



a ray of hope through patient awareness and education

ISDI Information

Newsletter of the Inflammatory Skin Disease Institute

Spring 2008

Methicillin-Resistant *Staphylococcus aureus* (MRSA) and Skin Disease

People with inflammatory skin disease are at greater risk for MRSA, when their skin is broken. With many types of skin disease, the skin/bodies barrier is cracked and broken.

Staphylococcus aureus ("Staph") is a common type of bacteria (germ) that is often found on the skin and in the nose of healthy people. It can also grow in wounds or other sites in the body, sometimes causing an infection. For example, Staph is one of the most common causes of skin infections. Penicillin is a drug that was once commonly used to treat staph infections. However, over time many Staph bacteria have become difficult to treat with penicillin and antibiotics related to penicillin. These new or resistant forms of Staphylococcus aureus are called methicillin-resistant Staphylococcus aureus, or MRSA. The illnesses they cause are the same as those caused by other Staph; the difference is in how they are treated.

Just like normal Staph bacteria, MRSA normally does not cause disease unless it enters an opening in the skin. However, some people including those with skin disease, are at higher risk for carrying MRSA or becoming infected with this type of Staph. MRSA more often occurs in people- in hospitals and healthcare facilities. It can also occur outside the hospital in people who receive multiple antibiotics, as well as in people who have close contact with a person carrying the germ or by touching objects contaminated with MRSA (e.g., clothes, towels, bedding, athletic equipment, benches in saunas or hot tubs, bandages).

Staph bacteria (including MRSA) are most often spread by close contact with infected people or the

things they touch. It is not spread through the air. Many people carry Staph bacteria on their skin without any symptoms. Symptoms of a MRSA or other Staph infection depend on where the infection is located. Infections of the skin are the most common, and cause symptoms such as redness, warmth, pus and a wound that does not heal. According to Dr. Kimberly Soderberg, a dermatologist at Oyster Point Dermatology with offices in Newport News and

Many people carry Staph bacteria on their skin without any symptoms. Symptoms of a MRSA or other Staph infection depend on where the infection is located.

To help prevent Staph infections:

- Wash your hands often, especially when you're exposed to someone with an infection or when you touch objects that may be contaminated.
- Keep cuts and scrapes clean and covered.
- A void sharing personal items such as towels, sports equipment, razors, etc.
- If a sore or cut becomes red, oozes, causes pain or isn't healing, see a doctor.
- Don't insist on antibiotics for colds or other viruses.
- If prescribed antibiotics, take all the pills, even if you feel better before they are all gone.
- See your health care provider if you think you may have a Staph infection.

Williamsburg, Virginia, "atopic dermatitis may be secondarily infected with staph. Clinical infection is not always obvious. Extreme bouts of itchiness with open scratch marks is a helpful pearl when looking for signs of staph. Your doctor may refer to these infections as boils, furuncles, impetigo, or abscesses. Infections can also develop in the blood, bone, bladder, lungs, and other sites. Symptoms there will depend on the site of infection, but can include fever or pain at the site.

Some Staph skin infections can be treated simply by draining the affected area and keeping the wound clean. For more serious infections, antibiotics can be used to treat these infections. If antibiotics are prescribed by your healthcare provider, it is very important to finish taking all the pills and to call your doctor if the infection does not get better.



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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.

Director's Message



Someone said to me recently, "If skin was not all over your body, skin disease wouldn't be either." I had to ponder that for a minute. It is a true statement. ISDI 'gets it'. More than 80 million Americans are affected with skin disease; it is costing the United States \$38.6 billion a year in medical services and loss of productivity. As Director of ISDI, I want more people to 'get it'. ISDI will continue to provide education, and awareness and work with

the American Academy of Dermatology, the Society of Investigative Dermatology and the National Institutes of Health to improve quality of life and lessen the burden of skin disease. You too can help. Stay in touch with your elected officials; watch how they vote on health issues. Educate them on how skin disease affects you personally. Let's work together to lower the statistics.

LaDonna Williams
Executive Director

Letters to the Editor:



Thank You!!!

Just wanted to say thank you for suggesting CeraVe for my father. He is almost 88 years old, has seen several dermatologists regarding his skin problems, and has now tried CeraVe. He could not be happier! Finally, he has relief from constant itching and is able to sleep through the night. He has bought whatever jars of cream he could find in Suffolk, Va. And I have bought what I could find at the CVS in Williamsburg. He relates that he has told several friends at the retirement center where he lives about it, but they say they cannot find it in Suffolk. I have suggested the internet. I do hope it will be easier to find in the future as it seems to be so effective. Daddy is forever grateful to you, as am I! The Inflammatory Skin Disease Institute is indeed a worthwhile cause and your efforts are much appreciated.

