson
18117 12th West
Lynnewood, WA 98037
425-771-7264
E-mail: yodelo@aol.com

REGION ONE

NY, PA, VT, NH, NJ,
CT, RI, MA, ME
Shelly Licursi
311 White Birch Drive
Cinnaminson, NJ 08077
609-786-8766
E-mail: MICLIC72@aol.com

REGION TWO

DE, MD, WV, VA, NC, SC
Robin Joyce
Route 1, Box 189-F
Sandy Ridge, NC 27046
910-871-3277

REGION THREE

TN, GA, FL, AL, MS,
LA, AR
Debra Bowie
3694 Shady Hollow Lane
Memphis, TN 38116
901-346-0513

REGION FOUR

KY, OH, IN, IL, MO, MI
Angela DelGrande
4408 Appleton Place
Kettering, OH 45440
937-643-9752
E-mail: toriedog@aol.com

REGION FIVE

WI, MN, IA, ND, SD, NE
OPEN

REGION SIX

TX, OK, NM, CO, KS
Donna Rice
2902 West Elm Diracle
Katy, TX 77493
281-391-4407
E-mail: dsrice@infohwy.com

REGION SEVEN

WA, OR, ID, MT, WY, AK
Shari Gelivich
1344 S.E. Rex
Portland, OR 97202
503-236-3203

REGION EIGHT

CA, NV, UT, AZ, HI
Chris Beeler
1002 E. Gifford Drive
Tucson, AZ 85719
520-887-7188

CANADIAN CONTACT

Barbara Rockwell
3080 Ballydown Crescent
Mississauga, Ont L5C 2C8
905-896-9620

HARLEQUIN SUPPORT GROUP COORDINATOR

Patricia Steinitz
314 Richey Ave.
Pittsburgh, PA 15214
412-231-1201
E-mail: Pas1st@aol.com

STATE CONTACTS

Kansas
Tiffany Karst
913-268-3692

Kentucky
Cynnne Bates
606-276-0142

Massachusetts
Susan Overstreet
413-259-1267

Mississippi
Charlene Wiggins
228-769-2454
E-mail:
bobchar@sunherald.infi.net

New York
Cathy Lopez
718-842-7269

South Carolina
Nancy Bryant
803-559-9369

Wisconsin
Theresa Tremmel
414-538-4922

NEWS & NOTES

Researchers Further Understanding of Ichthyosis Vulgaris

Drs. Wilas Nirunskisiri, She-Hui Zhang and Philip Fleckman at the University of Washington in Seattle have been investigating Ichthyosis Vulgaris. In a summary of their work, Dr. Fleckman wrote "we have been interested in individuals with Ichthyosis Vulgaris for a number of years, and have previously shown that a subset of individuals do not have a granular layer in their epidermis. A few years ago we showed that epidermal cells from individuals with Ichthyosis Vulgaris and no granular layer have very little profilaggrin, a protein that makes up much of the granular layer in human epidermis." At the time, they also determined that the problem was not in the gene that codes for the profilaggrin protein.

Dr. Fleckman also explained that "profilaggrin is thought to help form the mechanical barrier in the top part of the epidermis, and may also function to bind water to the very upper layers of the epidermis."

Their latest findings, published in the June 1998 issue of the Journal of Investigative Dermatology, show that the problem (too little profilaggrin protein) involves stability of something called profilaggrin messenger RNA. Dr. Fleckman describes this substance as "the intermediate that is produced from the gene, that directs the formation of the protein." He goes on to say that "one explanation of these findings is that in these cells something that normally stabilizes the profilaggrin messenger RNA is missing in people with Ichthyosis Vulgaris.

The researchers are looking to extend these studies and are working with investigators and the Laboratory of Skin Biology at the National Institutes of Health (NIH) in Bethesda, MD. If you are part of a large extended family with several individuals with Ichthyosis Vulgaris, and are interested in participating in this research, contact Dr. Sherri Bale at the NIH at 301-402-2724.

"Dear Doctor" column helps more families find F.I.R.S.T.

Dr. Paul Donahue writes a syndicated medical advice column that appears in a number of local papers nationwide. On Monday, July 6th, he published a letter from a man with lamellar ichthyosis, and responded with information about F.I.R.S.T. The office received over 300 calls in the following two weeks and we've added more than 150 families to our mailing list so far!

