

Ichthyosis Focus



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Summer 2005

Supplemental Security Insurance and Medicaid for Children with Ichthyosis

By David Gates

Supplemental Security Income (SSI) Overview:

SSI is a program administered by Social Security that provides a monthly cash benefit and, in most states, Medicaid (also known as Medical Assistance in some states). The amount of the cash payment depends on the other income the individual, his/her parents (for a child under 18), or his/her spouse has and whether the individual (for adults 18 and older) is paying his or her share of household expenses. Social Security sets the maximum amount SSI pays every January. In 2005, it is \$579 a month (\$869 for a married couple). Some states pay an additional amount above the federal SSI payment, which is known as the "state supplement." For example, Pennsylvania pays an additional \$27.40 per month on top of the federal SSI payment for Pennsylvania residents receiving SSI in 2005 (\$872.70 for a married couple).

Why SSI is important for children with ichthyosis:

In addition to providing additional income for lower income families, SSI is important in most states because it is the way most children with serious disabilities or medical conditions qualify for Medicaid. Medicaid comes automatically with SSI; a separate application is not necessary in every state EXCEPT: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio,

Oklahoma, and Virginia.

Note: The States above may not use more restrictive standards in determining Medicaid eligibility for persons on SSI than those in effect on January 1, 1972. These states must also provide for deducting incurred medical expenses from income through "Medicaid spenddown" so that individuals may reduce their income to that state's income eligibility level.

Why Medicaid is important:

Medicaid is important because it provides free health insurance and, in many states, covers medical services, medications, and equipment well beyond that covered by many commercial health insurance policies, at least until age 21 (due to a federal law known as "EPSDT" which ends at age 21). For example, many skin creams that might not be covered under commercial insurance are commonly covered under Medicaid.

Who can qualify for SSI:

Because qualifying for SSI is the most common way children with disabilities or serious medical conditions qualify for Medicaid, this article will discuss the SSI eligibility criteria.

There are 3 main eligibility criteria for SSI:

1. Assets - For children and adolescents under 18, certain assets in their own

name and certain assets in their custodial parent(s) name are considered in determining eligibility. Assets that are considered include money in any bank accounts, stocks, money markets, life insurance, if it has a cash surrender value, real estate that is not the child's home, cars (if more than one), and boats. In a one-parent household, the parent and child together cannot have more than \$4000 in countable assets, of which no more than \$2000 can be in the child's name. In a two-parent household, the parents and child together cannot have more than \$5000 in countable assets, of which no more than \$2000 can be in the child's name. Assets that are exempt (don't count towards the eligibility limit) include the home in which child lives, furnishings, and one car.

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The editor invites your correspondence. We welcome your comments, observations and suggestions. Please send your letters to Ichthyosis Focus at the address listed above.

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Correspondence Corner

Hello to everyone at F.I.R.S.T.:

I thought you folks might want to put something on this topic in the newsletter. We had a fire last night and the circumstances are definitely relevant for other people with ichthyosis, as many of them also use petroleum-based moisturizers. JR and I want to share this with all of you, so you can prevent it from happening to you.

Ever heard of spontaneous combustion? Well, it actually does happen and last night it happened to, of all things, my laundry! I did my laundry as usual at the Laundromat. When the dryer was done, I pulled the clothes out into a basket and loaded them into the car to toddle on home. I didn't fold them, but believe me, that will never happen again. From now on the laundry will get folded immediately!

About five hours later, right after I was done cooking dinner, I started getting nauseous and had no interest in eating because there was this awful smell. I assumed it was from dinner, which was breaded pork chops. I've never cooked anything with breading before, so I thought maybe the smell just didn't match the item. I mentioned it to JR; he didn't notice it, but he does refer to my nose as being "canine," since I can smell things long before he can.

The smell got worse and began migrating around the house. By nine o'clock it was really bad. We searched all over the house for the source and just couldn't find it. I suggested to JR that we call the fire department's non-emergency line, as I just didn't want to go to bed until I knew we were safe. We even tested the smoke alarm; the odor was so strong and our eyes were burning a bit, but the alarm hadn't gone off. The smoke alarm was working.

The fire department sent out a truck and the firefighters came in with a handheld camera device that monitors heat levels. They checked out everything from the top down. They kept mentioning burning plastic (the smell reminded them of that), asking if we had a dishwasher and maybe a plastic lid fell on the heating element. Nope, the only dishwasher in the house is me. While we were standing around being stumped, I decided to pick up the laundry baskets and move them out of the way to the bedroom. I picked one up and as I dropped it on top of the other, POOF, a big puff of black smoke billowed up. The firefighters hustled that basket out of there faster than I could blink and realize what was going on.

They were picking up stuff and chucking it out on the wet pavement in the parking lot. When they got to the center of the laundry load there were flames! Flames! In my laundry! It turns out that all the ointment residue in my clothes can make quite a heat sealer. The clothes always get really hot in the dryer, so hot in fact, that they are too hot for me to touch for five to ten minutes after they come out. Because all the towels were bunched up in the center, and they were so hot, the heat just kept building and that's how the combustion came about.

The firefighters were amazed. None of them had ever heard of such a thing as laundry spontaneously combusting before. They even took pictures so they could use them in firefighting classes. They recommended that I fold all my clothes immediately so that the heat disperses and suggested we stack towels no more than three high.

No one was injured and the firefighters now have a new smell in their knowledge base, burned fleece! Fleece is made of recycled plastic, so that explains why they kept thinking that plastic was burning. About half the clothes that I wear daily are burnt to a crisp, but that's okay. We are just so grateful that no one was injured and the apartment didn't catch fire. We have renter's insurance, but I don't know yet if it will cover replacing the clothes and towels.

JR and I lay awake for probably two hours before we could sleep. Every minute or two, one of us would say, "Wow." "Wow, we're okay." "Wow, that was exciting." "Wow, now that it's over, I'm really scared!"

So what's the moral of the story? Well, there are several. First, fold your laundry. Second, make sure you have renter's or homeowner's insurance. Third, even if it seems silly, do not hesitate to call the fire department, ambulance, police, or whomever if something doesn't seem right! They said they would rather come out and have it not be an emergency than

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Correspondence Corner

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rescue folks from a burning building. Fourth, have fire extinguishers in your home, vehicle, and workplace. Fifth, test your smoke alarms regularly but recognize that your smoke alarm may not alert you until the problem has gotten pretty big, so trust your nose!

