



# ICHTHYOSIS FOCUS

Vol. 14, No. 3

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

Summer 1995

## SAN DIEGO 1995 A Special Report on the National Family Conference

Heather and I, together with Caitlin and our newest addition, Lorenzo, arrived in San Diego on Tuesday of the week of the 1995 National Family Conference, that was set to begin on Friday evening. Planning had begun nearly a year before, and for about three months I'd been devoting the majority of my time to the myriad, hair-pulling details that go into an event of this magnitude.

Never before had F.I.R.S.T. committed itself to such an ambitious conference—a conference spread over three days, including a dozen faculty, and organized for 400 people. Last September, the Board of Directors approved a budget of about \$26,000 (nearly three times the budget for the Chicago conference). We planned on conference fees recapturing about 80% of this cost. The Foundation would then underwrite the remaining 20% of the conference, offering some relief to families who, in most cases, accepted huge financial sacrifices to bring themselves and



Madonna Taylor making her way to the Saturday Mom's Group breakout session on the Bahia Belle.

their families out to San Diego.

We gave some of our time that week to family pursuits (a trip to Marine World, one to the San Diego Zoo), but mainly we spent the week bringing a tangle of details together into a seamless program.

In all, nearly 270 people arrived at the Bahia Hotel that week. I had predicted that the majority of our attendance in San Diego would be families from California and the

Southwest, but I was wrong. In fact, we drew families from six countries; only a quarter of attendees were from California. Surprisingly, the majority came from east of the Mississippi. This fact tells a great deal about the great value which our membership places on these biennial national meetings.

Another great surprise was the large number of families attending the conference in San Diego whom we first met in Chicago in 1993. Over and over again in San Diego I heard the remark that it was like attending a family reunion. Old friendships were re-

*(Continues on Page 7)*

Over 260 members gather in San Diego for two and a half days in what proved to be F.I.R.S.T.'s largest and most successful national family conference ever.



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Tell us what you wish to see  
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from in *Ichthyosis Focus*.

Please send your letters  
to us c/o *Ichthyosis Focus* at  
our office in Raleigh.

# C O R R E S P O N D E N C E C O R N E R

Dear Friends,

I was really glad to hear from you. I  
have wondered how you were doing. You  
know, I turned 90 years young on January 10  
and had a big party. It was wonderful.

I don't ever remember making a pledge  
to F.I.R.S.T.—I just send a "love gift" when I  
remember to. I did read with interest about  
your upcoming national conference. I know it  
will be good this year. Best wishes.

Mrs. J.E. Nash  
Birmingham, Alabama

*The following two letters are addressed to  
Cheryl E. Ryder, author of the article "Learn-  
ing To Inhabit My Skin," which appeared in  
the Winter 1995 issue of Focus.*

Dear Ms. Ryder,

To say "thank you" for the heart wrench-  
ing account of your struggle with ichthyosis  
(and anorexia) is completely inadequate.  
Your article has done more good than you  
will ever know. You have called attention to a  
most perplexing issue, which every parent of  
a child with ichthyosis faces. It must have  
been very difficult to expose yourself in this  
very personal way, and I hope it has helped to  
heal you. In giving to others this way you will  
receive many graces to carry on your mission.

On behalf of my family, and especially  
my son, Tom, who is four years old and has

ichthyosis, I extend my deepest gratitude.

Justine Seman  
San Antonio, Texas

Dear Cheryl,

I am now 76 years old and know what  
you and your children are going through. All  
through life I've had to keep my skin covered  
so (I thought) no one would notice. Luckily,  
my face and neck are not affected. I think I  
have the mildest form of ichthyosis, but even  
though they say it is mild, I always had scales  
falling all over the house, my clothing, and  
bedding. I remember in school the doctor  
gave the school a note excusing me from tak-  
ing gym showers. Neither of my children are  
affected, nor my grandchildren.

About two years ago I received a sample  
of a lotion from [Dermal Therapy]. I use the  
lotion after I've patted myself dry from a  
bath. It has helped a lot. No cure, but it keeps  
the flaky skin from falling all over. One 16  
oz. bottle goes a long way. Try it and good  
luck.

I think it helps ichthyosis if you live in a  
warm and humid climate. I've always noticed  
my skin is a little better in summer than win-  
ter. But, of course, air conditioning counter-  
acts the benefits of the climate.

Mary Agnes Adee  
Janesville, Wisconsin

**F.I.R.S.T. CAN NOW BE REACHED ON-LINE VIA COMPUSERVE**

**Our CompuServe address: 74722,1571**

**You may also reach us through the INTERNET by addressing email  
this way: 74722.1571@compuserve.com**

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publication do not necessarily reflect the views of F.I.R.S.T. or Foundation officials.

**Deadline for submissions to the next issue of FOCUS: October 6, 1995**

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

I would like to respond to Carol O'Connell and Sheryl Gorecki, whose letters appeared in the Spring 1995 issue of *Focus*.

I, too, am an adult with ichthyosis vulgaris, but, thanks to F.I.R.S.T., I am now better than I have ever been. When I was born back in 1928, doctors knew very little about this condition. My sister, who was born in 1917, also has it, so my parents knew what it was when my skin became so dry and scaly. My mother used to stand me in front of the fireplace and rub me down with cocoa butter, leaving me greasy as a greased pig!

I was always embarrassed and ashamed to meet new people. I always felt I had to explain what was wrong with me. But, in the long run, I have not let it interfere with my life. I am married, with two grown sons and three beautiful grandchildren. I entered nurse training in 1945 and retired less than two years ago after working for 45 years as a registered nurse. I found out that when people get to know you, they don't think about your skin.

I know everyone is different, and that one care regimen will not work for all. But I will outline my skin care routine in case it will help someone else.

I always shower using tepid water, and instead of soap I use Surgi-Kleen Plus cleansing gel from Sween. It can be diluted 2-to-1, or even 3-to-1, and is still very effective. While still wet, I pour some Whirl-Sol Bath Additive (a bath oil) on a damp wash cloth and rub myself down. Then, while still damp, I lotion myself with Alpha-Hydroxy Moisturizer from Dermal Therapy. By following this regimen my skin is almost normal looking. It also helps that I live in Southeast Texas, which has a warm, humid climate. Best of all, these products are not expensive. I found out about these companies and products from F.I.R.S.T. Thanks for all your help.

I would like to encourage people with ichthyosis to make friends and get on with life. Everyone has something wrong with them; none of us was born perfect. It takes a lot of courage, but a positive attitude is the most important attribute a person can have.

You may print my address and phone nu-

ber. I will be glad to hear from anyone, and I will answer all letters as soon as I can.

Vera Ponder  
Box 950-1136  
Woodville, Texas 95979  
409-429-3991

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

Our daughter was born in January, 1995, with lamellar ichthyosis. We feel fortunate that we learned of your organization so quickly. *Focus* has been very helpful and extremely informative for us. I have one tip to pass along, and could use help with at least one problem.

We have found that the topical applications we use are easier to apply, penetrate more quickly, and leave our daughter more comfortable if they are applied warm. We bought a baby-wipe warmer at Toys-R-Us that wraps around the containers and is held in place with velcro closures. It is thermostatically controlled to maintain body temperature, and can be adjusted to fit many sizes of containers.

We bathe our daughter frequently in soft water, which seems to help very much. Bathing is rather difficult, however, because we do not have a good bath seat that will enable her to be comfortably submerged, and we simply hold her in the water. I am searching for a bathing device that will keep most of her under water, would be comfortable, and safe for water play. If anyone knows of any such device, please contact us.

We would also like to speak with other people who have children with lamellar ichthyosis. Please call or write:

Donna Heilweil  
634 Highland Road  
Ithaca, NY 14850  
607-257-6225

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

We wanted to thank you both very much for organizing a great national conference in June. It was our third conference and the best ever. We left San Diego with encouraging feelings. Your guest speakers were excellent and helpful information was delivered by all.

