



a ray of
hope through
patient
awareness
and education



U.S. Capitol Building

ON THE HILL: Skin Disease Research Day Presents UNDO BURDEN

There are approximately 3,000 diseases that affect the skin. Skin disease is in the top 15 groups of medical conditions that has increased dramatically in prevalence, soaring health care costs, and affecting men, women and children of all races. Skin disease affects 1 in 3 people in America, ranging in severity and causing great discomfort and emotional stress that can be very limiting to the quality of life.

April 4-5 was when Washington, DC, "THE HILL" received a better understanding of how devastating and costly skin disease can be, not only to the patient but also to the families and caregivers. Physicians, patients and advocates provided information to legislators to urge congress to support a 5% increase to the National Institutes of Health (NIH) for FY 2007. Increased funding provides continued opportunities for advancing basic research and technology. Investment in

skin disease can and has improved the health of Americans. The momentum needs to continue to ease the burden of millions of Americans suffering from skin disease.

Over 65 million Americans see physicians annually due to skin disease. **Get involved.**

Contact your elected officials and let them know how increased funding for the NIH can help. As a constituent you can attest to the importance of increased funding and explain your skin disease and the impact the disease can cause. ☀



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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.

Director's Message



disease.

May marks the 5 year anniversary for ISDI. For 5 years the Inflammatory Skin Disease Institute has been dedicated to improving the lives of people with inflammatory skin disease. As we enter our 5th year, ISDI will continue to focus on our mission. We will educate the public so people with skin disease are accepted and understood. As our awareness bracelet says, "Look Within". The Inflammatory Skin Disease Institute will continue to advocate on behalf of every man, woman and child who suffer with inflammatory skin disease to help improve their quality of life. The ISDI supports research so that people with inflammatory skin disease can have more options for treatments, enhanced medical care, lessen the undo burden and someday, hopefully, a cure.

As a not-for-profit the Inflammatory

Skin Disease Institute relies on our private and corporate contributions. I am so thankful for all our past supports and our dedicated volunteers; together we can make a difference through education and awareness. It is an honor to have continued involvement with the American Academy of Dermatology (AAD), the Society of Investigative Dermatology (SID), and the American Academy of Asthma, Allergy and Immunology (AAAAI).

To celebrate this very important anniversary, I'm inviting you to join us and show your support by sending a tax-deductible donation of \$5 (or more if you wish!) for every person you know that suffers with an inflammatory skin disease.

Many thanks for your continued support in helping ISDI to meet its mission.

LaDonna

LaDonna Williams
Executive Director
ISDI



*ISDI networking-sharing dinner.
Supporting patients and caregivers
involved with skin disease*



*Getting Involved
Attending the SID (Society of
Investigative Dermatology) Meeting*

ISDI is providing awareness and education at health seminar.



ISDI Honors Two Scholarship Award Recipients

ISDI recently honored Daniel H. Anderson and Anna Abrams with a scholarship award for their outstanding essays on their skin disease. Excerpts of both essays are featured below.



Daniel Anderson

Wilmington, Delaware
Will be attending State University New York (SUNY) Maritime College.

The Challenge of the Disease

Beginning at the age of 8 I was faced with the biggest challenge of my life. I was diagnosed with a chronic skin disease called, Psoriasis. I learned then, that I would have to live with this condition for the rest of my life, as there is no cure. Psoriasis is an immune system dysfunction that causes my skin cells to reproduce more rapidly than normal. Most of my body was covered with raised and inflamed, red areas topped with white, scaling skin. These patches, called plaques, would join together to cover large areas of my skin and would itch and burn tremendously. This skin condition was a huge challenge because for the next nine years I was teased by my peers and embarrassed in front of my friends and others. I had to learn how to live and cope with this disease.

Each day I would wake up and would have to go through a regimen for taking care of my skin. It was time consuming and uncomfortable. In the morning I would apply topical ointments. In the middle of the day I would apply lotions and then apply them again before I went to bed. Although the purpose was to treat the symptoms, often the treatment would burn intensely rather than be soothing.

Anna Abrams

Myrtle Beach, South Carolina
Will be attending University of South Carolina



I cannot remember a day in my life when I did not have eczema. I seem to have been blessed with a trio of eczema, asthma and allergies. I have been through many embarrassing moments, sleepless nights, and itching frenzies. However, I have also noticed from examples in my life that having this adversity has helped me become a stronger person and overcome challenges.

Eczema has made me a little insecure about my appearance over the years. But I have also learned with that, that appearance is not everything and that a friend who judges you by that is not worth having. So I try to be that friend that does not judge a person on their looks. From my experiences with this skin disorder, I have become a stronger person in facing adversity and have even increased my self-esteem.

Letter to the Editor:

Dear Editor:

I'm 41 and I have atopic dermatitis since my childhood. Being a long time user of Protopic — it changed my life, I took steroids systemic before — I'm interested in getting your newsletter regulary.

