



ICHTHYOSIS FOCUS

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Unlocking the Secrets of a Rare Ichthyosis

Gabriele Richard, MD, Assistant Professor of Dermatology and Genetics at the Thomas Jefferson University in Philadelphia, received an American Skin Association Categorical Disease Grant for Childhood Skin Disease Research. Specifically, she studied the genetics of Netherton Syndrome (NTS), a rare form of severe ichthyosis associated with other abnormalities.

NTS is an inherited disorder that presents at birth with generalized redness, thickening and scaling of the skin, which may persist through life or change into scaly, itchy plaques. The hairs may be sparse, fragile, and short due to multiple swellings along the hair shafts, at which the hair breaks easily. Also characteristic of NTS is a predisposition to allergies, infections, and sometimes, failure to thrive. The skin conditions reflects a disturbance in the process of "cornification," which is necessary to form the horny layer of our skin, thus protecting the body from water loss and mechanical, biological, and chemical damage.

In her progress report, Dr. Richard stated that her team had "made remarkable progress in uncovering the genetic basis" of Netherton Syndrome. For the study, Dr. Richard recruited NTS patients from 21 families. Although the families were of diverse backgrounds, including Northern European, Mediterranean, Middle Eastern, and African American origins, the genetic studies suggested a single disease gene. The research team pin-pointed this gene to a small area "on the long arm of chromosome 5" and succeeded in identifying a gene called SPINK5 as the NTS gene. This information was revealed after Dr. Richard's team found disease-causing mutations (changes in the DNA code) in SPINK5 in 14 of the 21 tested NTS families in the study. Mutation screening yielded a total of 19 distinct mutations. Based on the team's data and mutation-detection strategy, they successfully performed the first prenatal diagnosis for NTS.

Dr. Richard reports that her team's work has paved the way for "molecular diagnostic testing in NTS, accurate genetic counseling and carrier detection, and prenatal diagnosis of NTS."

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Gabriele Richard, MD

A note from Dr. Richard: *Our research group greatly acknowledges the support of F.I.R.S.T., along with the ASA, NAAF, and the National Registry for Ichthyosis and Related Disorders, as well as the participation of many families in our studies. With the help of a F.I.R.S.T. research award (awarded in 1999) we were able to perform genetic linkage studies to localize the Netherton Syndrome gene and to initiate mutation analysis of SPINK5. The financial support allowed us to amass a critical amount of data to successfully apply for NIH funding of our research. As a result, we were able to*

screen more than 31 NTS families to date, identifying 24 distinct SPINK5 mutations in 23 families. In 8 families genetic testing revealed no mutations in SPINK5, suggesting that these patients may suffer from another type of congenital ichthyosis. In the course of our research studies we have developed an effective mutation screening strategy, which enabled us to establish molecular testing for Netherton Syndrome on a routine basis. Diagnostic testing and prenatal testing are now being offered by our CLIA certified Molecular Diagnostics Laboratory at the Department of Dermatology and Cutaneous Biology, Jefferson Medical College in Philadelphia, PA.

Register Now!!!
2002 Conference
A Family Affair: Caring,
Sharing & Support

July 5-7, 2002
Seattle, Washington



Deadline for Registration
June 14, 2002
See pages 14 & 15 for details

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Correspondence Corner

Dear Jean,

I have finished reading my newsletter, Winter 2002, and though I enjoy all the articles, there has been a sector of the population that has been forgotten, our Senior Citizens who are 55 and over. Those of us who might be alone in dealing with this problem, who have experienced much discomfort in taking care of our skin, the largest living organ on our body.

In the article titled "The Ichthyosis Registry Needs You", it says, "with the exception of Ichthyosis vulgaris". This eliminates many of us who have problems every day. Maybe it's not life threatening, a determination most dermatologists make when we go in to see them. Maybe the skin is OK on my face, but I have to maintain it, and my body, every single day. What miracle have they found out about ichthyosis vulgaris that we are excluded from learning about? I was contacted by email one time, to see if I would be agreeable to email others who had my same problem, I sent in an email saying yes. That was it, never had another email again. We can contribute as seniors – in many ways. If nothing else, give us some forum where we can share ideas and life challenges. New products come out every issue, but we are on fixed incomes and are not always able to invest. We have to be satisfied with what we are now using. And how about those who are in retirement and or assisted living homes? Who takes the time to consult this venue on the care of their skin? Most seniors ache in many areas, but those of us who have Ichthyosis have one more ache, it is the calming and treating of our skin. I am sure these business and care facilities have no idea of Ichthyosis. Medical doctors and dermatologists treat this as though it is not a real concern. The answer is EDUCATION.

And please don't let it be just targeted only to the young. Look at the registration form for the 2002 Family Conference. There is a place for 18 and older, but we are much older, and have ourselves to take care of. How about a check off space: **Senior, 55 and older**. Will there be topics at the conference just for seniors? The one meeting I attended on the West Coast about 8 years ago, the seniors were forgotten. Please don't get me wrong. I was once a child, and to my parents it was a real dilemma. Now I am grown up and would like to discuss this part of life with someone who has been around a while.

I would be more than proud to assist in any way to get a communication line formed for Senior Citizens with Ichthyosis. I have a computer, and the ability to use it. I love people, and have the caring and feeling for the sensitivity involved in dealing with this problem. Thank you for reading my thoughts, and hope to hear from you.

Sincerely,

Beverly A. Browne
ItalHug@aol.com
El Dorado Hills, CA

Editor's note: Individuals with ichthyosis vulgaris are excluded from the Registry for two reasons. 1. The Registry application requires specific criteria for diagnosis and, of all the ichthyoses, ichthyosis vulgaris is the most difficult to diagnose clearly. 2. The number of people with ichthyosis vulgaris (estimated incidence between 1 in 250 and 1 in 5,300) could potentially overwhelm the resources of the Registry. So ichthyosis vulgaris is excluded because of the potential for being overwhelmed by people whose diagnosis could not be confirmed. Research into any of the forms of ichthyosis has the potential to help all individuals with ichthyosis. The Registry provides a ready source of subjects with clear and complete diagnoses to researchers interested in investigating the ichthyoses. There is a study currently being conducted across the country for the treatment of ichthyosis vulgaris. Contact Maureen in the national office for more details, 800-545-3286.

What's New, What's Hot & What Works...



I find 2% Nizoral Shampoo really helps control scalp flaking. Work it in, leave it on for 5 minutes and rinse off. You do need a prescription for it, but a little bit goes a long way. Order it in quantities of two and you will have it for a while. It comes in 4 fluid ounces and is made by Janssen Pharmaceutica, Inc., Titusville, NJ. Be sure to ask for 2% Nizoral; ketonazole 2% is the active ingredient.

