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thank YOU!

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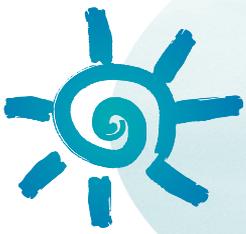
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Newletter of the Inflammatory Skin Disease Institute

ISDIInformation



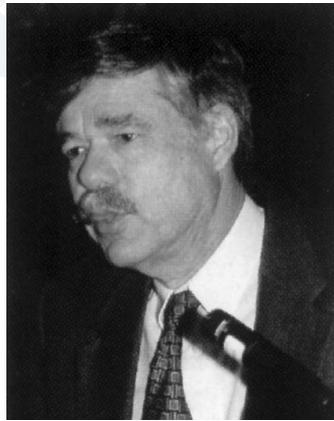


a ray of hope through patient awareness and education

AADA Moves Forward an Agenda to Place Patients & Dermatologists First

The most successful way to resolve issues with managed care companies is to meet with their medical directors face-to-face. The American Academy of Dermatology Association (AADA) has been actively meeting with insurance carrier medical directors on a national, regional, and state level since 1999. The AADA continues to advocate on behalf of patients and dermatologists.

To date, the Academy has met with UnitedHealthcare, Aetna, CIGNA HealthCare, Humana, Anthem Blue Cross Blue Shield, Missouri Blue Cross Blue Shield, and PHS. All of these insurance carriers have been open and receptive to listening to the Academy's message. Discussions with carrier medical directors have covered topics ranging from how dermatologists can get the new treatment for skin diseases covered; coding and reimbursement issues that are important to both patients and dermatolo-



David Pariser, MD, AADA Secretary-Treasurer, and ISDI Scientific Advisory Board Member is a key force behind Medical Directors Summit Meetings.

gists; and the development of evidence-based guidelines to assure that skin diseases and conditions are treated correctly.

In addition to face-to-face meetings with medical directors, the Academy has convened national and regional conferences with key managed care company representatives to get the message across. To date, the

Academy has sponsored five Summits. The Summit meetings are longer and the topics discussed more broad-based in nature than the one-on-one meetings with carriers. A concerted effort has been made to include a presentation from patient support groups. LaDonna Williams, Executive Director of the ISDI, and her son, Zach, a sufferer of severe eczema, put a human "face" on the discussion when they attended the meeting in 2000.

The Summit meetings have been an exchange of information and a learning experience for both the Academy and the insurance carrier medical directors. Early on it became apparent that by involving medical directors as speakers on the program, they would feel invested in the meeting. Medical directors have discussed their views on best practices; the importance of evidence-based guidelines and how their company

conducts the development of these guidelines; and other noteworthy developments in managed care.

Planning for the 2005 Medical Directors Summit is currently underway for a fall meeting in Chicago. Patient advocacy will again be featured on the program. The Academy continues to move forward an agenda that places patients and dermatologists first. ☀

ECZEMA

TOUGH WORD TOUGH DISEASE

is now available as an informative video on eczema.

**For more information contact:
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ExDirISDI@aol.com**



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Comments and topic
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Institute (ISDI), 2004

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

*This issue of ISDI Information
is partly supported by an
unrestricted educational grant
from Riverside Regional Medical
Center.*

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.

ISDI Honors Two Scholarship Award Recipients

ISDI recently honored Kelly Thomas and Kathryn C. Drohan with a scholarship award for their outstanding essays on their skin disease. Both essays are featured below.

How My Life Has Been Affected By My Skin Disease

by Kelly Thomas



I have had eczema since I was born. Dry, scratchy skin has plagued me since I can remember. Being diagnosed with eczema has affected me by changing my outlook on life. I have learned the importance of not judging others by their appearance. I discovered that through my extensive visits to doctors and dermatologists, I would like to pursue a career in medicine. I have learned that I am a strong and determined person.

When I was in sixth grade, I had a bad outbreak of eczema on my face and neck. My friends never teased me about it, but when I met someone new they would treat me differently. They would ask me weird questions that I felt very uncomfortable answering. I didn't know how to react. Sixth grade was a hard year, but ninth and tenth grades were worse. In ninth grade I started developing warts on my

hands. This was the result of a cream that had a high steroid count. Over the next year the warts multiplied, at the end there were about fifty warts on my hands. I couldn't imagine what others thought of me when I showed my hands. I was extremely self-conscious, only a few kids from school teased me. Now when I see others with flaws that they can't control, I look past it to see the person within.

Throughout my entire life I have seen over ten doctors/dermatologists just for my skin problems. Each has prescribed me with a new lotion or cream, and medication. Each new doctor telling me that the last doctor was wrong in giving me the past lotion. Right now I use two creams, Triamcinolon 0.1% and Elidel 1%, and I take 20 mg of Doxepin at night to control my itching. I have worn cotton gloves to bed for the past five years. This has made me think about my own future. I would not want others to go through the same turmoil as I did. I would like to pursue a career in medicine, particularly in dermatology. I know

I would be a good dermatologist because of my own experiences. I understand what it is like to have a skin disease and will be able to relate with my patients.

