

# ICHTHYOSIS FOCUS

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

Winter 2000

## What are Retinoids and Where Do They Come From?

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Vitamin A is the name for a group of naturally occurring compounds that are necessary for normal growth and development. The usual dietary sources of Vitamin A are green and yellow leafy vegetables and certain animal products such as fish oils and liver. When Vitamin A is eaten it can be stored in the liver, and high doses can lead to toxic effects. The term *retinoid* is used to

describe Vitamin A and its chemical derivatives. Many of these occur naturally in foods, but there are also many synthetic derivatives which have been man-made (synthesized). So there are both natural and synthetic retinoids. Both good and toxic effects of Vitamin A have been known for a very long time, with some writings dating back to the ancient Egyptians. In the early 1900's, lack of Vitamin A (deficiency) was associated with cancer development and also with skin changes. Based on these findings retinoids were studied as a treatment for skin disorders and cancer. One problem with naturally occurring Vitamin A is that the amount needed to cause the good effects is close to that which causes toxic effects. By the time enough is taken to achieve a clinical benefit, side effects such as headaches, bone pain and bone changes can begin to occur. To try to increase the amount of benefit and decrease the toxic side effects, many people became interested in creating and studying synthetic derivatives of Vitamin A. Hoffmann LaRoche, with headquarters in Basel, Switzerland and Nutley, New Jersey, was one of the companies most interested in these drugs. This program was largely spearheaded by Dr. Werner Bolag. They spent a great deal of effort studying retinoids for cancer treatment

and prevention. The use of retinoids for skin conditions followed soon after, initially in animal models and then in people. In the 1970's, retinoids were beginning to be studied in Europe and the United States for many skin conditions. Many rare disorders with scaling of the skin, including many of the different types of ichthyosis, showed improvement with retinoid treatment. In the U.S., Dr. Gary Peck found that patients with a very severe form of cystic acne could be cured by the retinoid isotretinoin, so that after a short course (several months) of treatment the disease usually did not come back. Later studies would show that isotretinoin and other retinoids could be useful to prevent new skin cancers in some patients who were developing a very large number of skin cancers. However, to achieve this type of benefit, the drug had to be continued or the benefit was lost.

### HOW DO RETINOIDS WORK?

Retinoids work in multiple ways, i.e., by different mechanisms. Retinoids are required for the normal growth and development of many cells and tissues. The process by which new cells grow and develop is called differentiation. Retinoids enhance this process, so that for some cells which are not growing normally,

*continued on page 4*

### A New Website for F.I.R.S.T. [www.scalyskin.org](http://www.scalyskin.org)

Thanks to the donated services of Matthew Vecera and his employees at Accurate Imaging, F.I.R.S.T. has created a state-of-the-art website providing valuable information about ichthyosis, the foundation, member services, giving opportunities, direct email access to the national office, plus much, much more. The new address for our website is [www.scalyskin.org](http://www.scalyskin.org) and we encourage everyone to visit our site.

## Family Conference

Friday - Sunday, July 7 - 9, 2000

Park Ridge Hotel at Valley Forge, King of Prussia, PA

Details & Registration page 12-15



# Correspondence Corner

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

My name is Alison MacEachern, I live in Topsfield, Massachusetts, I am twenty years old. I was born with lamellar ichthyosis and experienced many difficulties learning to cope with my skin disorder while growing up. I know so many of us feel as though we've been cursed with this horrible external flaw. We all feel emotional downs and go through what my mother calls "pity parties" for ourselves. I'm sure many of you have experienced these and cried out "why me?" I know I have. I suffered through the teasing and name calling throughout elementary school. What I have realized now is that something beautiful was happening inside myself even though it all seemed like a long endless nightmare. I was building inner strength and wisdom. Learning incredible discoveries about the contents that are inside of myself. I slowly learned that inside all of us, despite the flaky surface of our skin, we have inner beauty. I realize I haven't been cursed, I've been blessed. I found out that if I had not been born with this skin disorder, I would be a completely different person on the inside. I believe strongly that this skin problem has developed many wonderful qualities in my personality and in my thoughts. I know everyone else holds within themselves more love, understanding, compassion, intelligence, and appreciation. We cannot allow the fact that our skin is not the same as everyone else's to put us in a position where we feel less about who we are. I am confident that everyone reading this right now has at one point felt excluded, alienated, or just plain out different. Well let's make sure that today we change that and make sure we never experience those negative emotions again. Let's think positively. I suggest that you take out a pen and pad of paper. Now think of all the wonderful qualities you possess inside. Then start listing down how you're different in good ways. You'll be amazed to find out that you are a beautiful person, and you better believe it. I discovered that I was indeed different than the average person, but not because my skin is severely dry and flaky, but because I see life from the larger perspective. I have great understanding of people and see the beauty inside everyone. The people that don't understand or don't have knowledge about ichthyosis are the ones who find ways of putting down. When those times occur think to yourself you are the better one and you will be strong. Don't ever allow anyone to leave you in tears or in pain. Don't allow yourself to feel pain and sorrow. Learn to love yourself for you, know that you're great, hold it in your heart and that's all you need to know. I came to a point in my life where I realized I can allow this disorder to suffocate me with resentment, anger, and frustration. Or I can pick my head up, be the best I can be, and learn to love myself as a person. If someone was to ask me about my skin, I first remind myself they don't know, it's alright for them to be curious. I then explain why my skin is the way it is. With confidence, however, don't be intimidated explaining. In fact you don't need to explain at all if you don't want to. If someone asks "why is your skin peeling?" you can simply say "why are your eyes blue?" From that they will realize you were born that way and hopefully leave it at that.

