



ICHTHYOSIS FOCUS

Vol. 13, No. 3

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

Summer 1994

F.I.R.S.T. SETS 1995 NATIONAL CONFERENCE FOR SAN DIEGO

Mark The Weekend of June 16th, 17th & 18th, 1995
For A Weekend of Workshops, Seminars,
Lectures, Family Get-Togethers ... And Just Plain
Vacation Fun in the Sun & Surf



BAHIA HOTEL · SAN DIEGO

The Keynote for F.I.R.S.T.'s 1995 national conference is *the family*, so we've set up the conference in San Diego next June with the family in mind.

Set on a small island jutting into Mission Bay, and just three blocks from the Pacific Ocean, the Bahia Hotel will offer us a fantastic opportunity for family vacations while the larger family of F.I.R.S.T. members come together for its biennial national conference.

It has been nine years since F.I.R.S.T. had its national conference on

the West Coast. We felt that taking the conference out west required that we create a very good reason for members across the country to go all that way. So we've built in two features to make a trip to California worth the time and expense: A stunning setting in the heart of a vacation mecca, and a conference program of extraordinary merit, with information, programs and activities for all.

Most who attended the national con-

ference in Chicago in 1993 agreed that it was the best ever. Well, we learned a lot from our experience in Chicago (it was the first conference that executive director Nick Gattuccio had ever planned and organized), and we think the 1995

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F.I.R.S.T. ELECTS NEW PRESIDENT & VICE PRESIDENT OF ITS BOARD OF DIRECTORS

After Six Years Of Dedicated Service,
Frances McHugh Steps Down as President

Effective June 1, 1994, F.I.R.S.T.'s Board of Directors made some significant changes. After six years of dedicated service, nearly two of these as President of the Board, Frances McHugh stepped down.



Frances McHugh

Frances had informally announced her intention to step down at this time nearly a year earlier to allow the Board time to arrange for a replacement. In the interim, some of F.I.R.S.T.'s new Board members stepped

forward into positions of leadership. Most notably, Deborah B. Vilas of New York moved into the position of Board Secretary, then Vice President in mid-1993. Ms. Vilas formally assumed the Board Presidency at the time of Frances's departure.

Frances may be best remembered by fellow Board members as perhaps this Foundation's most important stabilizing influence. During a pe-

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Tell us what you wish to see
and whom you wish to hear
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 F.I.R.S.T.

I'm enclosing a check in the amount of \$20.00 to support our organization. The quarterly newsletter is my lifeline to health and political updates, and invaluable tips for maintaining my daughter Karissa's skin (lamellar ichthyosis). I want to take this opportunity to thank Claudia MacNaughton (Region VIII Coordinator) for lending an ear, encouraging me, and sharing her daughter's ichthyosis stories with me. Thanks to F.I.R.S.T. and my regional reps, I gain the strength and knowledge I need to ensure my daughter a quality life.

Michele Sherrill
Saugus, California

Dear Folks,

I have traveled to south-central Virginia a few times and always found that after taking a shower there my skin is demonstrably better. I have ichthyosis vulgaris. I wonder if it's a hard/soft water thing? Would a water softener work? What exactly determines hard/softness of water? Has anyone else noticed this phenomenon?

Ken Strehle
Mt. Pleasant, South Carolina

Water hardness/softness is a function of the water's mineral content. Anyone with observations or insights on this issue are encouraged to write. Ed.

Dear staff, present & former,

You're doing such a tremendous job. I, and I know many, many others, are truly grateful for your hard work and perseverance over the years. I wish I could be of more help, financially and physically, and if I lived near Raleigh I would be a most avid volunteer.

I'm still an ardent fan of glycerine and

rose water, Aqua Glycolic Lotion (many thanks to Herald Pharmacal for their price break to F.I.R.S.T. members), and most of all Accutane. I've been on Accutane since it was first made available, off and on, and it's a mainstay of my life. I wish it were not so *horribly* expensive. Wish we could get a price break on that!

I'm old enough so that I don't have to worry about the side effects of Accutane with the exception of keeping my blood lipids down and dealing with inflamed eyes. My doctor keeps close tabs on my blood work and I enjoy pretty good skin.

I look forward so much to receiving the newsletters.

Marjouie Locke
Vero Beach, Florida

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

I am the mother of three beautiful children: Louis (10), Jillian (5), and Hannah (3). Louis and Hannah both have congenital ichthyosiform erythroderma (CIE).

Until last month, when I received a telephone call from Heather Gattuccio, I had never spoken with another parent who had a child with ichthyosis, or anyone who had the disease themselves. In fact, it wasn't until Hannah was born that we finally got a diagnosis for Louis, too. For years, I thought that I must have been exposed to some toxic substance when I was pregnant with him.

At last, so many things started to make sense. The extremely high fevers, the intolerance to heat, the chronic scaling and dry skin. Even after getting a diagnosis, however, it has been frustrating dealing with those in the medical community who know little to nothing about ichthyosis. I have tried numerous skin lotions and creams on the advice of well-

(Letters Continue on Page 6)

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Deadline for submissions to the next issue of FOCUS: October 1, 1994

NOTES FROM THE E.D.'S DESK

by Nick Gattuccio

As business trips go, this one was pretty hard to beat—San Diego in June, mid-70s, four hotels in four days, each one of them vying for F.I.R.S.T.'s national conference contract. The price was right (free rooms), and I was treated like a king. I was even treated to a round of golf on a championship course.

I felt a little guilty taking the round of golf, though. This was at the last hotel I visited, and I knew already that this hotel didn't have a strong chance of being selected. In fact, the Bahia Hotel was the first one hotel I inspected, and I knew right away that it was perfect in every way.

I have been thinking about the '95 national conference since the day we closed our '93 conference in Chicago. That was a very good meeting. Attendance was excellent, the schedule appealed to a very wide range of interests, the member workshops were very well received, and our professional "faculty" was both excellent and interesting.

But the Chicago conference wasn't perfect. It was the first conference of its type that I had ever organized, and I made a couple of mistakes and a few weak choices. Most people didn't notice these details, but I did.

I learned a great deal from my experience planning the Chicago conference, and this experience should add a great deal to our meeting in San Diego next year. For example, although our conference space in Chicago (actually, the Chicago suburb of Schaumburg) was perfect in every way, the hotel itself was so isolated that everyone was virtually stranded.

Not so in San Diego. As ideal as the space itself is, it is also within a short walk of equally ideal spots. For example, it is only three blocks from the Pacific Ocean, where a lively com-

munity (called Belmont Park) straddles a boardwalk on the beach front, and where restaurants and other diversions abound. The Bahia itself is on a small island (a spit, really, as it's connected to the shore) that juts into Mission Bay. It has two beaches and endless choices for water sports. Just minutes away (also on Mission Bay) is Marine World, which you can reach by water taxi from the hotel dock), and the world famous San Diego Zoo is just 15 minutes away.

