



# ICHTHYOSIS FOCUS

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Published by The Foundation for Ichthyosis and Related Skin Types, Inc., (F.I.R.S.T.), P.O. Box 20921, Raleigh, North Carolina 27619-0921 (formerly The National Ichthyosis Foundation). Telephone 919-782-5728. F.I.R.S.T. is a non-profit corporation for the benefit and education of its members and the public regarding medical, psychological and social aspects of the ichthyosis, a family of primarily genetic skin disorders marked by excessive scaling. Letters, suggestions and contributions are welcomed.

## We're on our way!

At the very first F.I.R.S.T. Board of Directors Retreat in Dallas, Texas the first weekend in December, your board members were challenged to do whatever it takes to push ahead with the goals and objectives of the Foundation. "We're definitely on our way towards growth and expansion," says Board President, Ellen Rowe.

Ellen was re-elected to another term of office during the weekend's board meetings. Also elected were Frances McHugh of Delran, NJ, vice chairman; Andrea Thorn of Jackson, MS, secretary and chairman of the Bylaws Committee; Georg'Ellen Betts of Raleigh, NC, chief financial officer; Cynnie Bates of Lexington, KY, and Lynne Alba of Norristown, PA, co-chairs of the Nominating Committee.

Heather Gattuccio of Portland, OR was elected to a three-year term of office. Also serving on the board is Hans Kummer of Seymour, CT. Hans was re-elected to a three-year term in 1991.



Front Row: Georgie Betts, Cynnie Bates, Ellen Rowe and Andrea Thorn. Standing: Susan Snyder, Frances McHugh and Lynne Alba. Not present: Hans Kummer and Heather Gattuccio.

During the retreat workshops, the board took a close look at its duties and responsibilities to the Foundation. Areas explored included policy administration, long range planning and evaluation, personnel issues, financial duties (including fund raising), as well as public and community relations.

Leadership for the Foundation was discussed, along with plans for a smooth transition of responsibilities as

new board members join the board of directors. The Nominating Committee was instructed to look at the current composition of the board and make recommendations which will enhance the strength of the board and help F.I.R.S.T. grow in the coming years.

The board, with the assistance of a facilitator, learned how important it is to work together as a team, and how vital each member's contribution is to the overall health of the organization.

**Our new toll free number is: 1-800-545-3286**  
We'll put you in touch with your Regional Representative

## Update on research

by Sherri J. Bale, Ph.D.

In July of 1991, the Laboratory of Skin Biology at the National Institute of Arthritis, Musculoskeletal, and Skin Diseases (N.I.A.M.S.) in Bethesda, MD initiated a study of the ichthyoses designed to learn about the genetic and molecular basis of this group of skin disorders. Although we had many of the clinical, laboratory, and analytic tools we needed to do the work, we were lacking the most important component of the study — ichthyosis patients and their

families. F.I.R.S.T. put out a call for interested patients in their newsletters and at the national conference held in Williamsburg, VA last summer.

The response from members of F.I.R.S.T. has been tremendous. To date, we have ascertained (identified and obtained medical/family history information) 117 families. Of these 95% have contacted us after hearing from F.I.R.S.T. that we were looking for persons with ichthyosis to participate in research. Not all of the 117 families have been eligible to participate in our

studies, however. We are preferentially looking for multiples (multiple family members with ichthyosis) EH, LI, CIE, and ichthyosis vulgaris families. We are also looking for simplex (only one person in the family with ichthyosis) families with EH where both parents are available for study and are willing to participate.

Forty-one percent (48) of the 117 families were eligible by these criteria. As of December 16, 1991, we have seen, examined, obtained blood and/or skin biopsies on 62 ichthyosis patients

... Continued on next page

and 75 of their relatives in 23 families (total of 137 persons). This accounts for 48% of all eligible families identified thus far.

A breakdown of the types of families, and whether they were multiplex or simplex, is shown in the table below. Of the multiplex EH families evaluated, the largest had 21 persons with ichthyosis. The largest lamellar and CIE families we have seen each had three persons with ichthyosis. The largest ichthyosis vulgaris family had eight affected persons.

Type	No. of Families	Multiplex	Simplex
EH	27	9	18
LI/CIE	49	12	37
Vulgaris	6	3	3
X-linked	10	7	3
Other/unknown	25	9	16
<b>TOTAL</b>	<b>117</b>	<b>40</b>	<b>77</b>

All but two of the 23 families were seen in Bethesda at our clinics. The two largest families were seen in their hometowns. Five members of our research group ( Dr. John DiGiovanna, Dr. Donita Abangan, Ms. Sandra Santucci, RN, a medical photographer and myself) all travelled to the families' town and set up a clinic in a local doctor's office. On both of these occasions, we chose to travel ourselves rather than to have the families travel because of cost considerations. In each case, there were more family members than there

were of us. In one family we saw 16 people, and in the other we saw 32.

