

# NEWSLETTER

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## INTERESTING INFORMATION....

Ichthyosis is a rare condition which affects at least one in every 100,000 people.

Categorically there are four major forms of Ichthyosis.

1. Lamellar Ichthyosis (Congenital Ichthyosiform Erythroderma, non-bullous)  
Rate of occurrence: 1:100,000
2. Epidermolytic Hyperkeratosis (Congenital Ichthyosiform Erythroderma, bullous form)  
Rate of occurrence: 1:100,000
3. X-Linked Ichthyosis (Steroid Sulfatase (enzyme) Deficiency) Rate of occurrence: 1:10,000 males only.
4. Ichthyosis Vulgaris (most common form)  
Rate of Occurrence: 1:250

Various other syndromes include, but are not limited to the following:

1. Atypical Ichthyosiform Erythroderma with deafness and keratitis. Very Rare. Rate of occurrence: 14 or 15 reported cases.
2. Sjögren's Syndrome (including Mental Retardation).
3. Rud's Syndrome (Including Mental Retardation).
4. Refsum's Syndrome
5. Ichthosis Hystrix (Similar to Epidermolytic Hyperkeratosis but not all over the body).
6. Erythrokeratoderma Variabilis
7. Harlequin Fetus--Frequently stillborn.

We apologize if your problem is not listed. We would like to hear from you also.

## OUR BEGINNING....

Pam and I were introduced to one another by Dr. Mary Williams one day at the University of California Medical Center in San Francisco. Dr. Williams asked me to share with Pam, as a mother, what has happened over the years with my daughter.

Our girls, Deatra Landwehr---age 15, and Jaime Lyn Brown---age 2, have different forms of Ichthyosis, both of which are rare (1:100,00). Deatra has Lamellar Ichthyosis and Jaime has Epidermolytic Hyperkeratosis.

We talked about the problems of having a child with Ichthyosis and discussed how great it would be to have a support group. We definitely recognized the tremendous need for such an organization. So I mentioned to Pam that Dr. Williams and I had already discussed it, but it hadn't gone any further.

Meanwhile, Dr. Williams had received a telephone interview and didn't know exactly what it was for. Then she received a letter from a woman in Brooklyn. This woman had written to Dr. Williams because she had read an article that was the result of the telephone interview.

A few more letters arrived. So we decided that now is the time to formalize our new organization.

The National Ichthyosis Foundation held it's first official meeting on August 13, 1980, and it was at that time that we wrote a letter to inform people that we exist.

The second meeting was held on August 27, 1980, to write this Newsletter. So, here we are!

TO BE CONTINUED....

## SOMETHING TO THINK ABOUT ...

Each of us, who is familiar with any one of these conditions, is aware of the extreme frustrations and feelings of being alone and helpless.

It is our goal to provide moral and emotional support, as well as sharing medical information regarding methods of treatments.

## LET'S NAME OUR BABY...

PLEASE help us think of a name for our newsletter. Remember, this is YOUR newsletter, too. We are also looking for contributions of interest to publish. We welcome all you talented writers!

Are there any specific topics that you would like to know more about? Just let us know and we will try our best to comply with your wishes.

## YOU ARE IMPORTANT TO US ..WE NEED YOU

We have been very fortunate in obtaining assistance medically and legally. Our attorney, Mr. William Nachbaur, is helping us to Incorporate and become tax exempt; and our physicians, Drs. Mary Williams and Peter Elias, are eager to help in any way they can, including sharing the latest break-throughs in research as they occur.

At present, we are working on a questionnaire to gather information regarding the experiences and treatments we have encountered. If you have kept a diary of some kind, please copy and forward it to us. It will be most helpful in completing the questionnaire. Also, any ideas for questions to be included would be greatly appreciated. We are looking forward to hearing from you. We cannot stress enough the importance of such an exchange; not only to us, as parents, but also to the dedicated doctors doing research in Ichthyosis.

We are open to suggestions instrumental in making the National Ichthyosis Foundation an immediate reality!

## QUESTIONS FOR CONTEMPLATION...

Can you design a logo? Anyone interested? Please send us your drawings.

Do you have any suggestions on how we can raise money to help defray expenses? (i.e. Newsletter publication, postage, etc...)

Would you be interested in attending a national meeting in the future?

How frequently would you like to receive our newsletter?

How do you see yourself participating in our organization? Just how active would you like to be? What kinds of things would you be interested in doing?

Can you see us functioning in any way other than as a "support group"?

We welcome your dreams and ideas!

Do you know of anyone who would like to be added to our mailing list?

## PARTING THOUGHTS....

You are not alone!

We care about you!

Together we can find the strength to cope with and accept Ichthyosis.

There may be someone somewhere who needs your support.

Maybe, right now, they feel they can deal with it on their own; but knowing you are there, could be the light at the end of the tunnel for them!

So please REACH OUT!!!

WE ALL NEED EACH OTHER!!!