It was clear to me right away that the Bahia was the perfect location, because it is perfect for families. Some of its rooms are in a multi-story building, but most are like cabanas. Our keynote for the San Diego conference is The Family—and not just the immediate family, but the whole extended family, too. At the Bahia, we have the ideal family vacation destination combined with a friendly conference center. It is the best of both worlds.

The other big mistake I made in Chicago was not allowing enough time for the conference. We tried to squeeze too much into too short a time span. So we're making this conference longer than any in the past—from Friday afternoon through Sunday afternoon. This will not only give us more opportunities for meetings, workshops and other gatherings, it will also allow us more free time for breaks and fun while the conference is in session.

I can't say too strongly how much we're going to gear this national conference to broad family involvement. I offer a sincere invitation to everyone out there—parents and grandparents, uncles and aunts, friends and caregivers—to join us, our community, in what I assure you will be our best and most interesting, informative and fun national conference ever. This will be the conference of the F.I.R.S.T. family.

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...

Nicholas Gattuccio
Executive Director



1995 National Conference

(Continues from Page 1)

San Diego conference will be even better yet. Planning and organizing is already underway to make this happen.

Conference Set To Last Longer

Members who attended the conference in Chicago in 1993 filled out conference evaluation forms. The comment that turned up over and over again in these evaluation forms was the feeling that the conference was not long enough. This created the problem of our trying to squeeze too much into too little time.

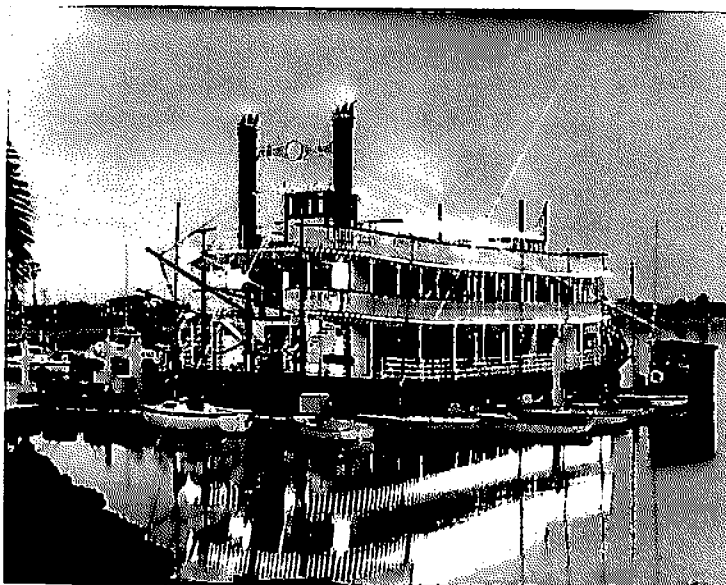
We've listened, and in 1995 we'll add an extra day. The conference will kick off on Friday evening, go all day Saturday, culminating in a party or banquet Saturday evening, and then will continue on Sunday until about 2:00 pm.

At the same time, we'll provide ample break periods so members can enjoy the sights and sounds of San Diego.

The Setting Is Idyllic

The Bahia offers one of San Diego's premier vacation locations. On an island jutting into Mission Bay, adjacent to two beaches (one private and one public), and ringed with water sports, members will have full access to a full array of water sports activities, including boating, sail boarding, swimming and much more.

The Bahia is just three blocks from the Pacific Ocean. On the oceanfront boardwalk three blocks from the hotel is



The *William D. Evans*, one of two sternwheelers at the Bahia Hotel. At our national conference we'll utilize both sternwheelers for conference events.

an array of restaurants, stores, rental shops (in-line skate rentals are big here), and one of the biggest roller coasters on the west coast. On top of this, San Diego's famous Marine World is on Mission Bay, just minutes from the hotel. For those interested in visiting the San Diego Zoo, it's less than fifteen minutes away.

The Greatest Conference Yet

All of that said, be assured that the heart of the weekend will surround the national conference program. As we did in Chicago, we'll have a broad-based program built largely on small workshops, seminars, discussion groups and work groups.

Groups sessions will devoted to scientific issues, treatment topics, youth groups, parent groups, and a broad array of topics geared to a variety of interests. There will be something for everyone.

Many of the country's most prominent researchers and clinicians in the field of ichthyosis will be attending to offer scientific presentations and answer questions. We'll again have representatives from the pharmaceutical industry ex-

hibiting products and speaking to members face-to-face. Most, if not all members of F.I.R.S.T.'s Board of Directors will be attending.

The Keynote Is The Family

The keynote to the 1995 national conference is *The Family*. You'll be hearing a great deal about this in the coming ten months.

By family we mean several things. We mean, of course, the immediate nuclear family, but we also mean the larger extended family. We want to encourage extended family participation in this year's conference—aunts, uncles, and especially grandparents.

And finally, by family we mean the global family of persons affected with ichthyosis. This is to be one great family gathering. We look forward to seeing all of you in San Diego.

DETAILS, DETAILS, DETAILS . . .

When June 16th, 17th & 18th, 1995 (Fri, Sat & Sun)

Where The Bahia Hotel & Resort
998 West Mission Bay Drive / San Diego, CA 92109
619-488-0551

Room Rate \$68.00 per night (family rate)

Family rate means two adults and all children under 18 stay for the flat \$68.00 rate. For more than two adults (18 and over) in a room, add \$15.00 per person.

This rate is guaranteed for 3 nights prior to, and 3 nights following the scheduled conference dates., for a total of 9 nights. Note that this special rate on the extended days is on a *space available basis*, so be sure to book your rooms well in advance.

You may book rooms at any time by calling the Bahia Hotel.

Registration Registration forms and fees will be announced and made available by late Fall, 1994.

Air Fares F.I.R.S.T. will announce soon an agreement with a travel agent for the conference, through which special air fare arrangements will be available.

Among the most popular items at the 1993 National Conference in Chicago was the conference commemorative T-shirt. The Foundation is running a contest this year for anyone wanting to design the 1995 T-shirt.

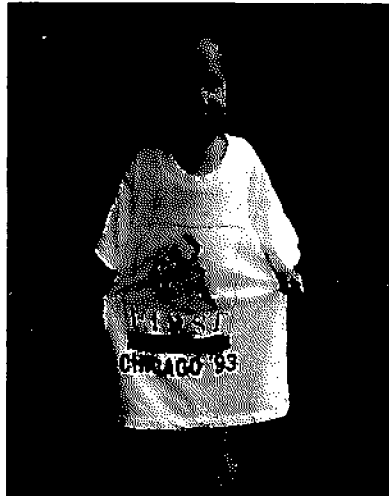
The winner will be selected by F.I.R.S.T. Board and staff in the spring of 1995, and will receive two nights stay at the Bahia Hotel for the national conference in June.