Sincerely,

Chandra and JR Rogers
Beaverton, OR

Dear Members of F.I.R.S.T.:

My name is Don McNeeley. I have a very mild case of ichthyosis vulgaris. My wife and I are discussing a change in living location as we look at our final retirement years and one issue that we desire to consider is a climate that is best suited for my skin. I would appreciate any recommendations concerning the best location for someone who has ichthyosis vulgaris.

Please send responses to:

Donald McNeeley
4528 McGregor Drive, Virginia Beach, VA 23462
Or email: don@cbrgroup.org

Dear Members of F.I.R.S.T.:

My name is Paola Stefano. I am a pediatric dermatologist and I work at a Children's Hospital in Buenos Aires, Argentina (Hospital Nacional de Pediatría J P Garrahan). I started a review about the efficacy and safety of systemic retinoids in childhood ichthyosis for the Cochrane Library. I would like to do this review with the participation of somebody who has ichthyosis and is using systemic retinoids, because I think this is the best way to know what is of interest to the consumer.

The objectives that are of interest to the physician are not always the same for the consumer. The majority of the papers on retinoids are in English, but the patients who come to my hospital do not speak English. I appreciate the opportunity to reach all of you through this newsletter and I look forward to the opportunity to talk with you.

Sincerely,

Paola Stefano, MD
Buenos Aires, Argentina
paolast@hotmail.com

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The United Way of America is the national organization dedicated to leading the United Way movement in making a measurable impact in every community across America. The United Way movement includes approximately 1,400 community-based United Way organizations. Each is independent, separately incorporated, and governed by local volunteers. The Foundation for Ichthyosis is the recipient of funds from many of the United Way community-based organizations. Through the Donor Choice Program, you can designate all or a portion of your donation to the Foundation. Simply write in "Foundation for Ichthyosis & Related Skin Types" on the Donor Choice Option form, and your gift will be sent to our office. Be sure to include our current mailing address and phone number, 1601 Valley Forge Road, Lansdale, PA, 19446, 215-631-1411 and our federal tax ID# of 94-2738019.

The Combined Federal Campaign (CFC) is the annual fund-raising drive conducted by federal employees in their workplace each fall. Federal employees and military personnel raise millions of dollars each year through the CFC to benefit thousands of non-profit charities. The Foundation is the recipient of funds from many CFC organizations throughout the country. The Foundation's CFC code is 0810, which is listed in the charitable organizations directory.

Contact your Human Resources Department to find out how you can support the Foundation using United Way or Combined Federal Campaign.

Supplemental Security Insurance and Medicaid for Children with Ichthyosis

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Some states, such as Pennsylvania, provide Medicaid (but not SSI) to persons under 21 who have countable assets above the applicable SSI limits if they meet the other SSI criteria. In other words, they have no assets limits for Medicaid for persons under 21.

2) Income - For children under 18, income of the custodial parent(s) is counted, as well as any income in the child's name. However, if the child is out of the parent's home for more than a month, parental income is no longer counted (until the child returns home). For persons 18 and older, parental income is not counted. However, income of a spouse, if any, is counted. Although there is a specific monthly income limit, it is impossible to tell just from the limit whether the individual's income is above or below the limit because all or portions of certain types of income are not counted. Furthermore, the rules about how much income of a parent or spouse is counted are very complicated. To get a reasonable idea of whether you or your child meet the income and asset limits, go to <http://best.ssa.gov/>. If you do not have access to the Internet, you can call Social Security at 1-800-772-1213. Ask the representative to have someone call you back to do an income and assets phone screening for SSI. For more detail about the various rules regarding financial eligibility for SSI, go to http://www.ssa.gov/OP_Home/handbook/handbook.21/handbook-toc21.html.

3) Disability - The individual must meet Social Security's disability criteria (or be 65 or older). Having a particular diagnosis does not, by itself, meet those criteria. For children and adolescents under 18, their condition must "meet or equal" certain criteria known as the "listings of impairments." These "listings" are divided by the bodily system affected.

One year ago, Social Security added a "listing" specific to ichthyosis. This

means that there are now criteria specific to ichthyosis for making the disability determination necessary for SSI and Medicaid (when Medicaid eligibility is dependent on disability). Those specific criteria are reprinted on pages 14 through 16 in this newsletter. Basically, Social Security requires medical documentation that a child with some form of ichthyosis has had extensive skin lesions for at least 3 months, despite continuing prescribed medical treatment. "Extensive" skin lesions are lesions that "involve multiple body sites or critical body areas, and result in a very serious limitation" to basic functioning like walking, using your arms or your hands. Children whose lesions don't last 3 months may still meet Social Security's disability criteria if they have frequent flare-ups. Social Security will consider how frequent and serious the flare-ups are, how quickly they resolve, and how the child functions between flare-ups. Social Security will also consider the extent to which the child must stay in a protective environment (e.g. air-conditioned rooms), amount of pain suffered, the extent to which treatment improves child's ability to function, and side effects from treatment. Children who have additional medical, cognitive, or behavioral problems may also meet Social Security's disability criteria if, taken together, their multiple problems would "equal" one of Social Security's "listings."

Since medical documentation is required, families should take a copy of Social Security's Skin Disorders "Listing" to the child's treating physician so the physician knows what information must be documented for SSI or Medicaid purposes.

Application tips:

Where to apply:

Apply at the local Social Security office. To find your local Social Security office, go to <http://s3abaca.ssa.gov/pro/foi/foi-home.html> or call Social Security at 1-800-772-1213. The application

form is fairly lengthy, so be prepared to spend an hour or two at the Social Security office.

What to bring:

- your child's Social Security card or a record of your Social Security number;
- your child's birth certificate or other proof of your age;
- information about the home where you live, such as your mortgage or your lease and landlord's name;
- payroll slips, bank books, insurance policies, burial fund records, and other information about your income and the things you own;
- the names, addresses, and telephone numbers of doctors, hospitals, and clinics that have seen your child; and
- proof of U.S. citizenship or eligible non-citizen status.

