

NIAMS IRPartners

Fall 2002

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

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National Institutes of Health



National Institute of Arthritis and Musculoskeletal and Skin Diseases

U.S. Department of Health and Human Services

A Wealth of Patient Services

By Susan Bettendorf

The NIH's Warren Grant Magnuson Clinical Center can be a confusing place. There are so many different study protocols and procedures. How do patients know where to go when they need something? Fortunately, the clinical center has a patient representative, an Office of Hospitality Services and an Office of Volunteer Services, working together to help patients figure it all out.

Patient Representative

Ms. Laura Cearnal, the patient representative at the clinical center, says she is impressed by the fortitude of patients who participate in NIH studies. "People sacrifice a lot to become part of a research study," she says. A patient's day can be a long one of traveling, testing, poking, prodding and waiting. Navigating the health care system is frustrating; navigating the system and study protocols can be even tougher. It's Ms. Cearnal's job, she says, to "catch the patients who fall through the cracks."



Ms. Laura Cearnal

Ms. Cearnal is a registered nurse with a master's degree in psychiatric nursing. She was formerly the head nurse of psychiatric units at the clinical center, and she understands why researchers require so much of a patient's time and cooperation. But as the patient representative, she can focus exclusively on the interests of the patient. "As a patient advocate, I'll help patients navigate the system," she says.

Many people with terminal illnesses or critically ill children are desperate to become involved in a protocol. Some are hesitant to raise questions because they don't want to be thought of as troublemakers. "I encourage people to come to me with questions or concerns," Ms. Cearnal says.

Many of the problems she has seen in three years as a patient representative are the result of differing perspectives between patients and staff. For example, how long is too long to wait for a prescription to be filled? Fifteen minutes may not seem long to the staff, but to the patient who's been at the clinical center all day, it feels too long. Ms.

From the Scientific Director . . .

In this issue of *IRPartners*, we're introducing "Research Updates," a new and regular column about clinical trials in the NIAMS intramural program. Patients have told us they rarely hear about the results of the very trials they are participating in. We've heard you, and "Research Updates" is one way we're getting the information out. In this issue, we share the results of a study on lupus.



In addition to our feature article on patient services, we'll introduce you to Mary Pott, a patient at the

NIAMS Community Health Center, and Robert Miranda-Acevedo, a new writer-editor in the NIAMS Office of Communications and Public Liaison, who will be working closely with our Community Health Center. We'll also provide some information on how to protect your skin from the sun.

We hope you enjoy this issue, and we look forward to bringing you many more research results and other stories that are of interest to you.

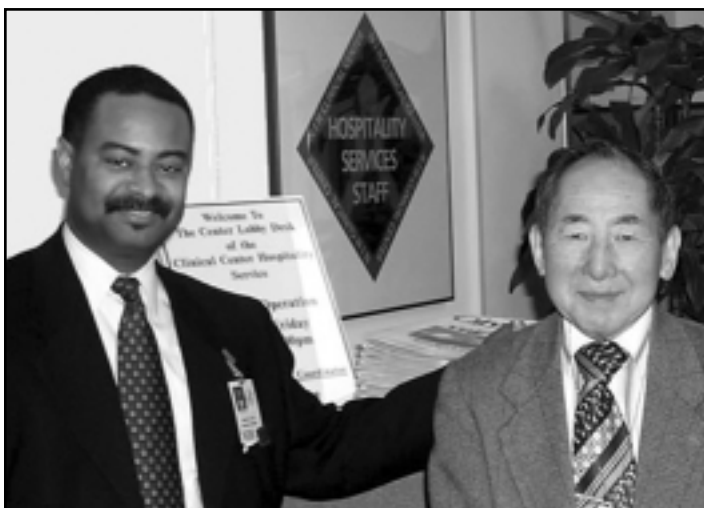
*Peter E. Lipsky, M.D., Scientific Director
National Institute of Arthritis and Musculoskeletal
and Skin Diseases, National Institutes of Health*

PATIENT SERVICES, continued from page 1

Cearnal can help the staff appreciate the patient's point of view and vice versa. She's also a sounding board for those who want to talk in confidence. Patients can call her at 301-496-2626 or e-mail her at lcearnal@nih.gov.

