



ISDI Information

a ray of hope through patient awareness and education

Newsletter of the Inflammatory Skin Disease Institute

Volume 6 Number 1



Certificate of Recognition

Dedicated to Improving Lives of People with Inflammatory Skin Disease

One out of 3 people in the United States suffer from skin disease according to the study “Burden of Skin Disease”. This study was conducted by a team of researchers at The Lewin Group. Data was collected on 21 skin diseases nationally with the assistance of the American Academy of Dermatology (AAD), the Society of Investigative Dermatology (SID) and the Coalition of Skin Disease (CSD).

What does this mean?
It means people in the workforce are affected which could limit types of employment which then affects earnings and productivity. It means children in school are affected which may lead to absenteeism and cause parents and caregivers to miss work.

It means families are spending billions of dollars on direct and indirect cost involving medical treatment associated with common but serious disorders like eczema, acne, psoriasis and rosacea just to name a few. This can cause an impact on our healthcare and economy.

together we all can provide a better awareness and understanding of inflammatory skin disease. The Inflammatory Skin Disease Institute works on a local, state and national level. We are proud to report December was declared as Inflammatory Skin Disease Awareness Month. Education and awareness does not have to be limited to one month, it should be a constant. ISDI will continue to meet our mission and remain dedicated to improving the lives of people with inflammatory skin disease.

All of these reasons are why the ISDI is dedicated to improving and providing greater awareness and education on the broad category of skin diseases with such a range in severity. Having inflammatory skin disease doesn't mean you can't lead a happy productive life. Working



Ruthann Newton and LaDonna Williams accepting certificate recognizing December as “Inflammatory Skin Disease Awareness Month” from the representative of Governor of Virginia.



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Comments and topic requests may be sent to the editor: c/o ISDI, P.O. Box 1074, N.N., VA 23601

If you would like to be added to our mailing list please contact the ISDI office at the address above.

Mission

The goal of the Inflammatory Skin Disease Institute (ISDI) is to promote public awareness and enhanced treatment of inflammatory skin diseases through education, research, and patient advocacy.

ISDIInformation is supported by an unrestricted educational grant from Novartis Pharmaceutical.

Director's Message



Happy New Year! As we start a new year we must be reminded of those who suffered through several disasters. The Inflammatory Skin Disease Institute is dedicated to improving the lives of people with inflammatory skin disease. It was a honor to work with the Red Cross, Salvation Army, LINK and the Orthopedic Surgery and Sports Medicine Specialists to continue our dedication and provide clean soft clothing, dressing gauze, bandages, clean water, rubbing alcohol and peroxide to those who lost so much in Katrina, an awful disaster which can only be

compounded if you have inflammatory skin disease. I thank everyone who volunteered and got involved with the ISDI to help ensure that those in need received some assistance. Being a parent of 2 with inflammatory skin disease I am aware of how traumatic the disease can be even under the best of circumstances.

As director of ISDI, I am honored and very proud The Inflammatory Skin Disease Institute closed 2005 with the exciting news: December was recognized as Inflammatory Skin Disease Awareness Month.

LaDonna Williams
Executive Director
ISDI

2005 Derm Day – Patient/Physician Conference

The 3rd Annual Patient/Physician Conference, "Inflammatory Skin Disease and the Quality of Life" was held at Eastern Virginia Medical School. Working with, educating and providing awareness to patients and families, ISDI continues to be dedicated to improving the lives of people with inflammatory skin disease. ISDI is planning their 4th Annual Patient/Physician Conference for December 2006.



Panel discussion – physicians providing education – patients providing awareness of the quality of life.

2005 Patient/Physician Conference kickoff Luncheon for Derm Day

Inflammatory Skin Disease and the Quality of Life
Where patients, family and friends are sharing experiences and emotions while enjoying lunch.



Letters to the Editor:

Dear ISDI Newsletter Editor,

I really enjoy your newsletter. I felt I had to write to you to let you know about a product I recently tried that has helped me so much. First of all, I have very dry skin. My fingers crack open on the edges and are so sore most of the time. I have tried so many lotions and creams that do not work.

