

Ichthyosis FOCUS



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Fall 2005

When Your Insurance Won't Pay

By Drs. Jason Theodosakis and David T. Feinberg

For those of us lucky to have medical insurance, the rejection of a claim can come as a rude shock. After all, we have been paying a monthly premium with the expectation that the cost of care will be covered when we need it. The insurer's decision may seem arbitrary, nitpicking, or just plain wrong. Still, as much as we may need help to pay for a particular treatment, the prospect of fighting a bureaucracy can seem daunting and futile. Trust us, it doesn't have to be that way.

When your insurance company tells you "no," following a few simple steps can often get the decision reversed in your favor. Here are the critical points:

Don't get angry, but do get involved. Insurance companies want to keep costs down, and that means denying payment for care and medications that they feel are not positively necessary. Don't take this personally. A denial-of-care notice, usually a letter or other official statement that denies payment for certain care, but not "care" *per se*, is often made by a computer or by a cursory review by insurance company employees.

Hold on to your written records, not just the denial of care notice, but *all* correspondence from the insurance company, in the event that your case escalates over time and is eventually heard by a panel of reviewers.

Talk to your doctor to determine if the denied coverage is for a treatment or drug that he or she thinks you absolutely need, rather than something that may be helpful. Patients sometimes misunderstand their doctor's intentions.

Realize that most plans base coverage on a concept called "medically necessary." Simply put, this means that without the care in question your condition could get worse. It does not mean that you are entitled to the newest high-tech treatments, especially if they are not yet fully tested.

Do some research. Many medical organizations have set up "practice guidelines," suggested standards for care,

which you will find on their Web sites. For instance, if coverage is denied for a drug that is widely prescribed for a heart attack, you could use this fact to further your case. (There are various Web sites. See www.americanheart.org, for example, and type "practice guidelines" in the search box.)

Call your insurance company and say, "I am appealing my denied care." Then put it in writing. When you call in a complaint, it likely goes to a customer-service department, where there is no legal constraint to respond. By initiating an *appeal*, the insurance company, generally by law, has to begin a *timely review* of your case, which ultimately will be heard by a neutral outside panel. Follow up the call with a traceable letter in which you again use the word *appeal*. (Send it by certified or registered mail, overnight delivery, or fax, making sure to keep the respective receipts for your records.) Then, have faith. Studies show that about 50% of the cases that go to neutral outside panels are decided in favor of the patient.

Notify your department of human resources. Send a copy of your letter to the head of personnel or human resources (HR) at work. Since the department actually purchases medical and other benefits on your behalf, the insurance company sees it, not you, as the customer. When the HR department puts pressure on the insurance company, things happen.

Finally, if you think a treatment or medication is urgent or required, get it. Launch an appeal later, when you have less to lose. Trying to save a few dollars by delaying care is never worth the risk to your health.

The ultimate solution to these problems really begins at home. Prevention and wellness are preferable to any kind of treatment. But when treatment is required, don't be afraid to go to bat against your insurance company and turns its "no" into a healthy "yes."

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Correspondence Corner

Dear Friends:

I have X-linked ichthyosis and use either Amlactin (ammonium lactate) or Epilyt. Amlactin keeps the skin moist and soft, but I find it does not eliminate the scales and, after a while, I have to use Epilyt for a week or two. I take a bath, soaking for one hour, and removing scales for about one hour more. I do this about every month or two during cold dry weather.

However, lately (summer months) I have tried using half Epilyt and half water, shaken. I don't know how this would work in colder dry weather.

It is easier to apply, and I find that it does not have the heavier (thicker) feel. I have not tried other proportions of Epilyt and water, which may work better for some.

Good luck,

Joseph Laffey, OMD
Peabody, MA

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

The cream that I bought in Germany for my daughter is not working here in the U.S.; we live in the California high desert.

I bought about 100 boxes of Physiogel Cream (the name in the U.S. is Impruv) manufactured by Steifel Laboratories. I wanted to make sure I had enough creams until I found the right one in the U.S. This is a great natural repair cream, but it is not working in the high desert. If anyone is interested in buying this cream from me, I have 150 gram jars (about 5 oz. or more; this size is available only in Germany).

