



Executive Director's Message



The year 2003 is starting with national budget cuts and war. It's an uncertain time.

As Executive Director of ISDI, I am proud to maintain a strong commitment to patient awareness and education to those with skin disorders. Already this year ISDI has attended the AAAAI (American Academy of Allergy and Immunology) and the AAD (American Academy of Dermatologists) conferences. We have

produced a new video, "Eczema Tough Word – Tough Disease" and a new brochure "The FAQs About Rosacea."

I am proud to be a part of this institute. Our outstanding Scientific Advisory Board continues to assist in meeting patient needs and concerns.

Our Board of Directors is well represented nationally and we are proud to announce the addition of the newest member, Barbara Layman.

La Donna Williams

LaDonna Williams
Executive Director

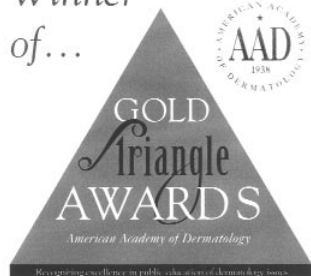


Our newest board member, Barbara Layman, working with us at the AAAAI meeting distributing educational materials.



Ruthann and LaDonna at the AAAAI Annual Meeting promoting public awareness and providing educational materials to attendees.

Winner
of...



2001

Getting Involved

NIAMS DAY 2003

This two-day event was held on March 10-11 and brought together patient advocate groups who benefit from research sponsored by the National Institute of Arthritis, Musculoskeletal and Skin Disease (NIAMS) branch of the National Institute of Health (NIH). Members of the NIAMS Coalition broke into small groups and visited their area representatives in Congress. The purpose was to stress the importance of increasing the NIH budget particularly NIAMS in 2004. ISDI encourages patients and physicians to become advocates by contacting their local representative and requesting an increase in the 2004 budget for NIAMS. ☀

Psoriasis

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Topical Steroids: These are cortisone and cortisone-like drugs. They work by quelling the inflammation in the skin. This makes the skin feel more normal and makes it look much less red and scaly. These treatments need to be used daily, because they only rarely induce remission (where the psoriasis goes away and stays away).

More often when treatments are stopped, the spots come back in exactly the same areas. Nonetheless, the creams are cosmetically nice, and, when used under supervision, they are relatively safe.

Dermatologists worry about absorption when large areas are treated, and they worry about toxic effects on skin such as causing skin thinning, bruising, stretch marks, and acne.

Tars: Crude coal tar ointments and other similar black, smelly potions were used to treat psoriasis before newer, more elegant drugs were discovered. Tars work by inhibiting skin replication, by decreasing inflammation, and by making exposures to ultraviolet light more effective. Tars in shampoos and decolorized tars in ointments are still used and still work. The Goeckerman regimen uses

nightly or twice daily applications of tar ointments to "photosensitize" the skin for subsequent daily treatments with ultraviolet radiation.

Calcipotriol: Because this is a derivative of a form of vitamin D and because the skin can synthesize vitamin D after exposure to sunlight, some patients refer to this treatment as "sunlight in a tube." Actually it works by affecting the movement of

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Great News for EVMS Patients

Recently, Eastern Virginia Medical School (EVMS), announced the newly created Department of Dermatology. Antoinette F. Hood, M.D., professor of internal medicine at EVMS, has been named professor and chairman of the new department.

Previously, dermatology was a division within the Department of Internal Medicine. ☀

Eczema Patient Conference/Children's Day Camp

ISDI is also pleased to announce that we are planning our first patient conference and children's day camp. Please contact ISDI for more information. ☀

Attention Parents of Children with Eczema

Has your 0 – 12 year old child had eczema for at least 3 months? If so, Wake Forest University School of Medicine needs your help. We are conducting a research study (BG 02-294) to develop a survey on the

family impact of childhood eczema (also known as atopic dermatitis or AD). Interested parents will be asked to complete some preliminary survey items, two other surveys about family impact, anxiety, a scale of eczema severity, and some general questions about your family. This will help us determine how well the preliminary measures assess the family impact of AD. It will take about 10 – 15 minutes to complete the surveys. In about one month, you may be called and asked to complete one of the surveys again so we can see whether family impact changes over time. Once we receive your completed information, we will send you a check for \$10 for your time and effort.

This study is voluntary, and all information gathered will be kept confidential. All names and other identifiers will be deleted when the information is entered into a computer system. If you are interested in participating, please contact Sabrina Brown at (336) 713-5091 or sabrown@wfubmc.edu. ☀

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, PO 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
ljordan@ab-t.org

Toby and Gloria Reyna
1410 W. Mistletoe
San Antonio, TX 78201

Andrette46@aol.com

Donna Collins
11956 Weir Street
Culver, CA 90230

Mary D. Johnson
8713 Acorn 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.co

Pyoderma Gangrenosum:
biffdunc@aol.com

Helpful Websites:
www.skincarephysicians.com/eczemanet/
by the American Academy of Dermatologists

www.aaaai.org
by the American Academy of Allergy, Asthma & Immunology

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 we will print some in future issues.

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. ☀

Hands...All shapes and sizes they tell a story

"One time several years ago I was at a local Kmart store. There was a young girl who was a cashier working there. While she was ringing up my items she commented about my hands. She said, 'what's wrong with your hands? They look so white and cold!' I told her that I had eczema and that's how they've always looked. Then she said, 'well they just looked really cold to me.' After I got home, I told my mom about what this girl said. She told me next time someone makes an ignorant comment about that; just tell the person that your hands were born before you were. So far no one has said anything like that again to me, but if they do I can't wait to use the line that my mom told me to use!" — Sheri H.

