

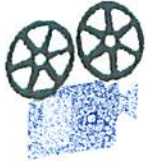


ICHTHYOSIS FOCUS

Vol. 16, No. 1

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

Winter 1997



INTERNATIONAL MEDIA ATTENTION FOR CHILD WITH ICHTHYOSIS

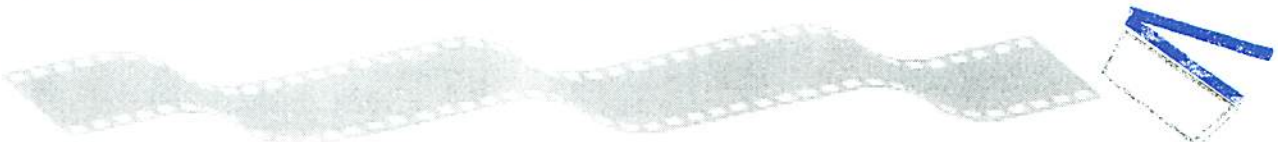
Dalton is a ten year old boy who lives in a small village in Ecuador. He has ichthyosis, as do his younger brother and sister. In October 1994, an Ecuadorian television station (ECUAVISA) aired a story about Dalton and his family, which was picked up by CNN World Report and televised worldwide.

ECUAVISA revisited Dalton in 1996, and ran a follow-up story which was also picked up by CNN World Report. The program aired in October and was repeated in January. This time, CNN listed F.I.R.S.T.'s address and telephone number at the end of the segment. We've received well over 100 calls and letters as a result of these broadcasts, most of them requesting additional information about ichthyosis and our foundation.

Dalton's village is so remote that there is no regular mail service, but the reporter at ECUAVISA, Maria Soledad Bejarano, is delivering items mailed to the station. F.I.R.S.T. has sent recent newsletters and Spanish translations of some of our publications to Dalton's family, as well as skin care products that have been donated by Medicis Pharmaceuticals (Theraplex Emollient) and Dermal Therapy Research (Alpha Hydroxy Lotion).



CNN reaches more than 170 million households in over 130 countries. An additional 260 million households receive all or part of the World Report program through CNN's contributing stations. Thank you CNN and ECUAVISA, for the international exposure and increased awareness that this type of programming creates. Many thanks, also, to Ms. Bejarano, for continuing to follow Dalton's story and providing information and support to his family. A video transcript of these broadcasts can be purchased from CNN for \$10.00. Please contact Elena Levitan at the National Office for details.



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CORRESPONDENCE CORNER

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

I wanted to pass along some things that
have helped my 4-year-old son Evan, who has
EHK.

The first thing is elastic shoestrings. We
have found these novelty, curly, elastic
shoestrings that we use in high top canvas
shoes and he seems to get less blisters on his
feet and ankles using these as opposed to
regular laces.

The second thing is *Elizabeth Arden's* 8
hour skin protectant cream. I use this to put on
any open sores prior to getting in the bath tub.
This is the only thing that stops the water from
stinging the sores and I have tried many
things. I can also put it on new open sores that
are hurting and he says it doesn't hurt when I
put it on him. In fact when he tears off a piece
of skin, he goes straight to the bathroom so
that I will put this "salve" on his sore. It is so
nice to have something that comforts him. I
bought this cream to see if it would help
prevent blisters like I read it would but I have
not had the opportunity to try it like that yet.

I would also like to thank all of the
members of the FIRST family who answered
my question about having a dog a couple of
years ago. We still have the dog, Evan is no
longer scared of dogs and he's doing great.

Being a member of FIRST and getting the
newsletters helps so much. I know that there
are other people with skin like Evan's and I
feel less lonely, especially on the days I receive
the Focus.

Thank you !!
Diedra Long
176 E. Elm St.
Mt. Gilead, OH 43338

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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.

WANT A PEN PAL
FROM
BERMUDA? I

Hi ! My name is Diana Hall and I
am 21 years old. I have CIE and I
would like to meet pen pals between
the ages of 21 and 25 who also have
CIE or another type of Ichthyosis. My
hobbies are listening to music
(anything with a decent beat),
watching TV (especially *The Young*
and *The Restless*), hanging out with
friends, swimming, reading and
having lots of fun!

