

# ICHTHYOSIS FOCUS

Vol. 15, No. 3

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

Fall 1996

# FIRST NAMES NEW EXECUTIVE DIRECTOR



Dear Members,

After almost five months of hard work by our Executive Search Committee, we are pleased to announce and welcome our new Executive Director, Mark S. Levitan of Bryn Mawr, Pennsylvania, the Main Line suburb of Philadelphia.

Mr. Levitan, 61, comes to us with a distinguished background in healthcare, management and consulting. He currently serves as Chairman of the Board of HomeCare USA, and as a Board member of MEDIQ Incorporated. Mark devotes his energies to many charitable and civic organizations including: The Philadelphia Health Management Corporation, The Main Line Art Center, as well as serving in the capacity of Chairman of the Board of the Philadelphia Division of the American Cancer Society. A nationally recognized expert, Mr. Levitan has authored numerous articles, given speeches and testified before State and Congressional committees

on matters of health care. Mark has also served as a member of the adjunct faculty of the health care program of the University of Pennsylvania's Wharton School and as a member of the Leonard Davis Institute of the University of Pennsylvania where he is currently a senior fellow and member of the faculty.

A native Philadelphian, Mark received a B.S. in Economics from the University of Pennsylvania Wharton School of Business. As a first lieutenant in the U.S. Air Force, Mark served as an instructor pilot. Married to healthcare executive, Martha L. Waters, their extended family includes four grown children, their spouses and four young grandchildren.

Mr. Levitan's professional history includes
MEDIQ Incorporated; Chief Operating Officer,
Albert Einstein Health Care Foundation; President
and Chief Executive Officer, Shared Medical
Systems; President and COO, Hospital of the
University of Pennsylvania; Executive Director,
American Medicorp, Inc.; Senior Vice President.
Mark began his career as a CPA with Bershad and
Company, Certified Public accountants.

Mr. Levitan's experience as a Chairman and Chief Executive Officer in both publicly traded and not-for-profit settings offers FIRST a wide and varied background in healthcare leadership.

Please, join the Board of Directors of FIRST in welcoming Mark Levitan to our wonderful family.

Warmest Regards, Deb Vilas

### FIRST TO INCREASE VISIBILITY

Our new Executive Director's location affords the Foundation a unique opportunity to gain more national visibility by relocating our headquarters to Philadelphia. Mr. Levitan's reputation as a leader in the healthcare industry of this large metropolitan area, as well as the proximity to Washington D.C. will greatly benefit FIRST. As we say good-bye to Raleigh and our supporters there, we would like to express our heartfelt gratitude to Georg'Ellen Betts, a former board member and CFO, who has been overseeing management of our national office. On a volunteer basis, she has kept the office open and accessible in the absence of an executive director since June, through not only the recent birth of a granddaughter, but a hurricane as well. We extend our deepest appreciation to Georg'E and to all of you who have supported FIRST through these challenging times. With your continued support, we will move forward to meet our goals and mission.

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# CORRESPONDENCE CORNER

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

I am writing to request support and information for contact with people in a similar situation. My 10- year-old daughter, Joelle, has ichthyosis connected with her diagnosis of CHILD syndrome. In all these years we have never spoken with another human being who has this skin condition.

Joelle is a beautiful, bright 5<sup>th</sup> grader who makes mostly A's and B's on her report card. She is well liked by her peers which is no accident on her part as she works hard at calling as little attention to her differences as possible. At the same time, she may be in some sort of denial because she refuses to care for herself as she should. Due to inflammation on her right foot, webbed toes, scaling toenails, red, wet soles, she has developed a limp over the years and, needs physical therapy to develop posture and weight bearing. She has atrophy on her right leg muscles because she uses her left side so much more. She understands this, and the need to participate in her exercise program and to use her topical ointments, but it is a fight to get her to do these things. I realize that as she moves into adolescence, this situation could become more complicated.

This brings me to why I am writing. I believe that Joelle would greatly benefit

from talking to someone like herself, and, I would also benefit from talking to someone going through similar frustrations as a parent of such a special child. Do you think you can lead us to some person(s) who might be able to help us and hopefully we could help them as well?

Jan Collins 2603 Aylesbury Lane Austin, TX 78745

Since writing this letter, Joelle and her mother, Jan have been in contact with another FIRST family affected by CHILD syndrome. Joelle is recovering from successful plastic surgery on her right foot.