When I had my warts, I went through the very painful procedure of laser treatments. Each procedure was more painful than the last. I know that my strong will and determination got me through those three procedures. My hands were sore for days after the procedures.

Living with eczema has been difficult but it has taught me so much. I have gone through the experience of being teased or treated different. Since I know the effect on the person, I always try to look past a person's physical appearances. Because of my eczema I hope to someday become very successful in my career because of it. My procedures and treatments have shown me that I am strong-willed and determined, I never gave up. Having eczema can be hard but it has given me a different outlook on life.

Continued on page 3

"Summertime and the living is easy...."

During these summer months please remember: fishing, boating, gardening, golf, and vacations in general spell fun. Don't allow the sun to spoil a good time.

According to Mark V. Dahl, MD, Department of Dermatology at the Mayo Clinic in Scottsdale, Arizona, sun damage causes about 80 percent of all skin cancers. Sunscreens and measures to avoid the sun help reduce risks for skin cancers. They also reduce risks for wrinkles, pigment spots, and roughness. Every ultraviolet (UV) ray that hits your skin damages it a little and this damage adds up over time. Sun exposure also damages DNA in the genes of your skin, setting the stage for later skin cancer. It is important to stay out of sunlight and tan-

ning booths. There is no such thing as a safe tan.

The ozone layer of the atmosphere screens out some rays, but others get through. In the early morning and later afternoon, the rays pass more sideways through the ozone layer and are better screened out. Shaded areas clearly reduce the potential for sun damage. However, even shaded areas contain UV rays bent by the atmosphere and bounced off snow, buildings, and other objects.

Sun Safety Tips:

A broad-spectrum sunscreen, that has an SPF of at least 15 and screen out UVA and UVB rays, should be applied liberally. The SPF testing requires application of large amounts of sunscreen. It's equivalent to an amount the

size of a golf ball to cover the whole body. Most people under apply sunscreen, so they get much less protection than they bargained for.

Sunscreens are available in creams, lotions, gels, and sprays and should be applied to all exposed areas. Sport sunscreens are less likely to wash off and less likely to sting or burn if sweating washes them into your eyes. Reapply and use even on cloudy days and during all months;

- Wear protective clothing, wide-brimmed hats and sunglasses;
- Stay in the shade when possible; and
- Avoid peak-hours – try to plan outdoor activities in the early part of the day or late in the afternoon.



Often people with inflammatory skin disease react differently to the sun's rays. Your dermatologist may have specific suggestions for sun safety.

It's never too late to start protecting your skin.

Have a great summer and Block the sun – not the fun. ☀

Patient Corner

Continued from page 4

Penpals

Continued from page 4

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Infant/Toddler Atopic Dermatitis/Eczema

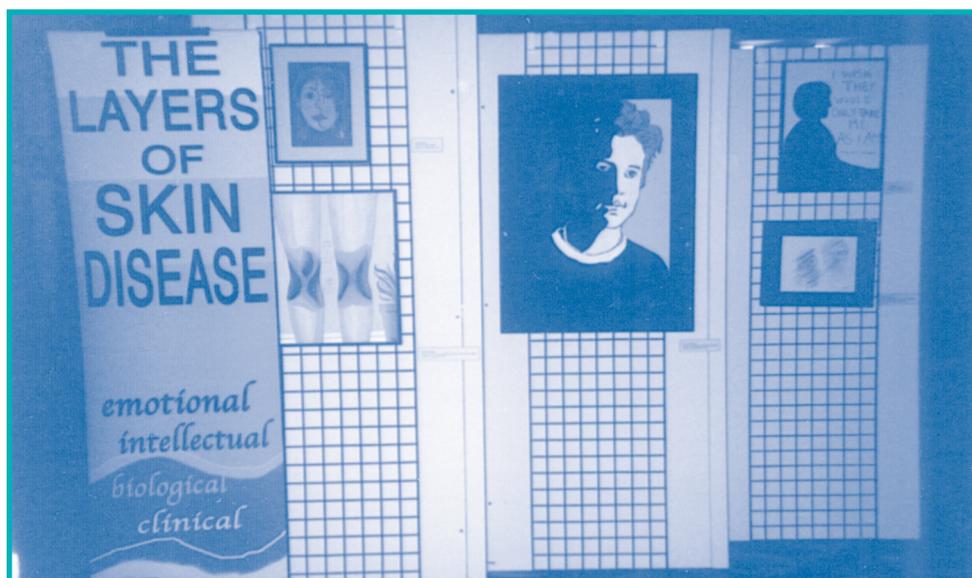
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The Layers of Skin Disease

A patient art exhibit presented by the Society of Investigative Dermatology and the Coalition of Skin Diseases was held in Providence, Rhode Island at its 65th Annual meeting. In just two years the exhibit has doubled in size. The "emotion of their skin disease" was expressed in different mediums from acrylics to weavings. Children and adults participated in this exhibit.





