



ICHTHYOSIS FOCUS

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Ichthyosis can lead to depression

Depression has been called the world's number one health problem. Certainly, having ichthyosis can be depressing. But how do you know if you or your loved one with ichthyosis is clinically depressed and needs medical help? This topic was discussed at our 1990 Summer Conference in Orlando, Fla.

Several of our members have become so depressed that they have attempted suicide. We hope that the following information will help you determine if you are depressed, and we urge you to get help from your Mental Health Clinic, a social worker, psychologist or psychiatrist if you feel hopeless about your skin. You may be able to benefit from antidepressant medications.

Some signs of depression include: early

morning awakening (at least two hours before your usual time of rising); feeling worse in the morning with mood lifting somewhat later in the day; significant weight loss and lack of appetite; irritability or agitation; low self-esteem, sometimes to the point of self-loathing; poor concentration; difficulty making decisions; feelings of hopelessness; low energy or fatigue; sometimes sleeping too much; overeating; intense emotions; boredom. If you have more than one or two of these symptoms, you may be suffering from depression. Get some help and experience the joy of feeling good.

Many people find it difficult to acknowledge that they are depressed. Depression is painful, and a depressed person may withdraw from

others which only causes the depression to deepen. No two people react to depression in the same way, but most people do notice a disruption in their sleeping habits. People who are depressed procrastinate a lot. They don't seem to have much energy, and avoid social contact. Rejection may be particularly hard for someone with ichthyosis to handle, even though the rejection may have nothing to do with skin. This can lead to depression.

Major changes in life can make us more vulnerable to depression. Be on the lookout for signs of depression in yourself or family members, especially teenagers with ichthyosis who are trying to form an identity and integrate their appearance with their personality.

Correspondence Corner

Mary McNeill, Rt. 1, Box 745-D, Broadway, NC 27505, would like to hear from others who have ichthyosis. She recently moved and has not found many new friends. Mary is 60 years old and retired. She would like to get to know some other people who have skin problems.

Jackie Rohde wants to pass on this helpful tip: Mix one tube of Lac-Hydrin with 2 oz. of glycerin. Mix well and apply topically. What a difference, she says! She also takes flax seed oil capsules and cod liver oil capsules. She wonders if anyone else has tried these? Her address is 3630 Bel Pre Rd #33, Silver Spring, MD 20906.

Robin Brooks, 226 Troy Dr., Newport News, VA 23606 has a 14 month old daughter with severe ichthyosis. If you are a parent who can offer advice and support to Robin, please get in touch with her.

Mollie Bowling has ichthyosis vulgaris and wants to let you know that she finds pure lanolin to be the most soothing thing she has ever used. She

says it is easier to spread when it is mixed with water. Drug stores can order it for you. She also suggests keeping a plant mister in your car. "I squirt myself on hot days, and it evaporates and brings instant relief." Mollie's address is 1718 Wellesley Ave., Los Angeles, CA 90025.

Joe and Marlene Huffman have a five year old son, Patrick, who has lamellar ichthyosis. They are proud of the way he handles questions and comments from other children. The Huffmans would like to talk with other families who live in their area or with others who may have children in school. "If we can help at least one other person or family, then we'd feel that we've given back a small part of what we've gained from F.I.R.S.T.," they say. Their address is 1326 DeSoto Ave., Glencoe, MN 55336.

Dorothy L. Keller, 1296 E. Gibson Rd., Unit E, Woodland, CA 95695, writes that in 61 years of enduring ichthyosis, Aqua Glycolic Lotion By Herald Pharmacal, Richmond VA, is the only

product that has provided relief. "I use it morning and evening and it keeps the scales to an absolute minimum and enables me to enjoy my smooth feeling skin. I want to share my enthusiasm for this product with others who have given up hope of ever finding help." This lotion can be purchased directly from Herald. Call 1-804-745-3400 to order it.

Charles Eichhorn, our former executive director, says he recently found a bath sponge wrapped in a twine mesh from Jean Nate that may be of interest to some people. It's called the SISAL BATH SPONGE from the Beauty Buff series. Product number JN681. Charles paid \$4.99 for this sponge.