I recently got engaged to a
wonderful person named James and I
work at one of the highest ranking
banks in Bermuda. I still live at home
with my parents and I have one
brother named Brian and a dog named
Taffy.

Looking forward to hearing from
someone soon, who I can relate my
good and bad experiences with. Trust
me, there have been many of those !!
But I always tell myself to keep your
head up, look at the bright side and
don't quit !!

Diana Hall
6 West Park Lane
Pembroke HM 07
Bermuda

Tel. & Fax: (441) 292-6933

P.S. I am very sorry to read about
Nick and Heather leaving FIRST. My
family and I send our love and best
wishes to the both of them and their
children.

*"For some strange reason, human
beings tolerate stresses and pressures
much more easily if at least one other
person knows they are enduring it."
Dr. James Dobson*



IN SYMPATHY

We are deeply saddened to report the death of 13 month old Charles Edward "Teddy" Hoffman of Over Land Park, Kansas. Teddy died on February 21st during surgery for placement of a gastrostomy tube. Our heartfelt sympathies go to his parents, Kurt and Susan Hoffman, brother, Henry Robert and all of his family and friends.

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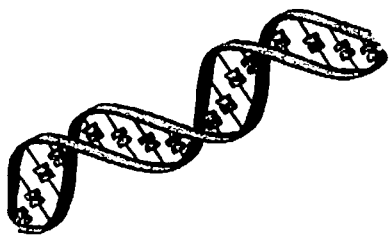
Deb Vilas
New York, New York
(12/97)

Leonard Milstone, MD
Chairman
Medical Advisory Board

1997 National Conference Postponed

After weeks of research, discussion and contemplation, FIRST's Board of Directors have concluded that it is necessary to postpone the bi-annual national conference originally scheduled for this summer, until 1998. A variety of factors led to this decision, including a limited selection of appropriate sites and a scheduling conflict with an American Academy of Dermatology conference.

RSN Program Director, Elise Johnson, said "each region will be encouraged to have a Regional conference" this summer to help fill this void. We know this postponement is very disappointing and we hope each of you will be able to attend the conferences or "get together" in your region.



GENE THERAPY THAT IS ONLY SKIN DEEP

An article appearing in the November, 1996 edition of Nature Medicine describes the "first example of a successful genetic therapy for treating a skin disease." This article entitled Corrective Gene Transfer in the Human Skin Disorder, Lamellar Ichthyosis, was authored by principle investigator, Paul A. Khavari, M.D. at Stanford University School of Medicine's Department of Dermatology. Dr. Khavari and his collaborators took skin biopsies from individuals with lamellar ichthyosis, determined these skin cells (keratinocytes) lacked the transglutaminase 1 gene, then used a retrovirus to introduce a copy of the normal gene into the keratinocytes. These cells grew normally when cultured and were then used to regenerate normal skin on immunodeficient mice. This skin not only appeared normal, but also functioned properly. These results lasted 4-6 weeks.

When interviewed, Dr. Khavari described this study as a "baby step" toward successful gene therapy for ichthyosis, as well as other genetic skin disorders. He indicated that his current focus is to answer the question, "Why does the normal gene turn off over time?"

SECOND ANNUAL ICHTHYOSIS AWARENESS WEEK May 10-17th

Once again, a week has been set aside for a nationwide information, education and fund raising event to increase awareness of ichthyosis and FIRST.

We're encouraging everyone to use all or part of this week to increase the public's awareness of ichthyosis and to do some grassroots fund raising. Call the national office to find some simple or ambitious ways to host an event.

**** 800-545-3286 ****

RECIPES, RECIPES, WE NEED RECIPIES !!

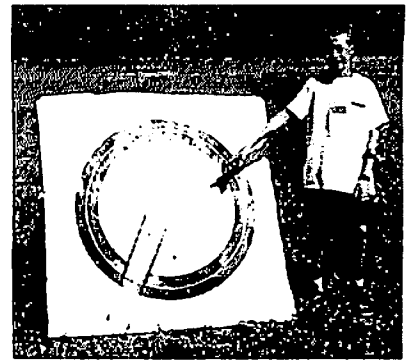
Debra Butler of Rochester, New York has generously offered her time and talents to producing a FIRST cookbook to help raise funds to help continue the services offered to members. She needs YOUR help. Debra has currently collected only about half of the recipes needed for this project. Please take a few minutes today to copy or xerox some of your family favorites and send them to her at the address below.