Although we are only in the early stages of our efforts to understand the genetics and molecular biology of the ichthyoses, we feel we are moving ahead rapidly. Much of our success in this project depends on having appropriate families for study, and F.I.R.S.T. has done, and continues to do, an exemplary job of making this possible. We would like to express our sincere thanks.

## Tell Me Doctor

by Melodie Buxman, M.D.

### Q. Do patients with Ichthyosis have problems with nutrition?

A. We seem to be receiving many letters requesting information about nutrition. Several of our members are working hard on a brochure containing nutritional information, especially for parents of children with ichthyosis. This will be most welcomed.

The skin is the largest organ of the body, thus what happens to it is very significant with respect to the whole organism. It is important to realize that the skin requires large amounts of iron, minerals, and protein to continue functioning. In some forms of ichthyosis, where there is increased cell proliferation and turnover (recessive ichthyosis and epidermolytic hyperkeratosis), the demands are very high.

Thus, we frequently see iron deficiency anemia in children with ichthyosis, and hair of poor quality. The body cannot make some of the building blocks of proteins, and these must come from food. Examples would be the sulfur-containing amino acids, cystine and methionine. These are vital to growth and also production of good quality hair.

Adequate, or even super-adequate, protein and iron-containing foods are needed to maintain growth in children with excessive skin production. It has been postulated that one reason why children with ichthyosis may be smaller than other siblings in the family

may relate to nutrition. Thus, a good diet and supplementary vitamins and minerals would be important.

**Q. I have ichthyosis vulgaris and eczema, mainly on my hands. I am wondering if I can and should use Lachydrin cream for my hands as they are often dry and cracked. I already use Lachydrin for the dry skin on my arms and legs with great results.**

A. Nature has arranged us so that normally the dead surface layer of skin is thick enough to protect us, but flexible as well. If the dead layer is abnormally thick, for whatever reason, the upper layers crack because the skin doesn't bend. The soles are less likely to crack because they are covered and thus are more moist.

There are two components to cracking: thickness and dryness. In ichthyosis vulgaris, the hands may be dry because of ichthyosis, or because of an associated eczematous hand dermatitis. (Many persons with ichthyosis vulgaris have atopic dermatitis, a form of very dry skin with eczema and sometimes asthma or hay fever). These people tend to have hand problems with water, detergents, and cold weather; and may need topical cortisone cream as well as good moisturizers to control their eczema. We have found that Lachydrin is an excellent moisturizer, since it is able to "pull" water into the skin from the atmosphere and also retain it in the skin.

In addition, lactic acid in some way encourages the skin to shed, thus improving the appearance and texture

of the skin. There is also early evidence that Lachydrin may help to prevent recurrent flare-ups of hand dermatitis by improving resistance of the skin to damage by drying agents.

Although Lachydrin works somewhat in all forms of ichthyosis, I have found it most helpful in the types where there is decreased shedding, but not increased cell turnover (ichthyosis vulgaris and x-linked ichthyosis). In the increased turnover types (CIE, Lamellar and Epidermolytic Hyperkeratosis), improvement is less, and the medication may sting.

It is necessary to use Lachydrin for about a month before expecting significant improvement, but once improvement is seen, it can be nicely maintained with relatively infrequent applications of cream.

**Melodie M. Buxman, M.D., is a dermatologist on the F.I.R.S.T. Medical Advisory Board. She will be happy to answer your questions. Please send your questions to the F.I.R.S.T. office, and we will forward them to her. You may send them anonymously if you do not wish to be identified. Also, we will be happy to answer psychological, social, as well as medical questions that relate to skin. Mail your questions to FOCUS: P.O. Box 20921, Raleigh, NC, 27619-0921.**

# Cool suit changes child's life

by Nancy Ott

For years, my daughter was not able to go outside unless it was cool. Then, a miracle happened which changed our lives forever.

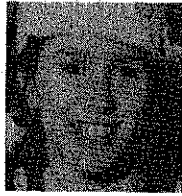
My daughter is Frances Ott. She was born Feb. 18, 1981 with lamellar ichthyosis. Living in South Carolina has not been easy for her. The heat and especially the humidity here are unbelievable. Although high humidity is good for her skin, it causes the temperature to be even higher considering the heat factor. Five out of 12 months in a year, the temperatures range anywhere from 80 degrees and up, with the heat factor being over 100 degrees for weeks at a time. As you all know, with lamellar ichthyosis, Frances is unable to perspire. She could not go outside at all during the day from May through September without having a heat stroke.

