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For more information contact:  
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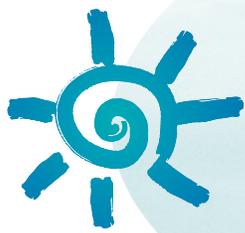
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Newletter of the Inflammatory Skin Disease Institute

**ISDI** Information





a ray of hope through patient awareness and education

## Eczema Conference – Tough Word – Tough Disease

In November, the Inflammatory Skin Disease Institute held their first eczema conference at the Eastern Virginia Medical School (EVMS) in conjunction with the new Dermatology Department. Dr. Toni Hood, Chairperson of the new Dermatology Department at EVMS, stated, "this conference is the first of many that ISDI and the Department intend to hold in the future." Plans are presently in the works for a joint spring program.



Patients, family, and friends taking a break and getting to know each other.

Adults and children from New York, Pennsylvania, Maryland, North Carolina, and Virginia were in attendance at the one-day eczema conference, Tough Word – Tough Disease. Dr. Margery Scott and Dr. Robert Pariser discussed topics such as "Treatments Old and New – Tried and True." Attendees asked many questions about the recently released Topical Immunomodulators (TIMS) such as Tacrolimus (Protopic) for moderate to severe eczema and pimecrolimus (Elidel) for mild to moderate eczema.

Dr. Hood conducted a patient panel discussion with patients ranging in

age from 7 to 35 years. The statement, "the itch that rashes" was made by Dr. Hood. Most of the attendees and the panelists agreed that the unbearable itch is the hardest part of the disease. Seven-year old Melissa stated "the only thing that gives me any comfort at night is when my mommy rubs my back and sings to me."

"Eczema is a constant for many. The itchy, sleepless nights takes us into unavoidable public settings in the day like work and school," stated LaDonna Williams, Executive Director of the ISDI. Zach, an 18-year old senior on the panel stated, "I used to be

embarrassed when I had to shake hands at work or school but I have learned a comeback when people ask, 'Why do your hands feel so rough?' I just say, 'That's a real man's hand and laugh it off.'"

At the end of the day the information packed conference had eczema patients and families networking among themselves and exchanging e-mail addresses. Kelli, a 15-year old, shared tips with younger attendees about friends that tease her really aren't good friends. The conference provided educational information and resources as well as patient support. The Dermatology Department at EVMS is a welcome addition to the Tidewater area and Virginia.

The plans have begun for a second annual eczema conference. If you or a family member need information, please contact ISDI at (757) 223-0795. ☀

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Comments and topic requests may be sent to the editor, c/o ISDI, PO Box 1074, Newport News, VA 23601.

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**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.

# Living with Itch

Submitted by Vishal Khanna and Lauren Dawson

Steven Feldman knows all about the effects of chronic itch. As director of Wake Forest University School of Medicine's (WFUSM) Psoriasis Treatment Center, Feldman sees patients on a weekly basis whose lives have been greatly affected by the recurrence of itch. However, his understanding of the effects of itch goes much further than just a clinician's empathy. Feldman's youngest son, Noah, has both atopic dermatitis and urticaria, two conditions directly related to the uncomfortable experience of chronic itch. "The most concrete effect is the missed sleep when he's itching and wakes us up," says Feldman. Noah's condition has led to many sleepless nights for the Feldman family. "But," Feldman notes, "there is also the parental sadness of seeing your child suffer."

The Feldman family is not alone in their experiences. At least 20 percent of the U.S. population suffers from chronic itch, and the effects of this condition can be tremendous. Ron Barkin's seven-year old daughter, Melissa, was a member of a panel discussion at ISDI's patient/physician conference for Eczema/Atopic Dermatitis, Tough Word – Tough Disease. Melissa suffers from eczema and asthma, and coping with the effects of the condition have been trying for her and her family. "My wife and I would take turns from 10 at night to 5 in the morning rubbing [Melissa's] back so she

would be comfortable," says Ron Barkin.

LaDonna Williams, executive director of ISDI and mother of two children with eczema, remembers those sleepless nights well. "Being a parent of two children with full body eczema I can feel the frustration and I can feel the pain," says Williams. "I can remember so many sleepless nights."

"Itch can be a debilitating factor in a person's life," says Gil Yosipovitch, M.D., associate professor at WFUSM and renowned itch specialist. "People can wake up from the itching, and a bad sleep can affect the entire day." Along with its effect on quality of sleep, says Yosipovitch, chronic itch can also affect behavior patterns and interactions with family and friends, and in some cases can lead to depression and agitation. In the most severe cases, says Yosipovitch, "the patient [can] scratch himself until he bleeds, and uses pain to alleviate the itch."

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When asked how eczema feels, Melissa Barkin replied, "It feels like you're on fire."