Debra Butler
647 Latta Road
Rochester, NY 14612

CAMP HORIZON MEMORIES

By: Ryan and Shelly Licursi



RYAN: When my parents first asked me about camp, I wasn't sure I wanted to go. But after I thought about it for awhile, I decided it sounded cool. I told everybody I knew that I was going away for a week by myself. I planned what I was going to bring all summer. But then in the car on the way to camp, I was so nervous, I had a stomach ache! My parents and brother Kevin stayed for about two hours while we met a lot of people and checked out the whole camp. When it was time for them to leave, I almost cried. I found out later, my mom had the same problem. We met our counselors and the kids in our cabin, had dinner, unpacked, went over the rules and the schedule and played some games. I was starting to have fun. I even slept on a top bunk! The next morning we raised the flag, had breakfast and got busy. We did archery, went fishing, built birdhouses, went swimming, played games, had a Western Night and told ghost stories around the campfire. That was all in the first day! It just got better and better. Over the next couple of days, we went on a hayride, made crafts, played volleyball, made a movie, had a carnival and celebrated several holidays, competed in the Olympics and had pizza and ice cream sundaes. Camp was better than I ever thought it would be.

All the kids I met were really nice, especially the ones in my cabin. My counselors were so great and I had a special secret pal. Everyone was friendly and caring. I can't wait to go back and see them again. I know I won't have a stomach ache next time!

SHELLY: This was Ryan's first time away from home. It was pretty scary for everyone. The staff was so friendly, kind, caring and supportive, it didn't take Ryan long to feel at home. It was obvious the minute we saw him that he had had a great time. He also seemed older. I think he gained a kind of confidence at camp that he couldn't have gotten anywhere else. We would like to thank the entire staff for giving their time and energy to provide such a wonderful experience for Ryan and all the other children.

SUMMER CAMPS FOR CHILDREN WITH SKIN DISORDERS

CAMP HORIZON

Millville, Pennsylvania

August 17-23

Ages: 8-13 (Campers)

15 (Jr. Counselors)

18 (Counselors)

Contact:

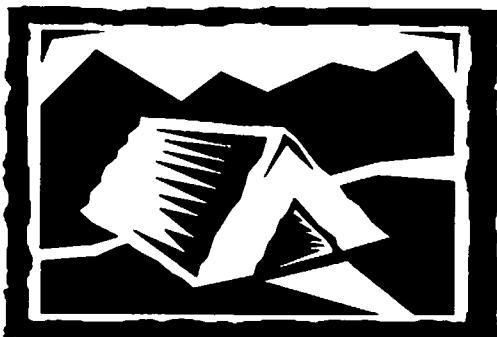
Dr. Howard Pride

Department of Dermatology

Geisinger Medical Center

Danville, PA 17822-1406

717-271-8050



CAMP DISCOVERY

Crosslake, Minnesota

August 9-16

Ages: 10-13 (Campers)

18 (Counselors)

Contact:

American Academy of Dermatology

847-330-0230



OUTGOING PRESIDENT DEBORAH VILAS



Dear Members,

How do I say "Goodbye" to the membership of FIRST as I step down from my tenure as President of the Board of Directors? I've given it a great deal of thought, and I've decided that I don't have to say goodbye at all. Thank goodness, because I hate separations and good-byes of any sort. I've been involved with the Foundation in a variety of ways since I first discovered FIRST, and I imagine that I will be a part of the FIRST family in one way or another for a long time to come.

My initial contact came about while I was pursuing a masters degree in special education. For a course on chronic illness, hospitalization and children, I chose ichthyosis as my topic for a presentation. While researching my own skin condition, I discovered that there was an organization called FIRST that actually offered support to people with my disorder. When I contacted the Foundation for information, Ellen Rowe, who was President at the time, took my call. I will never forget her genuine, friendly voice as she told me that she too had ichthyosis. I was thirty years old, and she was the first person I'd ever spoken to who shared my "different" skin.