I also have about 130 boxes (150 ml, about 5 ounces or more) of an antibacterial cleansing lotion called Oleatum Gel (Oilatum-AD Cleansing Lotion in the U.S.), also manufactured by Stiefel Laboratories. This works great on my daughter's skin. After I am finished rubbing her skin, I put this cleansing lotion on her body and let it soak in for 5 minutes, then just rinse off. I guess moving to the U.S. made me realize that I bought too much of this cleansing lotion. The expiration date is 08/2006.

If anyone is interested in these products, feel free to email me at lucasolo_244@hotmail.com.

Sincerely,

Lucy Solomon
Joshua Tree, CA

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The Burden of Skin Disease Report

At any given time, one in every three people in the United States suffers from a skin disease. The prevalence of skin disease exceeds that of obesity, hypertension, or cancer.

The effects of skin diseases range from simple itching and burning to severe emotional and social effects, to physical disfigurement or death. The large social and healthcare costs associated with skin diseases significantly impact on our nation's healthcare economy. Americans have overlooked the very real burden of skin diseases for far too long.

The American Academy of Dermatology Association and the Society for Investigative Dermatology commissioned a study by The Lewin Group to quantify the burden of skin disease. The study shows that skin disease is more prevalent than anyone ever imagined and carries serious medical and financial consequences.

The study conducted by The Lewin Group analyzed 21 skin diseases (see list below). Although ichthyosis was not included in the list, the benefits from this study will have an impact on all skin diseases and, thus, benefit patients with ichthyosis.

- Acne
- Actinic keratosis
- Atopic dermatitis
- Benign neoplasms
- Contact dermatitis
- Cutaneous drug eruptions
- Cutaneous fungal infections
- Cutaneous T-cell lymphoma
- Effects from sun exposure
- Hair and nail disorders
- Herpes simplex and zoster
- Human papillomavirus and warts
- Immunobullous diseases
- Lupus erythematosus
- Melanoma
- Nonmelanoma skin cancer
- Psoriasis
- Rosacea
- Seborrheic dermatitis
- Skin ulcers and wounds
- Vitiligo

The total annual cost of the 21 skin diseases above is staggering. The study estimates that the total annual cost was \$37.17 billion in 2004, which includes medical costs and lost productivity. The majority of these costs stems from treating common but serious diseases, such as psoriasis, acne, burns, wounds, and melanoma.

The study took into consideration the indirect costs of lost productivity for these diseases. Patients with skin conditions have a diminished quality of life that can exceed many non-skin related conditions. Because skin diseases are often accompanied by visible and physical abnormalities, they impose significant psychological burdens for patients and limit quality of life.

Major types of symptoms affecting skin include debilitating itching, impaired mobility, and severe psychosocial effects. Skin conditions may interfere with activities of daily living by, for example, restricting motion. Also they are often psychologically debilitating because of the physical discomfort and visible manifestations which impact patient self-confidence.

National Institutes of Health (NIH) research expenditures on skin disease are estimated to be approximately \$172 million in 2005. Federal funding for skin disease research has not kept pace with its prevalence of burden. This level of funding is significantly lower than the commitments attributable to other diseases with equivalent or lower health and economic burdens. Dermatologists and patient advocates are urging Congress to increase overall FY2006 funding for skin disease research.

The medical, financial, and emotional toll of skin disease must not go unrecognized in policy making, funding allocation, or when setting national health priorities. New treatments and cures for these skin diseases can be found if more money is invested in medical research.

As one of the most costly and rapidly expanding medical conditions in the United States, the burden associated with skin diseases should be a growing concern relevant to the health and economic well being of the nation.

If you are interested learning more about the Burden of Skin Disease Report, contact the American Academy of Dermatology Association in Washington, DC at 202-842-3555 or www.aad.org.

**Excerpted and edited from the Summary Booklet on the Burden of Skin Disease, sponsored by the American Academy of Dermatology and Society for Investigative Dermatology.*



Spotlight on April Kear

My name is April and I have a relatively mild form of EHK. A few weeks ago on a Sunday, I was trimming trees with a long pole trimmer. The branch was hard to cut through and when the trimmer finally cut the branch, I accidentally let go of the trimmer and it came down on my thigh. When I lifted the leg of my shorts, there was a silver dollar size area of “misplaced” skin. I cleaned up my branches and, a few minutes later, I sat down on my porch and gave my injury a ten-minute Reiki treatment. Afterward, I rolled up the material of the shorts on that leg, so that it would not rub the wound, and went on to other household tasks. I never washed the wound because it was not dirty, and I did not put any salve on it.