I've learned to live with my skin disorder, I've learned about myself, and about life and other people. Don't allow your difference to cause you low self-esteem, find a way to learn from it. I know its difficult, with time and patience you can find ways of thinking on the bright side of the situation. We can all unite in the belief and be confident that some day they will find a way to cure this skin disorder. When that day comes we can all jump for joy, but until that day let's stay strong and keep our heads high. When people stare, they aren't staring at our skin, they stare because we are magnificent!

I would like to share a number of books that I highly recommend to everyone even if you do not have a skin disorder.

[Living with Joy, Personal Power through Awareness](#), and [Spiritual Growth](#), by Sanaya Roman

[Creative Visualization, Living in the Light](#), by Shakti Gawain.

[Anatomy of the Spirit](#), by Caroline Myss, PH.D.

These books have greatly influenced my life in the most positive ways possible. I also recommend keeping a journal to write how you feel, what you want to change, how you can bring that change to reality, etc. I know it's hard to express to someone how you feel due to the fear that they won't understand. A journal is a great source to have when it comes to pouring out your emotions. Good luck to everyone, and please feel free to write to me with any questions or concerns. I am a full time student so I am quite busy, but I would love to hear your opinions. I have a lot of wonderful advice and support to give anyone who needs it. You can e-mail me at AlisonmacEachern@aol.com, or write to:

Alison MacEachern  
46 Wilmor Road  
Topsfield, MA 01983

## Dear Friends at F.I.R.S.T.:

I too am a sufferer of ichthyosis. I am 27 years old and am now taking Accutane every other day. I hope that I can help any child who is suffering from this skin "ailment." Since I am older than most of the children, I would like to let them know that it gets better and believe me...my skin has never stopped me. I read in the last letter sent out that a brother and sister joked that they should vacuum their skin flakes. Believe me when I tell you I too used to say that. Sometimes I pretended it was snow. Hopefully kids who have ichthyosis can email me and I hope that I can help them through every step. Since I know that adolescence is the most crucial period in anyone's life, as a survivor of ichthyosis it does get better. Find the true inner self and the true personality shines through. I even think sometimes my skin gets better.

Please give my email to anyone who has questions, needs advice, or a friend. Since I am going through it and have gone through the worst with ichthyosis, I may be able to help the children.

Thank you Ichthyosis Foundation for being out there. I wish I had known about you when I was growing up.

Sincerely,

Sofia Mamais  
Little Neck, NY  
mamais@excite.com

## Jane Bukaty Membership Assistance Fund

F.I.R.S.T. realizes that the fight against ichthyosis is not only a medical one but a financial one as well. As families of affected individuals maintain their daily routine of treatments, it can be complicated by the ongoing costs of medical supplies and other comforting aids and procedures.

Thanks to the generosity of an anonymous donor, the foundation has established the Jane Bukaty Membership Assistance Fund to help alleviate some of the financial burden that may be facing our members. Here's your opportunity to apply for some financial assistance for ichthyosis treatment!

Since the fund is limited, the following criteria must be met by the applicant in order to be eligible for MAF aid. The applicant must be a member in good standing. The applicant is required to submit a letter indicating their need for funding. The letter must include the amount of funding

requested, the specific product/treatment for which funds are required and a demonstration of the financial need for this product/treatment. Awards will generally not exceed \$100.00. Applications will be awarded two times per year as determined by the Support Network & Member Assistance Committee.

Requests can be emailed to the national office or mailed to the attention of the Jane Bukaty Membership Assistance Fund at 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446. You will be contacted by a member of the Support Network & Member Assistance Committee if you have been awarded aid from this fund.

*Donations to the Jane Bukaty Membership Assistance Fund are always appreciated and enable F.I.R.S.T. to make this fund available to more of our members.*

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The editor invites correspondence.

We welcome your comments, observations and suggestions.

Please send your letters to Ichthyosis Focus at the address listed above.