Before I knew it, I was assisting my regional coordinator, Lynne Alba, with a meeting in New York City for individuals and families affected by ichthyosis. Soon after that, I became a state contact, and then a regional coordinator for Region One. What began as a class presentation became the topic for my masters thesis, and the basis for a guide for teachers that was published in booklet form by FIRST. This was probably the most exciting moment for me. I was finally able to use my experience and knowledge to help children in a concrete way.

I was surprised and cautious when I was approached by Susan Snyder to sit on the Board of Directors. After all, what exactly did I have to offer in this regard? I considered myself more of a people person than administrator, but it seemed like a wonderful opportunity for service and growth. I was thankful that the organization was willing to take me on and mentor me into a leadership role. Frances McHugh was a wonderful teacher, and every board member, as well as the membership at large, taught me valuable lessons every step of the way.

If I was able to give FIRST half of what I've gained from this experience, I'd consider my presidency a success. My involvement has grounded me and given me perspective in a very basic way. I no longer feel like a misunderstood outsider, alone with different skin. I have come to see myself as more than my skin, and I feel part of a wonderful extended family that supports and nurtures its members. I feel honored to have been president during a time of expansion and change. However, as we expand as a foundation, I hope that we will always appear to newcomers and friends as a caring voice and listening heart on the phone, as well as a helping hand for the children of our membership.

Thank you all for your continued support and goodwill. I feel it even now as I pass the baton of leadership to our next President.

Warmest Regards,
Deb

NEWS AND VIEWS



PRESIDENT MICHAEL DUNLEAVY

Dear Members,

We begin a new year. One that is very different from the past several years in many ways: We have a new Executive Director and Director of Operations. We have a new home. There are several new members on our board. We have a new slate of officers and last but not least a new president. New! Not a bad way to start the year.

This last year was a difficult one for FIRST, with many of the new things presaged by the dramatic changes that took place in 1996. Throughout 1996 the thing that held us together was our belief in the basic soundness of the mission we fulfill, to serve our members and to provide support for those members and care givers within the Ichthyosis community.

I believe that as a group we have to thank Deb Vilas, our outgoing President, for her dedication and leadership throughout a very difficult period. Without her at the helm, holding us all together, I believe the reconstruction of our organization would not have had as positive an outcome nor provide as positive an opportunity for the future as we have at hand. I personally want to thank Deb for her good humor in difficult times, her good sense in the face of adversity and her dedication and leadership to reinvigorating FIRST and setting it on the path to the future. I personally find taking on the role of president following Deb Vilas a challenging one and will work hard to live up to the standard she has set. Deb, thank you for this past two plus years and for the heart and soul that you put into FIRST.

Well done.

Now to the new and the future. Most of you already know that we are not having a Family Conference this year. There are a number of reasons, but the primary one is

that we were operating without an Executive Director during most of the past year. At our November Board meeting, held in Philadelphia, we put in place a plan of action that we thought would lead to a conference on the East Coast this year. Alas, hotel accommodations could not be finalized in time to allow participants who wanted to come to get their plans in order.

Additionally, as we tried to come to grips with timing we also ran into a Dermatological Conference in Australia that many of our medical professionals were already committed to attending, therefore precluding attendance at our conference. It was not an easy decision for us to make. Particularly, after seeing the beneficial effects that our conference in San Diego had for our members in 1995.

At our Board meeting on February 2, we set the wheels in motion for a Family Conference to be held in June 1998, on the East Coast. Deb Vilas has accepted the challenge of leading a search team to establish a location for the conference. We will have the location selected in the next several months and will begin the process of facility selection. Program development is already underway. If you have any suggestions or comments on either location requirements or things you believe should be included in the program please contact Elena Levitan and she will add them to the criteria we will use in selecting the location and developing the final program. There will be a special report on the Family Conference in the next issue of FOCUS that will bring you up to date on where the conference will be, and what the program will contain. So, get your comments and suggestions in early so they can be included in the planning for 1998.