As a baby, that was easy to deal with. We just never went outside during the day. By the time she was two years old, she realized that other children in the neighborhood were outside and she wasn't. She just could not understand why she could not go outside. It was heartbreaking to watch her stand at the door crying to go outside. We have always made it a point to treat Frances as normal as possible. We learned that we just had to do some things differently from other people. If you cannot do something, then adapt it so that you can!

Rather than cause her more frustration, we moved to a neighborhood which had no children. If she could not go outside, then we would bring the outside indoors. We moved to a large house and turned our living room into a playground complete with tricycles, toys, etc... At the same time, we did not want to isolate her. Our friends brought their children over every day to play with Frances inside. My husband built an air conditioned playhouse in our yard for Frances and her friends to play in. When the weather was cool enough in the mornings or late evenings, we would go outside and play. We always used spray bottles filled with water to squirt her down when she began to get hot.

Frances has such a low heat tolerance that she would simply overheat if too many people were in a room, so you can imagine how we felt about going far from home. Family outings and vacations were impossible for us to even think about doing!

As Frances got older and began school, this became an even greater problem. Although she goes to a small private school which is completely air conditioned, she was still not able to go outside for recess, or go on field trips, or walks with



Frances Ott

home schooling her rather than subject her to all of this any longer.

Then a wonderful miracle happened which has changed our whole life. My brother saw a documentary that NASA made about a little boy named Stevie Roper. Stevie was born with a disease called HED and could not perspire. His aunt, Tootsie Moody, convinced NASA that if they could send a man to the moon, surely they could do something to help Stevie. And help they did.

A NASA contractor named Bill Elkins had founded Life Support Systems of Mountain View, CA, (LSSI). LSSI went to work adapting their cool suit technology to fit Stevie's needs and size. They decided that since it was a medical problem and a special circumstance, they would only charge for the actual cost of the suit. Mrs. Moody raised \$2,600 needed to buy the suit. Stevie got his cool suit in October, 1987. Everyone involved was happy and thought the story had ended there. Little did they know that it was only just starting.

I immediately called NASA, who put me in touch with Mrs. Moody. She was surprised when I called. She had no idea that there were other conditions which prevented people from perspiring. Not surprisingly, she had NEVER heard of lamellar ichthyosis. Unfortunately, since Frances did not have HED, her foundation could not raise the money for our cool suit, but she did arrange for us to purchase the suit directly from LSSI at cost.

Fortunately, we have Carolina Children's Charity. This is a local tax exempt organization which raises funds to help children with birth defects and disabling childhood diseases. All of the money raised stays in the "low country" (near Charleston, S.C.) to help low country children. They gave us \$2,100 to buy the cool suit and Easter Seals of Columbia, S.C. gave us the other \$600. Carolina Children's Charity has bought two other suits for local kids, one child with spina bifida and one with HED.

On June 29, 1988, Frances became the first girl in the whole world to get a cool suit. It was the start of a whole new life for us. We go to the park, on field trips, out to recess. We go to visit friends at their houses, we go to the lake, to family reunions, vacations, everywhere! There is absolutely no place where Frances cannot go or anything she cannot do!

the class. She had to sit in the office and wait until her class came back inside. Spraying her down with water just wasn't enough. It was a VERY FRUSTRATING time for her. We were considering

The cool suit has not only allowed her freedom, but it has opened many positive doors for Frances. Before the cool suit, people would stare at her or make ugly remarks about her skin that we have all heard at least a dozen times. Now people come up to us and say, "I saw you in the paper or I heard about your cool suit and I think it's great. Exactly what is the skin condition she has?"

We then have the opportunity to educate people about lamellar ichthyosis. No longer are people afraid of her. People are so receptive to her it is incredible. Sure, she still has all of the physical complications of lamellar ichthyosis, but at least she can now choose what she wants to do — and no longer is she a prisoner in her own body.

This cool suit is not only helping people with ichthyosis and HED, but it is also helping people with cerebral palsy, multiple sclerosis, spina bifida, peripheral neuropathy, head injuries, and epidermolysis bullosa. Adults, as well as children, are benefitting from this technology. Life Support Systems of Mountain View, CA is committed to continuing to help everyone who medically needs a cool suit by providing the suit at cost.

Over the past four years the HED Foundation found that there were many kids all over the world who needed these suits and unlike us, didn't have charity organizations that could buy the suits for them. They decided to open their foundation to all children who need suits, regardless of the condition. As of now, five ichthyosis children have cool suits. Three of these have been given by the HED Foundation.

Please consider helping a child by sending a contribution today. Not only will you help a child with ichthyosis, but you will help children all over the world. If you need a suit, or know someone who does, we urge you to contact the HED Foundation at 1-804-826-0065, or you may write to them at P.O. Box 9421, Hampton, VA 23670.