Design Specifications:

The T-shirt design should comply with the following guidelines.

- (1) May use either one or two colors in the overall design.
- (2) Must include the F.I.R.S.T. logo somewhere in the design. The logo should be clearly visible, but may be any size your design requires (the logo's width-to-

WIN A FREE STAY IN THE BAHIA HOTEL AT THE NATIONAL CONFERENCE: DESIGN THE CONFERENCE T-SHIRT



length ratio is .75 : 1). You may indicate the logo in your design with a correctly sized and proportioned box, and we'll insert the graphic.

(3) Must include in some fashion the year (1995) and the city, San Diego.

(4) The overall dimensions of the design area (either front or back) should not exceed 8" x 12".

(5) Design should appear on only one side of T-shirt (either front or back)

(6) Bear in mind that the conference keynote is "the family." A T-shirt design which in some way reflects this may be favored by the judges.

(7) Please submit your design full-size on suitable art paper.

Prize is two night's stay at the Bahia Hotel, Room and tax only.

ANGER

by Christiane Buuck

Editor's Note: Christiane Buuck is a ninth grade student at the Oakridge School in Arlington, Texas. She is a member of the local Alopecia Areata Support Group and the National Alopecia Areata Foundation (NAAF). Christiane's essay originally appeared in the quarterly newsletter of the NAAF. Copyright © 1994 by NAAF; reprinted by permission.

For five years I lived my life watching little kids in the grocery store tug on their mothers' sleeves and listen to them say in their high-pitched, taunting voices, "Look, Mommy! She's bald!" For five years of my life I saw the same mommies shush their children and look away and hurry on even though I knew that they were dying to stare. Of course, the kids did stare, no matter what "mommy" told them.

It was times like that I really wanted to crush their childhood curiosity with a single crushing blow. I wanted to scream after all those mothers, "Hey, look at me! You know you want to! Guess What? I'm just the same as you except I don't have hair! Hey, that's a shocker, isn't it? Looks aren't everything, let me tell you! So go ahead—stare, and I'll stare right back. Let's see who looks away first!" And sometimes I would do just that—not with the mothers, but with the kids I would make ugly faces and stare at them.

I was so angry. Why didn't they realize that I wasn't some freak show? If I was I would be charging admission. It's hard being you and visibly different. It wasn't just at the

grocery store that it became evident; there was school, any public pool, Wet'n Wild, the mall. Any place where people gathered, eyes stared. Some people even told me not to worry. I would make it through the chemotherapy. I would smile kindly as my Mom or Dad would say, "No, my daughter has an autoimmune disorder, not cancer. Her life is not in jeopardy, it just rejects hair. But thank you for your concern."

Personally, I didn't need their sympathy. I was doing just fine on my own, thank you. I was mad at them for assuming I was dying. I was mad at the countless incompetent doctors and the infinite pills, shots, topical rubs and blood tests. For crying out loud, I was a nine-year-old who just wanted to be a kid! I was also mad at all the people who called me "young man" or "son" when I wore hats. I realized at a very early age that our culture is very appearance-oriented.

As I got older, though, I began to realize that I had left most kids my age in the dust. They were just beginning to realize things I had been confronted with for years. I was mad about that, too. I had grown up faster. Now I realize that was for the better. I understand myself; I am not afraid to be myself; I love life. Every time I see someone with a visible difference—acne, a handicap, another bald person—I don't tug on my Mommy's sleeve and call it to her attention as well as the whole world's. I don't stare. I simply make eye contact and smile. "One up, pal," I think. "Never give up the ship. You're a hero in my book." And every time I hear someone groan and say, "I'm having a bad hair day!" I think to myself, "Hey! You're having a hair day!"

Correspondence (continued from Page 2)

meaning (but ignorant) physicians, only to then have to deal with the devastating effects that they had on my children's skin.

When I got the name of F.I.R.S.T. from NORD (The National Organization for Rare Disorders) about a month ago, I sent a letter. Heather called me about a week later! I cannot adequately explain how wonderful it was, after so many years, to finally talk to another parent who is wrestling with the same problems that I am. I felt so relieved. The parents that I come in daily contact with have difficulty understanding why, for instance, we intentionally pick the cloudy, overcast days to go to the amusement park, or why we cannot let our super-sports-enthusiast son play soccer.

Thank you for all the information that you sent, and also the skin-care ideas. It is a good feeling to know that I have somewhere to turn with my seemingly never-ending questions.

Heather Mattiuzzo
Lockport, New York

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

I am an adult with ichthyosis, work as a nurse educator, and conduct classes regularly. Needless to say, to avoid a lot of questions and to look presentable, I have tried many products to control scalliness. Recently, my friend and a Mary Kay consultant recommended a product, Advance Moisture Renewal Treatment Cream, and I was really pleased with the results.

After cleaning my face with a mild soap and water to soften and remove scale, I apply the cream under my makeup. It does not burn and results in a moisture barrier lasting all day. Here in California our humidity is in the dry range, and even touch ups do not leave me greasy.

Joyce Baron
Fairfield, California

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

I am writing in response to an article

by Nick Gattuccio in the Spring 1994 *Ichthyosis Focus*. Mr. Gattuccio was discussing the politics of the health care debate, and Clinton's health plan.

I am the mother of a 7-year-old son and a 3-year-old daughter, who both have lamellar ichthyosis.

Mr. Gattuccio, instead of worrying that *no* health plan will be passed, I am scared to death that Clinton's socialized medicine will pass. If this happens, it would be absolutely horrible for my two children.

We presently go to a dermatologist 75 miles away from our home. He has been absolutely wonderful to our children, and to two very scared parents upon the birth of our first child. Without a doubt, he would not be in our "alliance" under the Clinton plan. It would also be against the law to go to this doctor and pay for his services out of our own pocket. After almost eight years, we

F.I.R.S.T. endorses no health care reform legislation. Instead, the Foundation has endorsed a health care reform Statement of Principles.

would have to abandon a very knowledgeable doctor and trusted friend.

With a socialized medicine plan, incentives for researching little known disorders would be non-existent. Why would researchers try to develop new and better medicine? Incentives, even if they might be monetary, would be gone.

My husband and I both pay quite a bit for health insurance through our jobs. But we have the freedom of choosing whom we want to treat our children, and can change our doctor at any time.

There are problems with our health system, but let's work on the problems instead of abandoning a system that is the best in the world.