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Yosipovitch's interest in studying the mechanisms and effects of chronic itch has led him to conduct a number of studies focused on itch and to produce dozens of publications on the subject. One of

Yosipovitch's primary interests is to raise the awareness of chronic itch as a treatable symptom:

"Pain today is a topic in medicine which, throughout different disciplines, stands by itself. We may not cure all diseases but we try to relieve the pain. In that same sense, itch is an orphan system. But the amount of attention, until recently, given to it has been minimal. Physicians look at itch as a side effect of other problems, but we need to look at it as a symptom standing by itself. If we find ways to reduce itch regardless of trying to cure the skin disease causing it, it would be of great benefit to our patients."

Along with his research and publishing efforts, Yosipovitch has also been instrumental in developing and maintaining the International Workshop for the Study of Itch, a biannual international conference of global itch specialists from diverse disciplines. "In the first workshop," says Yosipovitch, "people from different areas dedicated to the multidimensional aspects of itch came together in Singapore. [This meeting] emphasized how much we need to learn about itch and how much we don't know."

What we do know, however, is that itch is not just caused by dry or scaly skin. The causes of itch are quite complex and dependent on a range of variables. To

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## Living with Itch

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understand the underlying cause of itch, it is important to first understand how skin and nerves work. Skin serves many important functions to the human body. It prevents water evaporation, protects the body from foreign organisms, and provides sensation for touch and feel. A complex relationship exists between skin cells, cellular chemicals, the nervous system, and the brain. The sensation of itch may relate to one or all of these components.

Our skin releases chemicals in response to certain stimuli. These stimuli may be foreign agents like chemicals or organisms, or they may be mechanical in origin, such as scratching. The chemicals skin releases include histamines, leukotrienes, and prostaglandins. These chemicals, in some instances, then connect to nerve cells that will send a signal to the brain. The brain tells us that a certain area itches, which causes us to scratch that area.

Based upon this process, researchers have come up with four basic mechanisms of itch: itch that originates from the skin; chemically-induced itch; itch related to damaged nerve fibers or internal diseases such as chronic renal failure or liver disease; and itch based on psychiatric reasons.

Current treatments geared toward itch tend to focus on topical therapy, light therapy, and systemic therapy.

### Topical Therapy

Topical therapy refers to any medications that are directly applied to the skin. The medications can come in many different forms. The most common are creams, lotions, ointments, and gels. The choice often depends on the location of the itch, patient preference, and the extent of the itch.

Topical treatments are usually the first line of therapy and the choice of treatment is directed at the cause of the itch. For instance, topical treatment for psoriasis is very different than treatment for dry skin. Again, a dermatologist can help decide the best option. Commonly used topical treatments are lotions that contain menthol, camphor, and/or phenol. These lotions work by causing a cold sensation as the solution dries. Recent developments in certain moisturizers which contain ceramides have, in some cases, been shown to also have unique anti-itch properties. Topical antihistamines and anesthetics, however, are often avoided because many people experience adverse allergic reactions when using them.

In the winter months, many people experience itch because of dry skin or atopic dermatitis. Hypoallergenic moisturizing lotions help and should be applied directly after bathing, before the skin dries.

### Light Therapy

In the mid-1900s, dermatologists noticed that many of their patients with

chronic itch felt better in the summer. This observation led dermatologists to discover that ultraviolet (UV) rays from the sun help reduce itch in many skin conditions helping slow the production of skin cells and reduce inflammation. Soon after, dermatologists began to use artificial light therapy as treatment for certain chronic itch conditions. Light therapy is most useful for severe psoriasis and for specific conditions in which topical therapy does not work. There are two types of light rays—UVA and UVB—and a dermatologist will help a patient decide which is best for them. It is very important that a patient NOT try to administer light treatments by themselves. Improper light therapy can lead to serious consequences.

### Systemic Therapy

Systemic therapy refers to medications that affect the entire body, not just the skin. Usually taken by mouth, the most common systemic medications are antihistamines. These medications slow the release of histamine and are therefore most useful for people with histamine-related itching (for instance, hives). Some antihistamines may work by sedating people. The sedation may help reduce the itching and allow people to sleep better. Unfortunately, most skin diseases do not respond well to antihistamines.

Other systemic therapies exist but are usually directly related to the specific

cause. For instance, there are medications specifically designed for people with itch secondary to renal failure. A dermatologist will assess the cause of the itch and then prescribe the appropriate therapy. Since systemic therapy does affect the entire body, many dermatologists prefer to use it only for severe cases or specific diagnoses.

Gil Yosipovitch has just returned from the second International Workshop for the Study of Itch in Toyama, Japan. He was a bit jetlagged, but excited about the future of itch research. “The complexity of the symptom has been revealed and we understand that many factors are involved,” says Yosipovitch. “The more of an understanding we get of itch, the possibility for more venues of treatment will arise. While Yosipovitch fully agrees that there is no simple equation or magic treatment for itch, “we will be able [in the near future] to better help patients reduce their itch and improve their lives.”