The injury had started to get watery as soon as I got it. I never dried it off. Within an hour or so, it had dried up by itself. I decided to go to bed without putting any salve on it. It never wept again.

On Monday, I knew that it was healing better than normal. By Tuesday, I could rub my fingers across the injury and, although I could see where the edges of the wound were, the edges of the injured skin were fused to the uninjured skin and felt smooth when I rubbed my fingers across it.

Because of the size of the injury, the skin did dry and crack in a few spots a day or two later. That was the only time I put salve on it, just to moisten the skin so it would not crack and bleed more. The wound never got infected and did not spread to the surrounding area. It healed faster and differently than any other injury that I have had.

By now you might be wondering what a Reiki treatment is. If I were to give you a Reiki treatment, this is what I would have you read and sign:

“Reiki is a hands-on form of healing. A Reiki practitioner acts as a conduit of the electrical energy that surrounds us. The practitioner requests that energy be directed to any part of the client’s body that is in need of healing. Reiki can aid in physical, emotional and spiritual healing. Reiki can effect changes that are surprising.

Reiki is not an exact science. A practitioner cannot promise any specific healing or outcome of any treatment. Reiki is not a replacement for medical treatment by a licensed physician. A practitioner may not diagnose medical problems or prescribe medications.

During a Reiki session, a client may experience any number of sensations, visualizations, memories, crying or sleeping. If, at any time, the client feels uncomfortable, the session may be terminated. It is possible to feel pain during a treatment. This should fade away when the treatment is over.

I understand that there is no guarantee of change in the state of my health or well being as the result of this Reiki treatment.”

That is my quick explanation for someone who is not familiar with Reiki. To be a little more specific, Reiki could be considered a New Age form of healing although it has been around for many years. It was “discovered” around 1920 by Mikao Usui, a Japanese Sensei. In Japan, Reiki was practiced by a secret society and was not well known. Mrs. Hawayo Takata, a Japanese woman who lived in Hawaii, learned about Reiki while visiting her parents in Japan. Because of her, Reiki is better known and practiced in the United States than in Japan.

A common scenario for a Reiki session:

The client lies on his or her back on a massage table in a dimly lit room. It is common to use meditative music and aromatherapy to set the mood. The client is told to “set their intention,” or in other words, to set into their mind their goal for this healing session. This is probably a good place to say that Reiki is like a prayer. You can ask for anything you want, but you need to realize that you may not get what you ask for. (For a long time, I just asked for whatever healing I needed and what I needed was mostly emotional healing.)

To start the session, the practitioner asks for the Reiki energy to flow around them for the highest good of the client. While the client is on the table, the practitioner moves around the client, placing his or her hands on or above the areas of the body that the practitioner is intuitively drawn to. Regular treatments are generally a half-hour to an hour.

You do not have to tell the practitioner what your intention is. During the treatment, the practitioner may receive thoughts, impressions, or ideas. Generally, the practitioner will tell you about whatever comes to him or her in case it helps you. The experiences that you can expect to have were stated above.

By now, you are shaking your head and saying, “What kind of hocus pocus is this?” And I cannot blame you. It is something you need to experience. Reiki is not a religion.

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Foundation Resources

Online Educational Modules for Healthcare Professionals

Thanks to ePharmaLearning, an online technology company in Conshohocken, PA, the Foundation has added a new resource to our website, www.scalyskin.org. Two online educational modules are available to health care professionals on issues relating to the diagnosis and management of ichthyosis patients:

- Types of Ichthyosis & Making the Correct Diagnosis (10 minutes) by Dr. Mary Williams, Professor of Dermatology at the University of California in San Francisco, CA.
- Management of Ichthyosis in the Neonate (13 minutes) by Dr. Bari Cunningham, Director, Dermatologic Surgery and Pediatric & Adolescent Dermatology at Children's Hospital & Health Center in San Diego, CA.