SCIENCE UPDATE Public/Private Chip Effort Reports Breakthrough on 'Biochip'

The United States Department of Energy and two private corporations have announced the development of a new technology that they claim will allow physicians and medical researchers to decode human genes 1000 times faster than is currently possible. They are currently working to lower the cost, making commercialization possible.

According to a report in the June 30th Washington Post, the Argonne National Laboratory has teamed up with Motorola Inc. and Packard Instruments Co. to make the technology affordable and, therefore, commonplace in a few years. If successful, the plan will allow medical researchers and clinical physicians to conduct tests on individuals in minutes that would identify genes and flag predispositions to particular illnesses.

The technology involved is a "biochip," which is analogous to a computer chip. A few drops of body fluid on the chip are subjected to thousands of biological reactions per second, including decoding genes. Officials hope that the private companies' expertise in producing inexpensive computer chips efficiently can be transferred to this technology.

**Reprinted from TGAC Hotline, An Information Service of The Genome Action Coalition, July 6, 1998.*

NORD Testimony on Rare Disease Research

**The following topics were discussed as part of the congressional testimony of Michael S. Langan, Vice President of Public Policy at the National Organization for Rare Disorders (NORD), and excerpted from a discussion of his testimony which appeared in the NORD On-Line Bulletin, March 1998.*

Disease-Specific Earmarks: A Danger to Research on Rare Diseases

NORD explained that Americans are very troubled by the Administration's initiative favoring cancer research over activities necessary to address other serious and life-threatening conditions. Mr. Langan reminded lawmakers that dividing the NIH budget for political, rather than scientific purpose is wrong. Funding priorities and the allocation of NIH resources should be established by the scientific

NEWS & NOTES

community with the aim of maximizing research opportunities, instead of catering to politically powerful lobbies.

Gene Therapy

We eagerly anticipate the many discoveries of the Human Genome Project, and await the day when gene therapy interventions become available for all inherited rare diseases. Unfortunately, of the 222 human gene therapy protocols to date, only 32 were designed for inherited disorders, and 16 of those were for a single disease: Cystic Fibrosis. The vast majority of gene therapy protocols target cancer, HIV, or cardiovascular disease.

NORD requested the designation of three additional vector laboratories so that gene therapy vectors may be developed for genetic disorders -- which remain the most likely candidates for the eventual success of this emerging technology.

RESEARCH STUDY

Clinical Delineation of the Keratitis-Ichthyosis-Deafness Syndrome

Principal Investigator: Dr. Ethylin Wang Jabs
John Hopkins University School of Medicine

Investigators: Dr. Laura Russell
National Institutes of Health

Dr. John DiGiovanna
Brown University

Dr. Peter Elias
University of California, San Francisco

The Keratitis-Ichthyosis-Deafness syndrome is a rare inherited disorder in which affected persons have 1) deafness present at birth, 2) gradual destruction of the cornea of the eye, possibly leading to blindness, 3) localized areas of disfiguring reddish skin thickening, and 4) thin or even absent scalp hair.

The investigators listed above seek to recruit patients with KID syndrome for a clinical study that will define different subtypes. The study will involve a detailed genetic history and physical examination; consultation with a dermatologist and a skin biopsy; consultation with an audiologist and hearing tests; consultation with an ophthalmologist and an eye exam; blood specimens for DNA isolation, and tests of liver, white blood cell and immune function. These studies will be performed at no cost to the patient and their results will be shared with the patient.

If you have KID Syndrome and might be interested in participating in this study, please contact:

Dr. Laura J. Russell 301-594-4884

The Medicine Program

The Medicine Program has been developed to help consumers who cannot afford their prescription medication. Individuals must qualify for assistance; eligibility requires that there be no current prescription drug or Medicaid coverage and there are income limits. For more information, contact the Medicine Program at PO Box 515, Doniphan, MO 63935, or call 573-778-1118.

Web site: <http://www.themedicineprogram.com/>.

**Reprinted from Alliance Alert, July 1998. A publication of the Alliance of Genetic Support Groups.*

**10% Lactic Acid (Alpha Hydroxy)
PLUS 10% Urea
MADE FOR F.I.R.S.T MEMBERS**

MONEY BACK GUARANTEE

Hundreds of FIRST members tell us this non-prescription moisturizer & exfoliant smoothes skin better than prescription products. New odor free formula only \$15.99 for a 16-oz bottle.