(continued pg. 8)

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Philadelphia Host to Board Retreat

Philadelphia, the city of "Brotherly Love", and new home for FIRST's national headquarters, appropriately, was the site for the FIRSTever board retreat on November 1st and 2nd, 1996. Conducting quarterly board meetings by teleconference and completing committee business via faxes and electronic mail allows far-flung board members to work as a unit, but nothing can replace sitting face to face around a conference table to really "get things done".

The retreat allowed new members to put faces to familiar voices and allowed members to say personal good-byes to Lynne Alba who left the board in December after two terms. The opportunity to meet, speak and plan with Executive Director, Mark Levitan, Director of Operations, Elena Levitan, Medical Advisory Board President, Dr. Leonard Milstone, as well as past board president, Frances McHugh, was a pleasure and an important step in the smooth transition of moving First's headquarters to Philadelphia.

In addition to making plans for our next national conference, the board developed some very ambitious plans to increase public awareness of ichthyosis, increase membership, fundraising and the services provided to members.

The board wishes to thank Nancy Dunleavy, wife of incoming president, Mike Dunleavy, for her help in organizing the retreat and for providing "chauffeur" services.

Frances McHugh, past president, Lynne Alba, outgoing board member, and Tiffany Karst, newly elected board member



(President, cont.)

New development projects will be started during the coming year. We will begin an active program of solicitation for funds from foundations, as well as private and public sources to support member activities and research into the various forms of Ichthyosis. Just as an example of what a proactive campaign can accomplish, Mark Levitan's Christmas Solicitation has generated more than \$14,000 in donations. To my knowledge it is our most successful single program to date.

Another FIRST. The RSN as well as the Medical Advisory Board are now represented on the FIRST Board. This is a giant step forward in bringing together all the elements that make up our organization into a single force for the future. This should enhance our ability to direct FIRST's resources toward a common set of goals and assure that we are using our time and efforts most effectively.

There are many more new things for FIRST in the coming year and I will report on more of them in the next issue of FOCUS.

Warmest regards,
Mike



BOARD WELCOMES LEONARD MILSTONE, M.D. TO ITS RANKS

We are pleased to announce that at the board retreat in Philadelphia, Leonard Milstone, M.D. was unanimously voted onto our governing Board of Directors. Dr. Milstone has had a long and distinguished relationship with FIRST. It began in 1982, when he became a member of our Medical Advisory Board. This board was established to provide our foundation with the professional expertise of dermatologists who are familiar with the Ichthyoses. The Medical Advisory Board has been a source of information and support to the organization and its members for the last fifteen years. Dr. Milstone has been its Chair for the past six years, and received a Distinguished Service Award for his dedication and service to FIRST in June of 1995. Electing Dr. Milstone to our Board formalizes a pre-existing link between the two boards and fortifies a partnership that will take us one more step on our path of growth.

Dr. Milstone is currently an attending physician at Yale-New Haven Hospital, and the Chief of Dermatology Service at the VA Medical Center in West Haven, Connecticut. He is also a Professor at the Yale University School of Medicine. He has a strong background in research, much of it specific to Ichthyosis, and has received many awards recognizing his contributions. These awards include the Anna Fuller Faculty Award, the NIADD Clinical Investigator Award, and the VA Clinical Investigator Award.

Dr. Milstone resides in Connecticut with his wife, Ellen. They have two grown children, Jenya and Aaron. We are honored to have Len on our Board, and we look forward to continuing our work with him and his colleagues on the Medical Advisory Board.

UPCOMING MEETINGS AND CONFERENCES

March will be a busy month for Executive Director, Mark Levitan, Program Director, Elena Levitan and FIRST's Board of Directors. The 11th and 12th will find Mark and Elena in Washington, DC to attend the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR). In addition to the general meeting, they will tour the Library of Medicine and meet with Dr. Steven Katz, Director of the National Institute for Arthritis, Musculoskeletal and Skin Diseases (NIAMS). The opposite coast will be their destination March 21-26 for the annual American Academy of Dermatology Conference in San Francisco, California. Several Board members will also be attending this conference to meet with the Medical Advisory Board, attend the CPA-SDR meeting, visit pharmaceutical representatives and staff the FIRST exhibit table.

