



ICHTHYOSIS FOCUS

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Special Issue

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

HOT TIPS

Here are a few bits of practical information from many different sources. F.I.R.S.T. does not recommend any particular tip or product over any other. For medical advice, please consult your own dermatologist.

Westwood Company in Buffalo, NY makes Lac-Hydrin, a prescription lotion, and Lac-Hydrin-Five which can be purchased over-the-counter. Products containing lactic acid or other alpha-hydroxy acids seem to help some sufferers of ichthyosis.

Bacterial infections can be a problem for some people with ichthyosis. Some dermatologists on our Medical Advisory Board suggest adding two **TEASPOONS** (not tablespoons) of Chlorox to one gallon of bath water. Carefully measure each gallon of water as you fill your tub and then mark the tub so that you can always fill with the same amount. For example, add 30 teaspoons of Chlorox to 15 gallons of water.

One mother recommends Kukui Skin Care, a pure, clear oil made from a Hawaiian nut. This product is made by The Hawaiian Kukui Nut Company, P.O. Box 685, Waiialua, Oahu, Hawaii 96791.

Others have had good results from Atrac-tain made by Sween Corporation, Lake Crystal, MN 56055. This cream contains 10% Urea.

Try adding a few ounces of pure glycerin to your cream or lotion, and the skin will stay moist longer. Glycerin bought by the gallon is less expensive than smaller bottles. Most pharmacists will gladly special order a gallon for you.

To remove scales on the scalp, apply your favorite lotion and wear a shower cap to bed. A morning shampoo, massage and brushing may help do the job.

More baths are better. Water helps make dry skin easier to remove and makes people with ichthyosis more comfortable. Be sure to apply lotion or cream immediately after gently towelling dry.

Natural fibers, such as wool or cotton, tend to wick moisture away from the body. You might consider cotton blends for clothing worn next to the skin. However, some people with ichthyosis find rayon and other synthetics to be very irritating.

If you have problems with yeast infections in the groin area or feet, wear cotton underwear and cotton socks. Have your dermatologist prescribe the appropriate prescription medication for yeast or fungal infections. These problems need medical attention.

Air conditioning can be very drying, especially for small children. Fresh air and fans may prove to be more comfortable. However, watch children for overheating and provide plenty of fluids when outdoors in the summer.

Children need to be children. Encourage your child to participate in normal activities and play with peers. Provide water bottles, or as one creative mom suggests, squirt guns, to cool off during hot weather. Another uses a plant mister. Encourage your child not to use ichthyosis as an excuse to avoid contact with others.

A pumice stone rubbed lightly on thickened skin may help loosen crust. Try this when the skin is wet and soft.

If you need to apply dressings or bandages, ask your pharmacist about some of the newest no-stick types now available.

Lacticare works well for some people. Also switching products every few weeks helps others stay clear of scales.

Sunshine can work wonders for ichthyosis, but too much sun can be miserable. We peel from sunburn, too! Always use a strong sunscreen when outdoors.

One mother asked, should I let my little boy play in the dirt? Of course, let him make as many mud pies as he wants. One way to remove dirt from the cracks and creases is to wash gently with a soft fingernail brush.

Depression can be a problem for people with severe and disfiguring skin disease. Seek help from a mental health professional if you see signs of this in your family member with ichthyosis, or yourself if you have this condition. Signs to look for may include increased irritability, significant changes in eating and sleeping patterns, overwhelming feelings of sadness or boredom.

Rumor has it that Hippocrates, the father of medicine, described patients with ichthyosis and commented that those living near the sea seemed to do better. So plan a trip to the beach!

Also, some of our friends say that soaking in salt baths will do the trick. Try adding a pound of sea salt to your bath water.

Oatmeal baths are also soothing. Several oatmeal bath products are available. Check your local drugstore.

Accutane, a prescription oral medication, has provided some patients with dramatic improvement. This drug needs to be monitored closely by your doctor because there are serious side effects. Ask your dermatologist about using this drug and consider the pros and cons carefully with him or her.

Some people get relief from pure lanolin. Mixed with water, it is easier to spread.

Teach children to apply their own creams and lotions. Learning to be responsible for one's own skin is an important developmental process. Sometimes kids refuse to cooperate with the skin routine. Let them assert their independence. When they become uncomfortable, or when appearance becomes important to them, they will once again be willing to follow a program of care.

Aqua Glycolic Lotion made by Herald Pharnacal in Richmond, VA is one product which helps many who suffer from this condition. The lotion can be purchased directly from the company by calling 1-804-745-3400.

Some of our members use Abolene Cream. Find whatever works for you. And remember, we are all different. What helps some people, doesn't work for others.

Give any new cream or lotion a decent trial. And don't expect miracles. Sometimes a product needs to be used for at least two to three weeks before results are noticeable. Don't give up too soon!

Jean Nate's bath sponges wrapped in twine mesh can help remove dry skin. Other bath sponges may also be useful, but be careful not to damage your skin by harsh rubbing.

Teach your child the name of his disease, but don't let it take on a central place in his life. Help him to find responses he is comfortable with when strangers ask questions or other children are rude.

Siblings have special needs, too. Growing up with a brother or sister with ichthyosis can be very hard, especially if the child with the disease gets a lot of attention and help from parents. Parents can be sensitive to feelings of guilt or embarrassment which may arise.

It helps to remember that normal families jerk and grind their way through the years. Adding a child with a genetic disease, or any handicap, causes family stress to skyrocket. Parents can oil the gears with lots of love, respect and empathy, as well as the facts about the disease, in order to make childhood a happier ride for everyone.