**Dermal
Therapy**

Order directly from the
manufacturer (800) 668-8000

F.I.R.S.T. neither recommends, nor endorses, products or services advertised in *Ichthyosis Focus*.

theraplex[®]

MOISTURIZERS

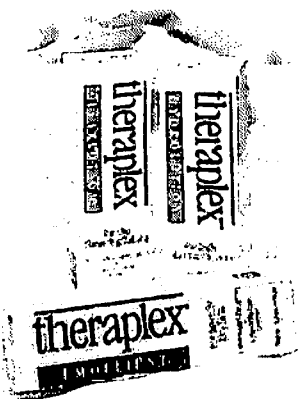
All the benefits of petrolatum without all the grease.

THERAPLEX offers a unique, patented ACTIVATED DELIVERY SYSTEM[™] that allows moisturizing agents to penetrate quickly without leaving behind a greasy residue. All THERAPLEX moisturizers are hypoallergenic, noncomedogenic and fragrance free.

CLEARLOTION is a liquid petrolatum formula for use after bathing to help seal in moisture and replace natural oils.

EMOLLIENT is a concentrated, barrier moisturizer of pure petrolatum with 82% of the oils removed that make ordinary petrolatum sticky and greasy.

HYDROLOTION[™] is an ideal everyday moisturizer that has all of the heavyweight protection of petrolatum in a light, greaseless formulation.



THERAPLEX now offers a discount to all F.I.R.S.T. members!

THERAPLEX Moisturizers	Reg. Price	F.I.R.S.T. Price
CLEARLOTION	\$11	\$7
EMOLLIENT	\$13	\$8
HYDROLOTION	\$11	\$6

ORDER DIRECT & SAVE!

Call the THERAPLEX Hotline

1.800.716.4606

What's New, What's Hot, What Works!



... a regular feature about skin care problems and solutions.

Elizabeth Franke from Parkland, Florida writes:

I would like to share with your readers the system I use to treat my Lamellar Ichthyosis. I've been told I have a mild case of this form of the disease, but perhaps my routine will help someone who is dissatisfied with what they are currently using. Please note that the creams I use do not work alone, nor do they work on unmoistened skin.

After a shower, I dry my skin to the point where it is just damp, and then I apply Betamide Lotion. This lotion is 25% urea and 4% lactic acid. I find that it works better than lotions that contain urea only or lactic acid only. Betamide can be purchased by mail order from Beta Dermaceuticals in San Antonio, Texas. Their phone number is 1-800-434-2382, or 1-210-349-9326. On top of the Betamide, I apply Eucerin Original Moisturizing Creme. That's the heavy cream that comes in the plastic tub with the white top. It can be purchased in most drug stores, and I greatly prefer it to Vaseline.

The Betamide stings my face a bit, so I cut it with Lubriderm Lotion. I think that the Lubriderm has the best consistency for mixing with the Betamide.

I hope your readers find this information useful. Thank you for an interesting and informative newsletter. I look forward to receiving them in the future.

Glori Stilson from Greenville, Texas writes:

I recently made a discovery that is making my life a lot easier and I wanted to share it with all the other women out there. Ever since I can remember, I have not been able to shave my legs easily. It took me three times longer than my sister or my mom to do it because of my skin (I have EHK). At the store one day recently, I found mitts that fit over your hand and, when rubbed in a circular motion, removed the hair from your legs. It didn't take me long to figure out that the mitts were nothing more than 400 grit sandpaper. Just buying big sheets of sandpaper is much cheaper than buying the special mitts, and this really works. Always go in a circular motion, but it will easily remove the hair from your legs, and my skin feels really good afterwards. I can even wear pantyhose now with no fear of snags or pulls from that really tough, sharp skin I get above my knees. You have no idea how great this feels until you try it! When I do it regularly, it keeps the scales to a minimum and has really improved my skin. I just follow up with Aloe gel or Cocoa Butter, and my legs look better than they have in years. My family thought I was nuts at first, but they were stunned when they saw the results.

F.I.R.S.T. neither recommends, nor endorses, products or services advertised in *Ichthyosis Focus*.

How to Apply for Social Security Benefits

* This was adapted from an article by Selma Riemer in the *EB Reporter: Journal of Dystrophic Epidermolysis Bullosa Research Association of America, Inc.*; Volume 12/1998.