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#### Pen Pal in Michigan

Hi! My name is Travis Majszak and I turned 15 on June 8<sup>th</sup>. I live in Michigan and I am not really sure what kind of ichthyosis I have but it is enough for kids to tease me. For all of my life I just wanted to be friends with someone who wants to really be friends with me. I like to play a saxophone. I have one friend and his name is Josh. Travis Majszak, 5906 Goodrick Road, Traverse City, MI, 49684

# F.I.R.S.T. PART OF THE 1996 COMBINED FEDERAL CAMPAIGN (CFC)

F.I.R.S.T. has become eligible to participate in the 1996 Combined Federal Campaign (CFC). Federal employees will now be able to designate F.I.R.S.T. as a recipient of contributions made through CFC payroll deductions.

F.I.R.S.T.'s number in the CFC handbook is 0810

Dear FIRST.

I have recently come across a procedure called "Wet wrapping" that I have been using on my 2 sons with CIE. This procedure is marketed in England as "Tubifast Wet Wraps" and is apparently commonly used for severe atopic exema. Although not

perfect and a little time consuming it has helped.

After bathing and applying emollients, the Tubifast tubular elastic bandages are cut to fit arms, legs and torso, then immersed in warm water and pulled on the child. Dry bandages cut to the same lengths are then pulled on top of the wet wraps. The wraps are secured by tying strips at the shoulders and legs. The child now looks like an Egyptian Mummy! The wet layer actually cools the skin as the water gradually evaporates, reducing itching. Moisturizers are deeply rather than superficially absorbed.

I only use "wet wrapping" on 5- year- old Peter at night, but as 15- month- old Geoffery is trying to crawl, I use them all day, by making holes for fingers and toes. They not only keep him cool, but also offer all over protection for his skin which otherwise is extremely sore and broken at the end of the day. Anything is worth a try! Yours sincerely,

Carolyn Hames, Leicester, England

The manufacturers of "Tubifast" offer two guides to "wet wrapping," which are available, free of charge from: Seton Healthcare Group plc, Tubiton House, Oldham OLI 3HS, England

In the United States "Tubifast" is distributed by : Acme United, Medical Products Division, 75 Kings Highway Cut-off, Fairfield, CT 06430



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### NATIONAL ICHTHYOSIS AWARENESS WEEK



Bowl-a-thon announcer, Harry Alba

by: Lynne Alba

May 20-26, 1996 found many members of FIRST busier than usual. The first Ichthyosis Awareness Week motivated us to educate our communities about ichthyosis as well as raise funds for the Foundation.

In Kansas, the Karst family held a garage sale which brought in \$1500 and with other private donations raised \$2800 for the video fund!! Four year old, Jessa Karst, has lamellar ichthyosis and her Mom, Tiffany, says the garage sale was a lot of work, but a lot of fun too.

Chris Beeler, Region 8 RSN coordinator held an Awareness Week Raffle, consisting of southwestern oil paintings by Tucson artist Anna Yanez. The lucky winner was Mike Friel of Tucson. A total of \$400 was realized for FIRST.

In Texas, a rummage/bake sale, raffle and picnic kept Vic and Donna Rice, Dave and Anna Purcell and David and Kathy Clark all busy. Raffle items were donated by the family of Haley Rice and help with the rummage sale came from FIRST members Mona and Karl Heinz all the way from Lancaster, Texas. A picnic at

the park was a pleasant end to a hot and 20 people, all affected by or with family

Tracie Pretak of Wilcox, from her daughter Bailey Jones and several thousand people about brochures at various locations, had four articles about Awareness Week and writing campaign all for the purpose of funds in the amount of \$807.66 primarily charities (such as MDA's Shamrocks for Association's Hearts for Valentine's how important the concept of awareness dates of next year's Awareness Week."



John Montgomery and John Jr. picnicking in Texas

busy day and was attended by with ichthyosis.

Pennsylvania along with help mother, Karen Jones educated ichthyosis! They passed out different newspapers feature conducted a tremendous letter education. They also raised by borrowing an idea from other St. Patrick's Day and the Heart Day.) Tracie can't stress enough is. She is anxiously awaiting the

Also in Pennsylvania, Harry and picnicking in Texas Lynne Alba, along with the help of their good friends, Rosanne and John Campanella, held a Bowl-a-Thon on May 25<sup>th</sup>. Their effort resulted in donations of \$850. Ninety bowlers attended the event and through the generosity of many local businesses, a raffle was conducted during the course of the evening and many bowlers went home with prizes. Very popular were some left over T-shirts from the national conference in San Diego! The date has already been determined for next years' Second Annual FIRST Bowl-a-Thon.

Many other members of FIRST educated the public during this special week. A feature article appeared in the Watertown, New York paper about Meade Piercy. It portrayed her as a "typical 9-year-old with a not-so-typical skin disease". Board member, Rich Graham spoke to his church about "Equality" and among the 500 listeners that day was another person with ichthyosis, who he was able to meet.