Easton B. Smith
Fairfield, CT

My daughter Jenna is eight years old and has ichthyosis. I knew right from birth that she had extremely dry skin. The hospital gave me Eucerin to use on her entire body but after two weeks there was little improvement so I brought her to a dermatologist. The doctor claimed Jenna had "Infantile Dry Skin." Since that day we have been to seven dermatologists. Lac-Hydrin Lotion, which is a great treatment for ichthyosis, was the only treatment prescribed but it stung her skin so badly it broke my heart. Others would recommend Vaseline, which worked when she was a baby. But now that she is eight and already worrying about her appearance, Jenna feels the Vaseline makes her skin too shiny. With the help of her doctor we now have a routine that seems to work well. Jenna uses Nizoral or Capitrol Shampoo and Head & Shoulders New Conditioner. She only uses soap once or twice a week and that is the plain white Dove bar. After her shower, Jenna dries off a little bit and then applies one of her two different creams. The one we use most is a mixture of Lac-Hydrin Cream and Cutivate Cream. It really seems to keep her skin looking good most of the day. When her skin is extremely dry we use a mixture of Lac-Hydrin Cream and Diprolene Cream. The nice thing about these two mixtures is that my pharmacy fills our prescriptions in Rubbermaid containers that are easily cleaned and refilled.

God Bless!!
Melissa Gay
Cumberland, RI

Our two year-old daughter, Tatum, has

Lamellar Ichthyosis. Recently we started using a drug called Protopic 0.1% in combination with PDS cream. Protopic is typically used in people with mild to moderate eczema. The active ingredient in Protopic is Tacrolimus, an immune suppressant used in transplant patients to prevent rejection of the new organ. We have had amazing results with this product and I thought it was important to let others with ichthyosis know about our experience.

We started using Protopic twice a day, every day, with PDS cream after baths. Immediately we saw Tatum's skin improve. It was not only visibly improved; it was very soft and smooth. Our doctor thought it would be wise to check a blood level at this point because Tacrolimus could be absorbed into the bloodstream. When we checked Tatum's level it was as elevated as someone taking the drug orally. We then went to twice a day applications every other day, all over, after taking baths. After one week Tatum's blood level dropping significantly but was still too high. After doing some research our doctor decided we should change the dosage to twice a day every third day just on certain areas, the face and lower legs. After using this regimen for two weeks Tatum's blood level was right where it should be. Her skin at this dosage is as improved as when we were using it more frequently. We are very pleased with the results we have had and hope our experience helps others.

Melissa J. Tierney-Osterloth
Wauwatosa, WI



Tatum Tierney-Osterloth with little sister Carter.

My two daughters, age 16 and 17, have Netherton's Syndrome, and we've found a hair care strategy that really works. Our doctor had been reading about testing Biotin (a coenzyme that works with Vitamin B complex vitamins) in balding men and he suggested we try that with the girls. Due to allergies to the gelatin capsules, the drugstore would measure the powder into paper envelopes. The girls would eat it with jelly or mashed bananas. Tera took it regularly but Mandy refused it because it was bitter. Over the years Tera's hair grew to shoulder length while Mandy's broke off at about half an inch. Finally Mandy decide to take the Biotin too and her hair is about 6 inches long now. This has made a world of difference with my girls! It does take some time before the hair starts to grow, so you have to be patient. If the girls stop taking it their hair tends to fall out in patches. In Germany we were able to get the insurance company to make an exception and cover the costs, but I don't think Biotin is overly expensive. The girls take regular tablets now.

Lisa Grasser
Litzlohe, Germany

The Medicine Program

Do you need prescription medications that you cannot afford but you do not qualify for government programs that pay for prescriptions, like Medicaid? The Medicine Program may be able to help. The Medicine Program helps patients, in cooperation with their doctor, to enroll in one or more of the many patient assistance programs that are now available from drug manufacturers. These programs provide prescription medicine free-of-charge to people in need, regardless of age, if they meet the sponsor's criteria. For more information about The Medicine Program, or to request a free brochure or application, call 573-996-7300. Or go to www.themedicineprogram.com. The Medicine Program requires a \$5.00 processing fee for each medication requested. A full refund of the processing fee is available, upon written request, to any applicant who receives no medication and is determined to be ineligible for assistance.

continued on page 13

How Much Do You Know about Ichthyosis?

The Foundation for Ichthyosis & Related Skin Types represents people with 28 different forms of ichthyosis and related skin diseases. In an effort to educate our readers, and the general public, we are providing a brief description of those 28 skin types. The most descriptive symptoms of each disease and how it is inherited are outlined below. The various forms of ichthyosis and related skin types are inherited in one of several ways:

- **Autosomal dominant:** The gene for the disease is carried on one of the 22 human chromosomes that do not determine sex, and is dominant over the gene for normal skin. A person with one dominant gene for ichthyosis skin and one gene for normal skin will have ichthyosis skin.
- **Autosomal recessive:** The gene for the disease is carried on one of the 22 human chromosomes that do not determine sex, and is weaker than the gene for normal skin. A person with one recessive gene for ichthyosis skin and one gene for normal skin will have normal skin. The person must inherit two recessive genes for that person to have ichthyosis skin.
- **X-linked dominant:** The gene for the disease is carried on the X chromosome and is dominant over normal skin. The person with one X chromosome for ichthyosis skin and an X, or Y, chromosome for normal skin will have ichthyosis skin.
- **X-linked recessive:** X-linked recessive traits are usually only found in males. Males with an X chromosome for ichthyosis skin and a Y chromosome for normal skin will have ichthyosis. Females with one X chromosome for ichthyosis skin and one X chromosome for normal skin will have normal skin. Females are carriers for recessive X-linked traits.
- **Spontaneous mutation:** A spontaneous mutation occurs during the process of cells splitting and differentiating in the developing fetus.

The incidence of the different forms of ichthyosis varies, but all are considered rare diseases.

TYPES OF ICHTHYOSIS

Acquired Ichthyosis: Late, or adult onset, ichthyosis can be caused by a variety of conditions including: an underlying malignancy, particularly lymphoma; drug therapy, particularly drugs given to lower serum cholesterol; endocrine abnormalities, especially hypothyroidism; nutritional deficiency; and kidney failure. Dry flaky skin is also seen as a dose-dependent side effect of oral retinoid (Accutane, Soriatane) therapy. Acquired ichthyosis is not inherited; the symptoms are acquired as a result of other conditions.