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**Retinoids continued**

additional retinoid can push their development towards normal. So in many of the scaly skin conditions such as ichthyosis, additional retinoid can help the skin cells grow (differentiate) more normally. This mechanism may also explain how retinoids act to prevent cancer. Retinoids can help many different skin diseases, which have different specific causes. Because retinoids can affect the overall process of skin growth, they can improve many different diseases. However, they are probably not working by correcting the specific underlying cause of each disease.

**WHAT ARE SOME OF THE DIFFERENT RETINOIDS?**

Naturally occurring retinoids found in the body include *retinol*, *retinal*, and *retinoic acid*. There are several other names that you might see on food, vitamin, or medicine labels. Plant sources contain compounds called *carotenoids*, which are broken down into retinoids by the body. Animal sources contain retinoid in the form of compounds called retinyl esters (e.g., retinyl palmitate). Several retinoids are used as drugs either topically (rub on) or systemically (delivered to the whole body, as in a pill). Retinoic acid (tretinoin, Retin A, Avita, Renova), is used as a topical treatment for acne and may help other skin conditions such as sun induced skin damage, and thick or scaly conditions such as ichthyosis. The same drug is used systemically to treat a type of blood cancer (leukemia). Other topical retinoids include adapalene (Differin) which is used for acne and tazarotene (Tazorac) which is used for psoriasis. Isotretinoin (Accutane) is an oral medication used for a type of severe acne, and may also help scaly skin conditions (e.g., ichthyosis). Etretinate (Tegison) which has recently been replaced by acitretin (Soriatane) is used for psoriasis, ichthyosis, and other skin disorders. Fenretinide is another retinoid which is not currently approved by the Food and Drug Administration, but is being studied to prevent breast cancer and for other uses. Many thousands of retinoids have been created and these represent a great potential for the treatment of many different disorders.

**WHAT ARE SOME OF THE PROBLEMS THAT CAN OCCUR DURING TREATMENT WITH SYSTEMIC RETINOIDS?**

Almost everyone taking systemic retinoid therapy has some side effects but these are usually mild and easily controlled. Dryness and scaling of the skin and mucous membranes (especially lips) is common and usually controlled with creams and ointments. Blood test abnormalities can occur such as increases in fats (triglycerides and cholesterol), and these are often treated by diet. Occasionally retinoids can irritate the liver and cause abnormalities in test of liver function. This can be made worse by drinking alcohol which also irritates the liver. Some people have joint stiffness, which usually responds to "over the counter" pain or anti-inflammatory medications such as ibuprofen or naprosyn. Naturally occurring retinoids are important for the normal development of the fetus. Therefore, if a pregnant woman takes retinoids in doses higher than from a normal diet, they can interfere with development and lead to birth defects. The developing baby is very sensitive to retinoids and even one or two pills of isotretinoin (Accutane) can be very harmful.

**SHOULD I TRY RETINOIDS?**

That is a question that you must discuss with your dermatologist. For many conditions, a trial lasting a few months can help determine how much benefit you can expect, and whether longer treatment is worth the risk.

**WHAT IS THE FUTURE OF RETINOIDS?**

The retinoid drugs available today provide effective treatment for many serious disorders including severe acne, psoriasis, ichthyosis, and cancer. Pharmaceutical companies have developed many compounds, most of which have not yet been tested, but which have the potential to become powerful drugs. Therefore, there is still a very great promise for many new treatments for a spectrum of severe disorders.

**DISCLAIMER:**

*Dr. DiGiovanna has worked with several of the companies who have a financial interest in retinoids and has received financial support for research, publishing, and speaking.*

## Executive Director's Report



*Dear Members and Friends of F.I.R.S.T.:*

*Thank you to everyone who contributed to the foundation through the Holiday Appeal. The campaign has received over \$14,000 thus far and donations are still arriving. Our financial strength is one of the key ingredients to the success of the foundation and I continue to be impressed by the enormous generosity of our members. The Membership Renewal campaign will be sent to you toward the end of March/early April. So be on the lookout for your renewal notice in the next month or two.*

*I will be attending NIAMS Day in Washington, DC on March 1 with the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR). I will be meeting with the Budget Committee Members and my state senators and representatives to advocate on behalf of continued funding for the NIH for biomedical research.*

*Then on March 10 – 15, I will be attending the American Academy of Dermatology 2000 Conference in San Francisco. The foundation will have a booth at the conference with a lot of information to be handed out. There are over 17,000 people expected to attend this year, so I am really excited to meet and discuss ichthyosis with everyone. Our Medical Advisory Board will also be hosting its annual meeting at the AAD Conference.*

*Our Board of Directors held its annual retreat this past October in Philadelphia. It was a huge success and we really accomplished a lot during those two days. The foundation is in the process of recruiting new members to expand our board and we have created and restructured some new sub-committees to continue the mission of the foundation. If you are interested in learning more about the board or these sub-committees, please call or email me at the office.*

