

NIAMS IRP Partners

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A newsletter for patients of the Intramural Research Program (IRP), National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

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The Children's Inn: A Home Away From Home

By Elizabeth Freedman

When you're sick, there's no place like home. But if you're a young NIH patient and you can't be home, then there's no place like the Children's Inn. The Children's Inn is a private, nonprofit, family-centered residence for children who are being treated at the NIH's Warren G. Magnuson Clinical Center. Its purposes are to keep children together with their families during serious illness, reduce their stress and facilitate their healing through mutual support.

"The Children's Inn is a place where children can relax and play. It's a place where kids can be kids, not patients. The home-like atmosphere of the inn provides a safe haven and a sense of normalcy for kids and their families," says Jan Mahrer, director of development and public relations at the Children's Inn. When you enter the inn, the first thing you see is a warm, open foyer with a large fireplace. Nearby, a welcoming committee of overstuffed toy panda bears greet you. By providing this haven away from the stress of being in a clinical trial, the inn makes it easier for families to enroll their children in NIH studies—and remain in them.



A child enrolled in a NIAMS study gives Mickey Mouse a big hug in the Children's Inn library.

There is no cost to families for staying at the Children's Inn. The inn's one requirement of guest families is that the child be in a pediatric protocol. Children who stay at the inn range from 3-day-olds to young adults in their 20s. When the inn is at full capacity (37 families can be accommodated at a time), the youngest and sickest kids receive first priority as space becomes available.

From the Scientific Director . . .

Welcome to the summer issue of *IRPartners*. Our feature story highlights the NIH Children's Inn, a special place here on the NIH's Bethesda campus where children involved in clinical trials can stay with their families.



We'll also introduce you to Dr. Michael Ward, a rheumatologist who recently joined the NIAMS. In our regular sections, "Research Update"

and "Did You Know," you'll learn about some exciting cartilage research we're doing and ways you can protect your skin and keep it healthy.

We hope you enjoy this issue.

*Peter E. Lipsky, M.D., Scientific Director
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CHILDREN'S INN, *continued from page 1*

When children return to the inn after a long, hard day of doctors and medical procedures, they want to have fun. The inn provides it. Younger children can play in the large playroom filled with toys and art supplies, while older children and adults can hang out in the game room, shooting pool. The inn even has a Manager of Fun who organizes activities throughout the week, including bingo and arts and crafts. Local volunteer groups often visit and keep the children entertained.

This home-like environment stands in sharp contrast to the isolation of a motel room. "Staying at the Children's Inn provides a sense of community for the patient and his or her family and facilitates participation in the study," says Janet Jones, R.N., a research nurse for the NIH Pediatric Rheumatology Clinic.

Families are not the only ones who benefit from the Children's Inn. Raphaela Goldbach-Mansky, M.D., a NIAMS researcher at the Pediatric Rheumatology Clinic, appreciates the Children's Inn because it allows her to focus all of her time and energy on researching pediatric rheumatic diseases. Before the inn existed, Dr. Goldbach-Mansky spent considerable effort looking for places for children and families to stay, which took time away from her research.

The Children's Inn has made it easier for the Pediatric Rheumatology Clinic to focus on what they do best: studying diseases such as juvenile rheumatoid arthritis, lupus, scleroderma, dermatomyositis, familial fever syndromes, and other chronic diseases that affect children's joints, muscles, bones and skin. One exciting area of research involves learning how to treat children with biologic



The giant stuffed panda in the foyer is one of the Children's Inn's main attractions.

agents, new medicines that target specific biological processes involved in rheumatic diseases rather than suppressing the whole immune system as traditional treatments have done. Another project is determining the appropriate steroid regimen for children with juvenile dermatomyositis, which causes weak muscles and skin problems in children. Researchers

NIAMS Research Updates: Cartilage Regeneration

As a person becomes older, wear and tear on the joints is more apparent. Cartilage, the rubbery tissue that covers the ends of the bones in a joint, starts to deteriorate. This can lead to a number of problems, including osteoarthritis, the most common form of arthritis. Since cartilage does not regenerate naturally inside the body, researchers hope that one day they can transfer tissue created in a lab to parts of the body affected by osteoarthritis.

Currently, NIAMS researchers in the Cartilage Biology and Orthopaedics Branch are developing ways to grow new cartilage in their labs. Rocky Tuan, Ph.D., the branch's chief, thinks cartilage regeneration—or more specifically, cartilage tissue engineering—will someday help people who have cartilage deterioration in their joints. "The causes of osteoarthritis are multifactorial, and the disease can affect as many as 20 million Americans or more. Over half of people age 65 and older have at least one joint affected by osteoarthritis," says Dr. Tuan.

Several treatments to replace deteriorated cartilage now exist. One is total joint replacement, which replaces bone and cartilage with artificial parts. Another involves replacing damaged cartilage with cartilage obtained from a donor. As an alternative to these procedures, Dr. Tuan's lab is developing "bio-implants." This process involves growing cartilage cells in their earliest stages, and then transplanting them to damaged areas of joints of experimental animals so they may flourish on their own. Although this procedure is still in its infancy, Dr. Tuan sees great promise for treating patients.