The other day, my cousin let me try a moisturizing lotion that she had found called CeraVe. It is made by Coria. She told me how much better her skin was since she had started using it. I used it thinking it would be like all of the rest but I was wrong. It has helped my skin so much. My fingers have not cracked open like before. I like it so much that I recommended it to someone that I work with.

I just wanted to share my luck with some of your readers. It is certainly worth trying. I really was surprised at how well it has worked on my skin.

Thank you for all the wonderful information that I have gotten from the newsletter. Keep up the great work!!!!

JW
Baltimore, Maryland



ISDI works on a local, state and national level to increase awareness of skin disease.

Dear Editor:

I am 28 years old and I have had eczema since I was a child. I also have allergies with many sensitivities. My doctors, allergist and a dermatologist, tried to help me battle my eczema for years without much success. When I was a child my parents tried everything. Several years back I was put on Protopic. It was the first real successful treatment I have used. I have experienced the benefits, it has changed my comfort zone and I have real skin now.

C.G.

Congratulations on your wonderful website! Now you have a tool equal to the task of getting out your important message. All should be very proud of the results.

Jeff

I have been a resident of Hampton Roads since Sep of 2000. Beginning in March 2001, I developed an awful, facial skin rash which no physician or dermatologist has been able to eliminate. It seems to come and go for no specific reason, (mostly come), and when it does it is almost debilitating. The burning, itching, dryness and scaliness practically drive me to distraction. It is difficult to focus at work or in any other environment for that matter. Just taking a shower or washing my face (with tepid water, burns terribly. Initially I was treated with topical steroids, but after two years of those and terrible withdrawal symptoms, the only treatment that has given me any relief is Elidel. Now I'm not going to say it makes my skin clear up totally or feel perfect, but it does make my ailment tolerable. I have read the literature that the FDA has published on Elidel and have talked with my Dermatologist as well. As far as my doctor and myself are concerned, Elidel is still the therapy of choice for my situation.

J.Boyd

ECZEMA

Treatments Updated with New Label Information

On January 19, 2006 the Food and Drug Administration (FDA) announced the approval of updated labeling for two topical eczema drugs, Elidel cream (pimecrolimus) and Protopic ointment (tacrolimus) topical calcineurins (TCIs) with a box warning and a medication guide.

The labels have been updated to inform physicians and patients of rare post-marketing reports of malignancy despite the fact that no causal link has been established between the use of Elidel or Protopic and these rare post-marketing reports. The concern of the FDA for a potential risk for malignancies exists based on the use of oral calcineurin inhibitors at high doses in animals. It is important to remember the warning focuses on a theoretical risk--not clinical evidence.

ISDI understands patients who suffer with eczema should have multiple treatment options to help manage this chronic and life altering disease. **"The only treatment that has ever given me any relief is Elidel,"** states Jill, a patient with moderate eczema for 6 years. The use of topical calcineurins inhibitors on children age 2 and older often help manage their eczema symptoms and reduce the risks associated with topical steroid therapy.

ISDI works with patients with eczema and their families and has seen first-hand how eczema can affect the quality of life of the entire family with the rash, chronic itch and sleepless nights. We have heard statements like, **"I have had severe eczema since I was a child and Protopic is the first successful treatment I have used,"** and **"I have experienced the benefit of Elidel"** and **"The treatment, Protopic, has changed my comfort zone. I have new skin."** Statement like these have proven the TCIs, Elidel and Protopic are a welcomed alternative for the treatment of eczema. ISDI has worked with the American Academy of Dermatology (AAD) and the FDA in support of both Elidel and Protopic. Medical testing has shown because these medications are applied to the skin virtually none of it gets inside the body. It's not the same as taking a pill. These are valuable medications, and if used properly, in a manner consistent with its label, they allow millions of patients with eczema a better quality of life.

Novartis, the makers of Elidel (prescribed for mild to moderate eczema), and Astellas, the makers of Protopic (prescribed for moderate to severe eczema), are dedicated to providing information and will continue to educate and communicate with physicians and patients on the updated label.

www.aad.org/aad/Newsroom

www.fda.gov/bbs/topics/news/2006/NEW01299.html

www.elidel.com

www.protopic.com





THE FAQs ABOUT HIVES (URTICARIA)



ANSWERS TO THE MOST FREQUENTLY ASKED QUESTIONS ABOUT HIVES.