Hospitality

The Office of Hospitality Services, with its staff of five full-time employees, is keeping busy these days, assisting approximately 120 clients each day. Mr. Michael Daniel, chief of the Office of Hospitality Services, says, "We offer a range of services, such as escorts, concierge services and valet parking. If we don't provide them directly out of our office, we contact the people who do." Their goal is to make a patient's visit to the clinical center as smooth as possible.



Mr. Michael Daniel (l) and Mr. Fred Yamada, a volunteer who speaks Japanese, prepare to assist patients at the mid-lobby desk.

Hospitality Services has three sites located strategically in the clinical center: in the south lobby at the main entrance, on the first floor in the north lobby just outside the north elevator bay, and on the first floor near the main elevators (by the Masur auditorium entrance).

For patients with children, the office will arrange temporary child care with the Office of Volunteer Services. They also provide transportation between buildings on the campus and to restaurants and hotels in Bethesda and Washington, D.C.

If patients need an escort to a doctor's appointment or someone to show them how to navigate the clinical center, staff will accompany patients to their appointments and leave a business card. If patients need an escort when they're through, all they need to do is call. The office relies heavily on the Office of Volunteer Services for additional escorts and interpreters for non-English speakers.

Although the Office of Hospitality Services focuses on assisting patients, other visitors to the NIH are welcome to use their services also. In fact, the office works so closely with the NIH Visitors Center, many people don't realize they're separate offices.

Hospitality Services won the NIH Director's Award in 2000 for their record of outstanding service. Mr. Daniel says, "We receive plenty of positive feedback in the form of cards, letters and e-mails from the patients we've assisted, thanking us for our help." He encourages patients to take advantage of the new valet parking service. "It's free and convenient.

The NIAMS Community Health Center Celebrates Its First Anniversary



On hand to celebrate the CHC's success were (l to r) Unity Health Care's Dr. Janelle Goetcheus and Vincent Keane, and the NIH's Dr. Elias Zerhouni, Dr. Ruth Kirschstein, Dr. Peter Lipsky, Dr. Stephen Katz and Dr. Gregory Dennis.



Dr. Barbara Mittleman, director of scientific interchange at NIAMS, thanked community leaders for guiding the CHC from the days when it was just an idea through its first year of operation.



Some of the NIAMS staff who made the CHC a reality and contribute to its day-to-day operations.



NIAMS Council members Victoria Kalabokes (l) and Priscilla Cicciariello signed in for a tour of the 600-square-foot CHC facility.



Howard University's Dr. Warren Ashe (l), who helped pull together the community support that made the CHC possible, chatted with NIH Director Dr. Elias Zerhouni (r) and NIAMS Scientific Director Dr. Peter Lipsky about the Center's first anniversary.



A community leader who works with the CHC as well as a patient, Lillian Perdomo commended the CHC staff, particularly her physician Dr. Gregory Dennis, for providing what she called "excellent health care that is culturally adapted" to the needs of the neighboring African-American and Hispanic/Latino communities.

Mary Pott, a patient at the Community Health Center

Before Mary Pott developed rheumatoid arthritis—an inflammatory disease that causes pain and sometimes the loss of function in some joints—she lived independently and commuted from Reston, Va., to her job as a cashier at Dulles Airport. Since being diagnosed in 1996, however, Ms. Pott's health has slowly deteriorated, making tasks such as grooming or household chores more difficult.



When her poor health forced her to leave her job, Ms. Pott filed for unemployment and began to rely on government health care resources. Now, she walks with a cane and struggles with most of her daily activities around the house. Having lived with rheumatoid arthritis for almost six years now, Ms. Pott says she has bad days, but good ones, as well. "Some days I am quite agile and I can move around by myself with no trouble at all. Other days, I am practically immobile," says Ms. Pott. On this day, she walks with a cane around the waiting room at the NIAMS Community Health Center. One of her family members helped her make

her appointment at the center today, driving her all the way from Reston to Washington, D.C.

