

The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

Send all correspondence to;
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Volume I, Number 4

December 1980

FROM A MEDICAL POINT OF VIEW...

Our guest column this month is by Jane S. Rowe, M.D. She is Assistant Clinical Professor in the Child Study Unit at the University of California, San Francisco, where she specializes in Behavioral Pediatrics.

Parents of a three year old with Lamellar Ichthyosis write:

"Our son is a very intelligent boy with a warm and loving personality. We are so afraid that when he starts school in less than two years, he is going to be ridiculed and made fun of to the point where he will withdraw from society. At times we don't know what to do for him and we get scared and worried... who do we turn to for help in coping with this disease and emotional problems that go along with it?"

[This letter brings up several extremely important concerns of families who have children with chronic (or long-term) disease. The next few issues of Ichthyosis Focus will contain discussions of some of these concerns. It is important to bear in mind that many of these discussions apply to all children, not only children with chronic disease.]

Parents, your concerns are shared by most parents of children who look different from other children in some way. It is important to remember that you are the most important people for your son. The way he feels about himself is determined more by the way you feel about him than by anything, or anyone, else. A child whose parents think he is a "great kid" has the foundation to grow to have the self-confidence he'll need later on.

I am not talking about constant or forced optimism. In fact, you have already taken an important step in helping your son by acknowledging the sadness and emotional anguish you feel. Parents who deny having these negative feelings about their child's disease have a much harder time doing the positive things that need to be done. The unacknowledged negative feelings seem to get in the way.

You are definitely on the right track!

Question: How can we prepare our pre-school child with lamellar ichthyosis for the ridicule he might face when he starts school?

Answer: You are wise to think of this now. You have already begun to deal with this issue by the positive way you feel about your child. We all want our children to be sturdy and resilient and yet we want to protect them. Finding the balance is the hard part.

One way to help him become sturdy is to give him opportunities to be with children his age. At first this should be in a very small and protected setting with your personal supervision. For example, invite a child to your home for a short time--maybe just 30 minutes or an hour.

Gradually, at his speed, he can become used to being with more children and other adults in different settings--other homes, playgrounds, Sunday School, etc... When he feels comfortable, you may want him to attend a nursery school a few hours a week. Again it will be important to choose a place where there are plenty of sympathetic adults and adequate supervision. This does not mean a school for the handicapped unless there are severe complications.

MEDICAL continued...

If you have any questions that you would like to ask Dr. Rowe, please send them to "Ichthyosis Focus", 151 Toyon Drive, Vallejo, California, 94590

IMPORTANT NOTICE...

The National Ichthyosis Foundation is a charitable organization, and 100 per cent of the money collected by it will be used for charitable purposes, such as education, counseling, and research regarding ichthyosis. The organization's major expense at this time is publication of its newsletter. The organization's address is 151 Toyon Drive, Vallejo, California, 94590. The Articles of Incorporation as a non-profit organization have been approved by the California Secretary of State. An application for determination of the organization's tax-exempt status has been filed with the California Franchise Tax Board, and a similar application will be filed with the Internal Revenue Service. Although favorable determinations have not yet been received, we expect that all contributions to the organization will be deemed to be tax-deductible under Federal and California law.

A SPECIAL PRAYER ..

The American Academy of Dermatology is holding its annual meeting beginning this week in New York City. Please hold good thoughts and pray for the safe return of our doctors.

EASTERN CHAPTER...

The first meeting of our Eastern Chapter will be held on Saturday, January 17, 1981 at 2:30 p.m. For more information as to location and directions please contact Marisa Mandia, 687 E. 5th Street 2nd Floor, Brooklyn, N.Y., Phone (212) 854-7084. All are invited---those with ichthyosis, their families, and their doctors. Help someone who needs you by being there.

PRESIDENT'S NOTE...

The holidays always bring the thoughts of being grateful. It can also be a time of sadness when you think of lost loved ones.

This year is a happy one for me because I have found all of you. As we celebrate our holidays, you will always be in our hearts.

Celebrating should be the recollection of loved ones and so it will be.

Celebrate your holidays by celebrating life. Be happy and joyous knowing that we have each other now. As you and your loved ones gather together, look around you and rejoice. Life is so short. Touch your child's face. Kiss your husband's or wife's cheek. Let your eyes rest on an elderly parent who is celebrating with you. Your own aliveness and the lives of those you so dearly love should be the heart of your celebration.

Count your blessings as you look at them around the room on Christmas. Thank God for all the good and beautiful people. Think about how really fortunate you are. Pray that others will join our family this year.

A very Merry Christmas to all of you and may you have a Healthy and Prosperous New Year.

Love to All,

Barbara M. Landwehr
Barbara M. Landwehr

MIDWESTERN CHAPTER...

For all of you that live in the Illinois, Indiana, Ohio, Michigan area or any other Midwestern State don't forget December 7th. This is the date for your first Chapter meeting. The time is 1:30 p.m. at the offices of Dr. Frank Yoder, 29 West College Ave., Westerville, Ohio. For directions or any other information please feel free to contact him at (614) 890-7708.

Let's see everyone come!!!
You'll be glad you did.

SAN FRANCISCO BAY AREA CHAPTER...

Don't forget December 14th!!!
It's our Christmas Party! We invite everyone to come join in our Christmas celebration. The place is the Dermatology Foundation House at 301 4th Street (corner of 4th & Irving) in San Francisco. The time is 2:30 p.m. See you all there!!!

PARTING THOUGHTS...

To end our newsletter this month, is a touching letter by one of our children's cousins...

"My cousin, Robin-Lynn, was born on September 2, 1978. She was born with ichthyosis. When I saw her in the hospital incubator, only hours after her birth, I said to myself, "Why her?" I have learned to cope with her problem. I feel she is the same as everyone else. She has gotten better, and her future is sure to be a bright one, thanks to this Foundation! I say to all people who are afflicted with this and their families "there's hope." God has blessed you all, and you are special."

....Chris Kipcakli

Christmas---a time for caring, sharing, and most of all, giving of ourselves. Let's remember those we love and share our support this holiday season.

Merry Christmas
and Happy Holidays to all!!!

If you are interested in being added to our permanent mailing list, please fill in the form below and send to Barbara Landwehr, 151 Toyon Dr. Vallejo, Calif. 94590.

Name _____	Birthdate _____
Address _____	Phone () _____
Diagnosis _____	

COMMENTS: Why you are interested in our Foundation. If you don't have Ichthyosis who do you know that does? If you have it, tell us something about yourself and your family. Feel free to attach a separate sheet.