To everyone who took the opportunity to make Ichthyosis Awareness Week the success it was-CONGRATULATIONS- let's keep up the good work!!



The Karst family sale in Kansas

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### **BOARD WELCOMES NEW MEMBERS**

Over the summer months FIRST has been fortunate to gain three new members for it's Board of Directors. Gloria Flippin-Graham, M.D. is a dermatologist and clinical professor at the University of North Carolina School of Medicine. Besides her distinguished professional career, Gloria comes to us with a strong background in volunteerism and fundraising. Tiffany Karst is a licensed social worker who specializes in OB/GYN and Neonatology at the University of Kansas Medical Center. Tiffany has been involved with FIRST as a parent, a state contact for the RSN, and a faithful fund-raiser for some time now. Michael Pinnisi is a managing partner in the law firm of Pinnisi, Wagner, Sherwyn & Geldenhuys, P.C., and an adjunct professor of law at Cornell Law School in Ithaca, New York. Michael brings us his legal skills, along with "FIRSThand" knowledge of our mission, as his daughter, Rose, has lamellar ichthyosis. We welcome Gloria, Tiffany and Michael into the FIRST family and are thankful for their presence during this time of change.

### OCCLUSION AND ICHTHYOSIS by Donna Rice

Occluding the skin to prevent dryness and help remove scaling is a time-honored treatment for many forms of Ichthyosis. The manufacturers of plastic wrap would probably be very interested in our members' unique use of their products to wrap arms, legs, torso and often scalps. Sandwich bags on our daughter, Haley's, feet are such a common occurrence that her little brother refused to eat his sandwiches the first week of preschool when they came enclosed in "Haley's baggies."

More attractive (and expensive) occlusive bandages, wraps, and suits are available as evidenced by Carolyn Hames' letter (Correspondence Corner) on "wet wrapping" and many FIRST members' use of occlusion suits and retention bandages. The manufacturers of Vaseline produce a petrolatum gauze (sterile gauze impregnated with petroleum jelly) of various widths and lengths that can be warped around any part of the body, then held in place with stretchy, retention bandages (various brands are available: Spandage, Band-net and Tubular), allowing deep and long term moisturizing.

The same effects are reported with the use of occlusion suits and booties. A 1981 article in <u>Skin and Allergy News</u>, by Medical Advisory Board member, Dr. Eugene Van Scott, reported that treatment with alpha-hydroxy acids were "further enhanced when an occlusive, light-weight, nylon treatment garment was used by the patient." Those of you who were present at the Chicago conference may remember Georg'Ellen Betts' display of child size suits sewn by FIRST members. Premade nylon suits and booties are available to adults. The Sleep Sauna company in Pennsylvania also offers the purchase of material and instructions to make children's suits. Caution should be exercised when using any form of occlusion to prevent over-softening of the skin with long term use, overheating and deep absorption of emollients and topical ointments, particularly steroids. Many products warn against their use with occlusive dressings and consultation with your dermatologist is advised.



Geoffrey Hames, 16 months, staying cool with his "Wet Wraps"

# REGISTRY for I CHTHYOSIS 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 1-800-595-1266 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: Phillip Fleckman,

Registry Coordinator: Geoff Hamill, RN

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

# **REGIONAL SUPPORT NETWORK (RSN)**

PROGRAM DIRECTOR

Elise Johnson 18117 12<sup>th</sup> West Lynnewood, WA 98037 206-771-7264

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 Angela DelGrande 4408 Appleton Place Kettering, OH 45440 513-643-9752

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CANADIAN CONTACT Barbara Rockwell 3080 Ballydown Cres. Mississauga, Ont. L5C2C8 Canada

HARLEQUIN SUPPORT GROUP COORDINATOR Patricia Steinitz 314 Richey Ave. Pittsburg, PA 15214 412-231-1201

STATE CONTACTS

COLORADO Roxane Knapp 719-576-2311 KANSAS Tiffany Karst 913-268-3692

KENTUCKY Cynnie Bates 606-276-0142

MASSACHUSETTS
Susan Overstreet
413-259-1267

MISSISSIPPI Charlene Wiggins 610-769-2454

NEW YORK Cathy Lopez 718-842-7269

SOUTH CAROLINA Nancy Bryant 803-881-2036

WISCONSIN Theresa Tremmel 414-538-4922

### **RSN PROFILE**

ELISE JOHNSON PROGRAM DIRECTOR

Please welcome newly appointed Program Director, Elise Johnson, and get to know her through the following article.