These modules provide slide presentations, photos, and audio lectures on the above topics. The Foundation encourages you to share these modules with your healthcare providers. They are short enough to watch over a cup of coffee and provide a wealth of accurate information to newcomers in the world of ichthyosis.



Special thanks to ePharmaLearning, Inc., who provided the tools, production, and hosting service of these new modules. The Foundation gratefully acknowledges your generous support of helping individuals and families affected by ichthyosis.

New Resource Sheet - Medicine Assistance Programs

Having trouble with the costs of your medications? The Foundation's new resource sheet, *Medicine Assistance Programs*, provides information about various medicine assistance programs that may help you get your prescription medicines at a lower price, or no cost. Many programs exist to help people find their prescription medications at reduced cost or free of charge. This resource sheet helps you identify the program that may be of best help to you. To order this new resource, call Maureen in the Foundation office, 1-800-545-3286, or email her at info@scalyskin.org. Or check our publications order form on page 9 to order this and other resources.

When Your Insurance Won't Pay

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Let Your Doctor Help

Enlisting your doctor's help in the appeals process can make a big difference in your case. Doctors are used to dealing with insurance companies, and they know the lingo. That's why it's a good idea to cultivate positive relationships with your health care providers.

Ask your doctor to:

- Write a letter of "medical necessity" about the treatment or medication in question for you (or the doctor) to submit to the insurance company.
- Speak with one of the nurse reviewers or medical directors who are reviewing your case for the insurance company.

Dr. Jason Theodosakis ("Dr. Theo") and Dr. David T. Feinberg are the authors of "Don't Let Your HMO Kill You!" Dr. Theodosakis also is the author of the "The Arthritis Cure: Revised Edition." Dr. Feinberg, medical director of the UCLA Neuropsychiatric Institute, is a consultant to managed-care organizations.

Reprinted from Parade Magazine, September 19, 2004. © 2004 Dr. Jason Theodosakis and Dr. David Feinberg. All rights reserved.

Executive Director's Report



Dear Members & Friend of the Foundation,

Thank you to each of you who donated to our recent summer research campaign. To date, the response has been generous. The Foundation is eager to raise serious funds to help strengthen our research fund. If you have not had a chance to make a contribution, I hope this letter will serve as a gentle reminder to place a donation in the mail today.

I know, from polling our members, that ichthyosis research is your number one priority. Over the past year, a lot of discussion and planning has been taking place among our Board of Directors and Research Committee. When our board meets in early November for its biennial face-to-face retreat, increasing ichthyosis-related research will be at the top of our agenda. You can look forward to hearing more about the outcome of this meeting in an upcoming issue of the newsletter.

The Foundation's original founding members and devoted dermatologists, Drs. Mary Williams and Peter Elias, will be honored by the Foundation at a testimonial dinner on March 3, 2006, in San Francisco. Although both Mary and Peter are humbled by this honor, they want to help the Foundation raise money for our important work. The event is open to any of our members who are interested in celebrating with Mary and Peter. If you would like to receive an invitation or know of someone who would like to support the event, please let me know. We would be happy to add additional guests to the invitation list.



From Left: Mark Klafter, Mike Briggs, and Larry Silverman

On September 30, Mark Klafter and Mike Briggs, two members of our Board of Directors, took to the links and supported a grassroots fundraiser. BKR Cornwell Jackson, a Dallas-based multi-disciplinary financial practice, hosted its annual charity golf tournament in the small German town of Muenster, TX. Half of the proceeds raised from the event will be donated to our Foundation. Thirty-two teams and fourteen volunteers came together to have a good time and raise money to help families affected with ichthyosis. More than eighteen sponsors supported the event with generous donations, and all prizes and raffle items were donated by many local businesses. Everyone had a great time and the Foundation is very grateful to BKR Cornwell Jackson's executives for choosing our non-profit as a recipient of the event's proceeds.



From Left: Amy Legate, Larry Silverman, Mark Klafter, Mike Briggs, and Scott Bates

As a reminder, a lot of ichthyosis news and announcements are posted on our Foundation's website, www.scalyskin.org. I encourage you to take a few moments to visit our site and navigate through the pages. The site is updated regularly to provide the latest information to the ichthyosis community. For more information on our newest addition to the website, *Educational Modules for Healthcare Professionals*, see page 5.