I will be happy to talk further with anyone who would like more information about Frances and how the suit works. You may call me at 803-881-2036 after 3 p.m. or write me at : Nancy Ott, 503 Pitt St., Mt. Pleasant, SC 29464.

## ANNOUNCEMENTS

There will be a career conference held in Washington, DC for adolescents with physical disabilities. Contact the F.I.R.S.T. office for details.

Dr. Ervin Epstein, a long time member of our Medical Advisory Board is looking for EH patients for an exciting study. Call him collect at (501) 444-8282.

# A Summary:

# Federal Entitlement Programs for the Medically Needy

by Nicholas Gattuccio

The following is drawn largely from "Understanding SSI, Medicaid, and Additional Programs," published in the EB REPORTER [publication of D.E.B.R.A., national foundation for epidermolysis bullosa simplex], vol. 4, 1991. Articles by Laine Fleischer, MSW, and Charles Akins. Thanks to the EB REPORTER for permission.

The good news is that there are programs available to assist families in which one or more members suffer a financially burdensome "disability"; the bad news is that taking advantage of these programs often requires an arduous voyage through a bureaucratic maze of applications, long waits for determinations, and, all too frequently, lengthy appeals of denials of benefits. Regardless of the difficulties, however, these are important programs which all families with ichthyosis should look in to.

The programs to be summarized here fall under two headings: (1) Supplemental Security Income (SSI), which is administered by the Social Security Administration on the local level, and (2) Medicaid, which is a joint federal-state program administered by the state level. The first, SSI, is the key to the second, since in most states a child or adult who qualifies for SSI is often eligible for Medicaid. However, because these programs are managed and maintained on the state level, guidelines for entitlement, rules for qualifying, and benefits available through these programs will vary considerably from state to state. Unfortunately, then, it is up to you to track down each of the programs summarized here through your state's Social Security Administration (SSA) office and/or your state's Department of Health and Human Services.

## Supplemental Security Income (SSI)

SSI is the cornerstone. Federally funded and state managed, SSI is a program that makes monthly payments to aged, blind, and disabled people, including children, who have limited income and resources. SSI provides for disabled people of all ages (including babies) who meet the Social Security Administration's (SSA) definition of financial need. Benefits are available in the form of monthly supplemental income checks, or, via Medicaid and/or other state agencies, defrayed medical, pharmaceutical, or other health-care related costs.

The criteria for qualifying for SSI are twofold: financial and medical. In order to determine whether a patient may receive monthly checks under SSI, the recipient (or parents of the recipient, if he or she is under 18) must meet a "financial means test." Criteria for meeting this test vary considerably from state to state, and you will need to consult your local SSA office for the specifics as they apply to your area. Remember, though, that recurring or ongoing medical costs may be subtracted from household income when you determine whether you meet the "financial means test" (the term for this subtracting out of ongoing medical costs is "spend down").

The other key to qualifying for SSI is to show that the condition is "disabling" within SSA's definition of the term. Specifically, it must be shown (1) how the impairment(s) interfere with "substantial gainful activity," and (2) that the impairment will last longer than 12 months.

Until very recently, SSA used a very restrictive "listings-only" system for determining disability claims. Under this system, an applicant would be granted benefits only if he or she had a condition that the SSA carried on a preset list of disabling conditions, or if it could be shown that his or her disorder was substantively "equivalent" to one of these preset conditions. In February, 1990, however, the U.S. Supreme Court ruled in a case entitled Sullivan v. Zebley that this "listings-only" approach was an inappropriate means of ruling on disability claims. This Supreme Court decision has opened the door for many who had not previously been eligible for SSI benefits. **Anyone who has been previously denied SSI benefits because ichthyosis was not on the SSA's "list" should reapply.**

To find out about SSI, visit or write a Social Security office in your state, or call their central number: 1-800-772-1213. Remember, being eligible for SSI means a great deal more than simply receiving supplemental income. Depending on the state you live in, you may also be eligible for some or all of the following: Medicaid, state-paid Medicare premiums, food stamps, and/or other social services.

## Medicaid

Medicaid is a joint federal-state program that is administered locally, usually by your state's Department of Social Services (the agency may be called by a different name in your state). Under this program, the federal government reimburses states for a portion of their Medicaid expenditures, and, although eligibility varies from state to state, applicants must show financial need in order to qualify.