Chanarin-Dorfman Syndrome (neutral lipid storage disease): Chanarin-Dorfman Syndrome is a rare hereditary disorder of fat (lipid) metabolism. It is characterized by moderately red, itchy, dry skin and other skin changes. Skin scaling is fine, white to gray in color, and involves all skin surfaces. Large fat (lipid) droplets appear in most white blood cells in the bloodstream. Lipid droplets are also present in other cells, including skin cells and the ducts of the sweat glands. Muscle degeneration is also seen. Some people with the disorder may have nerve deafness, cataracts, and abnormally slow growth and development. Chanarin-Dorfman Syndrome is passed on through an autosomal recessive inheritance.

CHILD Syndrome (unilateral hemidysplasia): Congenital Hemidysplasia with Ichthyosiform erythroderma and Limb Defects. Distinctively patterned red patches of skin are seen covering one side of the body, with a sharp line down the middle of the body between the normal skin and ichthyosis skin. The entire half of the body may be involved, or segmental patches may be limited to one side of the body. Limb deformities are seen on the same side of the body as the ichthyosis skin. The organs on the affected side of the body tend to be underdeveloped or develop incompletely. Finger and toenails can be thick and deformed, and baldness can occur on the same side of the body as the ichthyosis. CHILD Syndrome is thought to be caused by an X-linked dom-

inant inheritance and is seen more often in girls than in boys.

Conradi-Hunermann Syndrome (x-linked dominant chondrodysplasia punctata):

Conradi-Hunermann Syndrome affects infants and young children and is characterized by facial abnormalities, mild-to-moderate growth deficiencies, large skin pores, and sparse but coarse hair. Affected children have a short neck and a broad, flat nose. Large pores in the skin, resembling orange peel, may occur on the body and scalp hair tends to be coarse and sparse. Dry skin lesions may be present and may show mild scale or increased pigmentation in a linear or swirled pattern. Calcification of the ends of the long bones markedly slows growth in the arms and legs, and scoliosis (curvature of the spine) may occur even in infancy. Buildup of fibrous tissue around joints may limit mobility. Cataracts may develop, and a small percentage of patients may be mentally retarded. Conradi-Hunermann is believed to be caused by an x-linked dominant inheritance. It is almost always seen in girls.

Congenital Ichthyosiform Erythroderma (CIE):

(Ichthyosis Congenita, Non-bullous CIE) CIE is characterized by generalized abnormal red, dry, rough skin. Fine white scales, that may be itchy, appear over most of the body. Skin on the palms of the hands and the soles of the feet is abnormally thick. Newborns are born as collodion babies with a tight shiny membrane resembling plastic wrap completely covering the baby. The membrane cracks and peels over the course of several weeks to reveal red, dry skin. Ectropion and eclabium (pulling back and turning out of the eyelids and lips) due to the tightness of the membrane are sometimes seen. People with CIE have an increased susceptibility to skin infections and heat intolerance is common. CIE is caused by an autosomal recessive inheritance.

Darier's Disease (keratosis follicularis, Darier-White): The onset of Darier's Disease is gradual, beginning with burning and itching in the scalp, face, and

Types of Ichthyosis

armpit areas, and extending to other parts of the body. Small spots of raised skin appear, becoming larger and darker with gray-brown scales or crusts. The enlarging spots eventually come together to form larger patches. The patches can be foul-smelling because of bacterial growth under the skin. Nails can show ridging, splits, and white or red streaks along the length of the nail. Raised white spots can appear in the mouth. Patients often complain of severe itching. The inheritance of Darier's Disease is autosomal dominant.

Epidermal Nevus Syndrome: (Ichthyosis hystrix, Linear Epidermal Nevus Syndrome) The term epidermal nevus is applied to a variety of congenital (seen at birth) skin lesions characterized by raised thickened patches of skin or wart-like yellow brown lesions, sometimes accompanied by an underlying redness (erythema). Epidermal nevi may be small (solitary), widespread but confined to one side of the body, or widespread and covering both sides of the body. Other associated problems can include mental retardation, seizures, skeletal deformities, and eye abnormalities. Epidermal Nevus Syndrome is a "mosaic" condition so the gene change does not occur in every cell of the body. It does not appear to be inherited.

Epidermolytic Hyperkeratosis (EHK): (Bullous Ichthyosis, Bullous Congenital Ichthyosiform Erythroderma (BCIE), Ichthyosis Bullosa of Siemens.) EHK is characterized by thick, blistering, warty hardening of the skin over most of the body, particularly in the skin creases over the joints. Scales tend to form in parallel rows of spines or ridges. The skin is fragile and blisters easily following injury. Babies are born with red, blistering, and denuded skin with areas of visible skin thickening. Over time there is a gradual decrease in blistering but an increase in the severity of the ichthyosis. Skin infection with commonly found bacteria (Staphylococcus and Streptococcus) is a chronic problem. The teeth, hair and nails are normal but scalp involvement can be severe, resulting in hair loss. Heat intolerance is common. Fifty percent of known

cases have been traced to an autosomal dominant inheritance, while the other fifty percent are thought to be caused by a spontaneous mutation.

Erythrodermatoderma Variabilis

(EKV): This condition is marked by two types of skin changes. One is well-outlined geographic (resembling a geographic map), circular, or targeted patches of reddened skin (erythema) that change shape and position on the body from day to day. There may be thin white lines around the lesions. The face, arms, legs, trunk and buttocks are usually involved. The second skin change is thickened patches of skin with yellow-brown-gray scale. These areas are sharply outlined with irregular borders and are usually fixed. These thickened patches develop independently of the shifting reddish lesions. Onset is typically in infancy, and there is progression

through childhood with disease stabilizing at puberty. EKV is caused by an autosomal dominant inheritance.

Giroux-Barbeau Syndrome: In Giroux-Barbeau the skin changes are similar to EKV but the reddened patches of skin tend to disappear in the summer and disappear completely in adulthood. After age forty a progressive neurological disorder appears involving a lack of coordination of the muscles, rapid involuntary eye movement, speech disturbances, and decreased reflexes. Giroux-Barbeau Syndrome is thought to have an autosomal dominant inheritance.

Hailey-Hailey Disease (benign familial pemphigus): Blisters that appear on the skin, break open and drain, creating surface craters and erosions in the skin.

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Types of Ichthyosis

These erosions develop in the neck, and in the armpits, groin, and pelvic floor.

Blistering can also occur in the fold of the elbow, on the scalp, arms and legs, below the breasts and on the trunk. Onset is sometime after puberty, usually during the person's thirties and forties. Severity may improve, stay the same, or worsen over time. Friction, heat, or injury can cause blister formation at any time. Over time, involved areas may show moist crusting, or fine scaling and redness. Pain, itching, and odor are frequent complaints. Hailey-Hailey is caused by an autosomal dominant inheritance.