EDUCATIONAL VIDEO UPDATE

To date, approximately one-half of the funds needed for the completion of the educational video about ichthyosis have been raised through the grassroots efforts of several FIRST members. These funds have allowed us to hire a production company (VPR, of Kansas City, Kansas) and more recently to purchase a script. We are dedicated to producing a high quality, professional video to aid FIRST members in increasing awareness and understanding of ichthyosis, particularly in the school age population. We will continue to report on the progress of this project.

REGIONAL SUPPORT NETWORK (RSN)

PROGRAM DIRECTOR

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18117 12th West
Lynnwood, WA 98037
206-771-7264

REGION ONE

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CT, RI, MA, ME
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910-871-3277

REGION THREE

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AR
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REGION FOUR

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Angela DelGrande
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OPEN

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Katy, TX 77493
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Nancy Bryant
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WISCONSIN

Theresa Tremmel
414-538-4922

RSN PROFILE

Angela DelGrande, Coordinator, Region 4

I'd like to take this opportunity to introduce myself to the FIRST family. I'm 33 years old and have been married to Mark for seven years. We have two boys, Mason (age 6) and Antonio Joseph, "A.J.", (age 2). We also have an insane beagle puppy and a feisty gray cat, "Torie" and "Bailey". Our house is noisy, in a constant disarray despite repeated attempts to clean up after A.J. and full of laughter and the smell of cooking garlic (my husband, the cook, is Italian). Mark is on active duty with the Air Force and, over the past six years, we have moved from New Mexico to California, then to Colorado, and now to Ohio. I've been an OB nurse for 10 years and have earned my MSN in perinatal nursing and post-graduate certification as a nurse practitioner. Mark has been a never ending well of support for me throughout all of our challenges.

Our journey into the world of skin disorders began on St. Patrick's Day, 1994. We worried throughout our pregnancy that something would "turn-up" with A. J. because Mason was born with a brain malformation that was diagnosed 2 days after his birth. We were almost convinced after several ultrasounds that all was well when I suddenly ruptured my membranes at 34 weeks

gestation—an event somewhat common among women carrying collodian babies. I waited in the hospital for 8 days until labor finally began. When A. J. was born, it was immediately apparent that something was wrong with his skin. He stayed in the NICU for two weeks in reverse isolation. Our world was suddenly filled with mineral oil and water baths, a misty isolate

and Vaseline-covered gauze and diapers. We had to learn how to provide TLC (and breastfeed!) wearing masks, gowns and rubber gowns. We were given a glum description of A.J.'s future by the "experts". His gumption and strength has proven them all wrong. Some days are easier than others and some days just plain stink have learned through the experience of parenting Mason, that providing support and advocacy to other parents in similar

circumstances enables me to heal. It is gratifying to know that conversation can make a difference in a parent's day. I look forward to talking with mothers and fathers who are looking for a long distance shoulder to lean on as they embark upon the parenting journey into the world of skin disorders.



*Angela with husband, Mark and sons
Mason and A.J.*

National **REGISTRY** for **ICHTHYOSIS** and Related Disorders

**Hey, Have you Contacted the
Registry?**

The National Registry for Ichthyosis and Related Disorders wants you to enroll. We are supported by the NIH, and are trying to encourage more research into diagnosis and treatment of Ichthyosis.

We will protect your privacy, and there are no requirements for participation in any projects. We would notify you of what projects are ongoing, and how to contact them if you are interested in participating.

Just give us a call at 1-800-595-1265 and ask about how to get enrolled. We will answer any questions you have, and it may provide an opportunity for you to become involved in research to find better methods of dealing with Ichthyosis.

Registry Director: Philip Fleckman, MD
Registry Coordinator: Geoff Hamill, RN

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

*In the last issue of the FOCUS, the Registry's toll free number was listed incorrectly. The correct number is: **800-595-1265***

CONGRATULATIONS

Dr. Ervin H. Epstein, a member of FIRST's Medical Advisory Board from the University of California at San Francisco, along with a group of researchers at Stanford University, led a research study blending genetic studies of fruit flies and humans to identify the mutated gene that causes basal cell carcinoma, a skin tumor that is the most common form of cancer. Reports on this important discovery were recently published in the research journals, Science and Cell. Our congratulations to Dr. Epstein and the research teams for this discovery.