Thanks a lot,
WS,
Aachen, Germany

It's Summertime, Block the Sun — Not the Fun

**Protect Yourself from the Sun
Not Just During Summer Months But All Year Long**

Some helpful tips:

1. Generously apply sunscreen to all exposed skin using a Sun Protection Factor (SPF) of at least 15 that provides broad-spectrum protection from both ultraviolet A (UVA) and ultraviolet B (UVB) rays. Reapply often, even on cloudy days, and after swimming or seating. (If one bottle/tube of sun block lasts all summer - you are not using enough)
2. Wear protective clothing, like long-sleeved shirts, pants, a wide-brimmed hat and sunglasses.
3. Seek the shade. The sun's rays are strongest between 10a.m. and 4p.m.
4. Use extra caution near water, snow and sand since they reflect the damaging rays of the sun which increases your chance of sunburn.
5. Don't seek the sun. Get Vitamin D safely through a healthy diet.
6. Avoid tanning beds. Ultraviolet light from the sun and tanning beds causes skin cancer and wrinkling. If you want to look like you've been in the sun, consider using a sunless self-tanning product, but continue to use sunscreen with it.
7. Check your birthday suit on your birthday. If you notice anything changing, growing, or unusual bleeding on your skin, you may want to seek medical advice. Skin cancer is very treatable when caught early.



People who have skin disease may be more sensitive to sun. Use caution and talk to your physician or pharmacist if you are on any medication that increases sun sensitivity.



Protect yourself. Block the sun and not the fun.





If you haven't had the opportunity to check out our new website, www.isdionline.org, you will find a lot of useful information. Check out the "links" page. These are also sites containing useful, up-to-date information about inflammatory skin diseases and treatments. NeoStrata Company sells skin care products. If you purchase any products from NeoStrata be sure to use this code:

ISDI1000. ISDI will get \$1 for every item purchased.

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

Congratulations to

Mark Dahl, MD

Mark Dahl, MD, professor of dermatology at the Mayo College of Medicine and Chairman of the Dermatology Department was named this year recipient of the Master Dermatologist Award from the American Academy of Dermatology.

The Inflammatory Skin Disease Institute is so proud of Dr. Dahl. It is an honor and a privilege to have Dr. Dahl serve on the ISDI scientific advisory board.

ANNOUNCING

Inflammatory Skin Disease Institute's 4th Annual Conference

"Living with Inflammatory Skin Disease – the Undo Burden"

SATURDAY,
DECEMBER 2, 2006
NORFOLK, VIRGINIA

Topics to be covered:
eczema, contact dermatitis,
psoriasis, acne, rosacea.

Pediatric Eczema Elective Registry (PEER)

Parents and referring physicians can contribute to a "landmark" scientific, observational, mail-based study that will follow approximately 5000 children with eczema during their growing years. Children between the ages of 2 years -17 years who have used Elidel cream to treat eczema may participate in this "real world" observational registry. No physical exams or labs are required. There are no medication requirements or medication restrictions during the entire observation period. The child's eczema may be active or in remission at the time of enrollment. Parents will receive free eczema educational materials and eczema skin care tips during the entire observation period. The parent completes a brief survey at Enrollment and then twice yearly for a 10-year observation period. Surveys can be completed from home by mail, e-mail, phone or fax. More than one child per family may participate. The parent receives \$25 for each completed questionnaire (total \$500.) during the observation period.

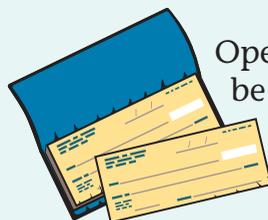
Enrollment is through the community-based physician who provides the Enrollment form and confirms patient eligibility on the form. Referring physicians (PAs/NPs) receive \$100.00 for each eligible patient enrolled. There is no limit to the number of patients enrolled per physician.

For Enrollment forms and/or further information contact (toll-free) 1-877-711-7337 (PEER) or www.Childrenseczemaregistry.com.

Get Involved...

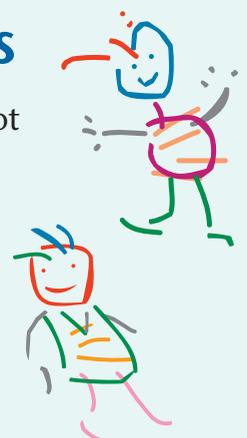
Increase skin disease awareness by calling your congressperson and request that they support House Resolution 652, which names December as Inflammatory Skin Disease Awareness Month.

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 you 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 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.

IT’S NOT ABUSE...

As a parent it gets really annoying when strangers come up to me and say, “What happened to that child?”, or “What did you do to that child?”, as if I abused her. Skin disease is red and sometimes bleeds...but it is not abuse.



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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Ruthann Newton speaking on occupational contact dermatitis at an employee health day.



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 ISDInformation 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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