Harlequin Ichthyosis (harlequin fetus):

The newborn child is covered with armor-like plates of thick skin that crack and split apart. The thick skin plates produce distorted facial features and often deformities in other parts of the body. The chest and abdomen of the infant may be severely constricted by the tightness of the skin, making eating and breathing difficult. Premature delivery is typical. Infants are at high risk for complication due to early delivery, difficulty breathing, infection, low body temperature and/or dehydration. Harlequin ichthyosis is caused by an autosomal recessive inheritance.

Ichthyosis Hystrix Curth-Macklin Type:

The clinical appearance of this disorder is marked by patches of spiny thickened skin. The patches range from spotty to generalized and severe. The palms, soles and face are generally not affected. Children with the disease usually show skin changes within the first few weeks of life, and involvement appears to be progressive. Ichthyosis Hystrix is caused by an autosomal dominant inheritance.

Ichthyosis Vulgaris (Ichthyosis Simplex):

Ichthyosis vulgaris is characterized by mild to moderate scaling with fine, white, scales that adhere to the skin. The arms, legs, and trunk are usually affected. The face is usually spared, but cheeks and forehead may be involved. Some patients also experience atopic dermatitis (itchy patches of skin) and keratosis pilaris (small horny spines of skin on the shoulders, arms and thighs). The markings on the palms of the hands and

soles of the feet may be accentuated (hyperlinear). Onset is usually after 6 months of age, but may be earlier.

Ichthyosis vulgaris commonly improves with age. It may also improve in summer or a moist warm environment. Ichthyosis vulgaris is fairly common with 1 in 250 people affected. It is an autosomal dominant trait.

Keratosis Follicularis Spinulosa

Decalvans: Flesh-colored, spiny, patches of thickened skin develop on the face, trunk, arms and legs, usually in infancy and early childhood. Elbows, knees and other joint surfaces are involved. Missing eyebrows almost always occurs. Scarring alopecia (baldness) is typical.

Photophobia (light sensitivity) is also common and is moderate to severe. There may be some improvement of the disease at puberty. The photophobia tends to improve in adult life. Keratosis Follicularis Spinulosa Decalvans is caused by an X-linked recessive inheritance.

KID Syndrome (keratitis, ichthyosis,

deafness): There is a generalized thickening of the skin with small horny patches that run together. The skin has been described as leather-like and grainy. Changes are present at birth, or soon thereafter, and are progressive. Severity ranges from marked to overwhelmingly severe. Thickened patches of skin on the face, ears, elbows, knees and backs of hands and feet may have a reddened base. The palms and soles are involved with numerous horny spots on the fingertips. Scalp hairs are usually sparse or absent, and eyelashes, eyebrows, and secondary body hair are also sparse or absent. Recurring bacterial and fungal infections of the skin are common, and scarring may result. Neurosensory deafness is present at birth and generally does not progress. Hearing loss ranges from mild to profound. Four-fifths of patients develop inflammation of the cornea, which may lead to blindness. KID Syndrome is probably an autosomal dominant inheritance.

Lamellar Ichthyosis: Lamellar ichthyosis is present at birth. The baby is covered by a tight shiny membrane (the collodion), that resembles plastic wrap. The membrane

cracks and peels over the course of several weeks to reveal red, dry skin. Ectropion and eclabium (pulling back and turning out of the eyelids and lips) due to the tightness of the membrane are sometimes seen.

Problems with temperature regulation, water loss, secondary infections and systemic infection can occur in the newborn with lamellar ichthyosis. In children and adults with lamellar ichthyosis the entire body is covered with broad, dark, plate-like scales separated by deep cracks. They may also have reddened skin (erythroderma), thickened skin on the palms of the hands and soles of the feet, thickened nails, and decreased sweating with heat intolerance. Lamellar ichthyosis is caused by an autosomal recessive inheritance.

Multiple Sulfatase Deficiency:

Multiple Sulfatase Deficiency is a very rare hereditary metabolic disorder characterized by impairment of several sulfatase enzymes. Symptoms appear during the first or second year of life. Speech and walking development are abnormal. Other characteristics include a depressed bridge of the nose, large head circumference, deafness, a pronounced funnel-shaped depression over the chest, spinal abnormalities, and ichthyosis. Multiple Sulfatase Deficiency is caused by an autosomal recessive inheritance.

Netherton's Syndrome (ichthyosis linearis circumflexa):

Netherton's syndrome is characterized by scaling of the skin in a distinctive circular pattern (ichthyosis linearis circumflexa). Hair shafts are fragile and break easily due to trichorrhexis invaginata, or "bamboo hair". Both skin and hair abnormalities are caused by the conversion of an abnormally large amount of epidermal skin cells into dead cells (cornification). Another characteristic of Netherton's Syndrome is a predisposition to allergies, such as asthma, or food allergies that can cause skin eruptions. Netherton's Syndrome can be diagnosed at birth by the presence of generalized redness of the skin, and, less commonly, by a parchment-like membrane (collodion baby) that can be peeled off the skin. Later, abnormal thickening of the outer layer of the skin occurs in combination with shedding of the scales. This results in circular reddish patches on the skin with

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distinctive double-edged scales along the outlines of the patches. Netherton's Syndrome is caused by an autosomal recessive inheritance.

Pachyonychia Congenita: (Includes Jadassohn-Lewandowsky and Jackson-Lawler subtypes.) Pachyonychia Congenita (PC) is characterized by multiple cysts on the skin, and, starting in childhood, fingernails and toenails that are thickened, darkened, and easily crumble. Thickened skin on the palms of the hands and soles of the feet is common, as is excessive sweating of the hands and feet. The skin on the knees and elbows can be thickened and spotty. Pachyonychia Congenita is caused by an autosomal dominant inheritance.

Palmoplantar Keratodermas (PPK): (Various Forms) PPK is a general term referring to localized or widespread thickening of the palms of the hands and soles of the feet. PPK may be a primary disorder or part of a more widespread disease; psoriasis, pityriasis rubra pilaris, or lamellar ichthyosis. In the primary PPK's the disease is more or less limited to the hands and feet. The thickened skin takes on a whitish yellow color with a sharp reddish border. Painful cracking of the skin can occur. Excessive sweating of the hands and feet can also occur. PPK is caused by an autosomal dominant inheritance.