If your state provides Medicaid to children and adolescents who meet the Social Security disability criteria but have assets or income (including assets or income of the parent) above the SSI asset and income limits (as Pennsylvania does), the application for Medicaid is made at the local state Medicaid office. Look in your local phone book (usually in the blue pages under State Government) or your state's web site for the phone number and address.

What to do if your child is turned down:

You will get a written notice that you have either been approved or turned down. You have the right to appeal if you are turned down. The notice will explain how. Also see <http://www.ssa.gov/pubs/11008.html> for more information on appeals. You do not need an attorney to appeal, although having an attorney is often helpful if you were turned down because Social Security did not think you met their disability criteria.

David Gates
PA Health Law Project
1414 N. Cameron St., Suite B
Harrisburg, PA 17103

Financial Planning for Young Families

By Janet McCoy, CFP, Sovereign Bank



“Financial planning,” these two words can stir feelings of fear and anxiety in many young families. But these feelings can be overcome by taking a thoughtful, practical approach to managing finances with the future in mind.

It's not uncommon for many young families to spend their money as fast as they earn it. That kind of spending pattern is a carry-over from the carefree days of not having any children. But when the kids arrive, the family dynamic changes, especially for those families who have a child with ichthyosis. Not only do such families have to deal with the normal costs of raising children, they also have the added expense of creams, lotions, and other skin care products, not to mention doctor's visits and other associated costs.

Rather than be overwhelmed with these new expenses, parents should come up with a strategy to tackle them head-on, while, at the same time, planning for such things as a new home, college, even retirement. In other words, borrowing from the Boy Scout motto, “Be Prepared.”

So, when and where do you start? Here are some helpful tips for securing a sound financial future:

Start saving right away for retirement. It's never too early to put a retirement plan in place. Even if it's only forty to fifty dollars set aside per paycheck, that money can add up to create a solid nest egg a few decades down the road. Automatic payroll deduction, where your money is automatically placed into a savings account, is a great way to save since you don't see the money and, therefore, can't spend it.

Many companies have 401k plans where they will match all or a portion of an employee's contribution. If it's a dollar-for-dollar match, you are essentially doubling your contribution!

Another savings vehicle is a Roth IRA. Money deposited into this account grows tax-free and is withdrawn tax-free at age fifty-nine and a half. Contributions are taxed as regular income, but not taxed when they are withdrawn during retirement.

Avoid credit card debt. By avoiding this kind of debt, you'll realize a better credit score, which can lead to a lower mortgage rate when buying a home. A simple way to avoid credit card debt is to

leave the credit cards at home. If you find something you want to buy on credit and you have to return home to get your card to make the purchase, this gives you time to think about whether you really need to buy the item.

To help save for college, look into educational IRAs, state-maintained college educational savings programs, or similar programs. Money in these accounts typically grows tax-free and can be withdrawn tax-free as long as withdrawals are for higher education expenses.

Be prepared for difficult times by maintaining adequate life insurance and an up-to-date will. Also consider trust funds and similar options to protect your assets for your offspring.

As you can see, financial planning doesn't have to cause heartache or heartburn as long as you think practically and think ahead.

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ATTENTION

Recently the Theraplex line of products was sold to Theraplex Company of Memphis, Tennessee. There has been a delay in getting wholesalers to restock Theraplex, but the problems have now been resolved.

Theraplex Products now can be ordered through your local pharmacy or at www.medichest.com Pharmacies can obtain Theraplex from their wholesalers (note: for easiest ordering give your pharmacist the wholesale number listed below). If you have any questions, or any difficulty obtaining Theraplex, please contact us at 888-437-2753 (toll free) or 901-347-8001, or at www.Theraplex.com. Thank you.

Description	UPC	Cardinal Health #	AmeriSource Bergen #	McKesson
Hydro Lotion	658800250080	3485919	363549	1985027
Clear Lotion	658800220083	3485893	363341	1732783
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Spotlight on John Buehler



John Buehler, a lanky teenager with an impish grin, stands somberly before two parent judges and quietly describes the disease that has scarred his skin and shaped his life. His 20-minute presentation is the final piece of his eighth grade language arts project at Olson Middle School in Woodstock, IL. But Buehler, an honor student, looks at the four-month project not just as a way to cement his A, but as a chance to educate people about the rare disease that covers his body with scales, creating a mosaic pattern with flaking skin. Buehler was born with lamellar ichthyosis, a rare recessive genetic skin disease that many dermatologists he visited knew little or nothing about.

The project is also an attempt to pre-empt in high school the bullying that he experienced as a first grader. His classmates called him “skin boy,” “lizard skin,” and “fish face.” In a gutsy gamble, the 14-year-old invited news reporters to his presentation in hopes that such monikers and the other painful interactions he has endured during the last eight years might be short-circuited.

In less than two weeks, Buehler will leave Olson's familiar hallways. In August he will be one of Woodstock High School's 500 freshmen, 300 of whom may have never seen him. “I'm preparing for another first or second grade experience, where they are asking me what it is and calling me names,” Buehler said.

In the classroom, Buehler passed his thick project binder to the judges. Under a laminated cover are John's first photos, a baby born red with a heavy coating of skin. Doctors took a biopsy and diagnosed his condition within days of his birth. His parents, Tom and Diane Buehler, discovered they both carried the gene for the disease, though no one in their families knew anyone who had it. Their daughter, Jessica, 12, does not have it.

Immediately, the couple learned the disease came with no cure and few treatment options. Doctors told the Buehlers they knew of only six cases in the Chicago area. Through the years, they experimented with various medicated creams, applying them daily to reduce the scales and itchiness or to simply keep John's skin moist.

At times, Buehler has scratched his skin raw and bloody. When he was 6, after trying yet another new medicated lotion, Buehler was so uncomfortable he could sleep only in an oatmeal bath. For a couple of months, his parents took turns watching him through the night to ensure he didn't drown.

Initially, the Buehlers tried to explain the condition to their son in simple terms. They would tell him that God doesn't give problems to people who can't handle them. But even the parents weren't exempt from negative comments. Well-intentioned mothers said they should be ashamed for keeping their child out in the sun too long. Tom Buehler's voice catches as he recalls picking up his son at child care once, just in time to hear a child's hurtful warning to another child on the playground: “You can't play with him; he has yucky skin.”