I want to close my report with an interesting Foundation fact. In 2006 (which is only months away), the Foundation will be celebrating its 25th anniversary of serving individuals and families affected with ichthyosis. On January 2, 1981, the Foundation officially became incorporated as a non-profit charity in the state of California. There will be more celebrating to come next year.

Warm regards,

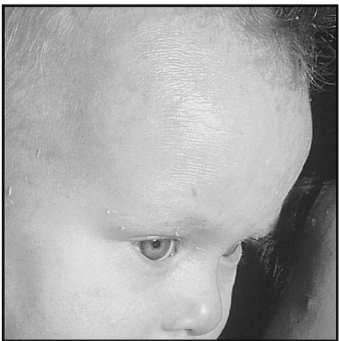
A handwritten signature in cursive script that reads "Jean".

Jean R. 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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For more information call 1-800-225-9411 or visit www.neostrata.com

* Fictitious name. Consult a physician before using on children.

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Spotlight On April Kear

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It is not magic. It is not a medical treatment and it will not interfere with any kind of medicine that you are using. We are surrounded by energy. When you are giving or receiving Reiki, you are simply asking the energy to work for you, by channeling it to a specific need.

Using Reiki is generally taught in three levels. This is the important thing that I want you to know. You can do Reiki on yourself. In fact, when you are doing it for others, you should always be keeping up with your own treatments. Once you have taken the first level class, you can begin giving yourself treatments. You do not need any equipment at all. You can do Reiki on yourself any time and any place, and no one will know that you are doing it.

Recently, I was at a play and had a patch of blisters that were itchy. They were on the back of my leg where I couldn't easily put my hand. I put my hand on the side of my leg and asked for Reiki energy to flow. In a little while, the itching stopped.

I said before that Reiki was like a prayer. The difference is that the person who does Reiki can be an active participant in the results.

If you have a skin disorder, I would suggest that you find someone in your area that does Reiki. If no one is listed in your phone book, call massage therapists, acupuncturists, or chiropractors. They should be able to point you in the right direction.

My explanation of Reiki is extremely incomplete. You can find more information on the Internet. You can buy books. But your best way to find out more about Reiki is to experience it. Even if you don't believe in Reiki, it can still work for you. Perhaps you could make some arrangement with a practitioner to get a short area-specific treatment when you have an injury or new sores. This could be the best way to see how Reiki works for you. If you cannot get a 10-minute treatment, tell the practitioner that you want him or her to focus on specific area. Or if you dare, see if the practitioner can tell you where he or she thought you had a problem after the treatment is completed.

Reiki cannot cure any of us of our skin disorders, but it can heal our hurting a little faster and it might even help "heal your heart" a little about having this health problem.

April Kear
Sellersville, PA

Camp Horizon 2005

by Ryan Licursi

Over the past seven summers, I have made the trek from my hometown in southern New Jersey to Millville, Pennsylvania, where I enjoy myself for a week of fun in the sun at Camp Victory. It is a small camp in central Pennsylvania used for many different types of camps throughout the summer. For one week in August, it is the home of Camp Horizon where children, ages 8 to 13 with chronic skin conditions, come from all over the country to forget about their worries and have a blast. It is a time to spread your wings, make new friends and reconnect with old ones, try new things, and just be yourself. I have experienced Camp Horizon as both a camper and a counselor

Being a camper is all about just letting go and having fun. From the moment you wake up in the morning to the second you go to sleep at night, there is some sort of fun activity planned. From fishing to swimming, arts and crafts, and archery, there is something for kids of all ages to enjoy. As a camper, my favorite activity was always the staff talent show. The word talent is a real stretch. It is mostly a bunch of silly acts where the counselors either make fun of themselves or other staff members in an effort to make the campers laugh for two straight hours. And they do just that! As they say, laughter is the best medicine.

For me, part of being a counselor is not much different than being a camper. I get to guide my group through the daily activities and participate in the fun. I especially like being part of the group that entertains the children during the talent show, so it really comes full circle. Another part of being a counselor is being there for the kids for whatever they may need. Having a skin condition myself, it is very easy for me to relate to the campers and the situations they face in their daily lives. It is very fulfilling to be a part of their Camp Horizon experience.