*I am really thrilled to officially announce the Jane Bukaty Membership Assistance Fund (see page 3). I know this fund will really help out some of our members and I look forward to receiving applications in the next few months.*

*Lots of great news to report about our new website, [www.scalyskin.org](http://www.scalyskin.org). A volunteer who is co-owner of a website company donated his service as well as his employees to set up our new website. I want to thank Laura Phillips and Donna Rice for their assistance in setting up the structure and getting the information together. It should be ready to go on-line within the next few weeks. Now anyone searching for a support organization for ichthyosis and the related skin types will have a great resource.*

*Another great addition to report...the foundation will soon be able to accept Mastercard, American Express and Discover. Donations, dues, conference registration, etc. will soon be payable by credit card. Look forward to this service to become available within a few months.*

*And finally.... The 2000 National Family Conference, F.I.R.S.T. Puts Me First (see page 12-15). Plans are going well and I am already receiving reservations. Since this is my first conference, I am looking forward to meeting old and new members. A lot of exciting ideas have been generated from our conference plans and I hope this year's conference is the best one yet. If you have any questions, please feel free to contact me at the national office.*

*Hope to see you in July at the conference!*

# What's New... What's Hot

## ☛ Recipe for Removing Grease from Clothing



Turn clothes inside out and wash in warm water with warm rinse; using Tide with Bleach, add 1 cup ammonia and 1 scoop of Biz detergent; let clothes agitate for several minutes, then turn the washer off and allow clothes to soak for 20-30 minutes; complete cycle; rinse clothes again; remove clothes from washer and turn right side out; spray the remaining grease spots with a mixture of one part each of Wisk, water and ammonia paying particular attention to collars, sleeves, knees, and hemlines; repeat wash cycle with 2 rinse cycles.

*Another recommended method:* Use a high quality stain remover and a detergent that contains a de-greaser (i.e.-Wisk or Era)

*\*Note: every couple of weeks check inside of washer drum for grease build up, usually around the water line. Scrape off grease and use a de-greaser such as Top Job or Mr. Clean.*

## ☛ Jack King from Glendale, PA writes:

I have been diagnosed with ichthyosis, but fortunately I have a type that only affects my feet and a little on my hands. I have found that taking 5,000 mg of Pantothenic Acid (vitamin B-5) a day helps the condition to a material degree. I also find using "Exomega Ultra Rich Treatment Cream" also gives me great relief.

## ☛ Jim Mackey from Brookhaven, PA tells us:

Ever found a magic pill you could swallow that would cure your Ichthyosis Vulgaris? Well, neither have I, but I have found the next best thing. It's called Alpha Hydroxy Lotion and it can be ordered directly from the manufacturer at 1-800-668-8000. After about two weeks my skin felt soft and smooth, and the scaling and flaking were gone. This product can take anywhere from 30 to 60, 90 days to begin working. So if you decide to give this stuff a try, don't expect results overnight.

## ☛ Khanh Bui from Silver Spring, MD suggests:

To be a profit to sufferers of skin disorders, please allow me to offer them my advice of cortisone pomade which works best in enabling me to alleviate my rebellious disease.

## ☛ Annie Crisostomo from Gulfport, MS writes:

My skin problem began when I was three months old. All of my skin is very dry, and the worst part are my hands. They look like the hands of an 80 year old woman with burns.

Recently my doctor prescribed Lac-Hydrin 12% and an antibiotic, Erythrom EST 250/5ml SUS ALPH. The antibiotic healed my skin and the cream keeps my skin moist and soft. I also use baby oil with aloe vera and vitamin E as often as possible to seal the water inside the skin.

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## *In Loving Memory...*

*Our most heartfelt sympathies to.....*

Dottie & Ralph Hester and family on the passing of their beloved son, Lance, at six weeks of age on October 27, 1999. Lance was born with KID Syndrome. Lance is survived by his parents and brothers, Shelby and Daniel.

The Getz Family in memory of James Haluska who died on November 16, 1999 at the age of 65 from lung cancer. Mr. Haluska was the father of Sue Getz and grandfather of Thomas & Lauren Haluska and Catherine & Sarah Getz.

Lisa Austin and family who lost her beloved son, Shane, on December 2, 1999 at six months and eleven days of age. Shane was born with KID Syndrome. Shane is survived by his mother, and two brothers, Drake and Alexander.

## **Share A Good Book**

The foundation is always interested in learning about informative or helpful books that have aided members through difficult or unique situations. Listed below are some books that have been recommended to the office at one time. We would like to update our list and are asking you to contact the office to share the names of books you have read and found helpful. You can reach the office at 800.545.3286 or email at [jpickford@scalyskin.org](mailto:jpickford@scalyskin.org).

*After the Tears: Parents Talk About Raising a Child with a Disability*, by Robin Simons

An excellent resource guide which covers the full range of domestic and professional issues confronting parents with special needs.