Please, Mr. Gattuccio, keep *Ichthyo-*

sis Focus an informative newsletter for skin disorders, not a political platform.

Sheila Ferrell
Ripley, Tennessee

First, let me appologize for creating the impression that F.I.R.S.T. (or that I, as a representative of F.I.R.S.T.) endorse the Clinton health care reform plan. The fact is, F.I.R.S.T. endorses *no* health care reform legislation. Instead, the Board of Directors has voted to endorse health care reform *principles* (see page 12 for the text of F.I.R.S.T.'s official "Position Statement on Health Care Reform").

Central to F.I.R.S.T.'s position on health care reform is keeping in place a great deal that is best about the present system, particularly access to specialty care (i.e., dermatologists), the ability to select one's own physician, and to change physicians at will.

What concerns us so deeply is that a great many people with genetic disorders are denied adequate medical coverage because they have a "pre-existing condition." Like many people with ichthyosis, you have medical insurance that takes care of your needs. This is how it should be. However, should you and your husband lose your jobs, or for some other reason need to re-insure, there is a very strong possibility that you would no longer be able to insure your children.

Medical research is another very important issue that you raise, and I assure you that we support your view that any steps that would stifle America's leading position in the world of biomedical and clinical research is unacceptable. In fact, F.I.R.S.T. supports the efforts of Senators Hatfield, Harkin, and Congressman Coyne to attach provisions for a "Biomedical Research Trust Fund" to any health care reform legislation (see page 10 for developments on this legislation).

Ichthyosis Focus will continue covering developments on important political issues, and F.I.R.S.T. will continue taking stands on these issues, because we feel that we owe it to the ichthyosis community to actively promote our best interests in a political climate where the patient is seldom the top priority for decision-makers. NG.

GRASSROOTS

TIFFANY & BRIAN KARST IN SHAWNEE, KANSAS, RAISE \$800 IN GARAGE SALE FOR F.I.R.S.T.

Editor's Note: Brian and Tiffany Karst of Shawnee, Kansas (many of you met them at the last national conference in Chicago), and their beautiful daughter Jessa, this spring enlisted the help of friends, family and neighbors to put on their own First Annual Benefit Garage Sale for F.I.R.S.T. Tiffany Karst wrote us to tell us about it:

23 May 1994

We just wanted to get a note to you telling you about the garage sale we had this spring to benefit F.I.R.S.T. It started out as a small, two-family sale, but as we told friends and family about our plan, it began to grow. It turned out to be a huge success! We are enclosing checks totaling \$800! We never imagined we would raise this much money from a two-day sale.

With only a weekend and a few evenings to get ready, we crammed our

garage with donated items brought over by our parents, co-workers, and friends. I took Friday off from work and my friend, Rhonda Rudicel, and I began selling. It was a lot of fun. We didn't have many large, high-priced items. It was mostly kitchen ware, books, and miscellaneous



Left to right: Jessa Karst, 22 months old, with friends Alexandra and Devin, at neighborhood garage sale for F.I.R.S.T. By Sunday the sign read, "Make Us An Offer!"

items. Our highest priced item was a pair of used golf clubs that sold for \$50.

We had a sign that said, "Proceeds to Benefit the Foundation for Ichthyosis & Related Skin Types." Many people asked about F.I.R.S.T. Some even donated a few extra dollars!

I'm also enclosing a picture taken that day. We had the sign hanging up, but by Saturday afternoon, we thought we would see how much we could get for the kids (pictured is our daughter, Jessa, 22 months old, and her two best friends, Alexandra and Devin). Their moms were a big help to me and Brian.

There are a lot of people we want to thank for helping us make our First Annual Benefit Garage Sale a wonderful success:

Rhonda Rudicel (Devin's mom)
Tammy Valala (Alexandra's mom)
The University of Kansas Medical Center's Department of Social Work (my co-workers)
Our mothers, Lola Wilks & Maxine McMillan
The Olathe, Kansas American Legion (for the use of their tables and a \$100 donation)

I would encourage other F.I.R.S.T. families to consider trying this type of fund raiser. It cost us about \$20 in advertising and supplies for signs, and it was *not* hard to get items for the sale. We just asked people we knew to donate *anything* they didn't need anymore. We had everything from storm doors to old books on transactional analysis!

The best part was that we were able to raise a nice amount of money without feeling like we were asking too much of those who gave. Everyone was happy—those who got their basements and closets cleaned out, those who found a bargain, and my family, because we could return something to F.I.R.S.T. for all the support we have received.

This organization has given us more than we can give a dollar value to, but hopefully this money can help the continuation of the education, support, and friendship made available to all of us.

Thank You!
Tiffany, Brian & Jessa Karst

FUND RAISER SET FOR THIS FALL IN WISCONSIN

24-Hour Volleyball Marathon Targets \$5,000 for F.I.R.S.T.

Thomas Buehler of F.I.R.S.T.'s Board of Directors has convinced his employer, New Resources Corporation, to volley for F.I.R.S.T. -- volleyball, that is. Later this fall, New Resources Corp. will challenge one of their clients, Gander Mountain, to a 24-hour volleyball marathon.

This is all to take place in the Wilmont, Wisconsin area. A firm date is yet to be set, but all is in place. In fact, Tom is looking for F.I.R.S.T. members that might like to participate.

The goal is to raise \$5,000, which would be split between F.I.R.S.T. (which is the charitable organization designated by Tom's firm, New Re-

sources) and another nonprofit organization that their opponents, Gander Mountain, selects.

So Tom wants all of you out there in Regions Four and Five to know that a fun event is in the works, and that all are invited to participate, either as spectators or participants.

If you think you might like to become involved in this, please contact Tom Buehler in Waukesha, Wisconsin at 414-542-1044.

Good luck, Tom! Pump up those Air Jordans and get a good night's sleep. You're going to need it!

And thanks from everyone here, and everyone out there, too.

Q & A

Q. My four-year-old son, who has lamellar ichthyosis, also has severe ectropion. His lower lids pull down and away from his eye significantly, and people constantly question me about pink eye. Is there anything one can do to correct this condition? Why do some who have a more severe case of lamellar ichthyosis not have ectropion?

A. Dr. Mary Williams, M.D.

Some degree of facial tautness is present in most, if not all, patients with lamellar ichthyosis. The tighter the skin around the lower lids, the greater the likelihood of significant ectropion. If the ectropion is severe enough, during sleep the eyelids will be unable to cover the eye. The excessive exposure to air results in inflammation, which is evident as pink eyes.

Since your son is experiencing pink eyes, a consultation with an ophthalmologist (medical eye doctor) is advisable. They will certainly recommend the use of artificial tears to prevent drying of the eyes.