Medicaid covers a wide range of medical services, although, again, services vary from state to state. Among these, your state's Medicaid program may cover the services of physicians, dentists, nurses, out-patient or clinic services, "sickroom" supplies, eyeglasses and prosthetic devices, laboratory and x-ray services, prescription medications (and non-prescription medications if accompanied by a physician's prescription), home health and personal care services, and institutional services such as the cost of hospital care. Note that some services and supplies require prior agency approval for coverage, while others are covered only under designated circumstances and in limited amounts. Furthermore, Medicaid does not pay for the services of a health-care provider who is not registered in the state's Medicaid program.

Under federal law, states provide Medicaid coverage to those who receive Aid to Families with Dependent Children (AFDC), welfare, and to those who receive SSI, although in many states this is not automatic. Furthermore, state agencies are not always forthcoming about services and entitlements that may be available to you. In short, you are well advised to do a little homework, make a few calls, and consult the advice of more than one information source in your state. Remember, too, that in most states Medicaid is available to people who are disabled according to the SSI definition, even if their incomes are actually over the Medicaid "financial means test" cutoff, and yet who have ongoing medical expenses. This is the process of "spending down" household income levels by subtracting out disability-related medical expenses.

## Title XIX Waiver

(Also known as Model 50 Waivers, or Care-At-Home Waivers)

Title XIX Waiver is the result of a federal initiative designed to assist families of children who meet the SSI criteria for physically disabling conditions and who maintain extremely heavy medical care needs in their own homes. The program is designed to assist in circumstances where the child's needs are so great that they would require nursing-home care were it not for their family's dedication to keeping them home. Under some circumstances, consideration of the parents' income is waived altogether so that the child may remain at home.

Title XIX Waivers cover extremely severe circumstances, and the criteria for qualifying are stringent. In addition to the general proviso that nursing-home care would normally be required for the child, additional criteria include:

- The child has no other health insurance coverage.
- The child has had a 30-day continuous stay in the hospital, or a six-month residency in an institutional setting.

In short, Title XIX Waivers are intended to create alternatives to institutional treatment of children whose families are committed to caring for them at home. Some states have a designated "Care-At-Home" Program Coordinator to assist with the process of qualifying for the program.

Again, because the programs vary from state to state, and because so many agency employees have only a limited knowledge of the entire spectrum of services and opportunities available, it is up to the parents to do their homework and track the program down. Begin with your state Department of Human Services (or whatever this agency may be called in your state). There may also be social workers at the hospital in which your child was (or is) treated who may be able to help. Ask around. You might also wish to contact your state legislator for information on programs available (or to ask pointed questions about why certain programs are not available in your state).

## Title V Programs

(Also known as Maternal Child Health Services Block Grants [1981], formerly called State Crippled Children's Services Programs, or Handicapped Children's Programs)

This is another federally funded and state administered program. Standards are set at the federal level by the Bureau of Maternal & Child Health in the U.S. Department of Health and Human Services, and the programs are operated by the states according to "guidelines" rather than strict regulations. They are intended to be fairly flexible in evaluating a child's eligibility, and they may provide reimbursement to providers of specialized medical care, including physical therapy, occupational therapy, and adaptive equipment.

Again, programs vary considerably from state to state. Attempt to locate personnel in an agency known as Children with Special Health Care Needs Programs. However, it may not exist in your state. If it doesn't, contact your senators and congressman to find out why.

## Children's Special Health Care Service

(Also known as "Crippled Children's Insurance")

Another program administered on the state level, which may or may not be available in your state. The program covers the cost of supplies and care which may not be covered by a family's primary health insurance carrier. Coverage includes much of what Medicare might cover, including prescription and nonprescription drugs (accompanied by prescription), respite nursing care, prosthetics or therapeutic clothing or equipment. The monthly premium is based on a family's income (again, taking into account the "spend down"), and in some cases premiums are covered entirely by the state. A family's financial circumstances as well as health-care needs are reviewed annually. Again, you will have to track this program down through your local, state or county health-care bureaucracy.

Children with special needs are also eligible for educational services through Public Law 99-457. This law deals with education of children who have developmental delays. Part H of P.L. 99-457 addresses the need to enhance development of handicapped infants and toddlers and to minimize their potential for developmental delay. Each family is entitled to an Individual service plan (IFSP) which includes the following elements:

- multidisciplinary assessment and identification of appropriate services;
- a written IFSP by a multidisciplinary team with a parent or guardian;
- early intervention services which include the frequency, intensity, and method of service delivery;
- the major outcomes expected for the child and family;
- projected dates;
- the name of the case manager from the profession most immediately relevant; and
- a plan for transition to Part B services, which is the 3 to 5 year old component.

The infants and toddlers identified for service under Part H have been defined as those who are experiencing developmental delays or have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay in one or more of the following areas: cognitive, physical, language/speech, psychosocial and self-help skills. Some children with severe forms of ichthyosis will qualify for services in several of these areas. Each state is responsible for implementing P.L. 99-457. Check with your local school system for more information.