Sincerely,
Alison Graves



Dear ISDI,

Thanks so much for making me aware of the new Eczema Aveeno Wash and Cream! So far they seem to be working pretty well. The redness and flaking has calmed down considerably and they haven't caused any breakouts. I'm gonna continue to use them and hopefully my face will not flare up again! Thanks a ton for the help!

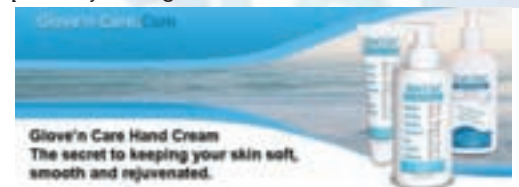
—Cassie

Dear ISDI,

I am a pet groomer. I wear latex gloves most of the day. Recently I received a sample of Glove 'n Care Hand Cream. It has been WONDERFUL and it has soothed and softened my dry hands after wearing the latex gloves. Can you tell me how to get more?

—Julie Krentz

Ed. Note: Glove 'n Care Hand Cream was developed by Essential Dental Systems, Inc. to relieve dry hands caused by latex gloves. It was originally just seen in dental offices. Now it is available to the public by calling 1-800-223-5394.



Sun Protective Clothing Covered by Insurance

By Carole Reilly, Fishkill, NY

We just won a fair hearing against our insurance company for sun protective clothing. Insurance companies can no longer qualify sun protective clothing as personal comfort items. Precedent has now been set, sun protective clothing qualifies as a medical device and thus as long as deemed medically necessary, reimbursement can be sought.

People with inflammatory skin disease may be extra sensitive to the sun. **BLOCK THE SUN, NOT THE FUN**

Expert ON CALL

The Inflammatory Skin Disease Institute welcomes questions from readers. Please call us at 757-223-0795; email: Ruthann.newton@isdionline.org and type "Expert on Call" in the subject; or write ISDI, P.O. Box 1074, Newport News, VA 23601 with your medical questions. ISDI will forward your questions to our "Expert on Call".

Q: What is Prurigo Nodularis?

A: Prurigo nodularis means "itchy nodules". A spot itches for some reason (sometimes these start from bites or eczema), and a patient typically scratches the spot furiously. Creating a sore by scratching is often the only thing that relieves the itch by replacing it with pain. Just before the sore heals, the itch returns and the area is again scratched open. This cycle repeats over and over and the skin in the area thickens to form a scaling lump. The disorder resists various treatments, but applications of powerful cortisone salves or injections of cortisone into the nodules are often the first lines of therapy.

CONGRATULATIONS TO HUGH A. SAMPSON, MD

Hugh Sampson, MD, one of ISDI's Scientific Advisory Board members, is the 2008-2009 President of the American Academy of Allergy, Asthma & Immunology (AAAAI). Dr. Sampson is Professor of Pediatrics and Chief of the Division of Allergy and Immunology in the Department of Pediatrics at the Mount Sinai School of Medicine in New York City. He also serves as Director of the Jaffe Food Allergy Institute and Dean for Translational Biomedical Sciences. Congratulations, Dr. Sampson!



NEW BOARD MEMBER PEGGY HOPKINS

Peggy Hopkins has two daughters and works from her home office near LaPlata, Maryland. She has an associate's degree in accounting and worked in the medical field for 10 years before starting her own business in 2003. She is co-owner of "Team 36 Racing" which actively supports ISDI. Peggy is no stranger to skin disease and has an understanding with her professional experience as well as on a personal level. According to Peggy, "understanding and awareness is key to education." "I am excited about serving on the Board of Directors and look forward to being personally involved with and supporting the mission of the Inflammatory Skin Disease Institute."



Thank you TEAM 36 Racing for sponsoring our ISDI Scholarship. Because of your dedication you help ISDI help others. For more information on Team 36 racing contact team36@comcast.net.

CONDOLENCES TO SCIENTIFIC BOARD MEMBER VINCENT BELTRANI, MD

The Inflammatory Skin Disease Institute wishes to express our deepest sympathy at the passing of a wonderful person, Mrs. Josephine Virginia Beltrani. She was the wife of ISDI's scientific advisory board member, Vincent Beltrani, MD, and one of ISDI's biggest supporters. Mrs. Beltrani will be remembered as a kind, gracious lady that always had a smile and a kind word for everyone