If inflammation of the cornea (keratitis) is occurring, it may be necessary to have surgery to release the pull on the lids, since chronic exposure keratitis can lead to corneal scarring and interference with vision. Oral retinoids (etretinate or isotretinoin) treatment may also improve ectropion, and might be considered as an alternative or adjunct to surgery if there is significant eye inflammation. However, long term treatment is likely to be required, since the ectropion would recur if the medication were discontinued.

The risks and benefits of surgery and/or retinoid treatment would need to be discussed with your doctors.

A. Dr. Joseph McGuire, M.D.

Ectropion is common in lamellar ichthyosis. Check your child when he is asleep to see whether his eyes are closed properly. If not, the cornea may dry out at night and become irritated and possibly cause scarring, resulting in reduced vision.

If the eyelids do not close completely, consider using methylallulose

eye drops. If this doesn't work, surgical correction may be necessary.

Q. I have a young daughter with lamellar ichthyosis who is having considerable trouble with her ears. In addition to the common problem of exfoliating skin bonding with natural wax to create plugs in her ears, her ENT tells me that she has the smallest ear canal he has seen in a child her age.

Is the skin in the ear (and, for that matter, the ear drum) affected by ichthyosis? Could my daughter's ear canals be small because of the tightness of the skin? Just how does ichthyosis affect the ears?

A. Dr. Mary Williams, M.D.

As you know, in some forms of ichthyosis, particularly lamellar ichthyosis and (nonbullous) CIE, the facial skin may be quite taut, pulling the lower eyelids down (ectropion) and pulling outward, or evertion (eclabion), the lips.

When there is marked facial tautness, the external part of the ears (pinnae) and the lower, fleshy part of the nose can be rather small. These structures are formed from cartilage, which is softer than bone. Presumably, their development is inhibited by overly taut skin, resulting in small ears with a minimal ear lobe, and a nose that is less full in the lower third. It seems likely to me, therefore, that ear canal development may be similarly affected.

Although I'm not sure that this particular problem has been previously

brought to my attention, this may have been an oversight on my part, since I do not routinely examine the ear canals in my patients.

Certainly, problems due to build up of wax/debris are common, particularly in patients with lamellar ichthyosis and (nonbullous) CIE. This question—i.e., what are the ear problems in patients with this or that type of ichthyosis—asks for the sort of information that is not readily available to patients or their physicians. I believe an ichthyosis registry should provide a much needed opportunity to develop and disseminate this type of information.

Q. Children with ichthyosis, particularly those with EHK, are very prone to infections of different kinds. Among these are yeast infections. Are years infections different from bacterial skin infections, and are they treated differently? Also, why are ichthyosis patients more prone to yeast infections, and how can they be prevented?

A. Dr. Joseph McGuire, M.D.

Yeast infections are caused by an organism called manilia or candida. They often occur in skin folds, around the neck, and in the groin and buttocks. Treatment is with an antifungal cream or gel. Persistent infections are sometimes also treated with oral anti-yeast medicines. Patients with ichthyosis are more likely to get these infections because the scale can harbor the organism.

Questions for the Q&A section of Focus, can be sent to the Focus Editor, P.O. Box 20921, Raleigh, NC 27619. Questions will remain anonymous. Questions may be edited for publication.

CELLEGY SEEKS PATIENTS FOR PHASE III CLINICAL TRIALS FOR GLYLORIN

Cellegy Pharmaceuticals is presently planning for phase III clinical trials for Glylorin, a product being developed to treat ichthyosis. Trials are set to begin this fall at 20 sites in the U.S., and a great many patients with several forms of ichthyosis will be needed at these phase III trial sites around the country.

If you think you might wish to participate in these trials, and if you know which type of ichthyosis you have, you may contact officials at Cellegy to be directed to a trial site near your area.

Contact Cynthia Selfridge at 415-382-6770.

RESEARCH NOTES

Summaries of Results From Ichthyosis Research Laboratories Around The United States

Researchers Find No Genetic Link Between Darier's and Hailey-Hailey Disease

In the recent issues of *The Journal of Investigative Dermatology*, researchers from the Stanford School of Medicine, Northwestern University Medical School, and the University of California at San Francisco School of Medicine report the results of an attempt to "find the genetic mutation underlying Hailey-Hailey disease" by analyzing a region of chromosome 12. The researchers searched near

the site where the gene for Darier's disease has recently been located. Involved in the study was Dr. Ervin Epstein, Jr., M.D., a member of F.I.R.S.T.'s Medical Advisory Board.

The study stemmed from assumptions based on many similarities between Hailey-Hailey and Darier's. Both are autosomal dominant disorders, and Darier's disease has several clinical and histological (that is, involving the microscopic aspects of the diseases) features which overlap those of Hailey-Hailey disease.

On the basis of these facts, they suspected that both may share a genetic link.

However, when they examined genetic material from several patients with Hailey-Hailey disease and analyzed the site on chromosome 12 near where the gene for Darier's disease is located, they discovered "strong evidence against this region being the site of the mutation underlying Hailey-Hailey disease." The researchers concluded that "despite the clinical overlap" between Darier's disease and Hailey-Hailey disease, the two disorders "result from mutations in different genes."

Elizabeth A. Welsh, Shigaku Ikeda, Anna M. Peluso, Jeannette M. Bonifas, John W. Bare, David T. Woodley, and Ervin H. Epstein, Jr. "Hailey-Hailey Disease Is Not Allelic to Darier's Disease." *The Journal of Investigative Dermatology*, vol. 102 (no. 6), pp. 992-993, June 1994.

I've been a volunteer for F.I.R.S.T. and the RSN for three and a half years. The work is occasionally demanding, but always rewarding. My husband, John, and I are originally from northwest Alabama, near Tusculumbia, where Helen Keller was born. For the last three years Lexington, Kentucky has been the place we call home. We have a little house built in 1939 that we are renovating ourselves.

Our first child, Joshua, was born December 30, 1987, with CIE, and was a colodion baby. A little brother, Will, arrived December 31, 1988, without ichthyosis. Josh is doing very well now, despite the typical early problems with skin care, growth and development, ear trouble, and the not-so-typical problems of recurring yeast infections and one bout with seizures. Josh is now a healthy six-year-old who eats like a twelve-year-old and loves to play outside with Will, friends from school, and our dog, Sally.

We sought F.I.R.S.T. because John and I were unable to find the information or support we needed to be the kind of parents we wanted to be for Josh and Will. We found that the people we met through F.I.R.S.T. were very understanding and

PERSONAL PROFILE

Cynn timer Bates
RSN Region Four Coordinator



Cynn timer Bates' sons, Will (l) and Joshua

extremely helpful. Through their help and our growing experience, we became less overwhelmed and more confident. Having children, and

knowing people through F.I.R.S.T., have made us better people and parents.