In the last six years, Ms. Pott has had two knee arthroscopies, two hip replacements and many hours of physical therapy in order to keep her mobile and to control the arthritis. She also has taken several different medications, but at the center she will soon be receiving injections of etanercept, a new, genetically engineered treatment for rheumatoid arthritis. Ms. Pott is receiving care as a participant in a NIAMS protocol studying rheumatic diseases in the medically underserved community to learn more about health disparities.

Now that Ms. Pott gets regular treatment at the center, she says, "My medical costs are much lower, and the advice I receive from the doctors at the clinic helps me cope with the pain. ...Blacks in the Washington, D.C., area need this type of treatment because many have diseases like lupus or arthritis." Ms. Pott predicts she will continue to visit the clinic because of the treatment she receives. "The clinic is concerned about the needs of the patient and helpful," she says. ▲

Robert Miranda-Acevedo, writer-editor, community liaison

Greeting people in both Spanish and English at the one-year anniversary celebration at NIAMS Community Health Center, Mr. Miranda is doing the type of work he loves: reaching out to people. His first exposure to working with the public was as an intern with the Bacardi Corporation in Puerto Rico, where he guided visitors through the factory, explaining the rum manufacturing process.

Mr. Miranda received his undergraduate degree in public communication from the University of Puerto Rico in San Juan. When he moved to Washington, D.C., he worked at the Department of Commerce in human resources for a time, but it was at the Department of Agriculture (DA) where he found he enjoyed public affairs. "When I began working in the community, I knew it was for me," he says.

As the editor for all Spanish documents produced by the Secretary of Agriculture's Office of Communications, Mr. Miranda developed fact sheets, reviewed press releases and wrote and recorded information for radio broadcasts. The DA

provides guidance on a wide array of issues, from food safety and school lunch programs to food export and rural development. "There was a huge need to get information out to the Spanish-speaking community, such as consumers and employees working in the food industry," he remembers. "It was a very productive and rewarding time."

Mr. Miranda left the DA last year and worked briefly as the internship coordinator at CBS' Washington, D.C., bureau, recruiting interns from the communications field who wanted to focus on news production. After the events of September 11, the news industry suffered along with the rest of the country, and CBS moved the internship program to its headquarters in New York City. Soon after, a NIAMS employee (and former DA intern) told Mr. Miranda the NIAMS Office of Communications and Public Liaison was looking for someone with his



In the early 1950s, a person diagnosed with systemic lupus had a 50 percent chance of dying within four years. One of the major causes of death was a serious complication called lupus nephritis, a form of kidney inflammation that can lead to kidney failure. Today, however, due to treatment advances, the 10-year survival rate for people with lupus is nearly 100 percent.

The research responsible for these advances has been driven over the past several decades in large part by NIH patients and doctors. Two recently published NIH studies show how safe and effective treatment strategies evolve rapidly when scientists asking the right questions follow a dedicated group of patients over the long term.

Long-Term Drug Studies

In the first of these studies, principal investigator Gabor Illei, M.D., and a team of NIH scientists followed 65 people with lupus nephritis for approximately 11 years. The 11 years actually comprised two studies: First, the patients participated in a drug study from 1987 to 1994. The scientists then called them back and asked to follow them for several more years to chart their progress. In the study that ended in '94, participants were given monthly pulse (intravenous) doses of prednisone (a corticosteroid), cyclophosphamide (an immunosuppressant drug used in larger dosages to treat cancer), or a combination of both.

The researchers were interested primarily in the safety of the different treatments. As Dr. Illei explains, "After the '87 to '94 study, we knew that cyclophosphamide was better than corticosteroids and that combination therapy was effective and faster acting [than either alone], but there seemed to be more toxicity with the combination. What we needed to know was the risks and benefits of combination therapy over the long term."

They found that after 11 years, the combination therapy did not cause more side effects and

might be superior overall: None of the 20 patients in the combination group had serious kidney complications, but 5 of the 21 people in the cyclophosphamide-only group did.

The Flare Study

The drug study spurred another set of questions about lupus. One of Dr. Illei's colleagues, NIAMS researcher Kazuki Takada, M.D., says, "We knew that some patients flare after the disease stabilizes with treatment. But we didn't know a lot about the importance of flares or how frequent they are. What can predict flares? What is the outcome of different types of kidney flares?"