NEWS & NOTES

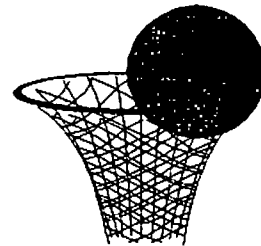
BASKETBALL'S HARDAWAY "GIVES BACK TO THE COMMUNITY"

When Orlando Magic basketball star, Anfernee, Penny Hardaway, left his hometown of Memphis, Tennessee to pursue his goal of a professional basketball career, he made a promise to help the community that raised him, if he ever "made it".

This past September, Mr. Hardaway made good on his promise by hosting a reception for over 15 local and national non-profit organizations, where he greeted the organizations' representatives personally and presented each with a donation to help continue their missions.

FIRST was fortunate to be invited to the reception and was represented by RSN Region III coordinator, Debra Bowie, her father, Mr. Alfred Harrison, who arranged FIRST's participation through his friendship with, Randy Wade, Mr. Hardaway's manager, and daughter, Jasmyn. Mr. Hardaway presented Jasmyn (who has lamellar ichthyosis) with a check for \$5000 for FIRST. Local media covered the event and Jasmyn was spotlighted on the evening news.

FIRST thanks not only Mr. Hardaway for his generous donation, but also Debra and her family for seeking this funding and representing the foundation at the reception. We would also like to offer our sincere sympathies to Mr. Harrison, who lost his wife, Ethel to cancer this summer. Many of us remember Mrs. Harrison's warm, friendly attendance at past national conferences.



Mr. Penny Hardaway with Jasmyn and Debra Bowie



N. O. R. D. REPORT

The National Organization for Rare Disorders, Inc.® (NORD), dedicated to helping people with rare (orphan) diseases.

HEALTH INSURANCE PORTABILITY ACT

The new Health Insurance Portability Act, authored by Senators Nancy Kassebaum and Ted Kennedy, was signed into law by President Clinton during August. Described by many supporters as "the first step" in health insurance reform, the bill is expected to help some, but not all Americans.

The new law will mainly help already insured people who change jobs, self-employed and some of those who work for small firms. It allows people who can prove they have been continuously insured for a period of time to maintain their health insurance after they leave their job if they can pay the premiums. The statute does not make insurance premiums more affordable, so unemployed people who cannot afford to pay for their insurance may lose their policy.

Whether a person is laid off, fired, quits or their employer goes out of business, they will be eligible to purchase an insurance policy as

long as they can show they have been continuously insured during the past 12 months. There can be no exclusions for pre-existing conditions and the person cannot be charged higher premiums than healthy people as long as they have not dropped their insurance coverage for more than 63 days.

INSURANCE NUMBERS

In 1994, the last year for which figures were available, one out of seven Americans had no health insurance. The report also found that 85% of the U.S. population had health insurance in 1994, while 15% was uninsured. Of those who are insured, most obtain their health insurance through their job (60.5%), 13% are covered by Medicare, 12% by Medicaid, and 10% have individual health insurance policies not obtained through their employer or union.

The above information was taken from "NORD ON-LINE BULLETIN" at:
<http://www.pcnet.com/~orphan/>

GLYLORIN RESEARCH STUDY CONTINUES

Cellegy Pharmaceuticals, Inc., in Foster City, CA., is developing a topical cream, *Glylorin*, for nonbullous ichthyosiform erythroderma and mild-moderate lamellar ichthyosis. *Glylorin* is a lipid restoration agent with antihyperproliferative, anti-inflammatory, and anti-microbial properties. This is a Phase III investigational study to determine the cream's effectiveness in people with these types of ichthyosis. The study is approximately 15 months in duration. During the first three study months, volunteers will be given either *Glylorin* or the placebo (the vehicle cream). Thereafter, all volunteers will use *Glylorin*. Participants must be at least 3 years old with generalized involvement of skin showing adequate scaling, be in good general health, not have any other significant diseases, and cannot be pregnant. This study is being conducted in over 20 cities throughout the U.S. If you are interested in participating or having your child participate in the study contact:

Cynthia Selfridge, R.N.