Camp is a rewarding and enriching adventure. As both a camper and a counselor, I can say that I have learned so much about myself and about others. I hope to continue to go to camp every year, and I will continue to keep in contact with the great people I have met there. I can't wait until next year!!!



The ichthyosis gang at Camp Horizon

Conference Chatter

Plans are moving along for the 2006 Family Conference in Atlanta, Georgia, on June 30, July 1 & 2. Our 2006 conference theme is *Soaring to New Heights*.

There are two important changes taking place during this conference as compared to the last few. First, the clinical screening is scheduled for all day Friday, June 30. In previous years, the clinical screening took place all day on Saturday of the conference weekend. Many of our members expressed some concern about having to leave an interesting breakout session for their scheduled appointments with our expert dermatologists. We've solved this issue by scheduling the clinical screening appointments all day on Friday, which is the opening day of the conference. Conference activities do not begin until 2:00 pm that day, so the majority of our members will have the opportunity to meet privately with our expert dermatologists before the official sessions begin.



Second, at the end of every conference our members wish they had more time to socialize with new acquaintances and old friends. Once again, we've heard your voices, and made plans to expand your social time. Instead of breaking out on your own for Friday evening, the program will include an optional social dinner activity. Also, on Sunday afternoon after the closing program, an optional group lunch will be offered to everyone.

Check this space in the winter issue of the Focus for more information about the conference program plan and how to register and make travel plans. Registration forms for the conference will be available in January. Complete conference information and registration forms will also be available on the Foundation's website, www.scalyskin.org beginning in January.

News & Notes

KID (Keratitis, Ichthyosis, and Deafness) Syndrome: Information for Patients and Healthcare Providers

There is a collaborative group of physicians currently studying the relationship between KID syndrome and skin cancer. In addition, this group is exploring the relationship in patients with KID syndrome and one or more of the following: acne conglobata (severe acne), hidradentitis suppurativa (draining sinuses in the groin or under the arms), dissecting cellulites (sinuses and cysts of the scalp causing hair loss), and pilonidal cysts.

If you are a patient and meet the above description, or are a provider, and want to learn more about this, please contact Renee Grau, MD, at renee-grau@ouhsc.edu, the University of Oklahoma Department of Dermatology, 619 NE 13th. Street, Oklahoma City, OK 73104, 405-271-6110.

Genetic Information Nondiscrimination Act

The Genetic Information Nondiscrimination Act (S. 306, H.R. 1227) is a bill that will prohibit discrimination on the basis of genetic information with respect to health insurance and employment. It was introduced to establish basic legal protections that will enable and encourage individuals to take advantage of genetic screening, counseling, testing, and new therapies that will result from the scientific advances in the field of genetics. It will also prevent health insurers from denying coverage or adjusting premiums based on predisposition to a genetic condition, and prohibit employers from discriminating on the basis of predictive genetic discrimination. Additionally, such legislation would stop both employers and insurers from requiring applicants to submit to genetic tests, maintain strict use and disclosure requirements of genetic test information, and impose penalties against employers and insurers who violate these provisions.

To learn more about the status of this bill and the Coalition for Genetic Fairness go to www.geneticalliance.org and click on Public Policy, or call or email the Foundation office for more information, 1-800-545-3286, info@scalyskin.org.

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Updated Guide Helps Consumers Negotiate Disputes with Health Plans

The Kaiser Family Foundation and Consumers Union on August 4, 2005, released an updated guide to help consumers through the process of resolving disputes with their health care plans. The resource, [A Consumer Guide to Handling Disputes with Your Employer or Private Health Plan, 2005 Update](#), includes information about how consumers can take advantage of their health plans' internal processes to resolve disputes, external review processes as allowed under state laws, and a new section about experiences with state external review programs that include data about the outcomes of consumers' appeals. The guide also provides tips for avoiding some common mistakes that may prevent consumers from properly filing and successfully resolving disputes through external appeals.

To receive a copy of the updated guide go to www.kff.org, or call 650-854-9400.