This is good news to folks like the Feldmans, Barkins, and Williams. It’s also good news to Ron Talento, another panelist in ISDI’s recent patient/physician conference. Talento has lived with chronic itch related to eczema all his life, and is experiencing it again through his daughter. “I just feel for her so bad,” says Talento, “because I know what it feels like to be a kid and [be] itchy and scratching.” ☀





# Executive Director's Message



As we close 2003 and prepare for 2004, ISDI begins to set new goals.

Our patient conference, "Eczema – Tough Word – Tough Disease" was an educational success. We are in the planning stages of a spring program on skin care and sun safety. With continued support from the Executive Board Members and the Scientific Board Members ISDI will continue to meet the needs and *remain dedicated to improving the lives of people with skin disorders.*

*LaDonna Williams*

LaDonna Williams  
Executive Director



The Inflammatory Skin Disease Institute is honored to receive our **2nd Gold Triangle Award** from the American Academy of Dermatology for excellence in public education of Dermatological issues.



*LaDonna and Ruthann accepting the Gold Triangle at the summer AAD Meeting 2003.*

**THANK YOU**  
**Remembering Our Volunteers**  
Thank You for Volunteering  
**554 HOURS**  
of Hard Work!  
**THANK YOU**



*Sharing information at the International Investigative Dermatology Meeting with Dermatologists from around the world.*

## NIAMS Workshop

Recently, the National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS), with support from the Office of Rare Diseases, sponsored a workshop entitled "Immunomodulatory Drugs in the Treatment of Skin Diseases: What Can We Learn about Pathophysiology?" on the NIH campus in Bethesda, MD. The meeting was co-chaired by Dr. Alan N. Moshell of NIAMS and Dr.

John R. Stanley, chairman of dermatology at the University of Pennsylvania. The meeting brought together speakers from the U.S. and Europe, representing academia and the pharmaceutical industry.

The focus of the meeting was on the already approved and about to be approved drugs that work by modulating the immune system for the treatment of

skin diseases. Some speakers addressed basic immunology of the skin and the immunologic basis of the various drugs' mechanisms or actions, while others focused on what we can learn about the disease by studying how the drugs work.

The first part of the meeting focused on psoriasis and atopic dermatitis as the two diseases where experience with these drugs has

been the greatest. Other diseases where these drugs have been used was also addressed later in the workshop. Finally, based on known or presumed disease mechanisms, a variety of other diseases were discussed where the use of these drugs has a scientific basis, but where experience in their use is limited or waiting studies.

*Continued on page 4*





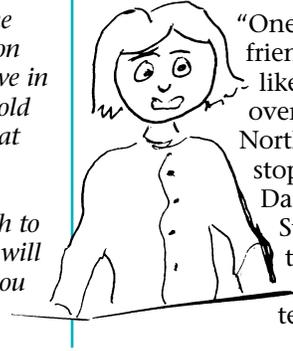
## Tasteless Comments

*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."*

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

The only thing pizza and people have in common is that they both start with the letter "P."



"One of my friends said I look like a pizza because I have red dots all over." Thanks to a schoolteacher in Northern Virginia this kind of teasing was stopped in one classroom. According to Daria Weber, RN, MSN, School Health Supervisor, it is so important to educate the schoolteachers and nurses on your children's skin disease. It decreases teasing and increases school attendance.

## ATTENTION PARENTS OF CHILDREN WITH ECZEMA

Wake Forest University School of Medicine is conducting a research study to develop a survey on the family impact of childhood eczema (also known as atopic dermatitis, or AD). For more information please contact SJ Brown at (336) 713-5091 or fax (336) 716-7554.

The Inflammatory Skin Disease Institute (ISDI) offers college scholarships for students with eczema. For more information or an application contact ISDI at (757) 223-0795.

## NIAMS

*Continued from page 3*

The meeting participants were enthusiastic about the potential of this class of drugs for the treatment of these often chronic and difficult to treat diseases, but did voice some concern about over exuberant use of them until there is greater familiarity, particularly with regard to unexpected long term toxicities. The attendees were enthusiastic

about the ability to conduct studies to learn more about the diseases via basic investigations that can be appended to clinical trials that are commencing, and the NIH's interest in funding such studies via the hyper accelerated grant review process. For more information please contact the ISDI's offices. ☀

## Letters to the editor



Thanks to the readers on this page for sharing their thoughts and allowing us to share them with you. We encourage readers to contact us with comments and experiences. Letters will be reprinted only with the writer's permission. Thank you for your support.

Dear ISDI:  
The conference was great! Thanks for having me on your panel. Even though I have the disease I learned more from others about the disease. I will be glad to do it again if I can help.  
Z.W.

Dear ISDI:  
Thanks so much for the books "Under My Skin." I will give the extra copy to our school-teacher and school counselor. We are looking forward to the confer-

ence. The experience will be so good for my daughter. She is in a flare now, soooo frustrating.  
J.B.

## EXCITING NEWS...

"UNDER MY SKIN"  
A Kid's guide to Atopic Dermatitis published by Fujisawa Healthcare, Inc. now comes in Spanish "Bajo Mi Piel"



Editor's Note: The Pen Pal Section will return next issue.