The Buehlers told their son to walk away from the teasing. But by fourth and fifth grade, that didn't work. After quarreling with boys who teased him, he went to anger management classes at the recommendation of elementary school teachers. Eventually, Tom Buehler decided to equip his son with the same communication skills he uses to sell information technology services. In some cases, he advised humor. If someone asked the boy if he was in a fire or stayed too long out in the sun, he might retort, “No, microwave punishment.” Or, “It was an industrial accident, don't ask.” Other times, he responded matter-of-factly or gave what his father calls “playground tutorials.” As he grew older, Buehler gained a reputation for being a friendly, smart, and funny kid, and that has carried him through the tough years of middle school.

Just before his presentation, Buehler sits in the school cafeteria with his friends, five boys who call themselves the school “nerds” and acknowledge that they are all on the honor roll. Derek Brown, another eighth grader, said he no longer thinks about Buehler's skin. But he conceded that as an elementary school pupil, he often called him names and “gave him crud” on the bus. “Every once in a while he'd say something back and I'd feel bad,” Brown said. Eventually he stopped teasing Buehler. They began playing basketball together and hanging out with other friends. Nobody brings up Buehler's skin disease, said Kera Radke, his language arts and math teacher at Olson. “It's not a big deal anymore. I'm thinking maybe it's old at this point.”

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Foundation Resources

The Foundation has added three new components to our ever-growing list of resources:

Online Educational Modules

Two new educational modules are being developed to be viewed from our website. The modules focus on two specific areas: management of ichthyosis in newborns, and types of ichthyosis and making the correct diagnosis. The modules will resemble a slide presentation accompanied with audio lectures. The target audience for the modules is health care professionals who are dealing with ichthyosis for the first time or need to be refreshed on the disease and its related issues. However, the modules can be accessed by anyone who visits our website and may provide helpful information to affected individuals or their families. An official launch date has not been determined. Visit our website periodically in the next few weeks to see this new resource, www.scalyskin.org.

Matching Gifts Brochure - There are many companies who provide a matching gift for its employees who make charitable contributions. Donors can double their gift to the Foundation by completing a simple matching gift form. The office has developed a brochure of participating companies and is including the brochure in its information and membership packets. If you would like to receive a brochure to share with relatives or friends, please contact the office at info@scalyskin.org, or call 1-800-545-3286.

PayPal - The Foundation is pleased to announce you can now make a donation, purchase products, and pay your membership through the convenience of using PayPal on our website, www.scalyskin.org. All transactions are fully secure. It's fast, private, and global.



Spotlight on John Buehler

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Before the judges, Buehler clenched his note cards, but rarely referred to them as he ran through the facts of his disease. Flaking skin covered his forehead and looked like an old peeling sunburn. But much of his face and body is clear, a feat that Buehler credited to his school project. While interviewing Dr. Amy Paller, chairwoman of the Department of Dermatology at the Feinberg School of Medicine and Northwestern Memorial Hospital, Buehler learned of a new medicated cream. He left the interview with a prescription. Within a week, much of his skin had cleared.

His research project had a second, unexpected benefit. Along the way, he became impressed with the statistics of his disease. He had always thought it neat that his skin acts as a natural sun block, but the rareness, with an incidence rate of 1 in 300,000, also began to make him feel "cool." "It's a challenge, and it's also a gift," Buehler said. Just as he's leaving the blend-in middle school years, he has discovered that he likes being different.

"A better understanding and a new hope for my personal situation helped me get through this project and almost makes the grade that I get for this project irrelevant," Buehler told the judges as he concluded. "Almost, but not quite."

By Mary Ann Fergus, Chicago Tribune Reporter. Copyrighted 5/25/2005. Chicago Tribune Company. All rights reserved. Used with permission.

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Executive Director's Report

Dear Members and Friends of the Foundation:

I hope everyone is enjoying a wonderful, warm summer. I know the summer months provide the best climate for ichthyosis. When the season changes and your skin care routine intensifies, please remember that the Foundation provides a comprehensive product listing for our members. This list is a compilation of more than 100 products that have been recommended to the office by members with ichthyosis. Feel free to contact the national office to obtain a copy.

For the past two years, the Foundation has been fortunate to receive a grant from Sovereign Bank to reprint some of the booklets in our resource library. "Release the Butterfly: A Handbook for Parents and Caregivers of Children with Ichthyosis" is in the process of being updated. This booklet contains very useful information on many common issues, including general advice about the skin, bathing, nutrition, coping resources, childcare & preschool, siblings, grandparents, and dealing with doctors. Watch our website and the newsletter for availability of the second edition.

On June 8, I traveled with Board Member Terry Tormey to Washington, D.C. to lunch with Senator Rick Santorum (D) of Pennsylvania. Senator Santorum is the founder of Operation Good Neighbor, the organization that funded \$15,000 for the Foundation's Teen Talk Program. On behalf of our members and all teenagers affected with ichthyosis, we thanked the senator and spoke briefly about the Teen Talk Program to the luncheon audience.



Senator Rick Santorum, Terry Tormey, Mike Dunleavy, and Jean Pickford



This spring, the Board of Directors unanimously elected John J. Schoendorf to join the Board. John is a Certified Public Accountant in the Miami, FL, area and is personally affected with Epidermolytic Hyperkeratosis (EHK). John has been actively involved in the Ichthyosis Support Network for the past few years. He is now volunteering his vast financial expertise on the Foundation's Finance and Audit Committee.

The full Board of Directors will be meeting in Philadelphia in November for a face-to-face retreat weekend. During this meeting, the Board and I will discuss current issues facing the Foundation, develop and/or modify organizational policies, and determine future programs and services.

From the fundraising front, the Foundation is growing stronger every day. Our current membership campaign is close to surpassing our projected goal. It is reassuring to know that our members appreciate the work of the Foundation and contribute generously to continue our programs and services.

