



# 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

By virtue of the authority vested by the Governor in the Governor's Commission of the Commonwealth of Virginia, after a body officially recognized  
**INFLAMMATORY SKIN DISEASE AWARENESS MONTH**  
 INSTITUTE, its mission and work being that of recognizing and educating the public about inflammatory skin diseases and their impact on society.  
 INSTITUTE, encompasses skin diseases often seen, known, and studied at all stages of life, including acne, psoriasis, rosacea, and eczema.  
 INSTITUTE, encompasses skin diseases such as a wide variety of skin conditions, with symptoms ranging from mild to moderate that cause significant pain and discomfort.  
 INSTITUTE, encompasses skin diseases including various forms of psoriasis, acne, rosacea, and other common skin conditions, and prevent and treat them.  
 INSTITUTE, recognizes those conditions that affect many millions of people in the United States, and its members are dedicated to improving the lives of people with skin disease.  
 INSTITUTE, has facilitated skin disease patient advocacy since the Commonwealth of Virginia, and is dedicated to making a difference in the community, community, and continue to do so.  
 INSTITUTE, has facilitated skin disease patient advocacy since the Commonwealth of Virginia, and is dedicated to making a difference in the community, community, and continue to do so.



*Mark R. Warner*  
*Anita A. Rauch*

*Certificate of Recognition*

## Dedicated to Improving Lives of People with Inflammatory Skin Disease

One out 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.

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

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.



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



Volume 6 Number 1

Published by the

## Inflammatory Skin Disease Institute (ISDI)

P.O. Box 1074

Newport News, VA 23601

Phone: (757) 223-0795

Fax: (757) 595-1842

E-mail: ExDirISDI@aol.com

## Board of Directors

LaDonna Williams,  
Executive Director

Ruthann Newton,  
Executive Assistant

Michael J. Carter

Lynn M. Fallon

Barbara Layman

Sally Noone

Kathryn D. Pavlovsky

Timothy Schroeder

Chele Williams

## Scientific Advisory Board

Antoinette Hood, MD

Vincent Beltrani, MD

Mark V. Dahl, MD

Joseph Jorizzo, MD

John Y.M. Koo, MD

David Pariser, MD

Hugh Sampson, MD

## Editorial Committee:

Vincent Beltrani, MD

Mark V. Dahl, MD

Ruthann Newton

Hugh Sampson, MD

LaDonna Williams

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.

ISDInformation 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." Statements 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](http://www.aad.org/aad/Newsroom)

[www.fda.gov/bbs/topics/news/2006/NEW01299.html](http://www.fda.gov/bbs/topics/news/2006/NEW01299.html)

[www.elidel.com](http://www.elidel.com)

[www.protopic.com](http://www.protopic.com)



The screenshot shows a Mac OS X desktop environment. At the top, there's a menu bar with standard Apple menu items like 'File', 'Edit', 'View', etc. Below the menu bar is a toolbar with icons for Back, Forward, Stop, Refresh, Home, AutoFill, Print, and Mail. The address bar shows the URL <http://www.isdionline.org/>. A status bar at the bottom includes links for Live Home Page, Apple, Apple Support, Apple Store, Mac, Mac OS X, Microsoft MacTopia, and Office for Macintosh.

**INFLAMMATORY SKIN DISEASE INSTITUTE**

Announcing ISDIInformation Newsletter will be transitioning to our website:  
**www.isdionline.org**

## 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

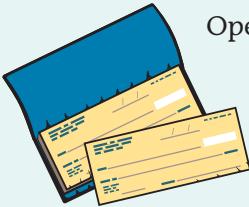
The FDA has approved iPLEDGE, an enhanced pregnancy risk management program designed to minimize fetal exposure to isotretinoin, a known teratogen. The goal of the iPLEDGE program is to ensure that NO FEMALE PATIENT STARTS ISOTRETINOIN THERAPY IF PREGNANT and NO FEMALE ON ISOTRETINOIN THERAPY BECOMES 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.

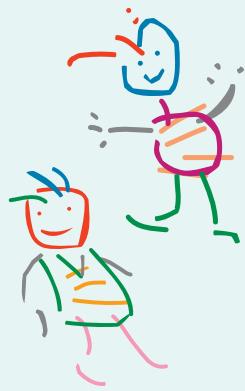
To learn more about the iPLEDGE program and how it will impact your therapy, click on:

<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.