My degree in elementary education is put to good use at home teaching our two boys and volunteering at school and church. I also sew for a local costume shop. When I do join the ranks of those who work for a paycheck, it will likely have less to do with education than with social work or nursing because of my experiences as a mother of a child with (and without) ichthyosis, and my work with the RSN.

I am very committed to F.I.R.S.T. and its goals of reducing isolation and providing more information about this disorder through the RSN. It is important to me to give back what

others gave to us. Helping others has helped me, too. We have been through our share of difficult and isolated times, and we know what a relief it can be to talk with someone who understands. I truly enjoy the work I do with the RSN, and I always look forward to letters or calls from people in our ichthyosis family.

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.

House Calls?

A record number of health care professionals will be running for Congress in 1994. Fifty-two will be running for the House, Senate or Governor's seats. Most of these are male and Republican. The majority are physicians, but there are also four nurses, two chiropractors, and five dentists.

Toto, I Don't Think We're In Kansas Anymore . . .

A 28-year-old entrepreneur in Washington D.C. has started a thriving business called the CVK Group. He gets \$27.00 per hour for holding a place in line for lobbyists and lawyers wanting seats in crowded congressional hearing rooms.

In fact, over \$100 million is expected to be spent on the health care lobbying battle this year. "In the last 20 years I've never seen anything like this," said James Thurber, who teaches lob-

bying at American University. "You have to watch out when you cross Pennsylvania Avenue. You're not going to get hit by a car, but by lobbyists and money flowing to the Capitol."

The biggest spenders so far are the Health Insurance Association of America (HIAA), which will spend \$13.5 million, the Pharmaceutical Manufacturers Association (PMA), which expects to spend \$14 million, and professional medical associations like the American Medical Association (AMA) and numerous medical specialty associations.

Why The Health Care Debate Is Important to Patients

Reason #32

100,000 Americans lose their health insurance permanently every month, according to the Commerce Department. Latest figures show that in 1990, 20% of Americans lost their health insurance for at least a few weeks during the year.

Reason #77

Although medical inflation is easing right now, it has been noted that throughout history medical inflation always goes down when there's the threat of health care reform. As soon as the legislation is defeated, as it was under Truman, Johnson, Nixon and others, the inflation returns with a vengeance.

Reason #13

The highest percentage of health care costs goes to hospitals. These expenses rose 8% in 1992. Physicians and clinic fees rose 8.8%. The cost of home health care rose 21.9% during that year. The highest expenses paid to hospitals goes for heart disease and child birth.

Reason #29

Despite the public's perception that America has the best health care system in the world, sporting access to the newest technologies, a recent Government Accounting Office (GAO) study found that Americans are *less* likely to get one high-tech procedure, an allogenic bone marrow transplant for leukemia, than are patients in six other industrialized countries that have what many call "socialized medicine." Sweden, England, New Zealand, Denmark, Canada and Australia all provide bone marrow transplants for three types of leukemia more often than do providers in the U.S. (see "Bone Marrow Transplantation: International Comparisons of Availability and Appropriateness of Use," GAO 1994).

Fact of the Month

A St. Louis University study of 840 adults found that a man who has an abnormal initial heart test is much more likely than a woman to get further treatment. Sixty-two percent of men had additional tests while only thirty-eight percent of women received additional tests. The study was printed in the March issue of the *Annals of Internal Medicine*.

The Cost of Health Care

The government spent \$3,940 per Medicare recipient in 1993. This is an 8.7% increase over 1992. Overall health care spending in 1993 for the public and private sectors was up 12% over 1992. This figure represents 14% of GDP.

NEW CENSUS FIGURES ON AMERICANS WITH DISABILITIES

Latest figures from the U.S. Census Bureau show there are now 49 million Americans with disabilities. Furthermore, nearly half of those with "severe" disabilities (24 million) lack health insurance. This compares with about 80% of people *without* disabilities who have private health insurance.

The figures represent an increase of six million people with disabilities, raising the total to 49 million from 43 million, a 16% increase.

Americans with disabilities repre-

sent about 20% of everyone living in the U.S.

The report, entitled *Americans With Disabilities: 1991/1992*, and published by the U.S. Census Bureau, reports that only 23% of those aged 21 to 64 with severe disabilities are employed.

The Disability Rights Education and Defense Fund (DREDF) has characterized the lack of private health insurance coverage for Americans with disabilities as "legalized discrimination within the insurance industry."

WASHINGTON UPDATE:

The Harkin/Hatfield/Coyne Initiative

Congressional Action To Create A Biomedical Research Trust Fund Gaining Steam

In the Fall, 1993, issue of *Focus* we carried a story by Senator Tom Harkin entitled "A Five-Dollar Cancer Cure" in which he outlined a proposal to create a Biomedical Research Trust Fund with an assessment of a 1% surtax on health insurance premiums in any new health care reform legislation. As initially drafted, the plan was expected to put nearly \$6 billion annually into the trust fund, raising by 50% per year the amount available to medical research in the U.S.

The plan was originally co-drafted by Senator Mark Hatfield. Since then, Congressman Bill Coyne has sponsored a House version of the Harkin/Hatfield plan.

Since first introduced, versions of the Harkin/Hatfield plan have been incorporated into three of the major health

care reform bills now before Congress. Each of these is before one of the important Senate committees.

Following is a summary of the Hatfield/Harkin/Coyne

plan in its versions before these three committees.

1. Senate Labor & Human Resources Committee. The bill reported out of this committee would phase in the Harkin/Hatfield proposal over five years, ultimately assessing a one percent surcharge on health insurance premiums. Revenue in the Fund would be allocated to NIH for spending on medical research.

2. Ways & Means Committee. In this version of the bill, revenues equivalent to a tax of one-half of one percent on health insurance premiums and on self-insured plans would be deposited into the Fund. Funds would be made available to medical schools, academic health centers and others to support research projects, and would not go directly to NIH, as provided for in the original

proposal.

3. Finance Committee. This version would also establish the Trust Fund and allocate revenues to NIH. It would assess a surcharge of 1.75% on health plan premiums, including self-insured plans. Of these revenues, though, only .25% (one-seventh of the total) would go to the Fund. The remainder of the funding raised by the 1.75% premium assessment would go to support graduate physician and dental training programs, and establish a similar program for graduate nursing education. Payments would also be available to medical schools to help meet additional teaching and research costs associated with the transition to managed competition.

Given the enormous uncertainties about pending health care reform legislation, the final outcome of the Harkin/Hatfield proposal for a Research Trust Fund is also very uncertain. Because Senators Harkin and Hatfield are attaching their plan as a provision tucked inside large, complex and controversial health reform bills, their Research Trust Fund proposal an orphan subject to the fate of the parent legislation.