I want to take this opportunity to thank Mike Briggs for his amazing efforts in raising money for the Foundation through United Way in Atlanta, GA. Mike is a loving and devoted grandfather to a three-year-old boy affected with EHK and serves on the Foundation's Board of Directors. Mike personally wrote to many of his friends and colleagues at United Parcel Service asking them to designate a portion of their United Way contribution to the Foundation. Checks have begun to arrive at the office. The estimated number of pledges totals over \$70,000. See page 3 to learn more about how you can give to the Foundation through United Way or the Combined Federal Campaign.

Plans are underway for an exciting fundraiser: a new testimonial dinner. The honorees are Drs. Mary Williams and Peter Elias. Mary and Peter are both prominent dermatologists in the field of ichthyosis, founders of the Foundation, and very deserving of this tribute. They agreed to accept this honor to help raise money for the Foundation. The dinner is scheduled for Friday, March 3, 2006, at the Renaissance Parc 55 Hotel in San Francisco. The dinner will coincide with the annual American Academy of Dermatology convention.

The new DVD focusing on teenage issues is nearing completion. Over eight hours of footage has been converted onto a tape, and I am currently reviewing all the interviews and organizing the format. I am hopeful that the DVD will be available for our members and friends by early fall.

As always, please do not hesitate to contact the office to say hello, share a good story, or ask a question. We are here to help you, so be sure to take advantage of the services and programs available to you and your family.

Best regards,

Jean Pickford
Executive Director

When Timothy* grows up, his parents want him to be ordinary. Just ordinary.



Problem Dry Skin (PDS) Symptoms
of Lamellar Ichthyosis
BEFORE



AFTER 4 WEEKS

PDS Symptoms of Lamellar Ichthyosis



BEFORE



AFTER 4 WEEKS
(outer, lower leg)



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Treatment of Hailey-Hailey Disease with Topical Calcitriol

Luca Bianchi, MD, Maria Sole Chimenti, MD, and Alessandro Giunta, MD

Letter to the Editor of the Journal of the American Academy of Dermatology:

Calcitriol, $1\alpha,25$ -dihydroxyvitamin D₃, can induce differentiation of epidermal keratinocytes into squamous and denucleated horny cells by regulating inter- and intra-cellular calcium concentration. Cytoplasmic calcium homeostasis is known to be impaired in keratinocytes from Hailey-Hailey disease (HHD) and the normal epidermal calcium gradient is weakened in HHD patients. These observations and our previous published study on the effectiveness of systemic calcitriol in HHD led us to a topical formulation of this compound in an HHD patient.

A 25 year-old woman with a 10-year history of biopsy-proven Hailey-Hailey Disease, mostly involving the chest, was referred to our clinic because of substantial discomfort and ineffective response to several therapies. Her father was also affected. She complained of a large reddened, superficial, crusted erosion on the front of the chest. After informed consent had been obtained, she started twice-daily treatment with calcitriol $3\mu\text{g g}^{-1}$ ointment (Silkis ointment, Galderma Laboratories) for one month. Local skin irritation was not reported. The patient experienced complete clearing of the lesion. After 3 months of follow-up, the clinical result is still maintained.

Hailey-Hailey disease, or benign familial pemphigus, is a rare inherited skin condition in which there is a problem with keratinocyte adhesion. The disorder, which is transmitted as an irregular autosomal dominant trait, causes significant symptoms. The skin in such areas as the genital area, neck, armpits, and behind the knees is

affected with red, scaly areas that may itch and blister. HHD has a chronic, relapsing-remitting course, which is made worse by sweat, moisture, ultraviolet radiation, and friction, or by bacterial, fungal, and parasitic infections. It can be relieved by several surgical and medical treatments. Our previous report has already documented the effectiveness of systemic calcitriol on HHD at the daily dosage of $0.25\mu\text{g}$. More recently, another compound derived from vitamin D₃, tacalcitol, was also topically effective on HHD lesions. Recent studies have revealed that the HHD region is localized to 3q21-q24 and that the disorder is caused by mutations in the ATP2C1 gene encoding a Ca^{2+} pump. Ca^{2+} pumps are thought to play an important role in maintaining cytoplasmic Ca^{2+} homeostasis. Extracellular calcium plays a critical role in regulating differentiation and adhesion of cultured keratinocytes. Low levels of Ca^{2+} induce keratinocyte proliferation, while normal levels of Ca^{2+} induce cell-to-cell adhesion and cell differentiation. HHD appears to represent a defect in keratinocyte adhesion due to dysfunction of desmosomal proteins. Experimental studies have demonstrated that HHD keratinocytes, ATP2C1 mutated, are deficient in intracellular Ca^{2+} regulation. Furthermore, the inhibitory effect of calcitriol on T cells and on some inflammatory mediators could also participate in the healing process. Our experience and the previous report with tacalcitol seem to indicate that topical vitamin D₃ derivatives, mostly affecting the calcium gradient in differentiating keratinocytes, could regulate and preserve the desmosome assembly and integrity, which is genetically altered in HHD. One month, twice daily, application cleared the lesion and the remission continued at three months observation.

In conclusion, we believe that calcitriol could be considered a therapeutic option for treating this inherited disorder and for maintaining, with occasional application, a disease-free condition.

.....
Luca Bianchi, MD, Department of Dermatology, Tor Vergata, University of Rome, Italy
Maria Sole Chimenti, MD, Department of Rheumatology, La Sapienza, University of Rome, Italy
Alessandro Giunta, MD, Department of Dermatology, Tor Vergata, University of Rome, Italy
Reprinted from the Journal of the American Academy of Dermatology, Sept. 2004; 51(3): 475-476, with permission from Elsevier.

Please contact Maureen in the Foundation office for a complete copy of this article with the accompanying references, 1-800-545-3286, or info@scalyskin.org.

Definitions of terms, in order of appearance:

Differentiation - the process by which cells and tissues in the body develop the characteristics they need to carry out their specific functions.

Epidermal keratinocytes - the cells of the skin that synthesize proteins that make up the cellular layers of the skin.

Squamous cells/denucleated horny cells - the flat dead skin cells that make up the outer layer of the epidermis.

Intracellular - within cells.

Intercellular - between cells.

Cytoplasmic calcium homeostasis - the relatively constant concentration of calcium within a cell.

Calcium gradient - the balance of calcium concentration within and between cells.