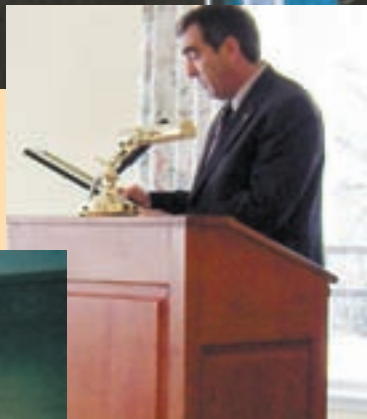
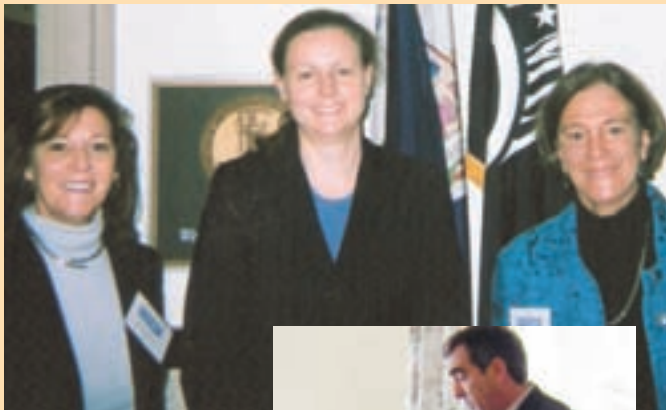


2008 Skin Disease Research Day
Apr. 9-10, 2008 in Washington, DC

The Inflammatory Skin Disease Institute attended Skin Disease Research Day to advocate for increasing NIH funding.

Diseases of the skin are serious medical conditions that require serious medical research. Burdens of skin disease are economic, physical, psychological, and emotional. There are more than 3,000 identified varieties of skin disease affecting nearly 80 million Americans.

GET INVOLVED: Contact your congressman to support the NIH funding increase. Tell your members of Congress that you support a funding increase to NIAMS. Let us help you help yourselves by getting involved.



GORLIN SYNDROME EDUCATIONAL SEMINAR
PATIENT/FAMILY EDUCATIONAL MEETING

Saturday, July 26, 2008
 9:00-3:00
 Columbia University
 Herbert Irving Pavilion
 New York, New York

Promises to provide current educational information regarding the early diagnosis and treatment of patients with Gorlin Syndrome and other dermatology issues.

ISDI is honored to be a partner in this seminar.
For more information: 1-866-834-1895 or info@bccns.org

PATIENTcorner



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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Inflammatory Skin Disease Treatment Questionnaire

The following questionnaire is designed to identify some of the challenges individuals and families face in the treatment of inflammatory skin disease. Please read the following statements and select which choice best describes that statement. If there are many members of your family with inflammatory skin disease, please pick one individual for whom you will base your answers. Please describe that individual's age and gender in the fields below.

Your/your child's age: ___ year(s) Your /your child's gender: Male Female

1. The cost of my/my child's medications makes it difficult to treat the skin disease.

Strongly Disagree Disagree Neutral Agree Strongly Agree

2. Concern for side effects of topical steroids (hydrocortisone/triamcinolone/ etc ...) limits my desire to use them.

Strongly Disagree Disagree Neutral Agree Strongly Agree

3. I have been given instructions on how to treat and manage my/my child's skin disease within the past year.

Strongly Disagree Disagree Neutral Agree Strongly Agree

4. I prefer to use alternative/natural methods and home remedies instead of prescriptions medications to treat my/my child's skin disease.

Strongly Disagree Disagree Neutral Agree Strongly Agree

5. Skin diseases such as eczema and psoriasis are life long diseases in need of preventative care.

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. It takes too much time to apply all the moisturizers and topical medications needed to manage my/my child's skin disease.

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. Skin diseases such as eczema and psoriasis should be treated with moisturizers/emollients when the skin is doing well (not flaring).

Strongly Disagree Disagree Neutral Agree Strongly Agree

8. I feel comfortable managing and treating my/my child's skin disease.

Strongly Disagree Disagree Neutral Agree Strongly Agree

9. I know what steps to take to treat my/my child's skin disease during a flare.

Strongly Disagree Disagree Neutral Agree Strongly Agree

10. The treatment plan is too complex for my/my child's skin disease.

Strongly Disagree Disagree Neutral Agree Strongly Agree

11. The unappealing formulation, such as smell or greasiness of my/my child's topical treatments makes it difficult to treat the disease.

Strongly Disagree Disagree Neutral Agree Strongly Agree

PLEASE RETURN TO: ISDI, P.O. Box 1074, Newport News, VA 23601

Questionnaire may also be accessed on line at: www.isdionline.org



ISDI honors 2 Scholarship Award Recipients

The Inflammatory Skin Disease Institute recently honored Tim Bowman and Tim Ellis with a scholarship award for their outstanding essays on their skin disease. For more information on the ISDI Scholarship Program go to www.isdionline.org and look under "Patient Information" or call ISDI at 757-223-0795.