Right now, Dr. Tuan's lab is focusing on the three main steps involved in cartilage tissue engineering. First, scientists identify and isolate undeveloped cells, such as adult stem cells from the patient, that have the potential to develop into cartilage cells, also called chondrocytes. They monitor the growth of these stem cells and try to direct them to become chondrocytes.

Second, scientists need a scaffold to hold the cells to allow them to develop into a tissue. Ideally, a

scaffold made of fibers acts as a temporary place for the cells to grow; it should be biodegradable, but should also be mechanically strong enough to hold the cells as they grow into the fibers. Dr. Tuan's lab is now using a synthetic web of fibers to create such a scaffold. Photographs taken with a microscope show that the cells seem to adapt and latch onto this fiber web, forming a structure of bone and cartilage.

Third, they must develop an ideal tissue environment in the lab, similar to that in a healthy joint. If the environment is unfavorable, the cartilage cells will not be able to maintain their

Stem Cells



Adult stem cells are not embryonic stem cells. Instead, adult stem cells are derived from parts of the body such as the bone marrow, bone, blood vessels and fat. The primary roles of adult stem cells are to maintain and repair the tissue in which they are found. However, because of their self-renewing ability, they are candidate cells to repair other tissues and organs.

characteristics, or they could simply die off. Dr. Tuan says that developing an optimal set of conditions is essential to successful engineering of high-quality cartilage.

Dr. Tuan's team is not ready to test cartilage replacement in people yet; however, he is optimistic about the future. "Hopefully, in about 5 years, we will see clinical trials for cartilage replacement," says Dr. Tuan. Also, one of the main keys to success is using adult stem cells. "The application of adult stem cells is important to cartilage research because of the versatility of these cells," he says. "Because cartilage cells are difficult to maintain, it is preferable to use adult stem cells that have the ability to develop into cartilage cells." ▲



Did You Know?...

Your skin is an organ, the largest organ in the body, and like all other organs, it needs to be kept in good working order. It's exposed to the environment 24 hours a day, and it can really take a beating. But caring for it is easy. Most dermatologists recommend a simple approach to skin care: Clean it, moisturize it and protect it.

Skin serves as a protective barrier, keeping bacteria and other harmful substances away from tissue, bones and blood vessels. It also enables us to keep cool in hot weather by releasing water (perspiration) which evaporates from the skin. And it contains nerve cells, allowing us to feel warmth, cold, touch and other sensations.

Skin is made up of several layers. The innermost layer is the **subcutaneous tissue**, which contains blood vessels and connective tissues. Connective tissue is the material between cells that gives tissues form and strength. The middle layer is the **dermis**, which also contains connective tissues and blood vessels, as well as nerve endings, hair follicles and sweat glands. The outer layer is the **epidermis**, the part that is visible.

The outermost part of the epidermis is made up almost completely of keratin, a protein found in skin, hair and nails. The cells here are dead, but not to worry: New skin is forming all the time. As the dead cells slough off, new skin cells replace them. The entire process takes about 30 days.

Clean It

- If you have normal skin, regular bar soap and water will clean the skin efficiently, removing dirt, oil, sweat and dead skin cells.
- If you have dry skin, soap may strip away too much of the skin's natural oils, leaving the skin feeling dry and tight. You may want to try a superfatted soap, containing fatty materials like cocoa butter or lanolin, or a cleansing lotion or cream that will clean without removing too much oil.
- If you have oily skin, soaps that are made for oily skin will help remove excess oil.
- Scrub gently when you wash, or you may make the skin irritated or red.
- When you dry off, gently pat the skin dry to avoid irritation and redness.

Moisturize It

Everyone gets dry skin from time to time. Dry winter weather, heated indoor environments or air conditioning can cause too much water to evaporate from the skin, leaving it dry. As people age, the skin also tends to get drier.

- Cover exposed skin when you're out in cold weather.
- Keep your home warm, but not too hot, and increase the humidity by using a humidifier.
- Bathe or shower with warm, not hot, water. Hot water will increase evaporation and leave skin drier. You may want to bathe or shower less often, especially during the dry winter months.
- Keep your shower or bath short. Ironically, staying in the water longer will actually speed up evaporation, leaving skin drier. (You can't put water back into your skin from the outside. The skin replenishes water from within.)
- As soon as you are done bathing, apply a moisturizer. The moisturizer should help your skin feel softer and more comfortable. Here are some tips about moisturizers:
 - Use moisturizer to prevent further water loss and allow the skin to rehydrate itself from within.
 - Reapply it during the day, for instance, right after you wash your hands.
 - Choose one that suits you and makes your skin feel comfortable. (More expensive lotions are not necessarily better.)
 - Check the ingredients. Lotions that contain a lot of alcohol will make your skin drier.

If a normal moisturizing regimen doesn't improve your dry skin, you may have a more serious skin condition, and you should visit a dermatologist.