To find the answers, Drs. Takada and Illei and other NIH researchers studied 92 people whose lupus nephritis responded to treatment. Their kidney disease was in remission, meaning they had not taken any immunosuppressant drugs for at least six months and yet their nephritis was not getting worse. The scientists followed the study participants for approximately 10 years, monitoring, treating and learning about their flares.

At the end of the study, 45 percent of the study participants had experienced kidney flares. The better someone had responded to treatment, the less likely they were to have a flare. Of those who did have flares, people who responded well to previous drug treatment were likely to go three years between flares. Those who had responded to treatment, but not quite as strongly, were likely to have a flare in approximately 18 months.

"We learned we cannot overlook flares. However, not all flares are equal," says Dr. Takada. "We also found that of the three different types of flares we described—proteinuric [a flare identified by the presence of protein in urine], mild to moderate nephritic [meaning kidney], and severe nephritic—one is associated with a much worse prognosis. In the group of patients with *severe* nephritic flares, 8 out of 15 reached kidney failure despite treatment

LUPUS, continued on page 6

IRP Nurse Recertified

Congratulations to Janet M. Jones, R.N., a research nurse in the NIAMS Clinical Program, for her recertification in pediatric nursing.

Let yourselves be pampered the way you deserve," he says.

The office is open from 6:00 a.m. to 5:00 p.m. every weekday, and some services are available on weekends. To find out more, visit the Web site at <http://www.cc.nih.gov/cc/hospitality/resources.html> or call 301-496-3475.

Volunteers

No story about patient services would be complete without mentioning the Office of Volunteer Services. Volunteers assist in the pharmacy, in laboratories, with child care, with recreation therapy and more. Working with the Office of Hospitality Services and Ms. Cearnal, the patient representative, volunteers will escort patients and visit new patients to orient them to the clinical center. But the biggest component by far is the interpreter program. The office has two staff interpreters who can speak French, Haitian-Creole, German and, of course, Spanish, the most requested language. For other languages, the office depends on its volunteers, who can speak more than 40 languages.

When Andrea Rander became the office's director in 1990, the office received just a few calls a week. The call volume has quadrupled since then. As the number of protocols increases, so does the number of people who need their services. "I never imagined that coordinating interpreter services would take up 75 percent of my time," says Ms. Rander. "But I'm glad to see that the interpreter program has been so successful."

Some volunteers are members of the community near the NIH. Some are families of embassy personnel. Some are on-campus staff. Ms. Rander is especially

grateful to the staff volunteers who often get called at the last minute and to their supervisors who give them the job flexibility to get involved. Many volunteers are HACU (Hispanic Association of Colleges and Universities) students who get to use their native language skills assisting patients in a medical setting, which sparks their interest in considering jobs in the medical field. "The patients get what they need, and in these arrangements everybody benefits," Ms. Rander says.



Ms. Andrea Rander

If patients need help when an interpreter is not available (usually between midnight and 8:00 a.m.), they may contact a live interpreter service by phone. The office also arranges for sign language interpretation.

Ms. Rander's future plans for the office include developing orientation videos in different languages, providing a card to all patients that reads, "Give this to a staff person if you need an interpreter," written in the 10 most frequently requested languages, and computerizing the request system so that patients can ask for an interpreter over the Web, as well as by phone or e-mail.

Ms. Rander says, "Anyone who can spare the time and would like to work with patients, we welcome you." Give her a call at 301-496-1807, or e-mail her at arander@mail.cc.nih.gov. ▲

with immunosuppressive drugs, compared to 3 out of 26 patients with other types of flares."

The doctors identified several predictors of kidney flares. "African-American ethnicity is a predictor. We don't know why yet. There is probably some genetic predisposition, as well as environmental factors," says Dr. Takada. "Also, people who have a low C4 after they stabilize have a high likelihood of developing a flare." (The C4, or complement

factor 4, test is a laboratory measure of the amount of a certain protein involved in inflammation in the blood.)

Drs. Illei and Takada say areas of future study include new treatments for lupus that are based on our increasing knowledge of the disease. They also want to find out if genetic testing can help determine how well someone will respond to therapy. ▲

Did You Know?...