An anonymous person recently sent a check to F.I.R.S.T. for \$50. The letter said, "I have become personally touched and moved by a child whose courage and spirit in accepting adjusting to life with lamellar ichthyosis is truly remarkable. This

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Siblings have special needs, too

Growing up with a brother or sister with ichthyosis may be very hard, especially if the child with ichthyosis gets a lot of attention and help from parents. There are several trouble spots to watch for if you are parents of normal children, as well as one with ichthyosis.

Over-identification, Or Am I defective, too?

Among young children this fear is more prevalent, but for any age, according to Dr. Hal Shigley, A Raleigh, NC psychologist, parents need to confront this worry frankly and factually, which usually dispels fears. Explain the genetics of the disease to older children, particularly ones who are planning to marry and have children of their own.

Embarrassment. Felt by siblings and parents alike, this uncomfortable state can fade when exposed. "At certain ages, kids are more vulnerable," says Dr. Shigley, referring to the early teen years. "The first thing a parent can do is acknowledge it and share some of the same things... give the child choices - don't force him to be part of the family activities all the time."

Guilt. "Guilt can creep in with very young

children and you're not even aware of it," says Dr. Shigley. "There's something called survivor's guilt, something akin to this happens to the non-handicapped sibling." He suggests giving the child clear separation from guilt. Offer facts about the sibling's condition, since lack of facts can exacerbate guilty feelings.

Isolation. Some sibs may feel different, and lonely. Make sure that the non-affected child has friends over often. Parents can help break the ice by telling friends about ichthyosis for the child. It also helps if the family does not make things worse by withdrawing from social life.

Need for Accurate Information. Siblings, like parents, want to know what, when, how, why, and what's next because lack of information adds to the mystery and disruptive power of the disease. Sharing facts can allay concerns. Talk about ichthyosis, don't hide it.

Concern for the Future. Here's a worry even young siblings have. It is important that normal siblings understand that they are not responsible for taking care of their brother or sister. If the child with ichthyosis is severely handicapped, other

children in the family need to know what the parents' plans are for caring for his needs.

Resentment. Dr. Shigley warns that if the family's focus of attention centers on the special needs of a child who is different, there will be resentment. "It's a natural reaction if things are out of whack," he says. The cure involves checking for balance and priorities, and treating each child in the family as exceptional.

Caregiving. "I don't think it's a good idea to give much caregiving responsibility to siblings," says Dr. Shigley, who thinks it muddles the family members' roles. "Get clear who's the mama, who's the daddy, and let the children be the children."

It helps to remember that even normal families jerk and grind their way through the years. Adding a child with a genetic disease, or any type of handicap, causes stresses to skyrocket. But parents who oil the gears with the facts, empathy, respect and love can turn a bumpy ride for siblings into smoother, happier childhoods for all.

—by Victoria Pritchett, a free-lance writer who lives in Cary, N.C.

Accutane brings satisfactory results

I am presently on Accutane, and I know that many members of F.I.R.S.T. are also on Accutane. My dermatologist recently asked me to write to the Food and Drug Administration regarding my treatment and the wonderful effects Accutane has had on my life.

Unfortunately, there are efforts to severely limit the use of or to remove Accutane from distribution in the United States. These efforts come from several different sources. However, the net effect may be one that is not necessarily

beneficial for the large numbers of patients who need this medication.

I would like to see more people write to the FDA about the good effects of Accutane, not only for people with dry skin, but also for the people with severe acne.

Dr. Neal Penneys, a dermatologist at the University of Miami School of Medicine says, "The views of a fanatical few can outweigh those of the silent majority of persons who have had satisfactory results from the use of Accutane. If

you are pleased with the results of Accutane treatment, write your comments to Commissioner, Food and Drug Administration, 5600 Fishers Lane, Rockville, MD 20857 and to the pharmaceutical manufacturer. It is important that the Food and Drug Administration hear from patients who have used Accutane and who support the use of this medication in a safe and controlled manner."