CONGRESSMAN WILLIAM H. NATCHER DIES

Chairman of the House Appropriations Subcommittee Which Oversees Medical Research In America

For 15 years Chairman of the House Appropriations subcommittee which oversaw funding of the Department of Health & Human Services, including the National Institutes of Health (NIH), Congressman William H. Natcher (Dem., Kentucky) was perhaps this country's most distinguished patron of medical research in America for a decade and a half. He died March 29.

Mr. Natcher took special pride in pointing out that under his legislative stewardship, funding for the NIH grew from \$73 million in 1953 to about \$11 billion today. That's 1400% over 40 years. On Mr. Natcher's 83rd birthday in 1992, NIH broke ground on a new office building complex that will be named after him.

Over his 40-year career in Congress, Mr. Natcher accepted no political contributions, took no honoraria for speeches, and he served as his own press secretary, administrative assistant and legislative assist-

"I have always believed that if you take care of the health of your people and educate your children, you continue living in the strongest country in the world."

ant. His office staff consisted of "five ladies," as he described them, who answered phones, greeted visitors and took dictation. Throughout his career he always financed his own campaigns and rarely spent more than \$7,000 on an election. He campaigned the old fashioned way: he traveled his district in a car and spoke to people on the street.

Mr. Natcher is known for never having missed a roll call vote in the House. From his first day in office until March 3, 1994, he set a record of 18,401 consecutive votes. The day before this streak ended, ill and hospitalized, and connected to an oxygen tank and intravenous tubing, he was wheeled onto the House floor on a hospital gurney to cast his four final votes.

"In an era of sound bites and high-tech media campaigns," said President Clinton, "Bill Natcher was a rarity." This is more true than ever for those of us who look to medical research for a glimpse of our future.

F.I.R.S.T.'S BOARD OF DIRECTORS ADOPTS POSITION STATEMENT ON HEALTH CARE REFORM

At its meeting of February 27th, 1994, F.I.R.S.T.'s Board of Directors formally adopted by unanimous vote the following Position Statement of Health Care Reform. Note that the Foundation does not support or endorse any specific health care reform legislation. Instead, the Foundation for Ichthyosis & Related Skin Types endorses broad principles that we feel any forthcoming health care reform legislation should include. Following is the full text of the Position Statement.

INTRODUCTION

The ichthyosis are a family of related genetic skin diseases characterized by dry, thickened, scaling skin. Other primary and secondary symptoms may include severe blistering, heat intolerance, restricted fine motor dexterity, susceptibility to infection, hearing impairment, and a host of psychosocial and developmental difficulties normally associated with a "disfiguring" ailment.

The Board of Directors of the Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.) recognizes the critical importance of the present health care reform debate to the health and welfare of the nearly one million Americans who have one of the many forms of ichthyosis. The Foundation therefore endorses the Health Care Reform Statement of Principles adopted by the Voluntary Health Agencies of the National Health Council, and calls upon Congress and the President of the United States to enact comprehensive health care system reforms which embrace the following principles.

ELIGIBILITY

Recognizing that health care is a right for all Americans, our national health care system must guarantee universal access, regardless of employment status, ability to pay, and/or pre-existing condition. This includes full portability of coverage regardless of employment dislocation and/or geographic relocation.

COVERAGE, SERVICES & BENEFITS

Coverage must address the continuum of mental and physical health care, including preventive, acute, chronic, rehabilitative, and long-term care. Health care services should be effective, appropriate, and timely. Medical effectiveness is defined by research findings; appropriateness (that is, services deemed "medically necessary") is determined by the patient, the family, and the health care team. Health care reform should ensure coverage of prescription and non-

prescription medications, treatment products, foods and/or equipment deemed medically necessary by the treating physician. This should extend to coverage of supplemental therapies (e.g., speech, physical, occupational, etc.) that are appropriate to maintenance of patient quality of life and employment opportunity. Quality of life and the psychological welfare of the patient should be considered in determining "medically necessary" procedures, protocols, therapies, equipment needs, medications, etc., in the treatment of any disease or condition.

ACCESS TO SPECIALTY CARE & CHOICE OF PROVIDER

Patients with genetic disorders require access to appropriate specialty care. There should be no encroachment on this free access by "gatekeepers," who may have an economic interest in impeding a patient's free access to specialists. Because of their extreme variability, allowable treatments for rare disorders should not be reduced to standardized clinical protocols. Rare disorders frequently require consultation with unique specialists who possess special knowledge and experience with the given disorder, and access to consultations with these specialists must be available. Furthermore, recognizing that chronic disease often involves lifelong treatment, and further recognizing that the maintenance of effective doctor-patient relationships is critically important to long-term treatment of chronic disease, continuity of care facilitated by free choice of physician is both medically sound and cost effective.

MEDICAL RESEARCH

Recognizing that medical research ultimately reduces treatment costs, health care reform should actively promote continued investments in biomedical and clinical research.

FINANCING & QUALITY OF CARE

Assurance of affordability and consistent quality of care must be a mainstay of any health care reform plan. There should be no institutional or systematic mechanism for linking quality of care to ability to pay. All patients should have equal access to the highest possible level of care. An open, flexible, simple, and accessible appeals process must be part of any health care plan to allow fair challenges to treatment determinations that run counter to the opinion of the patient and/or treating physician.

LETTER FROM THE PRESIDENT

by

Deborah B. Vilas

President, F.I.R.S.T. Board of Directors

Dear Members,

Believe it or not, as recently as three years ago I felt as if I were the only individual in the world who had ichthyosis. As a young adult, I had never met or spoken to another person with the disorder. When I questioned my dermatologist about the existence of others, I was told that it would only depress me to meet them. Of course, this advice couldn't have been further from the truth. I now have a new dermatologist.

Discovering F.I.R.S.T., and meeting other people who share similar histories, was an important turning point in my life. Not only did I discover that I was not alone, I also learned of important treat-



ment and cosmetic options that improved both my comfort level and my self esteem tremendously.

And so it was with eagerness that I joined the Board of Directors almost two years ago. It gave me the unique opportunity to serve an organization that had done so much for me.

My personal belief that children and adults should not have to live their lives feeling alienated and alone because of their skin, fit in with the Foundation's broader goals of education, support and advocacy.

I am proud of F.I.R.S.T.'s role as an invaluable conduit for information about the latest research efforts and treatment options. The Foundation's Education &

Publication Fund makes possible the publication of vital educational materials for our membership and the public at large. Through our Regional Support Network, there is nationwide outreach to patients and parents of children with ichthyosis.

As a Board member, I have witnessed enormous growth in the Foundation over the past two years. As its new President, I am looking forward to a challenging and rewarding term.