(Continues on Page 14)

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# LETTER FROM THE PRESIDENT

by Deborah B. Vilas

All I can say is, "WOW! What a conference!" I hope that those of you who attended our national conference in San Diego are as pleased as I am. There is nothing more renewing than connecting with the very reason why I became involved with the Board of Directors in the first place—all of you. Each person, adult, child or teen whom I was able to speak with, added to the momentum of the weekend. I only wish that there had been more time, so that I could have met every single one of you.

It is difficult to say what part of the conference I enjoyed most. The chance for our Board of Directors to meet face-to-face was a definite high point. Listening to members share their personal stories in the Journal Writing Workshop was both moving and inspirational. The general sessions were informative and fascinating. We are blessed with articulate, knowledgeable faculty who share their knowledge with us in terms the lay community can understand. Mealtimes were a great opportunity to connect with old friends and make some new ones.

Upon reflection, though, I must say that the hour that I spent with four teens chatting over coffee was probably the



best part of the conference for me. We talked about everything from religion to relationships. The honesty, depth and openness of these young people was inspiring, and it gave me great hopes for the future of our Foundation. They, after all, will form the next generation of vision and leadership for our membership. In an age where it is so tough to grow up, and with the added challenge of ichthyosis, these teens still face their futures with realism as well as optimism. A special thank you to them for including me in their gathering.

I would also like this letter to serve as recognition and thanks to every single volunteer that helped us to make this the best conference ever. From those of you who assisted in registration and sales, to those of you who spent time in the child care program, the Board and I extend our heartfelt appreciation. Thanks also to the coordinators of our Regional Support Network (RSN), for you are volunteers year round. And finally, our thanks to Nick Gattuccio and his wife, Heather. Their dedication and tireless effort kept us going. Thank you.

Best wishes,  
Deb

## F.I.R.S.T.'s 1995 Awards For Distinguished Service

At its 1995 National Family Conference in San Diego, our President Deb Vilas handed out the 1995 Distinguished Service Awards to several individuals whose contributions to F.I.R.S.T. over the past years have exemplified the spirit of selfless giving for the sole purpose of strengthening the Foundation and its ability to serve its membership. We ask you to join us in congratulating these individuals for their generous contributions of time, dedication and commitment to the betterment of F.I.R.S.T. and its members.

**Leonard Milstone, M.D.**  
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•  
**Henry J. Bukaty**  
(in memory of Jane Bukaty)  
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•  
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**Heather Gattuccio**  
RSN Coordinator  
Raleigh, North Carolina

•  
**Frances McHugh**  
Former Board President  
Delran, New Jersey

•  
**Lee Bailey**  
(for Westwood Squibb)  
Buffalo, New York

**Tracie (Jones) Pretak**  
Wilcox, Pennsylvania

•  
**Tiffany & Brian Karst**  
Shawnee, Kansas

•  
The First Annual  
*Frances Bernstiel Memorial  
Award for Distinguished Service*

•  
**Lynne Alba**  
Norristown, Pennsylvania

## THE PRESIDENT'S SPEECH AT THE 1995 NATIONAL FAMILY CONFERENCE IN SAN DIEGO

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It's 1969 and I am in the third grade at Brookwood School. It's a small private school in rural Massachusetts, located on a wooded hillside overlooking a picturesque pond and playing field. My teacher has just been called from the classroom to receive a phone call when David Breasted (I shall never forget his name) starts up a chant.

"Red skin, Indian! Red skin, In-di-an! Red skin, In-Di-An!" One by one, the rest of the class joins in, until the whole class is chanting, pounding out the rhythm of the chant on their desks. "RED SKIN, IN-DI-AN! RED SKIN, IN-DI-AN!"

To be honest with you, I can't remember exactly how I reacted. I'm pretty sure that I didn't cry, and I don't remember defending myself either. I do remember the shame, the hot, burning feeling in my face—the feeling of wanting to crawl into my desk to escape the taunting.

Now, I am not telling this story to tear at your hearts. I just want you all to know that I have been in that place, as I am sure many of you have. Or perhaps you have witnessed this pain in your children. But, from there...to here. How did I get from that eight year old to the woman standing before you as your president?

How many of you have seen *The Lion King*? I'm probably in the minority here, having seen it less than 20 times. One scene stands out in my memory. Simba, the lion, has reached adolescence, and he is torn between memories of his shameful past, and the urge to take his rightful place as leader. The wise baboon, a shaman if I ever saw one, whacks Simba over the head with a stick.

"Ow!" says Simba. "That hurts!"

"It is past," says the baboon.

"But it still hurts" groans Simba.

"Yes, the past hurts," he answers. "You can either run from it, or you can learn from it."

How do we help our children and ourselves learn from the hurt of having ichthyosis? One

way is to reframe our experience of ourselves. For instance, our condition, ichthyosis, is derived from a word that means "fish." Well, fish are somewhat slimy, have a strong odor, and are covered with scales. This is one way to look at it.

They are also strong swimmers. Their scales reflect a rainbow of colors. They work well in groups, and, they taste delightful when grilled on a barbecue with the right marinade.

REFRAMING. We need to find symbols for ourselves and our children that we can take pride in. On the CBS Morning Show last Sunday, I saw a spot on salmon. What an incredible fish! It swims upstream, leaping against currents, over rocks and up waterfalls, before spawning and beginning a new generation. Now that is a fish I can relate to!

From there to here. I am lucky to have had a very loving family. With their guidance, and my own will to succeed, I took my past pain and turned it into something positive and useful. As a child life specialist, I now work in a hospital, helping children through the trauma of illness and hospitalization. As your president, I am working hard to provide you with resources, support, and inspiration to see the inner beauty of yourselves.

Like the salmon, every one of you must make this journey uphill. But you are not alone. F.I.R.S.T. changed my life by bringing me into contact with all of you. I'm pleased to be swimming right along side of you. I don't have answers to make it all easy. But if you find your center, and assist your children in finding theirs, the path will show itself. Find what matters to you, and, like the salmon, leap for it.

I can't undo my past. I can't go back to Brookwood and stand up eloquently for myself in the face of the teasing by my peers. But, I can stand up before you now, my new peers, and say to you: "Say it loud. I'm red and I'm proud!"

Thank you.

# The San Diego 1995 National Family Conference: *An Album*



A great many of us had a chance to meet denizens of the deep at San Diego's famous Sea World.



Lisa & Rey Santamina with Jaymee Rae Gulmatico, from Santa Clara, California



Rebecca Butler and mom, Debra, from Rochester, New York



Haley, Adam and Andrew Rice, from Katy, Texas.



Vanda Darg and daughter Megan, all the way from England



Mellissa Bryant and her mom, Lori, from Alta Loma, California



Megan Piercey with cousin Morgan Fletchall. Behind are Megan's parents, Parker and Debra Piercey. Megan and Morgan entertained us at the Saturday night banquet with a knock-out lip-synch performance.

Aida Villa, Diandra Munoz and Robert Villa, from Tucson, Arizona.





E.P. and Erik Beeler, from Tucson, Arizona, survived the Giant Dipper in Belmont Park near the Bahia Hotel.

(l. to r.) Dr. Leonard Milstone, Chairman of F.I.R.S.T.'s Medical Advisory Board, Executive Director Nick Gattuccio, Nancy Dunleavy, and Michael Dunleavy, F.I.R.S.T. Board of Directors



The Steinitz family from Pittsburgh. (l. to r.): Dana, little Hunter, Patti and Mark

Jessa Karst, from Shawnee, Kansas



Denise Eastin with twin daughters Jolene (l.) and Tamara.

## San Diego: A Special Report (continued from page 1)

newed, new friendships were made, and by the end of the events on Friday evening nearly everyone there had jelled into one large congenial group. Spirits were high and expectations great, and few, I think, were disappointed.

Most everyone truly enjoyed the Bahia Hotel. Set on the shore of Mission Bay, with marina, docks, sternwheel boats, with plush gardens and its own harbor seals, the Bahia proved an ideal setting for a family conference and vacation. Set just three blocks from the Pacific Ocean, where a boardwalk, restaurants, shops, and amusement park kept everyone's free time lively and interesting, the Bahia's setting and staff were ideal complements to our weekend's events.