It has come to our attention through your letters, phone calls and e-mail that many of you are puzzled by the process of applying for Social Security Benefits for yourself or for your child.

The first step in the application process is to contact Social Security to schedule an appointment by calling 1-800-772-1213. The phone lines are often busy so your best bet is to call early in the morning. Next, compile all your medical records. It is important that you have all reports and all other pertinent medical data. In addition, have your physician write a letter describing ichthyosis, the prognosis and physical limitations. Please give your doctor the courtesy of ample time to prepare this letter. Please note that the reviewers see the documents not the patient so they must have a "total clear picture" of the patient. Make copies of all the documentation and be certain that you obtain the name of the representative at the Social Security Administration who interviews you.

If your claim is denied, request that it be reconsidered. Contact your state or congressperson and an attorney experienced in Social Security issues, to help you navigate the system.

Reputable attorneys in this area of law generally do not charge a fee unless the outcome is successful. Therefore, there is no up-front cost to the client. Your chances of receiving Social Security benefits are better if you are represented by a lawyer. Excellent sources for getting specialists are:

1. the National Organization of Social Security Claimant Representatives at 6 Prospect St., Midland Park, NJ 07432, (800) 431-2804
2. Allsup, Inc., 300 Allsup Place, Belleville, IL 62223, (800) 854-1418 or (618) 234-8434, fax (618) 236-5778, www.allsupinc.com.

I can't emphasize enough how important it is that you stay focused and try not to become discouraged. Often times the process is very long and arduous.

During the Social Security hearing the Judge listens to the applicant's testimony, and the lawyer can strengthen the case by testimony from the patient or the patients. In this way legal counsel can help you make the most of face to face contact with the Judge.

The process requires a tremendous amount of patience, fortitude and preparation.

Most often, legitimate claims for SSI or SSA Disability have positive outcomes and may enhance the quality of life for the patient and for the family.

Good Luck!

Additional Toll-Free Numbers for Free Legal Assistance, American Bar Association (ABA) Children's SSI Project:

The ABA Children's Project has compiled a list of hotline numbers for free legal assistance. Families can call the project to find local referral numbers and access free legal help and, in some cases, pro bono legal services. For your local number, you can contact the National Office at 1-800-545-3286.

R National **REGISTRY** for **I**CHTHYOSIS and Related Disorders

Registry Director: Philip Fleckman, M.D.
Registry Coordinator: Geoff Hamill, R.N.

University of Washington
Dermatology/Box 356524
Seattle, WA 98195-6524

E-mail: ichreg@u.washington.edu
URL: <http://weber.u.washington.edu/~geoff/ichthyosis.registry/>

1-800-595-1265

The National Institutes of Health (through its National Institute of Arthritis, Musculoskeletal and Skin Disease—or NIAMS) is sponsoring a National Registry for Ichthyosis & Related Disorders. The goal of the Registry is to develop a clinical database of individuals affected with the ichthyoses and other rare skin disorders (that is, a roster that compiles information about people with these disorders).

The Registry's purpose is to improve methods of diagnosis and treatment of the ichthyoses. We do this by creating a list of affected individuals. This should have a profound impact on research in the ichthyoses and related disorders, since one of the greatest obstacles facing researchers doing studies on rare diseases is locating affected individuals willing to help them out.

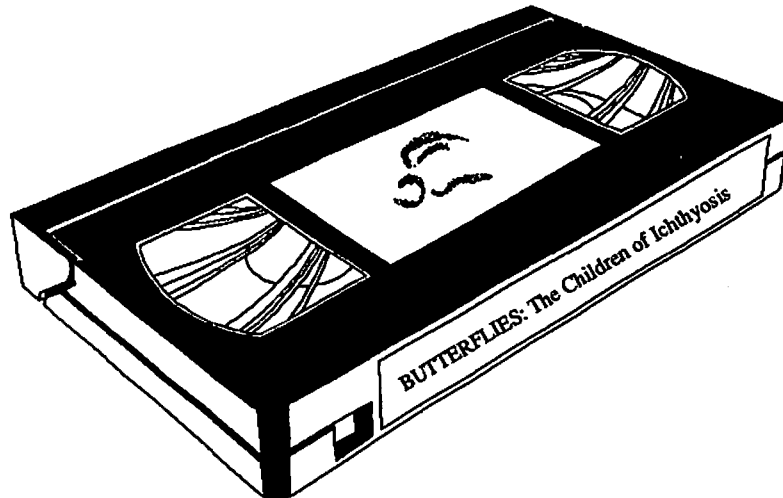
The Registry should solve this problem by creating a central resource containing diagnostic information about the individuals who have enrolled. Researchers can then easily locate affected individuals, as well as obtain information about the frequency and involvement of their disorders. In addition, even if you choose never to participate directly in research studies, the information you provide the Registry should prove valuable in better understanding these disorders.