Peeling Skin Syndrome (familial continual skin peeling, idiopathic deciduous skin): Peeling skin syndrome is characterized by cycles of continuous shedding of the entire outer layer of the skin in sheets, similar to the peeling following a sunburn. Reddened skin, itching, and seasonal variations are sometimes seen. The entire body surface is involved and the peeling is accentuated by mild rubbing. A variant of the disease is acral, largely involving the hands and feet. Peeling Skin Syndrome is caused by an autosomal recessive inheritance.

Pityriasis Rubra Pilaris (PRP): PRP appears to come in several forms and its classification is confusing even to the experts. The most common form begins in the adult years, usually starting as focal red, scaly, bumps and patches, often on the scalp and upper body. PRP typically con-

tinues to progress over weeks and months until most of the body is involved in a generalized red scaly rash, distinguished by "skip" areas or islands of normal uninvolved skin, a marked, waxy thickening of the palms of the hands and soles of the feet, and roughened bumpy skin over the hands, knees or elbows. The majority of adults with this classic form enter remission within three years. Children may also develop PRP. Preschool children may develop a more localized form with patches predominantly on the elbows and knees. Most cases are acquired, but an autosomal dominant form may exist.

Recessive X-linked Ichthyosis (steroid sulfatase deficiency): Symptoms usually begin between 1 and 3 weeks of age with development of large brownish scales that are hard to get off. The neck, trunk, arms and legs are usually involved, but the face, scalp, palms and soles are usually spared. Symptoms greatly improve in the summer months. Clouding of the cornea occurs in approximately 50 percent of adult males with x-linked ichthyosis. Males may develop undescended testicles in rare cases. Decreased estrogen production in mothers carrying affected children may cause failure of labor to begin or progress. The disease can be detected by amniocentesis. X-linked ichthyosis is caused by an X-linked recessive inheritance.

Refsum's Disease (phytanic acid storage disease): Refsum Disease is caused by a rare defect in lipid metabolism due to an inability to degrade phytanic acid, a fatty acid created by the digestion of plant products. Refsum's features failing night vision, retinitis pigmentosa, constricted visual fields, neurosensory deafness, peripheral nerve pain and inflammation, diminished deep tendon reflexes, impaired electrical impulses in the heart, and a scaly skin resembling ichthyosis vulgaris. In most patients there is slow but continual progression of the disease with symptoms starting to appear well after puberty. The first sign may be failing night vision. The features of Refsum's Disease involving the skin are a light color scaling with a wrinkled appearance, and accentuated creases in the palms of the hands. Refsum's Disease is caused by an autosomal recessive inheritance.

Rud's Syndrome: Rud Syndrome is characterized by ichthyosis and decreased functional activity of the sexual organs, with retardation of growth and sexual development. The ichthyosis is seen at birth or shortly after, and ranges from mild to severe, most similar to x-linked ichthyosis, or ichthyosis vulgaris. Rud's Syndrome can be caused by two modes of inheritance, autosomal recessive or X-linked recessive.

Sjogren-Larsson Syndrome (SLS): Sjogren-Larsson Syndrome is a rare form of ichthyosis associated with other symptoms. The three primary symptoms are ichthyosis, mental retardation and spasticity (spasms and tightening of the muscles). The ichthyosis is present at birth or shortly after. At first glance it resembles lamellar ichthyosis. Small, usually dark, scales cover most of the body with an underlying redness (erythema). The center of the face is usually spared and itching is common. Neurological symptoms are not seen at birth but develop by about two years of age. Individuals with SLS typically develop some degree of leg spasticity resulting in difficulty or an inability to walk, and mental retardation. The mental retardation may range from mild to severe. Most people with SLS have "glistening white dots" inside their eyes, although their vision is normal. SLS is caused by an autosomal recessive inheritance.

Tay's Syndrome (trichothiodystrophy, IBIDS Syndrome): Tay's Syndrome is a hereditary disorder characterized by reddened skin and ichthyosis, sparse and brittle hair, delayed physical development, mental retardation and the look of premature old age. Reddened skin may be present at birth, and the ichthyosis presents as fine dark scales covering most of the body. The hair is sparse and brittle, and finger and toenails are abnormal. Facial features include a beaked nose, receding chin and protruding ears. Loss of fat under the skin results in a prematurely aged-looking face. Low birth weight, short stature, and mental retardation are typical. Underdeveloped genitals may be seen in males and females. Tay's Syndrome is caused by an autosomal recessive inheritance.

Correspondence Corner

continued from page 1

Greetings from Bermuda! This is Cindy Ashton. We have been members of F.I.R.S.T. for quite a few years. Our daughter, Laura, was born with lamellar ichthyosis. She has gained so much by meeting people at your conferences. We have been attending conferences since she was four, but missed the one in Chicago. Our thought has always been that the three of us would benefit each and every time we met with you and the F.I.R.S.T. members. Laura was 14 at the last conference in Philadelphia. We told her that this was her conference and her opportunity to be bold, to meet other teens, and to discuss what was really on their minds. We took a back seat and she went full steam ahead.

We are planning to attend the next conference in Seattle. We have heard about it through the grapevine and are anxiously waiting for our latest newsletter. Laura has also been attending the summer camps sponsored by the AAD. These are all such positive experiences. Laura met a young man at last summer's camp and she has been telling him about the conference. She asked me if you might be able to send him and his family a newsletter with information in regard to the upcoming conference.

Thank you so much and we all look forward to seeing you in July!

**Most sincerely,
Cindy Ashton, David and Laura
Paget, Bermuda**

My name is Alexandra. I'm 34 years old and I'm from South Germany. I have had ichthyosis since my childhood. Now, at this time of year when the weather is cold and dry, it is the worst. When I undress it is 'snowing' scales. To treat my skin I spend the holidays every year at the sea. Sun, salt water and the warm climate are the best for my skin. The last three years, I have spent a week to ten days in Israel at the Dead Sea. The climate there is the best. I'm looking forward to next year when I will go to Israel again. And when I come back, I will have "normal" skin like other people. It is the time I am most beautiful all year.

Bye, bye, Alexandra Kuhn, Germany

If anyone is interested in carpooling to the F.I.R.S.T. Family Conference in July from the Salem/Portland, Oregon area, please contact Leanne Skokan at 503-769-9694, or email skokan@wvi.com.

**Thanks,
Leanne Skokanxxx
Portland, OR**

Foundation Notes

Dates are Set for Summer Camp Fun

The dates for the American Academy of Dermatology Camps are set for the summer of 2002:

Camp Discovery, Crosslake, Michigan - July 6 to July 13, ages 10 to 13.