Although a great many people arrived early, and for most of the week the family gathering built up steam with informal get-togethers and trips to see the San Diego sights, the conference events officially began on Fri-

day evening with a Mexican fiesta and reception. But the big day was Saturday—a full day of general sessions, meetings, seminars and workshops, a picnic lunch and, that evening, an Italian buffet and banquet, awards ceremonies, and a special lip-synch performance by Meade Piercey and cousin Morgan Fletchall of Ogdensburg, New York.

On Sunday everyone gathered for a special Father's Day breakfast. After breakfast we raffled our two special gifts—an exquisite hand-made quilt, made by Donna Rice's mother, Ruby Nell Howard, and a beautiful painting made specially by member Anna Maria Yanez of Tucson, Arizona.

What made this a truly great conference—far and away the best ever—was not anything we did in the way of planning and organizing. What made this such a stunning family meeting was the energy and vitality that everyone brought with them to San Diego. I wish to personally thank every one of you who came, for what you brought to San Diego and shared freely with everyone else, so that all of us could take something new and valuable home with us, something we had not had before.



Robbie Villa

by Heather Gattuccio

**I**t was an extraordinary experience manning the child care room in San Diego. My daughter Caitie, Betsy Wilford and I spent several weeks planning fun activities and gathering materials for these two days of excitement. We came armed with crayons, markers, buckets of glitter, stickers, stamps, videos, books, dress-up clothes, and a mountain of toys. Caitie took special delight in hand-picking items from her room that she wanted to share with her special friends. We had fun setting up the room. We were so well prepared...we thought!

We were expecting 42 children. They began arriving...and then they kept coming and coming and coming. When the two adjoining rooms came close to standing room only, Betsy and I started giving each other terrified looks. Caitie thought it was marvelous. She set off on her own, and I rarely saw her again.

I did a head count and discovered that we had 62 children in the room—20 more than had registered. Betsy and I jumped in, started soothing sad little ones who missed mommy and daddy and began organizing activities and play. We sent the older children to enjoy pool-side games with the hotel's activities director while setting up a screening of "The Lion King" on the VCR. I began talking up the clown that was scheduled to appear later that afternoon in hopes this would cheer up those children who continued to stare forlornly toward the door.

Eventually, things settled down and we began having fun interacting with this incredible group of kids. I watched with pleasure as children played together with the help of our wonderful group of teen helpers. Jessa's dad, Brian Karst, worked with a large group at the Play-Dough table. Suzanne Taylor and Crystal Tumlinson took turns holding and playing with baby Emily with the beautiful curls, the mellowest baby I have ever enjoyed knowing. Geoffrey Hamill, Coordinator of the Ichthyosis Registry in Seattle, mesmerized the older kids with his polaroid camera and good natured play. Joshua Carroll jetted around the room in his walker, chomping on Cheerios. Jolene

# THE CHILDREN REIGNED...



In the Child Care Room (l. to r.): Suzanne Taylor, Betsy Wilford (behind), Heather Gattuccio (holding son Enzo), Lynne Alba, and Dana Steinitz.



Sarah Getz, Katie Getz, Jessa Karst and Caitie Gattuccio

by Betsy Wilford

**M**y summer began with three wonderful days in San Diego. I had never heard of ichthyosis, until I met my friend, Deb Vilas. When she became president of F.I.R.S.T., she asked if I would like to get involved. When she told me about the national conference, I said that I would like to be part of it. Being a bit of a kid myself, I wanted to help out with child care. "Is it okay to pick them up?" I asked Deb. I was trying to understand how it feels to have ichthyosis. "How will I know if I'm hurting them?"

"Don't worry," Deb assured me. "The kids will tell you. Trust them, and trust yourself."

When I first walked into the child care room in San Diego, I was nervous and shy and trying not to feel either one. Nick and Heather Gattuccio's daughter, Caitie, was sitting on the floor with a toy phone. "What kind of pizza would you like?" she asked. "I'd like a large one," I said, sitting down beside her. "With pepperonies?" she asked. We agreed on

pepperoni, with some onions, but no mushrooms. As I sat there with Caitie, her confidence and imagination helped me to settle in and relax.

Later, as parents dropped off their children, there were a few tearful separations at the door. Some of the youngest were simply not going to stop crying, so their parents stayed with them. Caitie and I played pizza delivery with the older ones, using Play-Dough. We made slices and decorated them with everything that you could imagine would fit on a pizza.

As more kids arrived and I began to feel at home, I was no longer aware of which children had ichthyosis and which did not. I was surrounded by kids who were building toy villages full of animals and action figures, making Father's Day cards, or sprawling in the middle of Big Books reading to one another. Heather had organized a terrific variety of toys for the different age groups, and she was a beacon of calm whenever I felt unsure of what to do next. We had our hands full making sure everyone was safe, filled with snacks, and having fun.

At one point, while play-





Jasmyrn Bowie and Xssss Xxxx

and Tamara Eastin inspired a group of older kids to start making wonderfully creative Father's Day cards. Katie Getz comforted sad toddlers with words of wisdom—"They'll be back," she said sweetly, patting their hands. "They'll be back."

That afternoon, all of the kids were gathered together, anxious to see our scheduled clown. Betsy and I were equally anx-

ious to sit down and rest. Then, a dirty looking fellow dressed as a hobo walked in and told me he was there for an adult stand-up show. For the first time that day I ... well, one dad said he saw me get red and he feared for the clown's safety. The clown assured me he could improvise and went to his car for balloons. But the clown was grim—doing card tricks for toddlers. But the kids were good sports. Some even liked him. And A.J.'s dad, Able Gonzalez, saved the day by making balloon animals for the kids.

To the big people who stopped by, it may have looked like chaos. While there were no doubt chaotic moments, overall there was a crazy sense of order, due largely to the children themselves, who played and supported one another with laughter and grace. I continue to be amazed at how accepting all of our children are towards one another, those affected by ichthyosis and those who are not. No child was scorned or left out, and many told me they were excited to come back the next morning for day two.

Special thanks go out to Betsy Wilford, a true gentlewoman, story teller, and trooper. And to Christine Lindstrom, who was the only person that my five-month-old son Enzo would allow to hold him. He has great taste!

Special thanks also to Madonna Taylor, Chris, Erik and E.P. Beeler, Ebonye Bowie, Becky Butler, Jennifer Cruz, Geoffrey Hamill, Melissa Gay, Pat Hobson, Sue Getz, Shari Gelevich, and Jane Giuliana, Patricia and Abel Gonzalez, Carolyn Gramlich, Brian and Tiffany Karst, Danielle Lindstrom, Donna Rice, Dana Zoelle, Suzanne Taylor, Crystal Tumlinson, and the entire Ganemo family (especially Anna).

For the loan of toys, special thanks go out to the Berghers, the Martins, Deb Vilas, the Sherrils, and the LeBlangs.



Anna Ganemo, who came all the way from Sweden

ing outdoors, I overheard one boy ask a girl, "What's wrong with your hands?" Her sister explained, "That's because she has ichthyosis." For a moment, they talked about the different kinds of ichthyosis, and then continued their wild game of tag, up and down the lawn. I admired how this was a family where parents and children were teaching one another, and were supportive of each other, too.



Meade Piercey, Sarah & Katie Getz

Between sessions, when the parents stopped by to pick up their children, I listened to them talking about ichthyosis, and I realized how important the conference was as a place for them to share their experiences and exchange information.

Deb had told me how difficult it had been to have "different skin" when she was younger. I remembered my own experience with scoliosis (curvature of the spine), when I wore a back brace and put up with people's sometimes insensitive questions, like "What's the matter with you? Were you in a car accident?" I would answer them politely, when what I really wanted was to tell them to drop dead. Hearing Deb speak on Saturday night about "reframing" her experience helped me heal my own memories. And being with these children, I was inspired by the ones who were shy and reaching out as well as the more extroverted ones who were not going to let "being different" stop them from anything.