(800) 381-8539

CHILDREN'S SUCCESS STORY



Living with ichthyosis for 18 years, I often wonder what it would be like to have "normal" skin. Sure, I would love to go to the beach between 10 a.m. and 2 p.m. and get the ultimate tan. I'd love to go swimming and not have to slather on lotion as soon as I step out of the pool. Unfortunately, I have realized that these wishes are out of the perspective. I haven't let my skin condition consume my life, it's only a small part of who I am.

Having a mother who also has ichthyosis has been a tremendous advantage. Often times, she can relate to the frustrations that I encounter; she has already been through what I'm experiencing and offers me guidance and support. As a result, we are very close.

Because my sweat glands do not function properly, most sports are out of the question. When I was in the second grade, my mom enrolled me in dance to learn good posture and grace. Dance is therapy for me, it is a way to express my emotions and release my energy. In my sophomore year of high school, I joined the Junior company, which competes with other dancers at competitions. That was also the year that I participated in a tap duet. We never won a first, but it was great experience for me. In my junior year, I competed with a tap solo, and ended the year with a second place. I won first place in my

by: Tonya Richardson

senior year for my tap solo to the song, "Anything Goes". My hard work and determination finally paid off. I even discovered a new love that involves dance-teaching. I student-taught a class of 6th graders, in my senior year and despite their occasional lack of enthusiasm, I loved every minute with "my girls". I was so proud of them when they finished on stage at the dance recital. I eventually hope to teach dance at a local studio.

I have always been a person who never gives up, and I feel that my determination guided me through high school. The summer before my junior year, I had the unique experience to travel to the United Kingdom and Ireland as a "People to People" student ambassador. The top 5% of middle and high school students in the country were selected for this program. Approximately 13 high school students from Maryland traveled with a group from Vermont. My trip overseas is an experience that I will never forget. Being out of the country made me appreciate my home and I met so many friendly people. My homestay in the UK was a definite highlight. My favorite city was London, there was so much to do and the people have incredible fashion tastes! I would love to go back and stay for a longer period of time.

I am a freshman at the University of South Carolina, and I am majoring in journalism. It has been a rocky and exciting road. Of course, I have received numerous questions about my skin, and at times I have been very upset. Because of the tremendous support from my family and friends, I am slowly learning to deal with the comments. I refuse to let these questions upset me. I have much more important issues for concern, such as a career, a family and my own happiness.

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• Dermal Therapy Research February 1998

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SKIN

**Skin, skin, everywhere,
 in my bed and on the stairs.
 Hit my arm and there it goes,
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 Sometimes things get very rough,
 but I keep going cause I'm tough.
 I am gonna beat the odds,
 even with this peeling bod.
 So look out world and beware,
 skin, skin, everywhere.**

By: Ryan Licursi

*FIRST neither recommends, nor endorses products or services advertised
 in the Ichthyosis Focus.*

DIRECTOR OF OPERATIONS

Those of you who have called the foundation's toll free number in the past few weeks have already met, Elena Levitan, our new Director of Operations. In that capacity, Elena is responsible for the day-to-day operation of the newly relocated national office. The foundation is truly fortunate to have someone with such a strong and varied background to oversee our headquarters.

Ms. Levitan has a bachelor's degree in Commerce and Engineering and Marketing and graduated with honors from a Chef Training Program. Her work history includes Management Engineer, Systems Analyst and Sous Chef. She has extensive experience with various



computer systems and will be an invaluable asset in that area.

Ms. Levitan is the mother of 2 young children, Jonathan, age 2 and Julia, 6 months. She is the daughter-in-law of our new Executive Director, Mark Levitan, being married to his son, Ken.

In the area of, "It's a small world", when Ms. Levitan described her new position and FIRST's mission to her mother, she was informed that her father's severe dry skin was, in fact, ichthyosis vulgaris.

Please welcome, Elena Levitan to the FIRST family and give her a call to get to know her better.



WE'VE MOVED

FIRST's national office has a new home in the Philadelphia suburb of Ardmore, Pennsylvania. Our toll free number **800-545-3286** will remain the same, but please make a note of the new phone and fax numbers, as well as the new address.

**P.O. Box 669
ARDMORE, PENNSYLVANIA 19003**

PHONE: 610-789-3995

FAX: 610-789-4366