*Autobiography of a Face*, by Lucy Grealy

*Child of Mine: Feeding with Love & Good Sense*, by Ellen Satter, RD, Palo Alto: Bull Pub, Co., 1986

*Developing Social Skills: Issues for Adolescents with Chronic Illnesses & Disabilities*

Available from: University of Minnesota-NYCYD, Box 721, University of Minnesota, Minneapolis, MN 55455; (612)626-2825

*A Difference in the Family: Life With a Disabled Child*, by H. Featherstone

A mother's discussion of how parents and families cope with a disabled child in the family.

*Examining Your Doctor*, by Timothy McCall

A book that, according to the Boston Globe, is "about being a smart, aggressive, competent patient."

*The Exceptional Parent Magazine* For information call 1-800-247-8080

*Little Tree: A Story for Children with Serious Medical Problems*, by Joyce C. Mills

A therapist who tells stories as a healing process

## *'Ode to Shane*

by Lisa Austin

Ichthyosis they said, the word swam in my head  
"Ichy" what? I called back from my birthing bed  
The geneticist replied, "Oh it's much more than that  
KID Syndrome is where this boy is at"  
Blind, deaf and dumb, they said he would become  
Oh how they underestimated Shane Patrick Young  
Imperfect skin, hairless, without speech  
This angel came here with a message for us each  
The team of doctors was unforeseeable  
To feel their compassion was unbelievable  
To a family of nurses he also belonged  
As the time he spent with them, often was long  
Then, one day -for me- it all became clear  
Shane knew no different, he had no fear  
All goo'ed up and full of smiles  
To know my son was well worthwhile

He spread love and joy all around  
The wisdom within him knew no bounds  
Although, he did put up a good fight  
He couldn't stay long, he had packed very light  
A nurse worked all night with the IV lines  
I prayed to God, don't let it be his time  
The doctor had said "I've done all I can  
From here on out Shane is in God's hands"  
In comes the family to say goodbye  
He will leave behind gifts to remember him by  
Light and love shone in from every corner  
Oh how lucky was I to have been his mother  
A tribute to Shane's life, this is what I feel  
He accomplished more in six months than most  
people ever will.

## What is it like to be a Grownup with Ichthyosis?



As a growing boy, I must have thought my skin was just the wrapping I was contained in. I didn't know it is an organ. I didn't know it is actually Me. When something like Ichthyosis is going on with the largest organ in your body, it calls for the largest amount of care.

We didn't always have wonderful treatment products like now. Two old ones I recall are Rosewater & Glycerin, and Noxema; things which simply had no effect. Maybe this was the Doctors trying to help when they had no real help. Later on, they came out with Propylene Glycol under occlusion. For me this was the first therapy which worked. I could feel the skin of my legs against the rough denim of my bluejeans for the very first time. Even that small and temporary miracle required a treatment that was arguably worse than having inherited dry skin.

As a child I was subjected to very hot water baths, special abrasive washcloths, and other abuses. I suspect that most grownups with Ichthyosis have similar bad childhood stories. But today I don't pick at my skin until I bleed like I learned to do as a child. I also refuse to apply grease,

medical ointments, things that smell bad or sting. Instead I can use oils, lotions, and creams; not to make my skin look better for others, but because it feels good to me. I've had to *learn* this loving gentleness as an alternative to abuse, cruelty, neglect.

Today I use lactic acid therapy whenever I want, and my mild case of Ichthyosis Vulgaris is pretty easily managed. Combine that with perhaps the greatest change I made, which is to move South. I live in sunny South Texas, which is a friendly environment for my skin. The humidity and warmth of our long summers really relieve any physical discomfort and are good for me. The mild winters are pretty easy too. I take regular exercise, where I sweat a lot. I believe exercise somehow helps with skin issues by improving my overall health. I also comfort my face with baby oil used after shaving, or whenever I feel "dry." I've learned to simply love baby oil, and I'm not stingy in applying it to myself and to others!

Sometimes the treatments I use for skin care today cause me minor discomfort. I can accept that, knowing that sometimes things have to get a little bit worse before they can get a lot better. That is a lesson I didn't get as a child. It is one I learned after many years had passed; years of neglecting and ignoring my inherited dry skin.

David Morris  
PO Box 12412  
San Antonio, TX. 78212  
Phone (210) 735-2098

## A New Computer for the National Office



The national office has a brand new computer thanks to Elza & Jim Phillips and Laura & Jim Phillips! The office was in desperate need of a faster, more efficient computer system and the Phillips family came to the rescue! The foundation is now equipped with a Compaq Presario computer and Hewlett Packard monitor. Laura & Jim also donated their own personal Hewlett Packard laser printer to complement the package. Thank you for your extreme generosity!