Sunday morning, at the tail end of the conference, my jet lag was catching up with me. At breakfast, several teenagers offered to come and help with the children. A group of us, from toddlers to teenagers, and a few adults, got busy making our own San Diego Zoo out of Play-Dough. By then it was all one color—purple-brown. We made Seaworld whales, dinosaurs, and farm animals, adding candies, hair clips, and other odds and ends for color. Then the children began making all of the animal noises. One of the shy children watched from across the room. He was silent, until the kids got louder, until they were singing all of the sounds at once—and then he joined in, giggling.

I remembered having heard a man at dinner the night before say that he was 40 before he ever met another person with ichthyosis. Watching these children with their new friendships, I realized that because of F.I.R.S.T., things are already different for them.

When people ask where I've been this summer, I tell them about F.I.R.S.T. and how special it was to be part of the national conference in San Diego. I look forward to the next conference when I can see these kids again (two years older!), and meet more members of F.I.R.S.T., young and old.



Jessa Karst and Caitie Gattuccio play on the Marina beach at the Bahia Hotel

# Reflections on the Journal Writing Workshop

by Rich Graham

*F.I.R.S.T. Board members Rich Graham and Deborah Vilas conducted two Journal Writing Workshops that spanned two days at the National Conference in San Diego.*

Deb Vilas and I facilitated a workshop on journal writing, which was intended to be one way in which people affected by ichthyosis could share their experiences in a non-threatening and supportive atmosphere.

The format for the workshop was for everyone to write about incidents that happened to them or their children. After twenty minutes, we got together and had the opportunity to share aloud what we had written.

The sharing of what we had written led to discussions about what it was like living with this skin condition, both from a parent's perspective as well as from the perspective of a person who has ichthyosis. We seemed to all share the same hopes and worries.

As a person with ichthyosis myself (recessive X-linked), I immediately identified with what others had

written and was very moved by the stories of people who had more severe cases of ichthyosis. I got small glimpses of what others had suffered through (and survived), and made a vow to never again complain about my skin.

Being 44 years old and never really having discussed the emotional side of having ichthyosis with my own parents, I was particularly moved by the love and compassion expressed by the parents of children with ichthyosis. Children growing up with such supportive and open parents will develop a healthy attitude towards their skin and not feel so overwhelmed about it.

What I wrote in my journal that day was this: "If there is one thing I could share with all parents of children with ichthyosis, it is this—outside of a gene 'cure' or lotion 'cure', the best thing your children have going for them is the fact that F.I.R.S.T. exists. Your children will not feel isolated growing up and knowing that they are not alone."

Thanks to Deb and all the participants who made the workshop such a worthwhile experience for me.

## VERY SPECIAL THANKS TO CONTRIBUTORS TO THE SAN DIEGO RAFFLE

Anna Maria Yanez & Ruby Nell Howard



Aida Villa (l.), Anna Maria Yanez (artist of painting) and Robbie Villa

Two very special F.I.R.S.T. supporters deserve special thanks for contributing works of art and craft to help support our San Diego conference. The high point of Sunday's Father's Day breakfast was our raffle of two exquisite works of art—a hand-made quilt and an original painting.

Members purchased raffle tickets at \$1.00 each for chances to win the beautiful prizes. The raffle netted nearly two hundred dollars that went toward defraying costs of

the conference. Our thanks to all of those who purchased tickets.

Ruby Nell Howard, mother of Board member Donna Rice, contributed a gorgeous hand-made quilt. Member Anna Maria Yanez donated one of her original paintings—a pastel still-life of flowers in a vase. Both prizes were on display in the ballroom foyer over the weekend.



Jessa Karst (in her mom's arms) draws winners of the Father's Day raffle. Nick Gattuccio is holding up the hand-made quilt created by Ruby Nell Howard. On the easel at his left is the beautiful painting by Anna Maria Yanez.

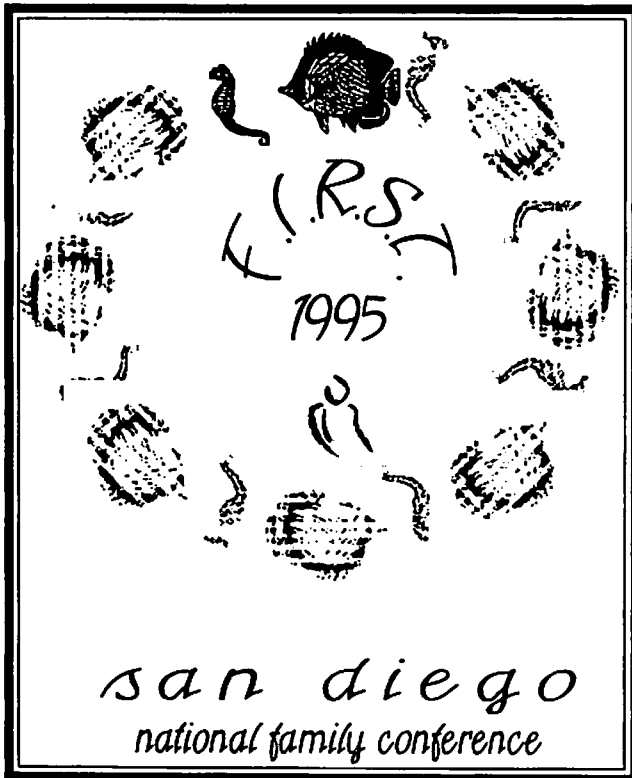
We can't thank our contributors enough. One way in which our organization grows and prospers is through the generosity of spirit and the goodwill of our members. Thanks to Ruby Nell and Anna Maria!



Wendy Vaughn and her mom, Madonna Taylor, from Highlands Ranch, Colorado

## T-SHIRTS

National Conference T-Shirts  
Available For Purchase



We have a surplus of National Family Conference T-shirts left over from our meeting in San Diego, and we're conducting a fire sale. Whether or not you were at the meeting, please consider buying one of our commemorative T-shirts. Just \$10.00 each. These are 100% cotton shirts with the above design on the front. Available in large and extra-large. Send your order to Nick at the office in Raleigh, and we'll ship for free.

## A Young Person's Perspective on the Conference

by Wendy M. Vaughn

In my opinion, I thought the conference in San Diego, overall, was good. I was really impressed with the fairly large attendance that we had this year. I really liked how the F.I.R.S.T. conference was international, too. I loved meeting people from different countries as well as from the U.S. I met quite a few people this year, and I got to talk to the "regulars." It was great to see them after two years.

On the other hand, I felt that I didn't get the chance to really talk to them, to get to know them. I feel that I'm not getting much out of going to the F.I.R.S.T. conferences except seeing the F.I.R.S.T. regulars. Don't get me wrong...I don't mind helping out other families with their kids. I'm privileged to know that there are some people that look up to me and my accomplishments! But I do feel that I'm not getting anything back in return. It's just that there aren't many people that can help me, tell me about the future.

This year's conference was good, but I, along with the other young people, thought the Youth Group could have been better. The individuals around the age of 18-20, along with myself, aren't saying the mentor wasn't good. She just wasn't speaking to us, like we were young adults. I also didn't think the parents should have been allowed to be in the Youth Group meeting room, because I feel the youth can't express themselves and talk about things that they can't talk about around their parents. One more suggestion is to set an age limit on the Youth Group. You might put the grade school kids together in one group and the high school and college young adults together in another so that we can talk with others that can relate to us.

One last suggestion is that I felt that the panel we had at the last conference in Chicago went very well. It was kind of like a question-answer panel.

Deb Vilas took the time out of her busy schedule to get a few of us young adults together in order to talk casually about dating, etc. I liked that a whole lot better because it was a casual get-together in order to talk about things we could all relate to.

I certainly don't want to say that the conference was bad, but I hope you will take into consideration the suggestions I have written about here. It was truly a terrific conference.

# BUILDING COMMUNITY AND THE POWER OF LANGUAGE

by Teri A. Adams, J.D.