Through P.L. 99-457 and all of its elements, Congress has established a new national agenda - to expand the opportunities and benefits of early intervention and preschool services to many more children and families in our nation. In particular, Congress has aimed to enhance child development, minimize the likelihood of institutionalization, and be supportive of families.

# Teamwork pays off

For the second year in a row, staff at Hibbard Brown & Co., 701 Alpha Drive, Pittsburgh, PA collected donations for F.I.R.S.T. None of their employees nor family members have ichthyosis. But they still teamed together and gave \$1,750.01 to the Foundation! Many, many thanks, gentlemen!

Receiving the gift for F.I.R.S.T. was Claire Amwake who has a nephew with EH. Claire's husband, Bill used to work at Hibbard Brown but left to go into business for himself. The Amwakes have supported F.I.R.S.T. since Claire's nephew, Ryan Licursi, was born. Ryan is in first grade this year. According to his grandmother, Frances McHugh, he is doing splendidly.

People like Claire and Bill Amwake, Joe Chester and Randy Beigel are what keep F.I.R.S.T. alive. We receive no grant money nor financial aid from the government. Very little of our budget comes from corporate contributions. Most of our donations are from individuals - families and friends of those with ichthyosis.

Without your support, we would not be able to continue to send out this newsletter or



Joe Chester, left, and Randy Beigel, right, present F.I.R.S.T. volunteer, Claire Amwake, with a check for \$1,750.01 from employees at Hibbard Brown & Co. in Pittsburgh, PA.

answer your telephone calls. So, many thanks to everyone who contributed this year. Your support is forever needed and certainly always appreciated! If you could give just \$5 more than you did last year, F.I.R.S.T. will be able to meet next year's budget. Please send in your donation today.

## Agencies & Persons to Contact for Assistance

SOCIAL SECURITY ADMINISTRATION (SSA) 1-800-772-1213

You will also find listings in your phone book for local offices of the SSA.

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

1500 Woodlawn  
Baltimore, MD 21241

STATE DEPARTMENTS OF HEALTH & HUMAN SERVICES

Your state's Department may have a slightly different name. Check your phone book, or call your County Health Department for help in tracking this down.

HOSPITAL DEPARTMENT OF SOCIAL WORK

Frequently, large hospitals, particularly public hospitals where your child may have been treated, maintain departments of social work specifically for the purpose of assisting families with catastrophic health-care circumstances. Personnel are generally very helpful in plugging parents in to public-assistance venues.

SENATORS & CONGRESSMEN

Many feel that their elected officials in Washington (as well as state representatives at your state capitol) are deaf and blind to their constituency. This is not true. The squeaky wheel does get the grease (usually). Your letters will be read. Keep a list of the names and addresses of all of your elected officials, and write to them. If you are having difficulty getting services that you feel you are entitled to, let your congressman know. He or she likely won't be able to solve your problems (you will have to do this yourself, unfortunately), but they should be informed that you are having problems, and they should know the nature of the problems you're having.

National Organization of Social Security Claimants Representatives (NOSSCR)

19 East Central Avenue  
Pearl River, New York 10965

(914) 735-8812

NOSSCR is a legal referral agency that is dedicated to assisting those who have been unjustly denied Social Security benefits to which they are entitled. The organization maintains a listing of attorneys throughout the country who specialize in claims appeals. If you feel that you have been unjustly denied your rightful SSI benefits, contact this agency for the names of attorneys in your area who may be able to assist you with your appeal. Be aware, however, that the services of these attorneys *may not necessarily be pro bono (free)*.

### WARNING:

Never accept as the final word any social worker's or other public official's opinion or assessment of any health-care situation. This goes for their assessment of the medical condition itself and its likelihood of being eligible for coverage by an entitlement program, nor their assessment of the range of entitlement programs available in your state. ALWAYS consult at least two or three sources. Programs may be buried very deep in the bureaucracy. More than one well-meaning advisor has been unaware of available sources of assistance.

*Nicholas Gattuccio and his wife, Heather have a little girl named Caitlin, who was born Jan. 6, 1991. Caitie has Lamellar Ichthyosis. They live in Portland, Oregon and are the F.I.R.S.T. regional representatives for the northwest part of the United States. Many thanks to Nick for his wonderful research which provided you with this in-depth FOCUS article.*

## We Welcome New Arrivals

**Dave and Lori Ann Land** recently found out about F.I.R.S.T. They had never heard of ichthyosis before Matthew was born on March 14. Matthew was a collodian baby like many other infants born with ichthyosis. The Lands are eager to communicate with other families to learn more about coping with this disease. Their address is 9-B First Drive, East, Randolph Air Force Base, TX 78148-5462. They can be reached at (512) 658-6605. Congratulations to Dave and Lori Ann on their new addition!