## New Address for National Office

As some of you may be aware, the national office has moved its headquarters from Ardmore, PA to Lansdale, PA. Lansdale is another suburb north of Philadelphia. Our new address is: F.I.R.S.T., 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446. Our local number is 215-631-1411 and fax is 215-631-1413. Our toll-free number 800-545-3286 has not changed.



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

I was pleased to see the New Year arrive, if for no other reason than to hear the last of the Y2K speculations. Any New Year allows a time for reflection and plans for the future, but the Year 2000 seems to demand it.

The fact that F.I.R.S.T.'s founder's day is January 2nd (the day we were officially incorporated as a non-profit organization), is even more reason to look back to our beginnings and see where we want to go. Our charge, to provide information, advocacy and support to individuals and families affected by ichthyosis hasn't changed in our 19-year history and will continue to be our primary function.

It has been an honor to serve on F.I.R.S.T.'s Board of Directors for the past 5 years and I appreciate the board's confidence in me as I begin a second term as President. I look forward to working with the dedicated members of the board and F.I.R.S.T.'s excellent staff.

We are very fortunate to have a group of individuals on the board and on our advisory committees with a long-standing commitment to F.I.R.S.T. Four of F.I.R.S.T.'s past presidents sit on our strategic planning committee. We have board members who helped found F.I.R.S.T., were members when it began or have been involved over much of F.I.R.S.T.'s 19 years. The continuity this affords us as we review policies and procedures or establish new ones to meet the foundation's needs is invaluable.

Please know that F.I.R.S.T.'s board of directors, medical advisory board, and staff are dedicated to providing this organization and its members with the most up to date information about ichthyosis, to advocate on their behalf and to offer support to all who ask.

I hope all of you will join us in Philadelphia this summer for our national conference and will contact the board of directors if you have any questions or concerns about the policies or procedures of F.I.R.S.T. The board can be reached at [boardofdirectors@scalyskin.org](mailto:boardofdirectors@scalyskin.org).

Sincerely,

*Anna Rice*

President, Board of Directors

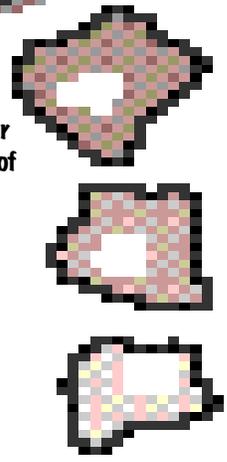
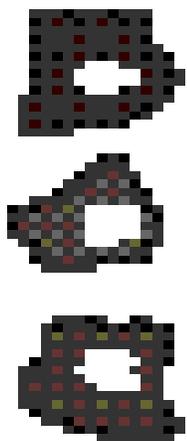


## Are you an Artist?

The foundation is in need of talented volunteers to donate their art services for some of our special projects. While working on these projects, we are often faced with the difficult task of finding appropriate artwork to be included in newsletters, fund raising campaigns, etc.

We know there are many creative, artistic members out there and we are asking for your help.

Are you willing to use your special talents in creating designs and/or pictures for use on F.I.R.S.T. material? If so, please contact Jean Pickford by email at [jpickford@scalyskin.org](mailto:jpickford@scalyskin.org) or call the office at 800.545.3286 to volunteer!



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F.I.R.S.T. neither recommends, nor endorses, products or services advertised in *Ichthyosis Focus*.



**Preliminary Program  
2000 National Conference  
*F.I.R.S.T. Puts Me First***



**CROWN CORK & SEAL**

Special Thanks to  
Crown Cork & Seal  
for its generous sponsorship of the  
National Family Conference

**FRIDAY, JULY 7, 2000**

**Registration** 4:00 - 6:00 p.m.  
**Reception** 6:30 - 9:30 p.m.

Light snacks, cash bar, time to mingle  
Sponsored by Bell Atlantic

**SATURDAY, JULY 8, 2000**

**Breakfast** 8:00 - 8:45 a.m.

Continental breakfast and late registration

**General Session** 8:45 - 10:30 a.m.

Opening Remarks  
What is Ichthyosis? How & who treats it?

**Breakouts** 10:45 - 12:00 p.m.

A. CIE/Lamellar  
B. EHK  
C. Vulgaris/X-linked  
D. Forms of Ichthyosis with Secondary Symptoms

**Lunch** 12:15 - 2:00 p.m.

**General Session** 2:00 - 3:30 p.m.

Panel Discussion with Questions & Answers

**Discussion Breakouts** 3:45 - 5:15 p.m.

A. Mom's Discussion Group  
B. Dad's Discussion Group  
C. Women's Discussion Group  
D. Teenager's Discussion Group

**Open Session** 4:00 - 6:00 p.m.

A. Ichthyosis Registry & Clinical Screening  
B. Ichthyosis Support Network  
C. To Be Announced

**Dinner & Entertainment** 6:30 - 9:30 p.m.

**SUNDAY, JULY 9, 2000**

**Breakfast** 8:00 - 8:45 a.m.

**General Session** 9:00 - 10:15 a.m.

Focus on F.I.R.S.T.