Camp Discovery, Crosslake, Michigan - July 27 to August 2, Teen Camp

Camp Horizon, Millville, Pennsylvania - August 11 to August 17, ages 8 to 13.

All campers receive full tuition and transportation scholarships through the generous contributions of The American Academy of Dermatology members, corporations, individuals, and organizations. Referrals for campers must come from a dermatologist. If you would like to attend Camp Discovery, please contact your dermatologist. For more information about Camp Discovery, call the American Academy of Dermatology at 847-330-0230.

Volunteer Recognition

Volunteer recognition is an important part of F.I.R.S.T. Family Conferences. Grassroots fundraising, education and awareness activities, volunteer leadership, and dedication to the foundation and its mission are recognized in deserving volunteers from the past year and the current year.

If you would like to nominate a deserving volunteer, or if you have contributed to promoting or supporting the foundation and its mission and would like to tell us about it, contact the national office, 1-800-545-3286. We want to acknowledge everyone's contributions.



Peyton Weary Receives Award

Dr. Peyton Weary, F.I.R.S.T. Board of Directors member, is being awarded the American Skin Association's award for Distinguished Contributions to Public Policy. Dr. Weary was chosen for this award for four decades of contributions in public policy to increase support for research in skin health and for his efforts to raise public awareness of skin cancer. He is the first recipient of this award.

Congratulations

Congratulations are in order for The Foundation For Ichthyosis Board Member, Beth Gray, and her family. Michael Paul joined the family this winter. Michael is the fifth child for the Grays. We wish the whole Gray family well and welcome Michael to The Foundation for Ichthyosis family.

Jane Bukaty Membership Assistance Fund

The Jane Bukaty Membership Assistance Fund has been established to help members of F.I.R.S.T. with financial support for expenses involved in the care of ichthyosis. The Support Network & Membership Assistance Committee awarded three members funds from this program during the last round of applications. Applications are now being accepted for the fourth cycle of considerations. The application process is simple. Complete an application form and send it in! The form is available in the "Members Only" section on our website, www.scalyskin.org, or one can be mailed to you at your request. Call the national office at 800.545.3286. The deadline for applications is June 30, 2002.

In general, the goal in taking care of ichthyosis is to hydrate (moisturize) the skin, hold in the moisture, and keep scale thickness to a minimum.

**Foundation for Ichthyosis & Related Skin Types, <http://www.scalyskin.org>*



Aquaphor® Healing Ointment helps heal dry skin associated with ichthyosis. Its unique petrolatum-based formulation combines a moist environment with the benefits of a semi-occlusive barrier that allows skin to breathe and absorb fluids.

Aquaphor is ideal for daily use because it is hypoallergenic, non-comedogenic, fragrance and preservative-free. Aquaphor Healing Ointment is safe enough for even the most sensitive skin.

*Special Offer
For Readers of this F.I.R.S.T. Newsletter*

MANUFACTURER'S COUPON

EXPIRES 1/31/02

**Save \$2.00
on any
Aquaphor®
Product**

(NO TRIAL SIZES)



Consumer: Coupon good on the purchase of any Aquaphor® Product, no trial sizes. Limit one coupon per item purchased. Any other use constitutes fraud. Not good with any other special offer. Consumer must pay sales tax.

Retailer: You are authorized to act as our agent to redeem this coupon and we shall reimburse you at face value plus 8¢ handling in accordance with our redemption policy. Cash value 1/100¢. Copies available upon request. Offer void if copied and where prohibited, taxed or otherwise restricted. Mail to: Beiersdorf Inc, PO Box 880504, El Paso, TX 88588-0504. Good only in USA.



Executive Director's Report

Dear Friends:

I am pleased to present the annual report for fiscal year 2001. The statement of financial position outlines the financial growth of the foundation for the past two years.

Since its creation in 1981, the Foundation for Ichthyosis & Related Skin Types, a mission-driven organization, has provided support and services to individuals and families affected with ichthyosis. As the Foundation enters its third decade with committed leadership, capable staff, dedicated volunteers, growing membership and increasing financial stability, it is even more dedicated to the basic principle of support and service to its members. This guiding principle is the underlying basis for which all programs, services and future plans are based.

Sincerely yours,



Jean R. Pickford
Executive Director

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Jean Pickford
Executive Director

Maureen Tierney
Program Director

Kelly Strother
Administrative Assistant

April 30, 2001

Dear F.I.R.S.T. members:



Elizabeth A. Gray

Fiscal year 2001 marked the 20th anniversary of the founding of the Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.), formerly the National Ichthyosis Foundation (N.I.F.). The foundation continues to grow in membership and services, providing information, education, advocacy and support to individuals and families affected by ichthyosis.

Beiersdorf once again provided funding for the Ichthyosis Support Network (ISN) as well as other program-related activities. One hundred sixty-nine members volunteer as part of the ISN, which links families all over the country with other families who share similar experiences involving ichthyosis.

Through the financial support of NeoStrata, the Foundation also funded a \$20,000 research grant to Karima Djabali, Ph.D. of Columbia University. Dr. Djabali's project on The Genetics of Woolly Hair and Keratoderma (Naxos Disease) marks another step towards better treatments and, ultimately, a cure for ichthyosis.

Other noteworthy accomplishments in fiscal 2001 include a one-day regional conference in the Houston area attended by 68 families, the awards of several financial assistance grants from The Jane Bukaty Membership Assistance Fund, and major improvements to the Foundation's web site, generously hosted by Accurate Imaging. When you have a few minutes, be sure to check out the new features and information available at www.scalyskin.org.

The Foundation is fortunate to have a highly dedicated and hard-working staff making the most of your donations and I am pleased to announce that, even with all of these accomplishments, the Foundation's net assets increased by 70% during this past fiscal year. This increase is due to several factors. Thanks to the generosity of all of our members and friends, the holiday appeal and grassroots fund raising revenues exceeded projected goals. Letter writing campaigns by the Board of Directors and Medical Advisory Board brought in over \$10,000 in new funding. In addition, The Foundation received several significant donations from long-time members and corporate donors. With our strategic planning process almost complete, this crucial increase in net assets couldn't come at a better time.

I appreciate the opportunity to serve all of you and hope that you are as proud of the Foundation's achievements as I am.