A Lifetime of Itching

Somehow I've always done well in school. It gives me an outlet. In spite of being hospitalized several times for my eczema, I have maintained my grade point and participated in school activities.

I believe that eczema has impacted the way I view myself. Although there are days that I have difficulty walking, I think eczema has made me tougher than I would have been without it. A positive effect of my eczema is my huge pain tolerance. Things that would normally cripple someone with pain barely affect me. I always find a way to

persevere. One of the greatest struggles that I have with eczema is the constant infections that I've acquired throughout the years. My open wounds are the perfect environment for bacteria. Recently, I've added an infection control physician to my list of doctors. I take one day at a time.

I have constant pain but it doesn't bother me that much. What bothers me the most is when people close to me say how horrible my skin looks or how I must hurt. They interject their opinion and make comments about how I must not be putting on enough cream and how they

would have cured this a long time ago if they had been me. Do they really think this is my choice? I live with my eczema day in and day out and I've learned to accept and deal with it. I know I probably will never be rid of it and I try not to think about it. With help from my friends and football I am no longer self-conscious. I have learned to accept me for who I am.

As I plan my future, I am mindful of my skin condition. I realize that the severity of my condition will impact the type of career I select. I try not to focus on that. I'd rather spend my time concentrating on the possibilities of the future. I am a strong individual. I have faced many obstacles yet, there is a world to discover. Having eczema has impacted my life on a daily basis. I will always carry the scars from eczema. These scars are both external and internal. I can choose to allow eczema to control my life or I can focus on the lessons I've learned to become a stronger individual. There is a future to discover...one day at a time.

With help from my friends and football I am no longer self-conscious. I have learned to accept me for who I am.

— Tim Ellis





Too much of life is based solely upon appearances. For this reason, having any kind of visible deformity or disease will impede any individual from having a "normal" desirable life. People will look at you with disgust, as though it is completely your fault

for looking the way you do. Or, they will ceaselessly harass you so that your imperfection becomes ingrained into your being. I was six when I was first diagnosed with psoriasis and for the better part of ten years, I had to cope with the humiliation of being the "weird" kid. However, at some point, I decided that I had had enough of this condescending treatment from my peers. I was tired of the petty name calling, of being embarrassed for my appearance,

and shying away from everyone. In less than one year, I managed to go from 25% body coverage to the practically 1 % body coverage of psoriasis that I now have today. I like to think that psoriasis had the greatest impact on how I handle challenges.

Initially, I felt no need to do anything about my psoriasis while I was in elementary school. The disease dominated large portions of my body but my classmates knew me for the person I was and didn't discriminate against me for my appearance. I wasn't pressured to change and had no incentive to apply the sticky ointments I'd been given for medication so I just took advantage of my situation and pretended the psoriasis didn't really exist. However, I was forced to face reality after I moved to a new state and entered a completely foreign middle school. I'm a military dependent child so the problems of having bizarre scaly flaky skin were compounded by the fact that I'd be moving into new areas and being forced to meet new people every four years.

At the middle school, I was endlessly ridiculed by the "cool" crowd. I became extremely antisocial and just avoided running into absolutely everyone. I was constantly stressed and went to great lengths to cover up the psoriasis patches with long sleeve shirts and pants, even during the summer. Half way through middle school, I decided that I couldn't go through the rest of my life in the same fashion, being constantly humiliated. I first started to exercise regularly, not because I was overweight, but instead because I wanted to have a more muscular appearance. I assumed that people wouldn't pick on someone that looked like they could beat them up (of course, I never intended to actually pick a fight, it was more of a bluff tactic). Then I went to my dermatologist and he agreed to allow me to use a new test topical steroid. By systemically eliminating psoriasis on one limb at a time, then torso, and lastly scalp, I was able to seemingly eradicate my disease. The steroids were painful because they burned when I was in the sunlight, but through dedication and perseverance, I prevailed.

I can't act as though psoriasis ended at that phase in my life because I still have random flares where plaques stubbornly appear on my skin and take months to treat. However, I've

Psoriasis has taught me to rise and meet challenges as opposed to cowering away from them and allowing them and everyone else to rule my life.

learned to not let it get out of control like the first time. I treat every plaque ardently until it disappears. Psoriasis has taught me to rise and meet challenges as opposed to cowering away from them and allowing them and everyone else to rule my life. It taught me the courage of taking the initiative in making decisions for the better. Most importantly, it taught me that I don't have to rely upon other people's opinions of me. I don't allow people to put me down just because I may look different. I straightforwardly acknowledge I have psoriasis and ignore negative comments on their part. I know the person I am on the inside and if they refuse to see that same person, I'd only be wasting my time to associate with such a shallow person. To all of these lessons of life I've learned, I owe psoriasis my appreciation.

—Tim Bowman



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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