New treatments are available for chicken pox. Ask your pediatrician about these BEFORE your child contracts this disease.

Water can make a difference. Some types of water can be more irritating than others. We have heard that some people prefer bathing in well water.

Try to refrain from picking or scratching in public if possible. Parents can help children in the same way they discourage nose picking and passing gas in public. Also, respect your child's body, and don't pick at loose skin in front of friends.

Applying lotions and creams to wet skin seems to work better than putting them on dry skin. The lotion tends to trap the moisture.

Some patients find relief from methotrexate for ichthyosis. Ask your dermatologist about this. Again, carefully consider the pros and cons because there can be serious side effects.

Epilyt is a product which can remove scales from the scalp, but it might be very irritating. This is another one to ask your doctor about.

Some children with ichthyosis have delayed motor development due to the tightness of their skin. Consult a professional early childhood educator if you are concerned about your child. Public Law 99.457 Part H provides special funds which entitle these children to extra assistance. Your public school system is a good place to seek help. Part H specifies programs for infants through age 3.

Benadryl may help some children sleep better if they are having a particularly itchy night. Consult your physician for correct dosage or other suggestions. Other drugs are available to relieve itching.

Body odor can be a problem for people with ichthyosis. Regular bathing is helpful. Adding two teaspoons of bleach to one gallon bath water may help. The problem seems to come from bacteria trapped in the dead layers of skin. Also try Hibiclens, an antiseptic/antimicrobial skin cleanser by Stuart Pharmaceuticals.

Thick scale can sometimes harbor so much infection, causing bad odors, that an oral antibiotic may be needed. Some patients remain on low doses of antibiotics for long periods to control infection. This must be monitored by a physician.

A skin biopsy is needed in order to diagnose exactly which type of ichthyosis you have. There are more than 40 related disorders. A biopsy is not painful and can lead to better treatment. This should be handled by your dermatologist.

Genetic counseling can answer parents' questions about family planning and provide information for people who are soon to marry and start a family. Most large university medical centers have a genetics department which can help you.

Some cosmetics can conceal skin problems such as excessive redness. Check with your local department store for special cosmetics. Or write to Dermablend Corrective Cosmetics, PO Box 3008, Lakewood, NJ 08701 for recommendations.

Dryness around the eyes can be particularly bothersome for people with severe ichthyosis. Ask your dermatologist for assistance with this. Surgery is sometimes recommended when it becomes difficult to completely close the eyelids or the eyelids are pulled inside out by the dry skin.

Neutrogena makes several products which can be soothing. Try out some of the products for extra dry skin. They also make several shampoos which are helpful.

Theraplex Emollient by Medicis Dermatologics is formulated from a highly active emollient fraction of petrolatum with activated hydrosilicone moisturizers. It is nongreasy and is highly absorbed by the skin. Theraplex Clearlotion and Theraplex Hydrolotion are also available.

Retin-A cream is sometimes prescribed for ichthyosis. This medication contains tretinoin which decreases the ability of the skin cells to stick together and may increase the turnover of skin cells. Certain types of ichthyosis respond very well to Retin-A. It comes in several different strengths. Ask your dermatologist if you might be a candidate for using this cream.

Ear canals can be a problem when they become clogged with skin and wax. Be sure to have your child's hearing checked for any impairments. Ear cleaning kits can be purchased at your drug store and used on a regular basis to keep ears clean.

Special cooling suits are available for children who cannot tolerate the heat outdoors. The suit is like a portable air conditioner made by NASA. For more information, contact the F.I.R.S.T. office.

Become a supporter of F.I.R.S.T.! We need your help to continue providing strength and hope to others who suffer from this disease. We can work together for a better future, more research, and more education for ourselves and the general public.

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

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The next best thing to being there

If you were unable to attend the Summer Celebration and Conference in Williamsburg, VA on July 3rd, you might want to order a video of the afternoon events.

The 3-hour video includes lectures by Virginia Sybert, M.D., William Rizzo, M.D. and Eileen Enny Leach, B.S., R.N.

You might see a few familiar faces in the audience if you have been to previous conferences. More than 100 adults and children attended the meetings.

This video also gives you a chance

to see some of our special children in action. Talk about some cute kids! You will wish you had been there, but this is the next best thing.

To order a copy of the video, send a check for \$25 to: Davenport Photography/Video, 4453 Powhatan Crossing, Williamsburg, VA, 23188.

NIH research continues

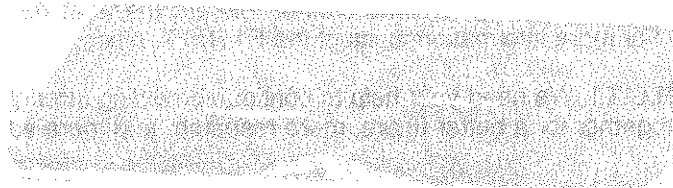
Research geneticists and dermatologists at the National Institute of Health in Bethesda, MD have begun work to locate the gene that causes ichthyosis. In order for this project to be successful, we must help provide them with families

to study.

The project has been funded to provide participants with all-expense paid visits to the clinic which is located near Washington, D.C. This is your chance to have a vacation and help with this important research.

Certain types of ichthyosis are being looked at first. In some cases, all members of family must participate. To find out more about the project, call Dr. Sherri Bale collect at (301) 496-4375.

Blood samples and small skin biopsies are needed. Don't pass up this opportunity for a free trip to our nation's capital to become part of this important project.



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F.I.R.S.T.
PO Box 20291
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