**Breakouts** 10:30 - 11:45 a.m.

A. Education discussion  
B. Tips for talking with your doctor  
C. Ask the Doctors  
D. To Be Announced

**Closing Remarks** 12:00 p.m.



# F.I.R.S.T. Puts Me First

## 2000 National Conference – July 7, 8 & 9

### King of Prussia, PA

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Country: \_\_\_\_\_

Phone (day): \_\_\_\_\_ (evening): \_\_\_\_\_ Email: \_\_\_\_\_



Name of those attending	Adult	Child	Age	Check if affected with ichthyosis
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>

Type of ichthyosis, if known: \_\_\_\_\_



Number of adults \_\_\_\_\_ x \$95 per person = \_\_\_\_\_  
(18 & older)

Number of children: \_\_\_\_\_ x \$50 per person = \_\_\_\_\_  
(1 through 17)\*

TOTAL = \_\_\_\_\_

\*There is no registration fee for children under one year of age

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 Wednesday, June 7, 2000.

(next page please)

I will need child care for \_\_\_\_\_ children (over one year of age)

Name

Age (date of birth)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I am an adult willing to help at the conference for an hour or two (child care, reception table, etc.)

Name

\_\_\_\_\_  
\_\_\_\_\_

I am a teen willing to help with child care at the conference

Name

Age (date of birth)

\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_



PLEASE MARK ALL APPROPRIATE BOXES

This is my first National Conference

I have attended National Conferences in the past (city/year): \_\_\_\_\_

I/We will be staying at the Park Ridge Hotel & Conference Center

I/We are combining the National Conference with a family vacation

For hotel information & reservations call 800-337-1801 toll-free or the reservation desk at 610-337-1800 and identify yourself as a F.I.R.S.T. member to receive the special conference rate of \$80.00/night, any occupancy.

You must call during EST business hours to make your reservation. If you have any questions or experience any difficulty, please call the F.I.R.S.T. office at 800-545-3286.

**Your reservation must be made by Wednesday, June 7, 2000**

Please complete this form and return to F.I.R.S.T. with your payment in full, in US funds please, to:

F.I.R.S.T. CONFERENCE, 1575 GARDEN CITY BLVD., SUITE 101, GARDEN CITY, NY 11530

## Conference Faculty

**Philip Fleckman, M.D.** A member of F.I.R.S.T.'s Medical Advisory Board, Dr. Fleckman is Principal Investigator/Director of the National Registry for Ichthyosis & Related Disorders. An Associate Professor of Dermatology at the University of Washington School of Medicine in Seattle, Washington, Dr. Fleckman also serves as Chief Editor of Dermatology Online Journal. Research interests include the pathophysiology of ichthyosis vulgaris and other inherited disorders of keratinization.

**Geoffrey Hamill, R.N.** Registry Coordinator for the National Registry for Ichthyosis & Related Disorders in Seattle, Washington, Mr. Hamill has worked with investigators on a variety of clinical research protocols, including trials for new medications, and began his career in 1986 as a neonatal/antepartum nurse.

**Leonard Milstone, M.D.** Member of F.I.R.S.T.'s Board of Directors, member of the Medical Advisory Board of F.I.R.S.T. since 1982, and has been Chairman of the Board since 1989. He is Professor of Dermatology at Yale University School of Medicine, and is Chief of the Dermatology Service, Veterans Administration Connecticut Healthcare System. In addition to his clinical and administrative duties, he actively pursues his interest in research which currently is directed toward iron metabolism in skin. Dr. Milstone is an internationally recognized expert on the diseases of ichthyosis and related skin types, and is an Associate Editor of the Journal of Investigative Dermatology.

**Mary Williams, M.D.** Dr. Williams received her medical degree from the University of Chicago School of Medicine in 1969. Following an

internship in pediatrics there, she moved to California to complete her pediatric and then dermatology residencies at the University of California San Francisco, where she has remained as a faculty member. Currently, she is an Adjunct Professor of Dermatology and Pediatrics and Chief of the Pediatric Dermatology Service.

Her interest in ichthyosis began during her dermatology residency, when she participated in the initial clinical trials of isotretinoin (Accutane) for disorders of cornification. With one of her patient's mothers, Mrs. Barbara Landwehr, she co-founded the National Ichthyosis Foundation, subsequently renamed F.I.R.S.T. (Foundation for Ichthyosis and Related Skin Types). She is currently a member of the Board of Directors of F.I.R.S.T. In addition to her clinical activities, Dr Williams has teamed with her husband, Dr. Peter Elias, to investigate the causes of ichthyosis in their research laboratory.