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*This article begins a regular feature in the pages of Focus, which will be devoted to disability rights advocacy and the law. Teri A. Adams, J.D., a disability rights advocate in San Francisco, will be writing a column in coming issues devoted to the special concerns facing members of the ichthyosis community. We invite questions for Teri, as well as comments about her columns. This column is intended not only to inform our community, but to provoke frank discussions, too. —ed.*

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I will be using this column to introduce myself, my background and my perspective, or “where I’m coming from,” as we say in San Francisco. Ultimately, I will be talking about disability rights law, and how these laws are relevant to persons with ichthyosis. But before we start talking about disability rights law, we need to talk about self-identifying as having a disability, and disability issues in general. I am hoping that readers of this column will write to me and let me know what they are interested in hearing about, and what they are not.

I will be 38 years old in October, and I was born with epidermolytic hyperkeratosis (EHK). I have been told by Dr. Mary Williams that I have a severe case of EHK.

As a result of this, I was placed in a segregated special education program when I started elementary school in the early ‘60s. This meant that the entire school was comprised of students with many different kinds of disabilities (we were called “handicapped” back then). There were no non-disabled students in the school. When I went to high school, I was integrated into regular classes, but I was still on the books as a special education student, and we had a special home/resource room.

After high school, I went to junior college for two years, and then went to a summer writing program at Michigan State, which was my first time away from home. When I returned, I decided to try

to get a job and continue college “later.”

To abbreviate this next period (in which “later” became almost ten years), I had a few employment experiences, some of them good, some of them bad, and even the good ones had bad aspects. At one company, I knew that it was because of my skin that I was never going to be promoted beyond a certain level. I then had my own company for a few years, during which time I decided to go to law school.

I finished my B.A. in English (creative writing) while working full-time, and then, in the fall of 1990, I began law school. I graduated in May, 1993.

Although I have not passed the California Bar, I did work for a well known and respected disability rights attorney for about a year ... until my grant ran out. I was then a benefits counselor for people with mental-health disabilities.

I am now a Student Affairs Officer at Stanford University in their Disability Resource Center, which provides accommodations for undergraduate and graduate students. This makes me one of the 70% of persons with physical disabilities in the U.S. who are under-employed (meaning I am overqualified for my position) or unemployed.

*“I believe, however,  
that how we identify  
ourselves, even  
down to the words  
we use, makes a  
tremendous difference  
in how we  
view ourselves in  
the world”*

I give you this rather lengthy background not because I think my autobiography is so compelling, but because I think it serves to explain why I think of myself as a person with a disability—not as someone with a “skin disease,” or as a “victim of a genetic

disorder.”

You may think that these distinctions are unimportant, or politically correct silliness. I believe, however, that how we identify ourselves, even down to the words we use, makes a tremendous difference in how we view ourselves in the world and at home, even in our self-esteem.

Long ago, when I was a junior high student, my wonderful English teacher, John Field, told us that “words are power.” As a wannabe writer back then, I thought that this was a wonderful idea, but I don’t think I truly understood until many years later what he meant. Because words not only have the power to evoke emotions and paint pictures and tell stories, they also have the power to define our world and ourselves.

If I say I have a “skin disease,” I sound, well, sick. And I’m *not* sick. This flaking and callousing are normal, *for me*. So are the painful blisters I get on my feet. The only time I am sick is when I get an infection, and anyone who gets an infection, whether or not they have ichthyosis, is sick. If I were to think of myself as sick or “diseased,” I can tell you I would feel much worse about things as a whole. If I thought of myself as “sick,” that would mean I have been ill for my entire life. And, were I to identify myself to others, who don’t know what ichthyosis or EHK is, as having a “skin disease,” their initial reaction is going to be that I’m sick (possibly contagious?), to be pitied, patronized, etc. Likewise, the label “victim” of ichthyosis. Victims are pitiable creatures who have no power, who must be taken care of, who.... That ain’t me. Or you, I hope.

Finally, I think that we should keep in mind, particularly those of us with EHK, that no cure or significant change in treatment options is likely to come along any time soon. If we go around thinking of ourselves as “sick” and waiting for a “cure,” we’re going to be wasting a lot of time in which we could be doing something else. Like working, or having fun.

So, I am relatively at peace with this thing. The negatives invariably come from the outside: personal rejections because I don’t look like a cover girl, jobs

I didn’t get because of my disability—you know. But not only does this put me in the company of a vast number of the population (which is what non-disabled people will tell you to “buck you up”), but it truly puts me in the excellent company of other people with different disabilities.

This is where the “community” part of this column’s title comes in. More and more there is a feeling among people with disabilities that we are a community, with a great commonality of experience, of difficulties, of political issues and concerns; there is even a growing disability culture. Repeatedly, I experience that people with other disabilities are extremely accepting of me as one of “them,” a sister.

This is a very powerful thing, particularly for someone, like most of us, whose disability is so unusual that we may never see others who have ichthyosis. It’s a resource—my friends who use electric wheelchairs told me of the one honest place where I could get my scooter fixed—and it’s support. Discrimination is discrimination; other people with other disabilities know exactly how you feel. And many of them know the law, and what the local resources are, where to get help ... you name it.

So, when I tell you about the laws that protect the civil rights of persons with disabilities—as I will be in the course of this column—I want you to think of all the people who worked to make those laws a reality. I want you to think of their voices and their power. This struggle isn’t over yet; we have to make sure that the small gains we have made are not lost in this political climate. Whether or not you decide to be an active participant in this community is up to you; until recently, I wasn’t much of a “joiner” myself. It’s important to remember, though, where these laws came from, their intent, and the issues they were designed to address. As a person with ichthyosis, as a person with disability, the disabled community’s issues are your issues.

*“Words not only have the power to evoke emotions and paint pictures and tell stories, they also have the power to define our world and ourselves.”*

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Send your questions about disability rights (be they about employment, education, or other areas of concern) to Teri Adams, c/o FOCUS, P.O. Box 20921, Raleigh, NC 27619. Your questions will be dealt with anonymously in this column.

## Correspondence Corner (continued from page 3)

We felt a real sense of confidence through the weekend.

It was great to see familiar faces, acquaintances turned into friendships, and to make new friends. Laura now has three pen pals. When we got home she said, "You know, my ichthyosis isn't so bad. I think I'm really pretty." What a great feeling!

We look forward to seeing you, Caitlin and Lorenzo again. I'm enclosing a check for \$100 to help F.I.R.S.T. continue its great effort. Thank you again.

Cynthia & David Ashton  
Paget, Bermuda

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

My name is Lisa Pullen and I'm from Brampton, Canada. I am 32 years old and I have lamellar ichthyosis. On both sides of my family I am the only one who has ichthyosis.

The very first conference I attended was for one day in Florida. I saved every penny I could from my job so that I could attend. To try and put into words what I got out of that one day would take too much time, but I will tell you this. Everyone, absolutely everyone, who has ichthyosis at some point or another has felt isolated. That feeling of being the only one with ichthyosis is probably one of the worst feelings to have, and it is hard to live with.

When I met people at the conference who had ichthyosis, the feeling of finally belonging became a reality. The loneliness, the isolation, were gone, because here was a group of people just like me. I was no longer the only one with it, no longer feeling self-pity, because I realized at that conference that there are varying degrees of severity with ichthyosis, and I realized just how lucky I am.

Some of those same wonderful people that I met in Florida were in San Diego, and it was like meeting friends you haven't seen in a while. The closeness had never left after Florida. I was also extremely fortunate to meet some new friends as well.

The information, the social contact, the feelings, the vacation aspect of the conference, all make for one of the most memorable, totally unforgettable, experiences you will ever have in your life. So if you get the chance to attend the next conference, do so. Even if you never go to another one, or if you are like me and start going to most of them, you will never in your life ever regret that decision.

Finally, to everyone I met at the conference in San Diego I wish to say Hi! I can't wait to see you at the next conference, and to Nick and all the volunteers I extend my heartfelt thanks for very special memories.