We are currently working hard to develop the Foundation into a better resource not only for our members, but for the pharmaceutical companies and researchers who seek to provide answers to the challenges of this disorder.

I would like to urge new members and longstanding members alike to join us in our efforts. With all the changes in health care this nation faces, our individual voices have never been more important.

I look forward to working with you all, and I invite all of you to write me with your ideas and recommendations for making F.I.R.S.T. even better than it is.

Sincerely,

Deborah B. Vilas, President

New Board President

(Continued from Page 1)

riod in the summer of 1992 when Foundation leadership was in a state of uncertainty, Frances stepped forward with a clear head and a steady hand. She assumed the presidency and orchestrated F.I.R.S.T.'s hiring of its first full-time salaried executive director, ushering the Foundation into its present phase of growth and expansion.

Throughout her long tenure on the Board of Directors, Frances was a tireless advocate for ichthyosis research, and a tenacious fund raiser. Probably no person in F.I.R.S.T.'s history was less reluctant to pick up the phone and call a corporate C.E.O. to pressure for support for F.I.R.S.T. And perhaps no one ever called back more often. She seldom took no for an answer.

This tenacious attitude extended to

her advocacy for research as well. She is on a first-name basis with many of the country's most prominent ichthyosis researchers—not because she runs in biomedical research circles, but instead because she learned who they were, got their phone numbers, and called them up to see what they were doing for patients in the ichthyosis community.

We will all miss Frances's graceful charm, her unwavering common sense and practicality, and her penetrating directness. She served this organization faithfully for six years, frequently the only one with the nerve to ask those penetrating questions that open cans of worms that most people leave untouched.

Frances's last directive as President was this: "Don't you dare let them give me a plaque. I have one already. One plaque is enough for one person."

We sent her flowers instead.

. . .

Assuming the presidency is Deborah B. Vilas of New York, a child life specialist at Bellevue Hospital. In addition to service on the Board of Directors as Secretary and Vice President, Deborah is the author of our forthcoming handbook for teachers.

Deb has already announced intentions to promote increased board involvement in Foundation operations by increasing the importance of board committees and drawing non-board members into board committee activities.

Moving into the Vice Presidency is Michelle Petersen, of Metuchem, New Jersey. Michelle is a Vice President for Trading Support with the Republic National Bank of New York.

Both new board positions are technically interim appointments until the conclusion of set terms at the end of the year. Both will then stand for election to full two-year terms.

Keeping Cool in Summer Heat

Deb Vilas tells us that "I've been keeping cool all summer by carrying along a product marketed by Stanbel, Inc., of Massachusetts. The company makes a product called 'Lunch-Pak' that is available in most hardware stores. It is a small (5" x 3" x 1") plastic container filled with a cooling gel. When frozen, it acts as a coolant in lunch boxes, picnic baskets and coolers. I carry it with me and apply it to my wrists, neck and arms when I need to be outdoors in the summer heat. I find it more convenient, portable and effective than a plant spritzer, which I have always used in the past."

Keeping Cool, Part 2

We know that many of you out there use cooling vests of some kind to keep yourselves or your children cool in the outdoor summer heat. We're starting a file here at the office so we can pass information about cooling vests on to others. So if you have experience with one of these products, please drop us a note here in Raleigh. Let us know what kind of vest it is, who makes it, how much it costs, how someone else can get one, and tell us how you like it. Other parents will be very glad to know about your experiences.

Parent Advocacy: "How To Thrive, Not Simply Survive"

Following are thirteen keys to being a successful parent advocate. They were developed by Judy O'Halloran and Sally Wade in their book of the same name. Reprinted by permission:

1. **Be an effective parent first.** Use the grieving process to motivate and energize. Try not to wear too many "hats" at once.
2. **Become knowledgeable.** Gather information on the physical, emotional and educational aspects of your child. Learn all you can about the service delivery system.
3. **Find and follow positive mentors.** Network with parents and professionals. Build your "heart network."

4. **Be organized.** Set up a filing system for information, contact and documentation purposes. Learn to convey what you are advocating for in as few words as possible.

5. **Set goals.** Think of goals at three levels: long range, mid-range, and short range.

6. **Develop confidence in yourself.** Research leads to knowledge. Knowledge leads to confidence. Confidence leads to action.

7. **Regard yourself as an expert.** Present yourself and act in a professional manner. You aren't the expert in everything, but you know your child better than anyone else does.

8. **Expect to work as a team member.** You do not have to start out as an adversary or antagonist.

9. **Keep a balance in your life.** Do not let your role as an advocate overshadow everything else. Have friends outside the area of disabilities.

10. **Honestly evaluate your own personality, talents, motives, etc.** Behind the scenes vs. the limelight. Individual child focused vs. children with disabilities focused.

11. **Listen to and understand the other person's point of view.** Be quiet. Don't argue with the person in your head. Really listen.

12. **Use positive reinforcement.** Recognize and acknowledge when a service provider "goes the extra mile." Recognize and celebrate your accomplishments.

13. **Choose your battles.** Advocate only for those things that are important to you. Realistically, evaluate the importance of each issue and your energy level.

In Memorium Jane Bukaty

Denise Eastin and Harry Buikaty in Southern California recently sent F.I.R.S.T. a proceeds from a family garage sale. They ask that the contribution be dedicated to the memory of Jane Bukaty.

IMPORTANT PLEASE KEEP YOUR ADDRESS CURRENT

We want to make certain that everyone receives their issues of *Focus* and other mailings. But it is up to you to keep us informed of your correct address

Because *Focus* is mailed 3rd class bulk, it is imperative that we have your correct address.

Remember, the U.S. Postal Service *does NOT* forward 3rd class bulk mail. If you are not at the address on the mailing label, they simply throw your copy of *Focus* away.

In Memorium . . . Mrs. Anna DiGiovanna

F.I.R.S.T. gratefully acknowledges contributions made in the name of Mrs. Anna DiGiovanna, mother of John DiGiovanna, M.D., an ichthyosis researcher at the National Institutes of Health.

We sincerely regret the passing of Mrs. DiGiovanna, and offer our sincere condolences to friends and family.

Evelyn Babbitt
John & Sheila Compton
Nelli Markova & Constantin Chipev
Laura Russell

Sherri Bale & Eric Spears
Virginia Kimonis
Gabriele Richard
Peter Steinert

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Regional Support Network

The Regional Support Network facilitates communication between members of the ichthyosis community. Parents can exchange practical tips and child-care information. Adults can support one another by sharing experiences in job hunting, self-treatment, medical issues, social coping strategies, and other issues. If you wish to join the support group in your area, please contact the representative for your region. *If you wish to join your area's Network, call your Regional Coordinator or F.I.R.S.T.'s toll-free number to receive your registration form.*

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