Protect It

- Exposing your skin to the sun may cause excessive dryness, wrinkles or dark pigmentation (age spots) and puts you at risk for skin cancers.
- Sunscreen or sunblock will help keep the sun's ultraviolet rays from harming the skin.
- See our Fall 2002 issue of *IRPartners*, where we explained more about skin and sun exposure: http://www.niams.nih.gov/ne/highlights/irpartners/fall2002/fall2002_3.htm#2 ▲

Michael Ward, M.D., Researcher

Researcher Michael Ward, M.D., who joined NIAMS in October of last year, spends a lot of time asking himself tough questions, such as, "How much improvement means a patient is better? Do you measure improvement on a pain scale, or by increased function or by slow progression of organ damage?"

Why does Dr. Ward ask these questions? He's a rheumatologist, and his research focuses on outcomes, or the results of treatments. When you're developing studies that test new medications or therapies, you have to consider how to measure the results so you can tell if the treatments are really working.

Originally from Chicago, Dr. Ward went to medical school at the University of Illinois and then did his residency at the University of Michigan in Ann Arbor. He says, "The training I got as a medical resident wasn't enough to help me evaluate the clinical literature. I felt I couldn't judge it. I would read the scientific literature but remain unclear on how the researchers reached their conclusions." He found himself drawn to the research aspects of medicine, such as statistical issues, study design and outcome measures. He decided to get a master's of public health degree in epidemiology at the University of Michigan. After that, he accepted two fellowships, one at Duke University Medical Center in Durham, North Carolina, and the other at Stanford University in California, where he later became an associate professor.

It was hard leaving Stanford and a job he liked, but Dr. Ward came to NIAMS because he was convinced it would be a great place for a rheumatologist and outcomes researcher.

"I figured at NIH I could get involved in collaborations that tackle broad health issues, like health disparities, behavioral research and the costs of disease." At NIAMS, Dr. Ward says, "I can remain close to patients and stay involved in their care. At the same time, I can be thinking about outcomes." He has to consider the whole patient—not just one clinical problem—in treatment since rheumatic diseases often involve multiple systems in the body. He recently began seeing patients at the NIAMS Community Health Center in Washington, D.C.



Dr. Ward now spends his days seeing patients, developing study protocols, analyzing data and writing reports. He'd like to consult with other NIH researchers who are developing outcomes criteria for research studies. "Being here is an opportunity for me to grow and be moving in different directions," he says. "I'd like to help make outcomes research a strong program here at NIAMS." Dr. Ward says he knows NIAMS is committed to outcomes research, because, well, "They're hiring people like me." ▲

Dr. Peter Lipsky Receives Research Award

The NIAMS congratulates Peter Lipsky, M.D., scientific director, for winning the Lee C. Howley, Sr., Prize for Arthritis Research. This prestigious award from the Arthritis Foundation recognizes researchers whose contributions during the previous five years have represented a significant advance in the understanding, treatment or prevention of arthritis and rheumatic diseases.

NIAMS Has Free Health Information

NIAMS has free health information (some in Spanish) available to the public, health professionals and organizations. Information is available on arthritis, lupus and other rheumatic diseases, skin disorders, joint problems and musculoskeletal diseases.

Contact the NIAMS at 1-877-22-NIAMS (free call), TTY: 301-565-2966. Check our Web site at www.niams.nih.gov/hi/. Many of our publications can be printed directly from our site.

Free information on osteoporosis, Paget's disease of bone, osteogenesis imperfecta, primary hyperparathyroidism, and other metabolic bone diseases and disorders is also available from the NIH Osteoporosis and Related Bone Diseases~National Resource Center (NIH ORBD~NRC). Contact the NIH ORBD~NRC at 1-800-624-BONE, TTY: 202-466-4315, or at www.osteo.org. ▲

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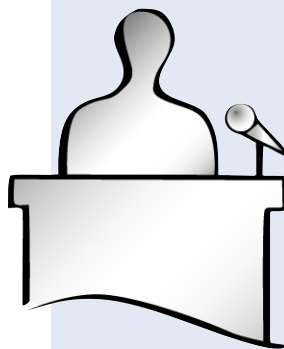
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learn more about rheumatic diseases at the clinic than they could if they had to travel from place to place to give treatments and monitor results. And just as the clinic provides children with a place where they can be diagnosed and treated in a state-of-the-art facility, the inn provides them with a home away from home.

If you would like to learn more about the Children's Inn or if you are interested in volunteering at the inn, please visit the inn's Web site at <http://www.childrensinn.org> or call (301) 496-5672. ▲



Need an NIH Speaker?

The NIH Speakers Bureau is a service that lists NIH researchers, clinicians and other professionals who are available to speak to school groups and other local and national organizations.

Speakers have expertise in such areas as arthritis, osteoporosis, autoimmunity and several dozen other topics covered by the NIH. To find out more about this service, sponsored by NIH's Office of Science Education, visit its Web site at: <http://science-education.nih.gov/spkbureau.nsf>.

NIAMS Community Health Center

The NIAMS has set up the NIAMS Community Health Center to help doctors and scientists understand the causes of rheumatic diseases and why many of these diseases occur more often and more severely in certain minority communities. With this information, we can find better ways to treat and prevent these diseases. There are no experimental treatments or medications being used at the CHC. Call 202-673-0000 for information.