**Arianna Vander Wheele**, was born last spring. She is the daughter of David and Marie Vander Wheele. They live at 3775 Almond Court, Castro Valley, CA 94546. Their phone number is (510) 538-2083. Congratulations on your new little girl!

**"JJ" Parham** is another new member of F.I.R.S.T. "JJ" was born on June 26 in Tennessee and flown to Vanderbilt University. His parents, John and Betty Lynn, report that he is doing well. "JJ" has lamellar ichthyosis. The Parham's address is Rt. 8, Box 140-B, Columbia, TN, 38401. If you want to call, the number is (615) 388-6987. Congratulations and good luck to the new family!

**Joann Villamarin** wrote to tell us that she has little girl who was born this summer with Congenital Ichthyosiform Erythroderma (CIE). She would appreciate any information others could share with her. Congratulations, Joann! We have certainly had plenty of little girls born this year. Maybe someday they can all meet each other at a F.I.R.S.T. conference. The Villamarin's address is 1800 South Road, Baltimore, MD, 21209.

**Gary and Cori Pyndus** are the proud new parents of Megan, born Aug. 22. Megan has EH as well as a cleft palate and spent a long time in the hospital. Gary and Cori are happy to have her home and want to talk with other parents who have children with EH. "We want to say thanks to everyone who has called and offered support." One F.I.R.S.T. family has even visited. Congratulations to the Pyndus's on their bundle of joy!

**Joni Nale**, daughter of Sarah Nale, 1708 Kelly Rd., Dyersburg, TN, 38024, was born with ichthyosis this summer on Aug. 21. She is home and doing fine. The Nale's phone number is (901) 285-8655. We have counted 19 new babies in 1991. Maybe F.I.R.S.T. should plan a big FIRST birthday party next year! Welcome to the world, Jonil!

**Tiffany Marie Sachse** is our newest baby born with ichthyosis on Sept. 19. She is the daughter of Donna and George Sachse, 25 Nicole Ct., East Haven, CT 06512. The Sachse's still have lots of questions about dealing with this disease and welcome help from other members of the foundation. Their phone number is (203) 467-7281. We are delighted that families are getting in touch with F.I.R.S.T. so quickly after the birth of a baby with ichthyosis. We have been trying hard this year to publicize our address and phone number. This perseverance is paying off! Best wishes to Tiffany Marie for a happy future!

## Correspondence Corner

**Carol Reed**, of San Diego, CA called to ask if only Caucasian people get Ichthyosis. No, Carol Ichthyosis knows no race boundaries. We have black and oriental people with these conditions as well.

**Gregory Li Calzi**, age 9, would like a pen pal. "I am in the fourth grade, and like to play basketball, baseball and football," says Gregory. "I have lamellar ichthyosis." Gregory's address is 97 Poplar Street, Garden City, NY, 11530.

**Deb Vilas**, age 30, would like to talk with others who have ichthyosis. She lives at 7 East 88th St., Apt. 4-B, New York, NY, 10128. Deb has Congenital Ichthyosiform Erythroderma. Deb is also working on a teacher's manual and would like to talk with school age children with ichthyosis and their teachers. Please give her a call at (212) 639-8624.

**Lori Bryant**, mom to Melissa Bonilla, would like to be in touch with other families of children with ichthyosis. Melissa is 10 years old and in fourth grade. She loves to swim and dance. Melissa has lamellar Ichthyosis and would like to talk with other children who have this disorder. They live at 11752 Mt. Lassen Ct., Alta Loma, CA, 91701. The phone number is: (714) 989-1758.

**Ellen Rowe**, president of F.I.R.S.T.'s Board of Directors, says that several people have asked her about pregnancy and breast-feeding. "I have CIE and have had two children and breast-fed them both. I didn't have any unusual problems during pregnancy. My skin stretched without cracking, and I continued to use the creams and lotions that I always used. Breast-feeding was difficult in the beginning, and my nipples cracked and bled during the first few weeks. Although it was a little painful, I am so glad I stuck with it. Breast-feeding was a very rewarding experience for me. I continued breast-feeding until they were both about a year old. Both of my children were born with normal skin, but I know I have passed the gene for ichthyosis along to them. I hope research will discover a cause, better treatments, and a cure, before this gene pops up in my family again."