Lisa Pullen  
Brampton, Ontario, Canada

Dear Nick & Heather,

Hope all is well with you. This is just a note to thank you for the conference in San Diego. I've been trying to write something since I got back and couldn't quite say what I wanted. I thought about the courage of the kids with ichthyosis, the spirit of the adults with it, and those who don't have ichthyosis who support those of us who do. Now I think I have it—the whole thing was a testament to the human spirit more than anything else. We came through for one another, and *that's* what it is all about.

People with ichthyosis and their supporters put up with much garbage in the "outside world." It was great to meet so many people willing to share their good and bad experiences and how they dealt with them. For me, personally, it gave me a chance to *vent* with people who knew what I was talking about. (Thank you, ladies—you know who you are!)

A special note of thanks should go to the parents who brought their children to San Diego. If there had been something like this when I was growing up it would have made a tremendous difference. Your children will thank you. Thanks again for a job well done. I look forward to seeing you (somewhere on the East coast?) in 1997. Take care and God bless.

Carolyn Gramlich  
Roseville, Minnesota

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

Some things to think about that might deserve consideration. My daughter, Karla, with lamellar ichthyosis, has lived in Florida for several years and that climate helps a lot. Karla also takes vitamins and herbs daily. One thing that really seems to help her skin is evening primrose oil, which is a natural essential fatty acid. Black current oil is also an essential fatty acid. We use American Health's Royal Brittany (500 mg.). This product also helps PMS. There is also emu oil, although we haven't experimented with it yet because of its high cost. But we're hoping to locate an inexpensive source. Have you heard, read or been offered any information about this oil.

Thanks for all your efforts and informative newsletter, as well as your caring and helpful attitude.

Mrs. E.L. Babcock  
Dearing, Kansas

*We are not aware of any beneficial effects of evening primrose oil or black current oil. Please keep us informed. —ed.*

We welcome letters from the community on any topic. Please understand that we must sometimes edit for space. If you wish to write anonymously, please let the editor know. Send your letters to F.I.R.S.T., P.O. Box 20921, Raleigh NC 27619.

F.I.R.S.T. does not endorse or recommend products or treatment regimens presented in *Focus*. As always, consult your dermatologist before adopting new treatments.

# ENROLLING IN THE NATIONAL ICHTHYOSIS REGISTRY

## A Personal Account

by Nick & Heather Gattuccio

At first we felt that, because Nick is executive director of F.I.R.S.T., it was our duty to set an example for the membership and enroll our daughter, Caitlin Irene, who has lamellar ichthyosis, in the new National Registry for Ichthyosis & Related Disorders. But then we realized how foolish that notion was. We saw that we should enroll Caitie in the Registry because it is the greatest opportunity our membership has ever had to make a significant contribution to ichthyosis research in America.

Hardly a week goes by that we do not receive a call at the office from someone in our community who asks how they can contribute to research in the ichthyoses. Until the Registry began this spring, it was always a difficult question to answer. Now, the answer is simple. We all have the opportunity to make ourselves available to virtually every ichthyosis research project in the country simply by registering with the National Registry for Ichthyosis in Seattle.

Enrolling in the Registry was a very simple matter. Nick called Geoff Hamill, the Registry Coordinator, at the toll-free number in Seattle and asked him to send the forms. Once in hand, there were just three easy steps. One involved filling out a simple "consent/assent form." This signifies that we understand the Registry and its objectives. It is a record of our consent to enroll Caitie. Second, there is a "Patient Enrollment Form." This is a questionnaire, which the Registry Coordinator, Geoff Hamill, filled out during a telephone interview (at the Registry's expense). Although Geoff will fill out the form, it was very important to go over our copy of the Enrollment Form before the interview so we could gather together the information Geoff would ask about (like social security numbers). However, you do not have to answer questions on this form that you do not wish to. The entire interview took about 20 minutes.

The third and final part of enrolling involved taking the "Physician's Form" to Caitie's dermatologist. The dermatologist fills this out (it takes about five minutes) and sends it back to the Registry for you. Caitie's dermatologist did this at no charge. If you do not have a dermatologist who can fill out this form for you, you may call Geoff at the Registry to learn if there are "regional experts" in your area who can help. You may also contact Nick at F.I.R.S.T. to learn if there is someone in your area who can fill out the Physician's Form for you.

Not only was enrolling Caitlin in the Registry extremely easy, we know that we can withdraw Caitie's information at any time. We also know that enrolling does not obligate us *in any way* to participate in research studies that we learn about through the Registry. We also know that absolutely *no* information about Caitie will be given out to anyone. Instead, when a research project comes to the Registry's attention, they will let us know about it, and will tell us how we can contact those doing the research if *we* decide we want to. The Registry will *never, under any circumstance*, give out information about Caitie to anyone.

We are pleased that we've enrolled Caitlin in the Registry. Even if we never participate in a research project, we still know that we have supported one of the most important things that has ever happened for the ichthyosis community.

## **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

**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 create a list of affected individuals for the purpose of stimulating research about these disorders. This should have a profound impact on research in the ichthyoses and related disorders, since the greatest obstacle 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.

# N.O.R.D. REPORT

*The National Organization for Rare Disorders (NORD) is an umbrella organization representing the interests of groups like F.I.R.S.T. in the difficult arenas of political lobbying and health-care advocacy. "N.O.R.D. Report" is an ongoing digest of highlights from NORD's newsletter, NORD ON-LINE.*

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## Quotes of the Day

"By the year 2000 or 2002, we would be so far below current levels of funding that I don't know if NIH will be a viable institution."

*-NIH Director Harold Varmus on the impact of proposed GOP cuts on NIH*

"The current health care system is rapidly moving toward the kind of integrated corporate monopolies that the old turn-of-the-century robber barons of oil, steel and railroads could only dream about."

*-Dr. Arthur Caplan, Univ. of Pennsylvania*

"We're the only advanced country in the world where the percentage of people in the work force with health insurance is smaller today than it was ten years ago."

*-President Clinton, March 7, 1995*

"While politicians did nothing, Wall Street was reforming health care with disastrous results."

*-Dr. David Himmelstein, Health Policy Analyst*

"A nation's budget is full of moral implications; it tells what a society cares about and what it does not care about; it tells what its values are."

*-Former Senator J. William Fulbright*

## NORD's Policy on Gene Patenting

More than 180 leaders of various religious groups have signed a petition to the U.S. Patent Office asking the government to reverse its policy of allowing patenting of human and animal

genes. Approximately 4,000 "orphan diseases" are genetic in origin, and many of the treatments envisioned to alleviate these illnesses are expected to come from the biotechnology industry. Patents for these treatments are a necessary financial incentive to entice companies into developing treatments.

However, in recent years it has become commonplace for American companies to apply for patents on genes and gene sequences, even before a diagnostic or therapeutic product has been developed. In such instances, any further research on that gene may become vulnerable to payment of royalties. The patent holder is in a position to hold humanity hostage to those royalties, and can charge any amount during the period in which the patent is in effect.

NORD believes that genes and gene sequences should not be patentable as they appear in nature. Rather, to secure a patent, a person or company should be required to do something to the gene to make it useful. Only then should that "product" become patentable.

It is not possible to patent genes in Europe. The European parliament has voted twice on this issue and has reflected the emphatic sense of the European public. In fact, the U.S. now stands alone in its policy of permitting patents on naturally occurring genetic sequences.

## SSI Under Attack

In its zeal to pare the federal budget and get the federal government out of the social services business, the GOP is leading an attack on SSI. This is the

federal program (in the Social Security Administration) that offers cash assistance—and in most states—access to Medicaid to the poor and disabled. Eligibility is determined by financial need and, for children, an "individual functional assessment" (IFA) to determine whether they are disabled.

Congress is presently considering a bill that would no longer offer IFAs to determine whether a child is disabled, but instead would restrict SSI to children who are so severely impaired they require institutionalization. If this bill is enacted, within six months an estimated 200,000 disabled children (including those with ichthyosis) will lose their SSI benefits.