—by Debra Dorazio

Dear Readers,

The last few months have been busy at the F.I.R.S.T. office. Bebe Blades, our secretary, got married in October, and while she was on her honeymoon, the rent came due on our post office box. Unfortunately, we did not realize this had happened until the post office had closed our box and returned some of the mail. Everything is now straightened out, and we hope you were not inconvenienced by this.

We have been busy with several mailings, one of which went out to those of you we had not heard from in a long time. We have let everyone know that we have limited funds and want to be sure to send newsletters to people who really want to receive the information. If you want to remain on the mailing list, but are unable to contribute to the foundation, please let us know immediately. Otherwise, we will remove your name from the computer.

We appreciate the wonderful support we have been getting this fall. You should feel proud to know that your contributions have helped keep the office open and have made it possible for this newsletter to be published. F.I.R.S.T. is supported almost

entirely by donations from individuals who care about ichthyosis. We received very little in the way of corporate donations.

Special thanks go out to two people who recently were instrumental in raising funds to keep us going. Bill Amwake of Pittsburgh, PA collected several hundred dollars from his fellow



Ellen Rowe

co-workers. Larry Getz in Woodbridge, NJ also collected several hundred dollars in donations at his office. Thank you, gentlemen, for your support and perseverance. You did a great job!

And many thanks to all of you who contributed to F.I.R.S.T. this year. Your participation has meant that we have been able to send out newsletters, hold a conference, and keep answering the phone. Plans are being made for next summer's conference, and we hope you will be able to join us. We appreciate your ideas and suggestions so please continue to write.

Sincerely,

Ellen Rowe
President

Each United Way has its own rules

F.I.R.S.T. Vice President Frances McHugh of Delran, New Jersey has recently investigated how the United Way of America designates funds because we have received several inquiries about how funds can be sent to F.I.R.S.T.

Frances reports that each United Way is a separately incorporated and independently run organization. Local volunteers govern them, and it is these volunteers who decide which agencies to fund based on community need.

Just as no two communities are alike, what one United Way does is not necessarily true for

any other United Way organization. Some do honor designations to any bonafide 501(c)(3) charity with no geographic limitations. Others will only honor non-member agency designations to those located within that particular United Way's service area. Still others limit designations to member agencies only.

Before you designate F.I.R.S.T., find out if your United Way will honor your request. We are a 501 (c)(3) organization and can send you a letter to verify this status.

Some United Ways do charge an

administrative fee to cover the cost of raising and processing the designation, but this policy varies according to locality. The best way to be sure that your donation reaches F.I.R.S.T. is to send your contribution directly to our office in Raleigh.



Frances McHugh

New booklets available

The National Research Bureau, Inc. recently published a booklet entitled "Skin Diseases You Can't Catch." The booklet explains that most people take their skin for granted, and that normal skin is rarely perfect. It also explains that skin is more than just a simple covering for the body. Its layers contain many different kinds of cells, blood vessels, glands, muscles and fibers.

This booklet gives a simple explanation of ichthyosis, along with a description of several other skin diseases. It states that "one person in every 250 has ichthyosis vulgaris, a common form of this disease. In its mildest form, ichthyosis may be dismissed as simple dry skin. But people with the more severe forms may have skin so rigid that it constantly cracks and breaks open.

People with the thick scaling of ichthyosis may have trouble sweating and may become dangerously overheated. In the worst forms of the disease, the skin will thicken around the eyes so severely that it causes the eyelids to turn outward. Plastic surgery may be needed.

People with ichthyosis sometimes find ingenious ways to overcome the restrictions imposed by the dry, taut skin. One runner arranged

for bystanders to slosh him with cooling water so he would not become overheated. A teacher with ichthyosis jokes about starting a criminal career - she has no fingerprints. A teenager discovered that daily use of an electric massager to the scalp helped her hair grow through the tough layer of skin.

Topical treatments are aimed at making skin thinner and helping it shed its keratin layer. Powerful synthetic derivatives of vitamin A are sometimes prescribed in capsule form."

If you would like a copy of this booklet, write to: Rhonda Wilson, Editor, National Research Bureau, 424 North Third St., Burlington, Iowa, 52601-5224.