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Ichthyosis Awareness Week

October 2 through October 9, 2005

One week out of each year our members host awareness campaigns and fundraising events to raise money and educate the public about ichthyosis. Ichthyosis Awareness Week will be officially celebrated during October 2-9, 2005. In actuality, Ichthyosis Awareness Week can occur anytime during the year - when you can devote your energy to raising awareness or funds for the Foundation.

Educating your local community can make life a little easier for those who are affected. The simple knowledge that ichthyosis is a genetic skin disease, is not contagious, not a bad sunburn, nor the result of poor bathing habits, can help the public better understand the disease and its symptoms.

How you can help...

The possibilities are endless. Start by contacting your local newspaper to let them know about Ichthyosis Awareness Week. Share your personal story with them, or let them know that you will be hosting a fundraising event.

For those of you who have always wanted to do something to help raise awareness and money for the Foundation, but have little experience, we have the answer. The Foundation staff has created an easy-to-follow manual on how to organize a grassroots fundraiser. It is available free of charge to anyone who requests it. It contains great information about how to contact your local media and the essential steps to create a successful event, plus much more. Please call the office at 1-800-545-3286 or email us at info@scalyskin.org with your mailing address to receive a copy.

“Now is the time to think about getting involved in an awareness week activity for this year.”

Treatment of Hailey-Hailey Disease

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Systemic - throughout the whole body. In this instance, taking the medication by mouth in a pill or other form.

Autosomal dominant trait - the gene for the disorder is carried on one of the 22 human chromosomes that do not determine sex and is dominant over the gene for normal skin.

Topical/topically - applied to the skin.

Extracellular - outside the cell.

Keratinocyte proliferation - the reproduction or multiplication of the skin cells.

Desmosomal proteins - structural proteins that help hold the cells of the skin together.

T-cells / inflammatory mediators - the cells and biochemicals that move to the site of an infection or injury, which work to destroy the infection and wall off the injured tissue.

Fundraising ideas:

- Auction
- Bake Sale
- Bingo
- Book Sale
- Candy Sale
- Car Wash
- Dance
- Donations in lieu of birthday gifts
- Dress Down Day at Work or School
- Garage Sale
- Golf Tournament
- Halloween Costume Contest
- Raffle
- Skate-a-thon
- Submit a personal story to local newspaper, radio, or TV stations
- Walk-a-thon

Conference Chatter

2006 National Family Conference

June 30, July 1, & July 2

Are you ready? The dates for next summer's national family conference are set. The conference will take place on Friday, June 30, Saturday, July 1, and Sunday, July 2 at the Crown Plaza Ravinia Hotel in Atlanta, Georgia. The hotel is in a great location, with many restaurants and shopping venues within walking distance. It includes a large indoor pool and a large private walking garden at the rear of the hotel. The conference program is still being developed and will be announced in an upcoming issue of the newsletter and on our website.



If you have attended a conference, you know first-hand how much is gained from meeting with other families and talking with knowledgeable dermatologists. That is why we see so many of you return to each conference year after year.

If you have never experienced a family conference, this is your chance! Since the conference is one year away, you will have plenty of time to make plans to attend. To quote a first-time conference attendee from the last conference, "I will never miss a conference again. My family and I gained so much from this experience, we are already making plans to see everyone in Atlanta in 2006."

News & Notes

Contact your Representative to Support Ichthyosis Congressional Earmark

In May 2005, the Foundation was fortunate to receive the support of Congressman Roy Blunt, R-MO, who submitted a "congressional earmark" to the House of Representatives Subcommittee on Labor, Health, Human Services & Education and Related Agencies (LHHS). The earmark requests total funding of \$750,000 for four goals that the Foundation, along with its consultants and Medical Board, can accomplish in 1 to 2 years: 1) identify the most representative and promising tools to develop; 2) connect patient volunteers (tissue donors) with laboratories that can create the tools; 3) deposit the tools with an organization that can distribute them to qualified investigators for years to come; and 4) encourage investigators to use the tools through the Foundation's independently funded research program.

We need your help and support to make a difference and put ichthyosis research in the forefront. Please contact your senator and local representative and ask them to support this earmark for ichthyosis research. Be sure to mention that you are a voting member in their state or district and are personally affected by ichthyosis. Visit www.senate.gov to find your U.S. Senator and www.house.gov to find your U.S. Representative's contact information. A letter of support has been drafted at the national office and is available for you to use in your request for support. Email the office at info@scalyskin.org to receive a copy of this letter.

The Foundation is only as strong as our membership. Please make the most of this opportunity and contact your representative today.

2005 NORD Annual Conference

The National Organization for Rare Diseases, Inc. (NORD) is hosting its annual conference in Arlington, VA on September 30 - October 2. The topic of this year's conference is "Access to Medical Care: Navigating Medicare, Medicaid, and Private Insurance." Families, including children with disabilities or special health care needs, people with rare disorders and chronic illnesses, medical and allied health service professionals, are invited to attend. For more information on attending this conference visit www.rarediseases.org or email dbolton@rarediseases.org.

If you do not have access to the Internet, please contact Maureen in the Foundation office, 1-800-545-3286, and she will help you with the relevant information.

What's New, What's Hot, What Works

Greetings:

I have a tip for those of us who have heavy-duty calluses on the bottoms of our feet. My brother, who works with wood building beautiful furniture, uses a "micro-plane" to remove tiny layers of wood. He suggested that I try to use it on my feet. It worked wonderfully! It works on the hard rough patches without cutting the soft surrounding surfaces. Of course, care and caution need to be used as with any sharp tool.

Now, instead of paying \$80.00 to the foot doctor several times a year, I just use my micro-plane and take down my own calluses. Remember you do need some protection, so don't remove all the hard surface. I tell you this from experience!

I purchased my micro-plane from the Lee Valley tool catalog, 1-800-871-8158. If I remember correctly, it was around \$20.00, plus shipping and tax.

Barb Karas
Gladstone, MI

Dear Friends:

I am a member of the Foundation for Ichthyosis and in the National Registry. I want to share with the folks of F.I.R.S.T. an over-the-counter product that's been soothing and a great help with my skin. I have lamellar ichthyosis. The product is St. Ives Intensive Healing. It is available in lotion and cream and can be found in most drug and grocery stores.