If the IFA is deleted from SSI regulations, NORD believes that children with rare disorders will suffer immeasurably. We urge you to contact your Senators and Congressmen to encourage them to **retain the Individual Functional Assessment provisions of SSI regulations**. Tell them that ichthyosis is not on the Social Security Administration's "Listing of Impairments," and that children with ichthyosis will be denied SSI benefits if the IFA is deleted.

## NIH Budget Under Threat

Although the House Subcommittee which oversees NIH appropriations has approved a 5.7% budget increase for NIH for the next fiscal year, there is concern that when appropriations legislation reaches the floor of the House there may be efforts to cut this back. NORD officials met with appropriations subcommittee chairman John Porter, who informed them that "a group of new freshmen Republicans will attempt to 'rob the NIH' of any spending increase."

Cuts in NIH spending will *profoundly* impact research across the board, and will seriously jeopardize the important research now underway to understand the ichthyoses.



# GRASSROOTS

## TIRELESS FUND RAISER TRACIE PRETAK DOES IT AGAIN!

You know her in the pages of *Focus* as Tracie Jones—so congratulations to Tracie on her May wedding and name change to Pretak!

Church pianist at the First Baptist Church in Johnsonburg, PA for the past four years, it struck Tracie's mother, Karen Jones (another prolific fund raiser) that Tracie might do a benefit concert for F.I.R.S.T. Well, not only did she do this concert, but she enticed a friend, Larry Bauer, to record the concert. Larry spent countless hours editing and finally producing a quality tape,



Tracie (Jones) Pretak and daughter Bailey Jones practice at home for concert

which were then offered to the congregation to purchase. Proceeds were contributed to F.I.R.S.T.

Including outright donations from Martha Johnson and Mabel Brent, net receipts from the concert and sale of tapes totaled \$250.00. Our sincere thanks go out to Tracie, her mom Karen Jones, Larry Bauer for all of his hours of work, and to all of the congregation of Johnsonburg's First Baptist Church for their hard work, generosity, and good will toward F.I.R.S.T.

## THE JANE COLLIUORI MEMORIAL GOLF OUTING RAISES \$900 FOR F.I.R.S.T.

Carl Colliluori of Monte Claire, PA, along with Shaun and Kathleen Kelly of West Norriton, PA, contributed nearly \$900.00 to F.I.R.S.T. this spring, proceeds from the annual Jane Colliluori Memorial Golf Outing which was held on April 29th.

An annual event to honor the memory of Carl's late wife, each year the family donates receipts from their event

to a worthwhile charitable organization. They know about F.I.R.S.T. and our work through Carl's cousin, Lynne Alba, a member of F.I.R.S.T.'s Board of Directors.

Our deepest thanks to Carl, Shaun and Kathleen, and to all of the friends and family members who came out this year to honor Jane's memory and to contribute to a worthy cause.

## SECOND ANNUAL KARST GARAGE SALE FUND RAISER NETS \$775

For the second year running, Brian, Tiffany and Jessa Karst of Shawnee, Kansas, produced a garage sale fund raiser extravaganza to benefit F.I.R.S.T. Along with friends, family and neighbors, they gave a weekend in May to raising funds to help develop programs and services for the Foundation. And it was again a wildly successful venture, netting \$775!

Tiffany and Brian are our RSN Kansas State Coordinators and recipients of a 1995 Distinguished Service Award presented at our San Diego national conference. Tiffany is presently working to develop funding and production of an educational video for F.I.R.S.T.

We gratefully acknowledge contributions to F.I.R.S.T. on behalf of our members and friends who have passed away over the past months. Our thoughts and prayers go out to the families and friends of Ramelle Henderson, Russell R. Rivenburg and Michael Coyle.

## *In Memorium...*

*In memory of...*

**Ramelle Henderson**

Ivyl & Owen Mackin

Helen & Mike Yohanek

Clifton & Laura Ray

Vernitta Rogers

Nick & Heather Gattuccio

Employees of Memphis

Light, Gas & Water

*In memory of...*

**Michael Coyle**

Dorothy Scanlan

Anne T. Barry

Elmer & Helen Johnston

*In memory of...*

**Russell R. Rivenburg**

Edward & Grace Roberts

## Help Finding Calmurid Cream

Many of you met Cindy Bremmer at the conference in San Diego, where she passed around samples of Calmurid Cream, which she tells us "has been the miracle for my lamellar ichthyosis." Unfortunately, Calmurid is not available in the U.S. However, Cindy tells us that Calmurid can be obtained through her British Columbia pharmacy. If interested, you may contact pharmacist Peter Levis in Coquitlam, B.C., at 604-936-1488. Or, you can contact Cindy directly. Her address is 834 Cedaroak St., St. Helens, OR 97051. (503-397-3082).

Cindy adds, "Also, I would like to hear from you if the Calmurid works. It's a thrill to know when someone else benefits. Actually, I'd enjoy hearing from you for any reason. I loved the conference, and when I went back up to the ballroom the next day to take a picture of the view, the room felt so empty I started to cry. My sudden burst of sadness took me by surprise—I missed all you people. It was great to start to get to know so many of you. Stay in touch."

## F.I.R.S.T. Officials Join Talk Radio

On July 7th, Board President Deborah Vilas, Executive Director Nick Gattuccio, and Chairman of the Medical Advisory Board, Leonard Milstone, M.D., joined New York radio talk show host Melinda Wheeler for a one hour broadcast of her show, "Health Styles." The show was devoted entirely to ichthyosis. The show consisted of a taped interview with Deb about her experiences growing up with ichthyosis, and then moved to live interviews of Nick and Dr. Milstone. Ms. Wheeler then invited listeners to call in with questions for the panel.

"It was a first small step on our road to public awareness," said Deb Vi-

las about the experience. "And it came off well. We got a lot of information out there about the disorder and our organization.

"I believe that we should all be looking for these inroads into our communities," continued Ms. Vilas. "Each of us probably has a radio station in our area that may broadcast these types of shows, or community newspapers that may have a health interest section or column."

## Neutrogena Introduces New Maximum Strength T/Sal Shampoo

Neutrogena recently introduced a new "Maximum Strength" version of its popular T/Sal Shampoo for the treatment of scalp. In this new version of the product, the concentration of its active ingredient, salicylic acid, has been increased to 3% from 2%. Salicylic acid is a keratolytic that softens scale and makes it easier to remove. The shampoo contains no colorants, preservatives or fragrance, and is specially formulated to

be mild and conditioning to prevent dryness. Maximum Strength T/Sal is available in 4.5 oz. bottles.

## A Book for All Seasons:

### Autobiography of a Face, by Lucy Grealy

Occasionally there appears a stunning book that brings to the page a vivid glimpse of experience that we can only begin to imagine. Lucy Grealy's extraordinary new book, *The Autobiography of a Face*, is just such a book.

Struck with a horrific cancer in her jaw at age nine, subjected to multiple surgeries that ultimately took half her jaw, and forced to endure two and a half years of intensive chemotherapy, Lucy was left a child utterly isolated by her experience and her appearance.

*I spent five years of my life being treated for cancer, but since then I've spent fifteen years being treated for nothing other than looking different from everyone else. It was the pain from that, from feeling ugly, that I always viewed as the great tragedy of my life. The fact that I had cancer seemed minor in comparison.*

This is truly a book for all seasons. The editor highly recommends it.

## Dr. Stephen Katz to Head NIAMS

### Dermatologist Tapped for Top NIH Post

Internationally known dermatologist, Stephen I. Katz, M.D., Ph.D., has been appointed director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the National Institutes of Health. Dr. Katz succeeds Dr. Lawrence Shulman, the first and founding director of the Institute, who retired last year (see *Focus*, vol. 13, no. 4).

The NIAMS leads the biomedical research effort for skin diseases in the U.S., conducting intramural research on the ichthyoses as well as supporting research efforts around the country.

"I view this appointment as a tremendous challenge," said Dr. Katz, "and an opportunity to participate in setting health research policy and priorities that address the chronic and often disabling diseases with which the Institute is concerned."