Another new booklet is available from the F.I.R.S.T. office. This booklet was printed by Westwood-Squibb Pharmaceuticals, makers of Lac-Hydrin Lotion. Many thanks to Westwood for this generous educational grant. Lac-Hydrin can be bought by a prescription from your doctor and has been most helpful in many cases of ichthyosis. If you would like a copy of this booklet, please send a self-addressed stamped envelope to F.I.R.S.T., Box 20921, Raleigh, NC 27619-0921.

The booklet covers topics such as : "Just What is Ichthyosis, Is It Contagious?, Is There A Cure? and The Implications of Ichthyosis."

Regional meetings suggested

Andrea Thorn, our first vice president, is interested in finding out if anyone is interested in attending workshops or regional support group meetings. "If it is virtually impossible for you to attend a national ichthyosis conference, but you wish you could just get together with some folks closer to you, let me know," says Andrea.

"I want to find out if there is enough interest in planning a regional support group meeting to improve communication on a more local level," she explains. Please write to Andrea, care of the F.I.R.S.T. office and let her know if you are interested in attending, helping to organize, or hosting a meeting in your area.

Tell Me Doctor

Q. What is the difference between CIE (congenital ichthyosiform erythroderma) and Lamellar Ichthyosis?

A. There is still some dispute about whether these two are variations of the same type of ichthyosis, or whether they are really fundamentally different. They are both inherited as recessive traits (that is, neither parent has ichthyosis) and both involve the entire body, including palms and soles. Only when the exact biochemical cause is unraveled will be able to categorize the differences.

Lamellar Ichthyosis is more severe with large plate-like, dark scales, while CIE tends to have redder skin with finer scales and is easier to treat with topical (surface) medications.

There are some recently discovered chemical differences between the two types, and these findings are very exciting and may lead to discovery of the exact defect, and perhaps in the future, more appropriate treatment will be designed for each type of ichthyosis.

Q. People say my skin has a bad odor. What can I do about it?

A. Thickened skin has a definite, but not unpleasant odor. There may be nothing that can be done about this unless the scale can be thinned down by treatment.

However, thick scale, especially on the scalp, may harbor bacteria, and low grade infection under the scale is not uncommon, and may even

lead to loss of hair, due to infection around the root of the hair. Of course, this may also occur on the skin surface. An unpleasant odor may result. Showering with an antibacterial soap like Hibiclens (nonprescription) may help. Sometimes an antibiotic by mouth is necessary. You may want to ask your doctor about this.

Melodie M. Buxman, M.D. is a dermatologist on the F.I.R.S.T. Medical Advisory Board. She will be happy to answer your questions. Please send your questions to the F.I.R.S.T. office and we will forward them to her.

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

Please put me on the mailing list:

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Ichthyosis type in my family _____ # Persons _____

Mail to: P.O. Box 20921, Raleigh, N.C. 27619-0921.

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

Correspondence Corner

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donation is offered with a deep love and respect for this child." Many thanks to this wonderful person and to all others who continue to support the Foundation with your contributions.

Susan M. Drake, R. 212 South Main St., Ashley, PA 18706 would like to meet other people with ichthyosis and hear how they handle problems related to the disease. Please write to her.

Karen Jones, 201 Mill Road, Johnsonburg, PA 15845, tells us that her granddaughter, Bailey Rae, recently had a severe case of chicken pox, and "we found out how loving and sharing she is...she shared the chicken pox with her 19-year old aunt and 21-year old uncle. All are doing fine now." Chicken pox can be a problem for children with ichthyosis; however, new treatments are available so contact your pediatrician.

Terri Hall, a F.I.R.S.T. board member and active volunteer, reports an interesting discovery about



Our Orlando conference was such a success that we've already begun plans for summer of 1991. We hope you can join us July 3, 1991 in Williamsburg, Virginia and then you can be part of our next family reunion portrait. Here are the happy faces from Florida. See anybody you know? You will receive more information about the Williamsburg conference soon.

the water which she uses to bathe her granddaughter who has ichthyosis. The well water at her vacation home clears up the little girl's skin. She is having the water tested to see what could be different about it. If you want to know more, write to her at 21 Woodclyffe Road, Hurricane, WVA 25526.

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

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