Margaret Vernet
Newtown, CT

*¿Leyó español?
¿Escribe español?*

The Foundation needs your help! We have several publications that we would like to have translated for our Spanish speaking members. If you can read and write Spanish and would like to volunteer for this project, please contact Maureen Tierney at the national office (800) 545-3286 or info@scalyskin.org.

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SSI Listing of Impairment 108.00 Skin Disorders

A. What skin disorders do we evaluate with these listings? We use these listings to evaluate skin disorders that may result from hereditary, congenital, or acquired pathological processes. The kinds of impairments covered by these listings are: Ichthyosis, bullous diseases, chronic infections of the skin or mucous membranes, dermatitis, hidradenitis suppurativa, genetic photosensitivity disorders, and burns.

B. What documentation do we need? When we evaluate the existence and severity of your skin disorder, we generally need information about the onset, duration, frequency of flare-ups, and prognosis of your skin disorder; the location, size, and appearance of lesions; and, when applicable, history of exposure to toxins, allergens, or irritants, familial incidence, seasonal variation, stress factors, and your ability to function outside of a highly protective environment.

To confirm the diagnosis, we may need laboratory findings (for example, results of a biopsy obtained independently of Social Security disability evaluation, or blood tests) or evidence from other medically acceptable methods consistent with the prevailing state of medical knowledge and clinical practice.

C. How do we assess the severity of your skin disorder(s)? We generally base our assessment of severity on the extent of your skin lesions, the frequency of flare-ups of your skin lesions, how your symptoms (including pain) limit you, the extent of your treatment, and how your treatment affects you.

- **Extensive skin lesions.** Extensive skin lesions are those that involve multiple body sites or critical body areas, and result in a very serious limitation. Examples of extensive skin lesions that result in a very serious limitation include but are not limited to:
 - a. Skin lesions that interfere with the motion of your joints and that very seriously limit your use of more than one extremity: that is, two upper extremities, two lower extremities, or one upper and one lower extremity.
 - b. Skin lesions on the palms of both hands that very seriously limit your ability to do fine and gross motor movements.
 - c. Skin lesions on the soles of both feet, the perineum, and both inguinal areas that very seriously limit your ability to ambulate.
- **Frequency of flare-ups.** If you have skin lesions, but they do not meet the requirements of any of the listings in this body system, you may still have an impairment that results in marked and severe functional limitations when we consider your condition over time, especially if your flare-ups result in extensive skin lesions, as defined in C1 of this section. Therefore, if you have frequent flare-ups, we may find that your impairment(s) is medically equal to one of these listings even though you have some periods during which your condition is in remission. We will consider how frequent and serious your flare-ups are, how quickly they resolve, and how you function between flare-ups to determine whether you have marked and severe functional limitations that have lasted for a continuous period of at

least 12 months or that can be expected to last for a continuous period of at least 12 months. We will also consider the frequency of your flare-ups when we determine whether you have a severe impairment and when we need to assess functional equivalence.

- **Symptoms (including pain)** Symptoms (including pain) may be important factors contributing to the severity of your skin disorder(s). We assess the impact of symptoms as explained in §§ 404.1528, 404.1529, 416.928, and 416.929 of this chapter.
- **Treatment.** We assess the effects of medication, therapy, surgery, and any other form of treatment you receive when we determine the severity and duration of your impairment(s). Skin disorders frequently respond to treatment; however, response to treatment can vary widely, with some impairments becoming resistant to treatment. Some treatments can have side effects that can in themselves result in limitations.
 - a. We assess the effects of continuing treatment as prescribed by determining if there is improvement in the symptoms, signs, and laboratory findings of your disorder, and if you experience side effects that result in functional limitations. To assess the effects of your treatment, we may need information about:
 - i. The treatment you have been prescribed (for example, the type, dosage, method, and frequency of administration of medication or therapy);
 - ii. Your response to the treatment;
 - iii. Any adverse effects of the treatment; and
 - iv. The expected duration of the treatment time must elapse to allow us to evaluate the impact and expected duration of treatment and its side effects. Except under 108.07 and 108.08, you must follow continuing treatment as prescribed for at least 3 months before your impairment can be determined to meet the requirements of a skin disorder listing. (See 108.OOH if you are not undergoing treatment or did not have treatment for 3 months.) We consider your specific response to treatment when we evaluate the overall severity of your impairment.

D. How do we assess impairments that may affect the skin and other body systems? When your impairment affects your skin and has effects in other body systems, we first evaluate the predominant feature of your impairment under the appropriate body system. Examples include, but are not limited to, the following.

- **Tuberous sclerosis** - primarily affects the brain. The predominant features are seizures, which we evaluate under the neurological listings in 111.00, and developmental delays or other mental disorders, which we evaluate under the mental disorders listings in 112.00.
- **Malignant tumors of the skin** (for example, malignant melanoma) - are cancers, or neoplastic diseases, which we evaluate under the listings in 113.00.

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SSI Listing of Impairments

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- *Connective tissue disorders and other immune system disorders* (for example, systemic lupus erythematosus, scleroderma, human immunodeficiency virus (HIV) infection, and Sjögren's syndrome) often involve more than one body system. We first evaluate these disorders under the immune system listings in 114.00. We evaluate lupus erythematosus under 114.02, scleroderma under 114.04, symptomatic HIV infection under 114.08, and Sjögren's syndrome under 114.03, 114.09, or any other appropriate listing in section 114.00.
 - *Disfigurement or deformity* resulting from skin lesions may result in loss of sight, hearing, speech, and the ability to chew (mastication). We evaluate these impairments and their effects under the special senses and speech listings in 102.00 and the digestive system listings in 105.00. Facial disfigurement or other physical deformities may also have effects we evaluate under the mental disorders listings in 112.00, such as when they affect mood or social functioning.
 - We evaluate *erythropoietic porphyrias* under the hemic and lymphatic listings in 107.00.
 - We evaluate *hemangiomas associated with thrombocytopenia and hemorrhage* (for example, Kasabach-Merritt syndrome) involving coagulation defects, under the hemic and lymphatic listings in 107.00. But, when hemangiomas impinge on vital structures or interfere with function, we evaluate their primary effects under the appropriate body system.
- E. How do we evaluate genetic photosensitivity disorders?
- *Xeroderma pimentosum* (XP). When you have XP, your impairment meets the requirements of 108.07A if you have clinical and laboratory findings showing that you have the disorder. (See 108.OOE3.) People who have XP have a lifelong hypersensitivity to all forms of ultraviolet light and generally lead extremely restricted lives in highly protective environments in order to prevent skin cancers from developing. Some people with XP also experience problems with their eyes, neurological problems, mental disorders, and problems in other body systems.
 - Other genetic photosensitivity disorders. Other genetic photosensitivity disorders may vary in their effects on different people and may not result in marked and severe functional limitations for a continuous period of at least 12 months. Therefore, if you have a genetic photosensitivity disorder other than XP (established by clinical and laboratory findings as described in 108.00E3), you must show that you have either extensive skin lesions or an inability to function outside of a highly protective environment to meet the requirements of 108.07B. You must also show that your impairment meets the duration requirement. By *inability to function outside of a highly protective environment* we mean that you must avoid exposure to ultraviolet light (including sunlight passing through windows and light from unshielded fluorescent bulbs), wear protective clothing and eye glasses, and use opaque broad-spectrum sunscreens in order to avoid skin