Greetings to all my friends and future friends at FIRST. My name is Elise Johnson, born in 1959, the fifth of five children. I was a collodian baby, later diagnosed with Lamellar and had the hospital in a panic. We lived near the U of Washington Medical Center, and had some wonderful doctors helping us from the start. My mother praises FIRST and expresses how much a support network would have helped in my early years. I met another child with ichthyosis, but was curious about how my skin would be as I aged. I would have appreciated talking with adults with ichthyosis. The RSN is an avenue for questions, answers and problems to be worked out together.

I am, happily, a "stay at home" mom, hold an M.A. in Clinical and School Psychology, and spent several years as a school psychologist working with children and families and teaching classes in social skills and anger management. As a therapist, I specialized in depression and eating disorders, taught parenting classes, and I continue to give seminars and presentations.

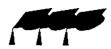
My husband Eric and I have been married for 13 years and have 2 awesome sons, Evan, 11 and Austin, 4. We also have a large white poodle who we dye blue, pink or sonic green depending on the seasons. I play the saw and several other unusual instruments, read way too much, and I am a maniac skier. We love Hawaii (it's great for the skin), diving, boogie boarding, and other outdoor sports. This has been challenging for my skin at times, but I have found ways to do what I want with an acceptable degree of comfort.

I am excited by my new opportunity with FIRST, and have enjoyed the chance to talk with some of you. Please feel free to call if there is something I or the RSN can help you with or to just talk. I have been impressed with the great jobs done by Heather and Donna in this position and I am working hard to catch up to their level of knowledge and organization. I look forward to getting to know each of you.

Elise with husband, Eric, and sons, Evan and Austin

# **NEWS & NOTES**

# GRADUATES!



Congratulations to recent High School graduates, Eric Beeler and Tonya Richardson. Eric graduated from Amphi High School in Tucson, Arizona and is using his scholarships to attend the University of Arizona , where he lives on campus. Tonya graduated in the top 10% of her class as a Merit Scholar from Frederick High School in Ijamsville, Maryland and was listed in "Who's Who Among American High School Students". Ms. Richardson attends the University of South Carolina and is majoring in Journalism. Many of you have watched these students grow into fine young adults and we are all proud of them. We wish Eric and Tonya continued success in the years to come.

### IN MEMORIAM

Contributions have been made to FIRST in the name of the following persons:

Maggie Babyak Ethel Harrison Max Legree Richard Steinman

All of us at FIRST offer our heartfelt sympathy to friends and family.

### **VIDEO PROJECT**

The concept of producing an educational video about ichthyosis originated in the Mom's group at the San Diego conference. Currently, "grassroots" fundraising has netted over \$8000 toward this project. Mr. and Mrs. Dick Rossman, owners of Crawford Sales, in Kansas City, Kansas, recently donated \$2000 toward this project. FIRST wishes to thank the Rossman's for this generous donation.



Pictured: Betty and Dick Rossman with Jessa Karst, daughter of Brian and Tiffany Karst of Shawnee, Kansas

# IT'S DIDI'S 80TH!

Mr. Aristide Rauch, father of Board Vice President, Michelle Petersen, was honored with a party in celebration of his 80<sup>th</sup> birthday, hosted by Michelle and her husband, Larry, in their New Jersey home. In lieu of gifts, party guests recognized this milestone with contributions to FIRST. We wish Mr. Rauch "Many Happy Returns" and thank his many friends and family members for their contributions to the Foundation.





Didi Rauch, (celebrated octogenarian) wife, Pupi Rauch and grandson, Matthew Aporta

### Call for Patients with Inherited Diseases of the Skin

We in San Francisco as well as skin biologists in other cities are interested in finding the chromosomal location and eventually identifying the genes whose abnormalities underlie several inherited diseases of the skin. Initially the group believes diseases for which this strategy offers the most likely insights include several disorders of keratinization (ichthyosis, Darier's disease, and Hailey-Hailey disease), forms of epidermolysis bullosa, forms of Ehlers-Danlos syndrome, psoriasis, atopic dermatitis and keloids. Ongoing studies of several such diseases have already been fruitful. We are eager to identify kindreds with these conditions-largely kindreds for the more common disorders (psoriasis, atopic dermatitis), and smaller and larger kindreds for the less common disorders (e.g. Darier's disease). If you know of such a kindred, please contact Ervin Epstein, Jr., MD, Room 269, Bldg.100, 1001 Potrero St., San Francisco, CA 94110; telephone: 800-285-1267. Investigators interested in collaborating more actively in such a linkage analysis at either the clinical or the laboratory level also are most welcome to contact Dr. Epstein.

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