Executive Director's Message



Awareness and education on the burden of skin disease goes beyond the dermatologist's office. The Inflammatory Skin Disease Institute (ISDI) continually develops new educational materials to increase awareness and education. The burden of inflammatory skin disease often is due to lack of education, awareness, and support. As executive director of ISDI, it is an honor to advocate for patients with inflammatory skin disease as well as provide networking programs which allow a better understanding of issues other than just the skin disease itself, but also its costs –



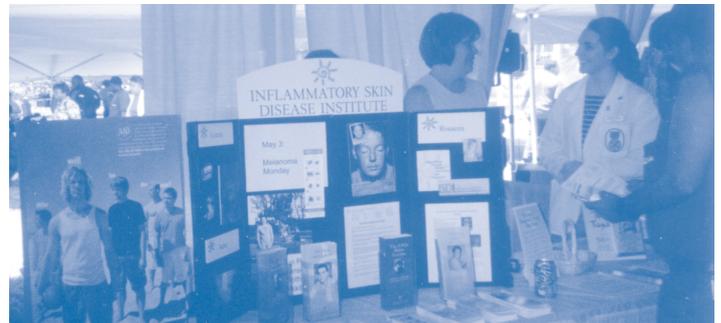
sleepless nights, pain, emotional stress, family involvement, missed work/school to mention a few. These lifestyle issues are 24/7 and go beyond what is seen in the doctor's office. It remains our mission: to improve the lives of people with inflammatory skin disorders.

LaDonna Williams

LaDonna Williams
Executive Director



ISDI providing education through community awareness programs held at Virginia Air & Space Center.



Sun safety/skin disease awareness program for the city of Norfolk, VA.



ISDI and Ferguson Enterprises, Inc. working together in the community to provide information on sun safety and skin disease.

ISDI Honors

Continued from page 2

By Kathryn C. Drohan



Having eczema since I was six months old, I never realized how having the disease affected my life. All I knew was that I had to take oatmeal baths that smelled disgusting, and I was forced to plaster myself with greasy creams that took hours to

soak into my skin. However, none of them ever seemed to work. After going to numerous dermatologists and pediatricians, there was always some new cream to try, or some new method to relieve the itching, but it was all in vain. Even now, at 18, I have to sleep with gloves on my hands to keep from ripping apart my skin. And recently I have been to the doctor for what appeared to be acne, but turned out to be, yet again,

eczema. I was put on Elidel, but even that doesn't clear my skin. Being 18 and having visible skin disease certainly puts a strain on your self-esteem. However, though many people stare at the scars and the open cuts, I've learned to ignore the comments and go on with my daily life.

Though having a skin disease has many negative aspects, I've learned numerous life lessons from having

eczema. The first lesson has to deal with concentration and patience. When life gets stressful, or I get anxious and nervous, the itching tends to increase to an irritating level. In order to ignore the burning desire to scratch, I am forced to concentrate harder on whatever I am doing. I have also learned that by being patient and taking the time to calm down, the itching

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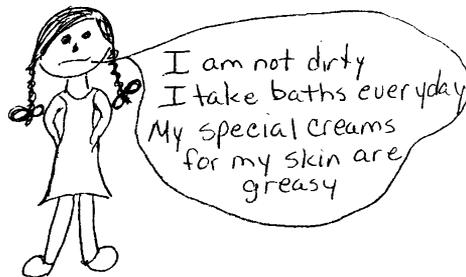
Tasteless Comments *by Ruthann*

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."

These times are great opportunities to educate people about that which they know nothing about. However, at the same time, I am irritated that I feel obliged to offer an explanation about my child. We all have our "pat answers" that we give in these situations. But if you are like me, you also have to hold onto your sanity somehow so as I am politely giving my "pat answer" I am thinking to myself what I really want to say.

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

Greasy Weezy



in future issues. By sending in your comments you are giving ISDI permission to print your statements and name in future issues of *ISDIInformation*.

My daughter has to take soaking baths daily to hydrate her skin and then apply special creams and lubricants to moisturize her dry, itchy eczema. They often leave a greasy film and cause her hair to look dirty. Other kids tease her and say hurtful things about her being dirty.

When in fact, she is probably the cleanest kid on the block.

- Clean Mom

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

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ISDI Honors

Continued from page 3

subsidies. In this way, having a skin disease has actually improved my concentration during daily activities and has helped me to become a better student. Another lesson from eczema also deals with patience. However, it is patience with others rather than myself. Other people are always commenting on how much I scratch or itch and are always scolding me to stop. I've learned to simply take a deep breath and have patience because I realize that they are ignorant to what having a skin disease is like. I've also learned to have compassion on those

who are physically different from others. I understand what it is like to have people stare and snicker, even if they do not know you. It has taught me not to judge others based on appearance. Overall, I have learned that life is much more than having a skin disease or being worried about physical appearance. I have learned instead to be grateful for the other gifts I've been given - my academic and musical abilities and my loving family and friends.

You can make a donation to support the ISDI scholarship program. Payable to ISDI Scholarship. Send to P.O. Box 1074, Newport News, VA. 23601.

Announcing the 2nd Annual Patient/Physician Conference to be held this fall: Eczema the Triad: Asthma? Allergy?

.....
For more information contact ISDI at (757) 223-0795 or email: ExDirISDI@aol.com.