The Registry will NOT give identifying information out to researchers. Instead, those enrolled in the Registry will be contacted *by the Registry* and informed of any appropriate research projects. At that time, you can decide for yourself if you wish to contact the researcher involved.

Please contact the Registry Coordinator, Geoff Hamill, to ask more questions and to obtain enrollment forms.

Educational Video Release

“Butterflies: The Children of Ichthyosis”



F.I.R.S.T. proudly announces the release of “Butterflies: The Children of Ichthyosis.” This very short, educational video is designed to be used as a tool to introduce the school age population to ichthyosis, and to educate them as to how it affects children.

The video is a natural adjunct to two of F.I.R.S.T.’s publications; “*Release the Butterfly: A Handbook for Parents & Caregivers of Children with Ichthyosis*” and “*Ichthyosis: A Guide for Teachers*.” A fact sheet is included with the video. It contains information on how to use the video as an effective tool to spark discussion and promote understanding in the classroom and community.

Thank you to all of the children and families who participated in the filming, provided artwork and home movies and their heartwarming thoughts of how ichthyosis has affected their lives:

Jasmyn Bowie
Rachel Freed
Katie Getz
Ethan Joyce
Jessa Karst

Keri LaBrandt
Ryan Licursi
Austin Milam
Meade Piercey

Haley Rice
Robbie Villa
Melissa Wiggins
Jasa Williams

and the Family of Teddy Hoffman

Thanks, also, to VPR Creative Group, who managed to keep production costs low by arranging for donated editing time and equipment, and especially to Tiffany Karst who oversaw every detail of the project, from raising the required funds to selecting a production company and coordinating filming at a local conference. Without Tiffany’s drive and determination, F.I.R.S.T. would not be able to offer this valuable educational tool to our members.



Royal blue ceramic 11oz. mugs with the F.I.R.S.T. logo in white. Get two mugs for \$12.00 (price includes shipping and handling).



Royal blue canvas bag with the F.I.R.S.T. logo in white.
 Size: 10.5" x 14" x 5".
 Tote bag cost \$12.00 (price includes shipping and handling).

OOPS! If you recently purchased mugs at the National Conference you may have noticed that the manufacturers spelled ichthyosis wrong. Please call the National Office at 1-800-545-3286 so we can send you replacement mugs free of charge.



Name: _____

Address: _____

Phone: () _____

Item	Quantity	Price	Total
F.I.R.S.T. Educational Video		\$ 7.00	
Two mugs with F.I.R.S.T. logo		12.00	
Canvas tote bag with F.I.R.S.T. logo		12.00	
Release the Butterfly: Handbook for Parents...		5.00	
Ichthyosis: A Guide for Teachers		5.00	
Grand Total:			

Please make payment by check or money order in U.S. dollars payable to F.I.R.S.T.
 Mail to F.I.R.S.T. at PO Box 669, Ardmore, PA 19003.

F.I.R.S.T.
P.O. BOX 669
Ardmore, PA 19003

Non-Profit Org.
U.S. Postage
PAID
Ardmore, PA
Permit No. 61

Please help us to minimize our printing costs. Call us at 1-800-545-3286 if you do not wish to receive future issues of *Ichthyosis Focus*.

F.I.R.S.T.
and the
DERMATOLOGY FOUNDATION

**Announce a New Grant Available
in the Area of Ichthyosis Research**

This NEW Research grant is aimed at investigators at the early stages of their career development to initiate a research project in the area of ichthyosis.

Funding level: One year up to \$10,000

Application deadline: October 15, 1998

Funding available: July 1, 1999

Information and applications for this research grant can be obtained from:
Dermatology Foundation / 1560 Sherman Ave., Suite 870 / Evanston, IL 60201
Phone: 1-847-328-2256 / Fax: 847-328-0509