Sincerely,

Elizabeth A. Gray
CFO, Board of Directors

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 John & Jacqueline
 Montgomery
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 Patti Napoli
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\$250 - \$499

In memory of Theresa Napoli
 50-Degree Company
 Harry & Lynne Alba
 Robert & Nancy Ash
 Robert Bialer
 Darlene Blackwell
 Robert & Debra Bowie

Coalition of Patient Advocates
 for Skin Disease Research
 Richard & April Cobb
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 Karoline Freed-Biggs
 Highland High School
 Dona Hoar
 Kurt & Susan Hoffman
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 Grace McMillan
 Terry Melton
 National Center for Nonprofit
 Boards
 Jennifer Nichols
 Robert O'Connor, Jr.
 Osmotics Corporation
 David & Anna Purcell
 Victor & Donna Rice
 Franziska Ringpfeil
 Jerry Roth, M.D.
 Aletha Shipman
 Elliot & Phyllis Shulman
 Dan Siegel
 Denise M. Yong

\$500 - \$999

In memory of Gerald Kamcza
 In memory of Clair Sulkey
 Aid Association for Lutherans
 Beiersdorf
 Dr. & Mrs. Wilmer Betts
 Frances Blankis
 Diana Clifton
 Dermablend
 Michael Dunleavy
 Schuyler & Denise Eastin
 Ernest Paper Products
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 Group
 Juvenir Biosciences
 Herman & Joyce Karst
 Joe & Chris LaBarbera
 Melissa Osterloth
 Jean Peters
 Chris & Laura Phillips
 Paula D. Rivers
 Virginia Scully
 Easton B. Smith
 Spear, Leeds & Kellogg

\$1000 - \$4999

In memory of Janine Giuliana
 In memory of Bill Robertson
 Aubrey Organics
 BP Amoco
 Henry J. Bukaty
 Greg Dalton
 Dermik Labs
 Dermal Therapy Research Inc.
 Human Race-Volunteer
 Exchange
 Joe & Dawn Johnson
 Tiffany Karst
 Kimberly Maurer
 Paul & Jean Meeker
 Dr. & Mrs. Leonard Milstone
 National Semiconductor
 Tim & Marcia Ohlwiler
 Eustolia Perez
 Nicholas Perricone
 James & Elza Phillips
 Tracie Pretak
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 Janet Showers-Patterson
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Roche Dermatologics
 Dr. & Mrs. Peyton Weary

\$20,000 +

Neostrata

ASK THE READERS: What Do You Do?

Dear Reader's: The "Ask the Readers" column was designed as a forum for our members to share effective solutions to some of the challenges of having ichthyosis. Lately we have had very few responses to the column. We would really like to hear from you; you are the Foundation's best resource for information and solutions. If it seems that this column is not of interest to our readers, we may make the space available for other information. Please let us know how you feel. **Sincerely, Jean and Maureen**

How have you and your child's school personnel partnered together to provide adequate time and resources for your child's ichthyosis?

My daughter Jenna is eight years old and was born with a type of ichthyosis still unknown to us. Her condition is a very mild form, although it is extreme enough to need daily showers and a ton of lotioning, and a lot of extra love with hugs and kisses daily. She of course carries lotions with her always, even to school.

This past summer my mom recommended that we look into getting an air conditioner put in Jenna's classroom. Here in New England, September, May, and June can be quite warm. After many phone calls, and a detailed letter from her doctor, she now has one in her classroom window! It will stay with her the next three years as she completes elementary school. We will arrange the same accommodations as she enters middle school. It totally reassures me while at work to know that she is not overheating in class. We also have an agreement with the school nurse and teachers that if it's over 70 degrees outside, she stays in for recess and is allowed to choose a friend to stay with her. Jenna loves this as it makes her feel special. And our children are special just as is every child in this world!

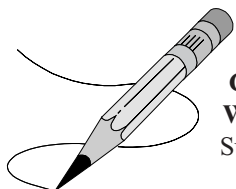
I would like to take a minute and sincerely thank F.I.R.S.T. It is so nice to have such a dedicated group of people and doctors always on hand to answer questions, and just be there when you need them. It has really helped to belong to this wonderful organization.

God Bless!!! Melissa Gay, Cumberland, RI

Here's our next question:

"What strategies have you and your doctor found helpful in getting your health insurance provider to cover some or all of the cost of your ichthyosis treatments?"

Send us your comments. We will print the responses in the next newsletter. Here's how to contact us:



E-mail: info@scalyskin.org

Fax: 215.631.1413

Call: 800.545.3286

Write: 650 N. Cannon Avenue,
Suite 17, Lansdale, PA 19446

What's New, What's Hot and What Works

continued from page 3

Soaring Words

Soaringwords.org is the healing place for millions of sick children and their families to reach out to each other. Soaringwords is an interactive web-based community and non-profit 501 (c) 3 organization. Soaringwords.org is not medical or clinical in nature, but rather an inspirational online environment to foster caring, empathy, hope and understanding as kids connect with other kids and parents connect with other parents. The Soaringwords.org website offers healing word stories, activities, live chats and online events, music and photos.

Rare Diseases Office

Congress recently increased the funding for the NIH Office for Rare Diseases to \$10,341,000. Funding for the Office had stagnated at approximately \$2 million per year, so this five-fold increase is a reflection of the letters, phone calls, and visits of National Organization for Rare Diseases (NORD) members to their federal elected officials asking for money for the Office of Rare Diseases. NORD asked Congress to appropriate \$24 million for the Office of Rare Diseases. A bill is currently pending before Congress (The Rare Diseases Act, S.1379) which will make the NIH Office for Rare Diseases permanent by writing it into law and to appropriate \$24 million to the office next year. The National Organization for Rare Diseases urges everyone with a concern about rare diseases to continue communicating with federal Representatives and Senators to educate them about the need for more rare diseases funding at the NIH and FDA and to support S.1379. Senator Edward Kennedy (D-MA) sponsored The Rare Diseases Act (S.1379). The following senators have already cosponsored the bill: Senators Jeff Bingham (D-NM), Hillary Rodham Clinton (D-NY), Susan M. Collins (R-ME), Richard Durbin (D-IL), Orrin Hatch (R-UT), Ernest Hollings (D-SC), James Jeffords (I-VT), John Kerry (D-MA), and Gordon Smith (R-OR).

2002 Conference Program

A Family Affair: Caring, Sharing & Support

(subject to change)

ADULTS

(AGES 18 AND OVER)

Friday

Registration

Dinner on your Own

Reception

* State of the Foundation

* Registry for Ichthyosis & Related Disorders

Saturday

Opening Remarks

Resourcing: The Mind, Body, Spirit Connection

Breakouts:

Ask the Doc's, Pediatric Concerns

Ask the Doc's, Adult Concerns

Importance of Family

Clinical Screening (appts. only)

Moms' Discussion

Dads' Discussion

Womens' Discussion

Mens' Discussion

Open Session(s)

* Make-Up Techniques

* Mini Massage

Sunday

What's New in Research

Moments of Grace: Courage in the Face of Change

Breakouts:

ISN Sign-Up & Training

Treatment Options

How to Support Your Kids Through a

Medical Procedure

Info Sharing/Helpful Hints

CHILDREN

(AGES 8 AND UNDER)

Saturday & Sunday

Free child care and activities provided by PANDA Dial-A-Sitter

CLINICAL SCREENING

A Clinical Screening will be available to all affected individuals. Physicians who specialize in ichthyosis will be available for one-on-one consultation. Screening appointments can be made on Friday, July 5 at the registration table.