### Eczema

Mr. Francis Gonser  
1022 West Grandview Blvd.  
Erie, PA 16509

Linda Jordan  
2306 Nave Dr.  
Johnson City, TN 37601

Andrette46@aol.com

Toby and Gloria Reyna  
1410 W. Mistletoe  
San Antonio, TX 78201  
(210) 734-0036

Donna Collins  
11956 Weir Street  
Culver, CA 90230

Mary D. Johnson  
8713 Acron Lane  
Hitchcock, TX 77563

Sheri Helmel  
2809 27th Street Court  
Moline, IL 61265

dreamboarder2@aol.com  
chica10029@aol.com

Maura Egan  
38 Tobblin Hill Dr.  
Shrewsbury, MA 01545

Lonestar1070@aol.com

wchele@hotmail.com

### Infant/Toddler Atopic Dermatitis/Eczema

Dafne Holsapple  
dafne@hawaii.rr.com

### Pyoderma Gangrenosum

biffduncan@msn.com

**Acne**  
Kate Ehlke  
wisconsin\_violet@yahoo.com



*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

# thank YOU!

ISDI is supported by corporate and private donations. We would like to thank the following donors (in alphabetical order):

Madeline Abbott (TIBA Inc.)  
Carolyn Abbott  
Allergan  
Lara Alkofer  
Ignazio Alcamo  
American East Corp.  
Anheuser Busch  
Alexandra Austin  
Astellas  
Bank of Williamsburg  
Barr Laboratories  
Stuart Bass  
BCCNS Life Support Network  
Elizabeth Bell  
Susan Bryant  
Joseph Buffa  
Bert Bateman  
Merril Bowditch  
Sasha Brown  
Buffa Ltd.  
Children's Skin Disease Foundation  
Commonwealth Sports Group  
Davis Boatworks  
C.D. West & Co.  
Karen Chaphe  
W.T. Chapin

Vicki Coleman  
Robert Collins  
Mark Dahl, MD  
Jane Dean  
Tina Denison  
Diageo  
Dominion Foundation  
The Honorable Thelma Drake  
Maura Egan  
Kate Elke  
Lynn Fallon  
Ferguson Enterprises, Inc.  
Leslie Finch  
Foundation for Basic Cutaneous Research  
The Honorable Joe S. Frank  
Fujisawa Healthcare Inc.  
Galderma  
Lisa Garner  
Genentech  
Donna Givens  
Alison Graves  
Jeanne Hall  
Nancy Hearn  
Bertha Kopp  
Joe Latchum  
Pam and Matt Green

H&H MultiService  
Don & Chris Hall  
Hill Dermaceuticals  
Hazel & Otis Hopkins  
Hyde Park Communications  
Joe & Mimmas  
Andrew & Tammy Jordan  
JSC Insurance  
Donald Keller  
Herbert Kelly, Jr.  
Diedre Klein  
Ronald Knippling  
E.T. Lawson  
John & Paige Lawson  
Barbara Layman  
Lewis McMurran  
Mike's Place  
Ralph Munro  
Betty Nelson  
Newport News Medical Society Auxiliary  
Novartis  
Deidre Ochipinti  
The Honorable Glenn Oder  
Ortho-Neutrogena  
Orthopaedic Surgery and  
Sports Medicine Specialist

Oyster Point Dermatology  
PADDA  
Patten, Wornon, Hatten &  
Diamondstein PLC  
Georgiana Paul  
Pembroke Construction  
Peter Paine  
Pfizer Pharmaceuticals  
Mr. & Mrs. Robert Phillips  
Ross Pollack  
Rita Pollard  
Marianne Prentiss  
Redex Industries  
Tim Richman  
Charles Rhodes  
Riverside Foundation  
Riverside Regional Medical Center  
Douglas Robins  
Leslie Roylance  
Rhonda and Steve Saunders  
Lynda Schneider  
Tim Schroeder  
Margery Scott, MD  
Rose Marie Seawall  
Micaela Sieracki  
Eric Smith

Jim Smith  
Mr. & Mrs. Jonathan Smith-George  
Denise Spady  
Richman Steel  
John & Sara Streker  
Mary Stuart  
Elizabeth Taylor  
Dicke Teagle  
Kathleen Terlep  
Tidewater Exterminating  
Tommy Garner Air Condition & Heating  
Troutman Sanders LLP  
Towne Bank  
Ann Vaughan  
Mike & Cindy Vick  
Virginia Automobile Dealers Assn.  
Jeff and Joan Verhoeft  
Patty Vonohlen  
Paula Wachstock  
James Wassum  
Susan Weiss  
Nancy Whitley  
Blake Williams  
Gladys Williams  
Judith Williams, MD  
Williams Honda

The Honorable Martin Williams  
Susan Wolf

INKIND:  
Steve Bennett-Esquire  
Danielle Cahill, Ph.D.  
Lydia Capps  
Country Hosting  
Michelle Dancy  
GJB Productions & Marketing  
Simon Harris  
Vicki Kalabokes  
Liz Newton  
Ruthann Newton  
Daniel O'Dorisio  
Omni Resource  
Jack Phillips  
Jane Phillips  
Patrick Phillips  
Elliot Torn  
Dr. & Mrs. Triehmann  
Two Peppers Productions  
Julia Wadell  
Blake Williams  
Zach Williams

Newport News, VA 23601  
P.O. Box 1074

Newsletter of the Inflammatory Skin Disease Institute

ISDI information



Permit #110  
Newport News, VA  
PAID  
US POSTAGE  
FIRST STD