cancer or other serious effects. Some genetic photosensitivity disorders can have very serious effects in other body systems, especially special senses and speech (102.00), neurological (111.00), mental (112.00), and neoplastic (113.00). We will evaluate the predominant feature of your impairment under the appropriate body system, as explained in 108.00D.

- *Clinical and laboratory findings*. We need evidence confirming the diagnosis of your XP or other genetic photosensitivity disorder. The evidence must include a clinical description of abnormal physical findings associated with the condition. There must also be definitive genetic laboratory studies documenting appropriate chromosomal damage, abnormal DNA repair, or other DNA or genetic abnormality specific to your type of photosensitivity disorder. However, we do not need a copy of the actual laboratory report, if we have medical evidence that is persuasive that a positive diagnosis has been confirmed by laboratory testing.

F. How do we evaluate burns? Electrical, chemical, or thermal burns frequently affect other body systems; for example, musculoskeletal, special senses and speech, respiratory, cardiovascular, renal, neurological, or mental. Consequently, we evaluate burns the way we evaluate other disorders that can affect the skin and other body systems, using the listing for the predominant feature of your impairment. For example, if your soft tissue injuries are under continuing surgical management (as defined in 101.00M), we will evaluate your impairment under 101.08. However, if your burns do not meet the requirements of 101.08 and you have extensive skin lesions that result in a very serious limitation (as defined in 108.00C1) that has lasted or can be expected to last for a continuous period of at least 12 months, we will evaluate them under 108.08.

G. How do we determine if your skin disorder(s) will continue at a disabling level of severity in order to meet the duration requirement? For all of these skin disorder listings except 108.07 and 108.08, we will find that your impairment meets the duration requirement if your skin disorder results in extensive skin lesions that persist for at least 3 months despite continuing treatment as prescribed. By *persist*, we mean that the longitudinal clinical record shows that, with few exceptions, your lesions have been at the level of severity specified in the listing. For 108.07A, we will presume that you meet the duration requirement. For 108.07B and 108.08, we will consider all of the relevant medical and other information in your case record to determine whether your skin disorder meets the duration requirement.

H. How do we assess your skin disorder(s) if your impairment does not meet the requirements of one of these listings?

- These listings are only examples of common skin disorders that we consider severe enough to result in marked and severe functional limitations. For most of these listings, if

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SSI Listing of Impairments

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you do not have continuing treatment as prescribed, if your treatment has not lasted for at least 3 months, or if you do not have extensive skin lesions that have persisted for at least 3 months, your impairment cannot meet the requirements of these skin disorder listings. (This provision does not apply to 108.07 and 108.08.) However, we may still find that you are disabled because your impairment(s) meets the requirements of a listing in another body system, medically equals (see §§ 404.1526 and 416.926 of this chapter) the severity of a listing, or functionally equals the severity of this listings.

- If you have not received ongoing treatment or do not have an ongoing relationship with the medical community despite the existence of a severe impairment(s), or if your skin lesions have not persisted for at least 3 months but you are undergoing continuing treatment as prescribed, you may still have an impairment(s) that meets a listing in another body system or that medically equals a listing. If you do not have an impairment(s) that meets or medically equals a listing, we will consider whether your impairment(s) functionally equals the listings. (See § 416.924 of this chapter.) When we decide whether you continue to be disabled, we use the rules in § 416.994a of this chapter.

108.01 Category of Impairments, Skin Disorders

108.02 **Ichthyosis**, with extensive skin lesions that persist for at least 3 months despite continuing treatment as prescribed.

108.03 **Bullous disease** (for example, pemphigus, erythema multiforme bullous, epidermolysis bullosa, bullous

pemphigoid, dermatitis herpetiformis), with extensive skin lesions that persist for at least 3 months despite continuing treatment as prescribed.

108.04 **Chronic infections of the skin or mucous membranes**, with extensive fungating or extensive ulcerating skin lesions that persist for at least 3 months despite continuing treatment as prescribed.

108.05 **Dermatitis** (for example, psoriasis, dyshidrosis, atopic dermatitis, exfoliative dermatitis, allergic contact dermatitis), with extensive skin lesions that persist for at least 3 months despite continuing treatment as prescribed.

108.06 **Hidradenitis suppurativa**, with extensive skin lesions involving both axillae, both inguinal areas, or the perineum that persist for at least 3 months despite continuing treatment as prescribed.

108.07 **Genetic photosensitivity disorders**, established by clinical and laboratory findings as described in 108.OOE.

- Xeroderma pigmentosum Consider the individual disabled from birth.

- Other genetic photosensitivity disorders, with:

1. Extensive skin lesions that have lasted or can be expected to last for a continuous period of at least 12 months.

OR

2. Inability to function outside of a highly protective environment for a continuous period of at least 12 months (see 108.00E2).

108.08 **Burns**, with extensive skin lesions that have lasted or can be expected to last for a continuous period of at least 12 months. (See 108.OOF).

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Have you moved recently or are planning on moving soon? Please let us know your change of address so you can continue to receive the Focus. Postage for the newsletter does not include forwarding.



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