Reprinted from NORD Online Bulletin, August 2005, a publication of the National Organization for Rare Disorders, Inc.®

Web Sites of Interest

Health Care Coverage Options

<http://www.nahu.org/consumer/healthcare>

The National Association of Insurance Underwriters has created a database that provides information on health insurance options for low-income U.S. residents and people who change jobs or have pre-existing health problems. The Health Care Coverage Options Database can be accessed at

<http://www.nahu.org/consumer/healthcare/>.

It provides a state-by-state listing of public health insurance programs for low-income residents, such as Medicaid and SCHIP (the State Children's Health Insurance Program). It also lists 32 states that offer high-risk health insurance pools for those with pre-existing health problems.

The database is presented in four parts: Employer-based Health Insurance Coverage, Individual Health Insurance Coverage, Assistance for Obtaining Health Coverage, and Health Care Coverage Contacts.

Reprinted from the Orphan Disease Update, Summer/Fall 2005, Volume XXIII, Edition 3, a publication of the National Organization for Rare Disorders, Inc.®

Drug Safety Information

<http://www.fda.gov/cder/drugSafety.htm>

The U.S. Food and Drug Administration (FDA) has added a new feature to its Web site that provides consumers with specific safety information about individual drug products. The new *Drug Specific Information* Web page presents information on more than 200 approved drugs. Each drug has a "core page" with links to all information about the product on the FDA's Web site. This includes general risk information and any past alerts issued about the drug,

The new page is located at

<http://www.fda.gov/cder/drugSafety.htm>.

It is part of the Center for Drug Evaluation and Research (CDER) Web site.

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For Travelers with Disabilities: A New Survey

Some people with disabilities and medical conditions have complained about airport security measures, especially if they have to go through intensive screening because of mobility impairment, service animals (such as seeing eye dog), implanted medical devices, medication supplies (such as needles for injecting insulin), and medical equipment.

As a result, the Transportation Security Administration (TSA) has developed a survey form for travelers with disabilities to provide feedback on their airline travel experiences. TSA says it will use the information to develop improvements in airport screening procedures.

You can find an online version of the survey at www.tsa.gov. (Click on "Travelers & Consumers" then "Persons with Disabilities & Medical Conditions.") If you don't have a computer, contact NORD and we will mail a survey form to you. When you complete the paper version, just fold it and mail it postage-free to the TSA.

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News & Notes

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National Institutes of Health (NIH) Reauthorization

Congress should have reauthorized the NIH several years ago, but the subject has been on the back burner until now. However, instead of simply reauthorizing the 27 NIH institutes and centers, Congressional Republicans are now proposing a complete restructuring of the \$28 billion agency.

The Chairman of the House Energy and Commerce Committee, Representative Joe Barton (R-TX), in consultation with Director of the NIH, Dr. Elias Zerhouni, is proposing that the institutes should be consolidated and the NIH Director should be given unprecedented authority to decide future spending priorities for research. Some NIH institutes, centers and offices would be merged or discontinued, and the remaining structure would be composed of two major divisions: one containing institutes that focus on specific diseases or organs, and the other focusing on basic research. Congress would no longer appropriate money to each institute, and the money would be lumped together into four baskets. The NIH director would then decide how the funds in each basket would be allocated. Right now, when Congress develops an NIH budget, it is dealing with 30 separate budgets.

The proposal met with mixed reviews from scientists, medical schools and patient advocacy organizations. Centralizing power to the NIH director, they opined, would

make research enterprise beholden to a single political appointee. In light of the current political controversy surrounding stem cell research, this may not be a good idea, some suggested. The Association of American Medical Colleges said the "huge reallocations" of funding will disregard all of the long-term planning the NIH has participated in. Some patient advocacy groups warn that the proposed restructuring will probably make it impossible to lobby for funding aimed at specific diseases.

Additionally, the number of institutes and centers would be capped at 27 in the future, and they would have to set aside five percent of their budgets for projects that cross institute lines. The NIH director could also award research grants independent of institutes and centers. If the restructuring becomes law, Congress will specify maximum budget increases for NIH in future years instead of authorizing "such sums as necessary."

The NIH was last authorized in 1993. Chairman Barton is rumored to be unhappy with the recent doubling of the NIH's funding, and he wants to prevent future rapid growth. The research community and patient advocacy groups are watching Representative Barton's committee very closely.

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