**Ho Jin Kim, M.D.** A new member of F.I.R.S.T. Medical Advisory Board, Dr. Kim recently completed his training as an Intern in Pediatrics at the Children's Hospital of Philadelphia and a Resident in Dermatology at the University of North Carolina Hospitals. He joined the faculty at the University of Pennsylvania School of Medicine in 1998, where he currently serves as an Assistant Professor. His interests include genetic disorders of the skin, dermatologic surgery, laser treatment of vascular malformations, and pigmented lesions. His hospital appointments include the role of Director of the Children's Hospital of Philadelphia Pigmented Lesion Clinic, and the staff dermatologist with the Children's Hospital of Philadelphia Vascular Malformations Clinic. Dr. Kim is a new addition to the F.I.R.S.T. medical advisory board.

## 2000 National Conference *F.I.R.S.T. Puts Me First* July 7, 8 & 9, 2000 – King of Prussia, PA The Park Ridge at Valley Forge

### Hotel Accommodations

The Park Ridge at Valley Forge (as of April 1, the name will change to Sheraton Park Ridge at Valley Forge)  
480 North Gulph Road  
King of Prussia, PA 19406  
610.337.1800 Reservation Desk • 800.337.1801 Toll free

For hotel information and reservations, call one of the above numbers and identify yourself as a F.I.R.S.T. member to receive our special conference rate of \$80.00/night, any occupancy. This rate does not include 6% Pennsylvania sales tax and 2% local room tax. This rate is guaranteed from July 3 through July 11. All reservations must be canceled by 4:00 p.m. on the day of arrival in order to avoid a no-show charge of one night's room and tax. Check-in time is 3:00 p.m. and check-out time is 1:00 p.m.

This special conference rate of \$80.00 is only guaranteed for rooms booked a minimum of one month prior to the conference and you must call during EST business hours to make your reservation. If you have any questions or experience any difficulty, please call the F.I.R.S.T. office at 800.545.3286.

### Airline Reservations

US Airways has the most flights into and out of Philadelphia International Airport. As the official carrier for F.I.R.S.T.'s National Conference they are offering the following discounted fares on roundtrip travel from July 1, 2000 to July 15, 2000:

\* 5% off the lowest applicable published fares

\* 10% off the same fares with 60 days advance reservations

To obtain these discounts, you must call US Airways' Meeting and Convention Reservation Office at (877) 874-7687 and refer to Gold File Number 74671373. There are also discounts on First Class and Business Class fares. Certain rules and restrictions apply. Call US Airways from 8:00 am to 9:30 pm EST for details.

RESERVE EARLY, AT LEAST 60 DAYS PRIOR TO DEPARTURE DATE, TO RECEIVE THE MAXIMUM DISCOUNT.

### Airport Shuttle

Tropiano, 1-800-559-2040, will provide transportation between Philadelphia International Airport and the Park Ridge at Valley Forge for a discounted rate of \$15.00 per adult, 1/2 price for children age 10 and under, and free for children age 2 and under, each way.

Advanced reservations are recommended, but not required. Upon arrival at the airport, travelers can also make arrangements from the "Ground Transportation Center" in the baggage claim area (Dial #19 on the white phones at the counter). Indicate that you are participating in the F.I.R.S.T.

# News & Notes

## Gene Therapy Controversy

Gene Therapy has been a highly regulated technology for several reasons: First, we still do not know whether new genes that are inserted into the human body reach the reproductive organs and therefore may cause irreversible changes in the future generations. Second, we do know that the engineered viruses (called "vectors") that are used to insert new genes into cells can form new, potentially dangerous viruses that can escape in the environment. For these reasons, the scientific community agrees that gene therapy protocols should be reviewed and discussed in a public forum to allay public fears about the new technology.

*Excerpt taken from NORD On-Line Bulletin, December 1999, a publication of the National Organization for Rare Disorders, Inc.*

## New Children's Disability Awareness Video

KidAbility, a newly released video, has been created to provide a great opportunity to understand and improve the lives

and conditions of individuals with disabilities. Produced by Edit Point of Central New York, Inc., KidAbility is designed to introduce children to other children with disabilities and equip them to feel more comfortable. It is crafted to foster sensitivity and acceptance towards people with disabilities. This upbeat, fast-paced disability sensitivity and awareness children's program was released in November of 1999 and is now available for purchase on VHS video cassette. This 26-minute video can be purchased by calling Program Development Associates at 800-543-2119 or write PDA at P.O. Box 2038, Syracuse, NY 13220. For a complete listing of disability related resources, visit PDA's website at [www.pdassoc.com](http://www.pdassoc.com).

## New Appointment

Congratulations to Amy Paller, M.D. for being named to the Board of Directors of the American Academy of Dermatology. Dr. Paller has been a long-time member of F.I.R.S.T.'s Medical Advisory Board and the medical editor of the foundation's newsletter.

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*.

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