TEENS

(AGES 13 – 17)

Friday

Registration

Dinner on your Own

Reception

* State of the Foundation

* Registry for Ichthyosis & Related Disorders

Saturday

Opening Remarks

Resourcing: The Mind, Body, Spirit Connection

Healthy Choices in a Fast Food World

Career Panel Discussion

Teen Talk/Doctor Talk

Sunday

What's New in Research

Coping with Social Challenges

Simple Strategies for Personal Safety

Moments of Grace: Courage in the Face of Change

TWEENS

(AGES 9 – 12)

Friday

Registration

Dinner on your Own

Reception

* State of the Foundation

* Registry for Ichthyosis & Related Disorders

Saturday

Opening Remarks

Resourcing: The Mind, Body, Spirit Connection

Creative Outlets for Personal Expression

Healthy Choices in a Fast Food World

Tween Talk/Doctor Talk

Sunday

What's New in Research

Simple Strategies for Personal Safety

Coping with Social Challenges

Moments of Grace: Courage in the Face of Change

** The Conference begins with registration on Friday, July 6, from 3 to 5 p.m. and wraps up on Sunday, July 7, at 12 Noon.

Room Reservations

Call 800.643.5479 to make your room reservations. F.I.R.S.T.'s discounted price is \$89.00 + applicable taxes per room, flat occupancy. Be sure to mention this group rate is reserved under Foundation for Ichthyosis. The deadline for room reservations is June 13, 2002. This rate is available from June 30 to July 9, 2002 if you are planning an extended stay.

Airport Shuttle

There is a free shuttle from the Seattle-Tacoma Airport to the Seattle Marriott Sea-Tac. The shuttle runs every fifteen minutes and pick-up is on the third floor parking structure. Stop at the Information desk in the airport for more details.

Airline Transportation

The following three airlines have an agreement with the Foundation for Ichthyosis to offer discount tickets on round trip airfares to the 2002 Family Conference:

US Airways is offering discounted round trip flights from June 30, to July 12, 2002.

- Call US Airways Group and Meeting Reservations, 877.874.7687.
- 8:00 a.m. to 9:30 p.m. EST.
- Refer to Gold File Number 38632202.

Delta Airlines is offering discounted round trip tickets from July 2, to July 10, 2002.

- Call Delta Meeting Network Reservations at 1.800.241.6760.
- Monday - Sunday, 8:00 a.m. to 11:00 p.m., EST.
- Refer to file number 182733A.

Northwest/KLM/Continental is offering discounted tickets from July 2, 2002, to July 10, 2002.

- Call Meeting Services Reservations Desk at 1.800.328.1111.
- Monday - Friday, 7:30 a.m. to 7:30 p.m., CT.
- Refer to WorldFile Number NMWE6.

Discounts range from 5% to 7% off published fares and 10% off tickets purchased 60 days in advance. Additional discounts may be available. Certain rules and restrictions apply.

Angel Flight America Program

You may be eligible for free airfare using the Angel Flight America Program, through the National Patient Travel Center. If you live within 1000 miles of Seattle, Angel Flight will fly a family in a 4-seater or 6-seater plane to the conference at no cost. Contact the National Patient Travel Center at 888.675.1405 and refer to the 2002 F.I.R.S.T. Family Conference Special Lift Program. If you live outside the 1000 mile limit, they suggest you use www.expedia.com or www.orbitz.com to shop for the cheapest tickets and order online.

2002 Family Conference Registration Form

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Phone (day): _____ (evening): _____ Email: _____

Registration Deadline by June 14, 2002

Adults (age 18 & over) – \$70.00

Child (age 17 & under) – \$35.00

- Please make all checks payable to F.I.R.S.T.
- F.I.R.S.T. also accepts Mastercard, Visa, and American Express. Please provide type of card, account number, expiration date, and billing address for credit card.

Name	Age	Type of ichthyosis
<input type="checkbox"/> Adult 18 & over <input type="checkbox"/> Teen age 13-17 <input type="checkbox"/> Tween age 9-12 <input type="checkbox"/> Childcare age 8 & under		
<input type="checkbox"/> Adult <input type="checkbox"/> Teen <input type="checkbox"/> Tween <input type="checkbox"/> Childcare		
<input type="checkbox"/> Adult <input type="checkbox"/> Teen <input type="checkbox"/> Tween <input type="checkbox"/> Childcare		
<input type="checkbox"/> Adult <input type="checkbox"/> Teen <input type="checkbox"/> Tween <input type="checkbox"/> Childcare		
<input type="checkbox"/> Adult <input type="checkbox"/> Teen <input type="checkbox"/> Tween <input type="checkbox"/> Childcare		

- Yes, F.I.R.S.T. may include our name and contact information in a conference roster to be distributed to conference attendees.
- Yes, F.I.R.S.T. may include the type of ichthyosis that affects our family on our nametags.
- Yes, I (we) will attend the 3-hour bus tour of Seattle on Sunday, July 7 after the conference. The bus will leave the hotel lobby at 2:00 p.m. and return around 5:00 p.m. Each ticket is \$10.00 per person. Your seat will be reserved when payment is received.

Number of adults (18 & older)	_____	x \$70 per person =	_____
Number of children: (1 through 17)*	_____	x \$35 per person =	_____
Number of individuals attending Seattle Tour	_____	x \$10 per person =	_____
Grand Total =			_____

- Please return registration fees with completed form to Jean Pickford, F.I.R.S.T., 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446. Kindly make checks payable to F.I.R.S.T. in US funds.
- Cancellations will be honored with full refunds until Advance Registration Date of Friday, June 14, 2002.
- * There is no registration fee for children under one year of age

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- ◆ *Loosens and removes scales**
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Please visit us at www.stiefel.com

Please help us to minimize our printing costs. Call us at 1-800-545-3286 if you do not wish to receive any future issues of *Ichthyosis Focus*. **Help F.I.R.S.T. reduce its postage costs – would you be willing to accept the Focus Newsletter via e-mail? Let us know.**



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Lansdale, PA 19446

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