**Beverly Dillehunt**, 614 Lufkin Circle, Fayetteville, NC, 28301, called with a tip for parents. Beverly's daughter, Darin, who has CIE and is in kindergarten, loves play dough. "I have discovered that when she plays with play dough her hands get very soft and some of the hard layer of skin comes off," says Beverly. Apparently, this only works with home-made play dough and not with the store-bought kind. Beverly wants to share her favorite recipe for "No-Cook Play Dough." Ingredients: 1 1/2 cups flour; 1/2 cup salt; 1/2 cup water; 1/4 plus 1 tablespoon cup vegetable oil; food coloring. Mix flour and salt. Slowly add other ingredients. Let your child mix them together.

**Margaret Vernet**, 8 The Old Road, Newtown, CT 06470, has had success with a new product and wants to let folks know about it. "I've experienced wonderful results in exfoliating, particularly on my face, with a product called Bio-Clear Washing Grains. However, it seems to have become unavailable for purchase," says Margaret. "They are dry granules and originally had been marketed by Helena Rubenstein. I'd like to ask the membership if anyone knows where this product may still be purchased." Margaret also sends her wish for "a New Year filled with the best for all of us." Thanks, Margaret. Her phone number is (203) 426-1685.

**Tanya Creech** of Raleigh, NC, says that she has recently begun using a line of skin care products developed by a health care company in Utah called NuSkin International. "The products contain no mineral oil, isopropyl alcohol, borax, harsh detergents, or petroleum products of any kind," says Tanya. Instead of the old theory of sealing in moisture with oil and wax, these products bathe the skin in humectants. Humectants are natural substances that attract moisture from the air all day long. Tanya reports that the skin on her face has improved dramatically. "Many people have commented on the difference which is clearly visible to anyone who sees me. I am excited about these products and welcome anyone calling me to discuss how they can try them, too. You can call me at (919) 787-6057, or leave a message at the F.I.R.S.T. office and I will return your call," says Tanya.

If you would like a pen pal, have a comment to make, or would like to be in touch with others who have Ichthyosis, write to: Ichthyosis Focus, P.O. Box 20921, Raleigh, NC 27619, and we will include your name and address in Correspondence Corner. We do not release names and addresses without permission.

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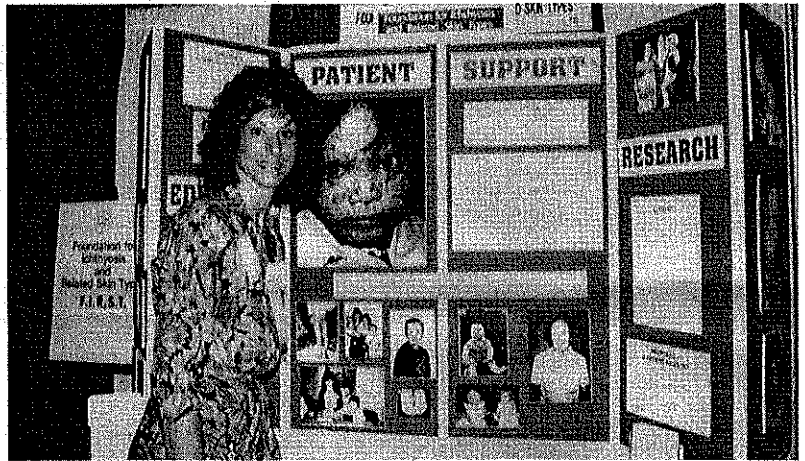
Dear Readers:

I am very excited to be named the first Executive Director of F.I.R.S.T. I look forward to an exciting year ahead of organizing our offices, expanding the Foundation's exposure nationwide and advocating for financial and medical assistance to enrich the lives of our members.

I know that every one of you has a distinct perspective and can contribute your individual outlook to broaden our approach and achieve our goals. Please feel free to call me at any time with your ideas and concerns.

Sincerely,

Susan Snyder  
 Executive Director



Susan Snyder, F.I.R.S.T.'s new executive director

Editor's Note: Susan Snyder became our Executive Director in October. She successfully organized a board of directors' retreat, designed a new literature display for the Academy of Dermatology meeting in Dallas, and single-handedly tackled our computer problems, all in her first month. She comes to us from Coopers & Lybrand, an

accounting firm, where she was Office Manager and Personnel Administrator. She has more than 12 years experience in administrative management, and brings with her extensive non-profit experience as well. She has been an active volunteer in community organizations, her children's schools and is a proponent of child advocacy. Susan graduated cum laude with a Bachelor of Arts from Boston University.

I want to help F.I.R.S.T. in the fight against Ichthyosis.

Please put me on the mailing list:  I do not wish to receive Newsletter

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All contributions to F.I.R.S.T. are fully tax deductible to the extent allowed by state and federal law. F.I.R.S.T. is a 501(c)(3) charitable organization supported entirely by private donations. A copy of the F.I.R.S.T. Annual Report is available to anyone upon request.