Dr. Katz is the first dermatologist to head an Institute of the NIH.

Cellegy Pharmaceuticals is developing a new topical cream for the treatment of ichthyosis. Many F.I.R.S.T. members participated in earlier portions of the clinical trials to help Cellegy obtain FDA approval for this new cream (called Glylorin). Now, dermatologists are conducting the final phase of clinical trials (Phase III), and they are seeking out patients with lamellar ichthyosis (LI) and those with non-bullous congenital ichthyosiform erythroderma (CIE) who are willing to participate.

All doctor's visits, procedures and medications will be provided free of charge, and at the end of the trial participants will receive a stipend for participation.

## CLINICAL TRIALS SET FOR NEW CREAM TO TREAT ICHTHYOSIS

The trial will continue for about 15 months. During three of the 15 months participants will receive

"blinded" treatment—that is, you will not know whether you are receiving the active cream or a placebo. Thereafter, all participants will receive only the active cream. No one under three years old may participate in the study.

Below is a list of research dermatologists who are conducting these trials. If you have LI or CIE, and if you may be interested in participating in the study, please call the dermatologist at the nearest trial site. If you have questions about the trials, you may call the director of Clinical Trials at Cellegy Pharmaceuticals in Novato, California, at 415-382-6770.

Nancy Esterly, MD  
Medical College of Wisconsin  
Milwaukee, WI  
414-257-6899

Sewon Kang, MD  
Univ. of Michigan Med. Center  
Ann Arbor, MI  
313-936-4070

Amy Paller, MD  
Children's Memorial Hospital  
Chicago, IL  
(Speak to Marge at 312-880-4698)

Mark Ling, MD, Ph.D.  
Emory University  
Atlanta, GA  
(Speak to Joyce Weinheimer at 404-778-3728)

Ervin Epstein, MD  
Oakland, CA  
510-444-8282

Moise Levy, MD  
James Nigro, MD  
Texas Children's Hospital  
Houston, TX  
713-770-3718

Gary Peck, MD  
Washington Hospital  
Washington, D.C.  
(Speak with Hildegard Jorgenson at 202-877-7734)

Matthew Stiller, MD  
Massachusetts General Hosp.  
Boston, MA  
617-726-5066

Philip Fleckman, MD  
University of Washington  
Seattle, WA  
206-543-5290

Anne W. Lucky, MD  
Dermatology Research Assoc.  
Cincinnati, OH  
513-232-3376

Neil Prose, MD  
Duke University Med. Center  
Durham, NC  
919-684-5146

Virginia Sybert, MD  
Children's Hospital & Med. Ctr.  
Seattle, WA  
206-526-2158

Ruby Ghadially, MD  
UC San Francisco  
415-750-2091

Leonard Milstone, MD  
Yale University  
New Haven, CT  
(Call Cynthia Selfridge at Cellegy for information: 415-382-6770)

Miriam Keltz Pomeranz, MD  
New York University Med. Ctr.  
New York, NY  
212-263-5244

Patricia Treadwell, MD  
Wisher Memorial Hosp.  
Indianapolis, IN  
317-630-7396

Jon Hanifin, MD  
Oregon Health Sciences Univ.  
Portland, OR  
503-494-5603

Hermon Solomon, MD  
Dermatology Clinic PA  
Wichita, KS  
316-685-4395

Sophie Worobec, MD  
Univ. of Rochester  
Rochester, NY  
716-274-4557

## Regional Support Network (RSN)

In addition to our network of Regional Coordinators, F.I.R.S.T. is developing a system of state contacts. Future Regional Coordinators will be drawn from our pool of acting state contact persons. Anyone wishing to become a state contact should call the RSN National Coordinator, Heather Gattuccio (919-859-2712), to obtain an application.

### RSN NATIONAL OFFICE PROGRAM DIRECTOR

Heather Gattuccio  
4279 The Oaks Drive  
Raleigh, NC 27606  
919-859-2712

### REGION ONE

NY, PA, VT, NH, NJ, CT, RI,  
MA, ME  
Shelly Licursi  
311 White Birch Drive  
Cinnaminson, NJ 08077  
609-786-8766

### 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  
Cynn timer Bates  
133 Elam Park  
Lexington, KY 40503  
(606) 276-0142

### REGION FIVE

WI, MN, IA, ND, SD, NE  
Carolyn Gramlich  
535 West Sandhurst, #111  
Roseville, MN 55113  
612-483-7700

### REGION SIX

TX, OK, NM, CO, KS  
Donna Rice  
2902 West Elm Circle  
Katy, TX 77493  
(713) 391-4407

### REGION SEVEN

WA, OR, ID, MT, WY, AK  
Sheri 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  
(602) 887-7188

### STATE CONTACTS

#### Indiana

Mark & Jill Wood  
317-841-9923

#### Kansas

Tiffany Karst  
913-268-3692

#### Mississippi

J. Charlene Wiggins  
601-769-2454

#### Netherton's Syndrome Contact

Cathy Sipper  
Rt. 1, Box 300  
Laverne, AL 36049  
(205) 334-6827

#### Canadian Contact

Barbara Rockwell  
3080 Ballydown Crescent  
Mississauga, Ontario L5C 2C8  
(416) 896-9620

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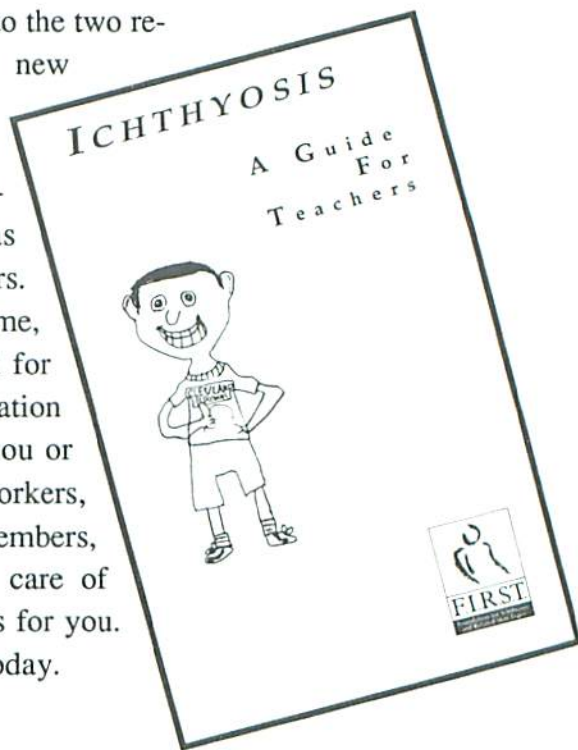
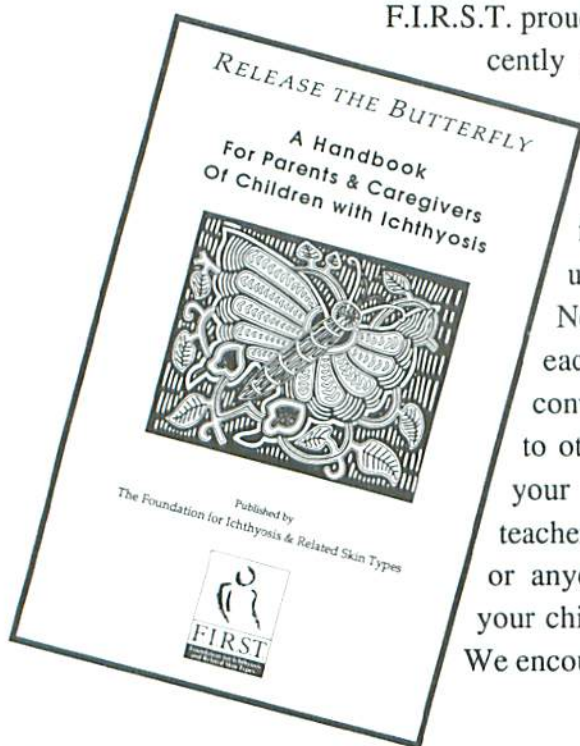
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