Presented by the Inflammatory Skin Disease Institute

ANNOUNCING
FAQs ABOUT HIVES
(Urticaria) Brochure
now available

NEW RULES

If you are taking Isotretinoin

The FDA has approved iPLEDGE, an enhanced pregnancy risk management program designed to minimize fetal exposure to isotretinoin, a known teratogen. The goal of the iPLEDGE program is to ensure that NO FEMALE PATIENT STARTS ISOTRETINOIN THERAPY IF PREGNANT and NO FEMALE ON ISOTRETINOIN THERAPY BECOMES PREGNANT. The iPLEDGE is the only way to prescribe, dispense and distribute isotretinoin. Prescribers, patients, pharmacies and wholesalers/distributors

are required to register meet specific requirements for the program. Prescribers, pharmacies, and drug wholesalers must be activated in the iPLEDGE program by March 1, 2006.

To learn more about the iPLEDGE program and how it will impact your therapy, click on:

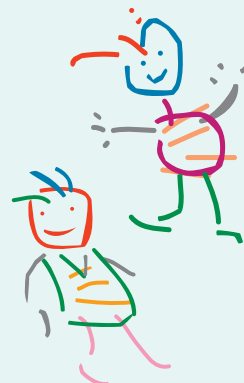
<http://www.fda.gov/bbs/topics/NEWS/2005/NEW01218.html> or

<http://www.ipledgeprogram.com> or call 1-866-495-0654.

Thank You for your Donations



Operating a non-profit organization would not be possible without financial contributions from private and corporate donors. Because of you we can continue to meet our mission. We do not charge membership dues or fees to patient families or caregivers. Donations made to ISDI and fundraisers are the only source of income that we have to produce and distribute our newsletter.





Tasteless Comments

If you are a person with a skin disease, or the parent of a child with a skin disease, you have undoubtedly been faced with those rude, crude, and even well meaning people asking “those questions.”

Do have any snappy comebacks that you want so much to say, or actually have said? Send us your responses and you might see yours in print.

Editor’s Note: The purpose of this section is three-fold: 1) it is an opportunity to educate and make the public aware of the disorder; 2) it lets society know it is not appropriate to stare and ask hurtful questions, and 3) it is an opportunity to let off steam with a touch of humor, allowing us to laugh.

‘Tis the season to be greasing!'

My roommates say, “Boy, you sure do buy a bunch of creams and lotions. Why do you have so many – you’re wasting your money.” My skin is dry and it cracks. Most people do not understand what it is like to have severely dry skin – especially in the winter. Unfortunately, I do. I have to understand. There is a time consuming regimen I go through everyday. Petroleum jelly after I shower allowing approximately 30 minutes to soak-in before dressing. Then creams to continue to moisturize followed by several applications of lotions throughout the day, with heavier creams at bedtime. Only to repeat in the morning.



PENPALS

Reach out to others and share challenges and triumphs in dealing with your disease. Patients often look to others in similar situations to discuss treatments, feelings, etc. The following readers have asked for their names to be presented as possible pen pals. If you are looking for support from someone who has the same disease as you, contact any of the readers listed below. Also, to be added to the list, send your name, address, phone, and/or e-mail to ISDI, P.O. Box 1074, Newport News, VA 23601 or ExDirISDI@aol.com.

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Dedicated to improving the lives of people with skin disease, ISDI attends meetings, workshops and programs to provide increased awareness and education.



how can I HELP?

Yes! I would like to help support the Inflammatory Skin Disease Institute (ISDI).

Name _____
 Address _____
 City _____ State _____ Zip _____
 Phone _____ Email _____

By donating to **ISDI** you will help us provide a ray of hope to people with inflammatory skin disease. An ISDI information subscription is given to all donors.

\$25 \$50 \$100 Other \$ _____

Completed form and payment may be sent to: **Inflammatory Skin Disease Institute (ISDI)** P.O. Box 1074, Newport News, VA 23601

ISDI does not in any way endorse any of the drugs, products, or treatments reported in this newsletter. **ISDI** is not a medical authority and is reporting information with the sole purpose of keeping patients informed. No drugs, products, or treatments should be used without discussion with a physician.

thank YOU!

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