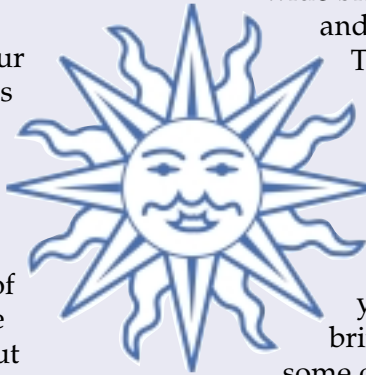
Did you spend the summer on a quest for the perfect tan? Dermatologists everywhere are flinching. Here are some facts:

- A suntan is not an indicator of good health. In fact, a tan is your skin's reaction to exposure to the sun's ultraviolet (UV) rays. To protect itself from these rays, the skin increases its production of melanin, darkening your skin color. When your skin tans, that's its way of saying, "I've been attacked."
- You may know that a few blistering sunburns in childhood are a risk factor for melanoma, a serious form of skin cancer, later in life. But a lifetime of tanning—not just burning—will put you at risk for other types of skin cancer as well. Tanning booths are not a safer alternative. The UV rays from tanning booths harm the skin just as the sun does.
- Sun exposure can cause wrinkles, age spots and leathery skin.
- Although everyone is at risk of skin damage by UV rays, fair-skinned people must be especially cautious. If you have a lot of moles or a family history of skin cancer, you could be at higher risk. See a dermatologist to assess your risk for skin cancer. In addition, certain medications may make you more sensitive to the sun, so be sure to read the information that comes with your medications.
- Your eyes need protection, too. Ultraviolet rays can burn the surface of the eye, much like they burn the skin. Long-term exposure to UV rays could contribute to the development of cataracts and macular degeneration, a disease that affects your central vision, later in life. Reflected sunlight (from the water, for example) is also dangerous.

So what are you supposed to do? Sit in the dark like a mushroom? Nobody is suggesting that. You can still enjoy summer. Just be aware of how much sun you're getting, and take the appropriate precautions:

- **Avoid being in the sun when it's at its strongest**—normally between the hours of 10:00 a.m. and 4:00 p.m. Plan indoor activities during

those hours, or do them in the shade. Some UV rays will still reach you in the shade—though not as many—because they are reflected off of concrete, sand and water. Even in the shade you should wear sunscreen or sunblock.



- **Cover up.** The more cover, the better. Long pants, a shirt with long sleeves and a hat with a wide brim that keeps the sun off your face and neck are best. If that's impractical, a T-shirt, long shorts and a baseball cap are reasonable alternatives. Tightly woven fabrics will offer more protection than loosely woven fabrics. Make sure the exposed skin is well protected with sunscreen, particularly the tops of your ears if you wear a cap instead of a hat with a brim. If your clothes get wet, they lose some of their protective ability.
- **Wear sunscreen or sunblock.** (What's the difference? Sunscreen chemically absorbs rays; sunblock deflects them.) Use a product with a sun protection factor (SPF) of at least 15. That means if you would normally burn in 10 minutes, the sunscreen will protect you 15 times longer (150 minutes). But remember:
 - Wearing sunscreen is not a license to stay out in the sun 15 times longer than you normally would.
 - A "broad spectrum" sunscreen protects against both UVB rays, the burning rays that are the primary cause of sunburn and skin cancer, and UVA rays, which penetrate deeper into the skin and also contribute to burning and skin cancer. The SPF indicates protection from UVB rays only; there currently is no standard rating to measure UVA protection.
 - Sunscreen wears off, especially if you sweat or go into the water. You will need to reapply it often, even the waterproof kind. Follow the directions on the sunscreen container.
- **Protect your eyes.** Wear sunglasses that block 99 or 100 percent of all UV rays. (Check the label.) Choose sunglasses that are close-fitting or that wraparound, which will prevent rays from filtering in from above and the sides.

For more information on sun exposure, visit the National Library of Medicine's Medline Web page at www.nlm.nih.gov/medlineplus/sunexposure.html.

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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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.

MIRANDA, *continued from page 4*

background. He applied and got the job. "I'm glad I got my bachelor's degree in public communication and then later studied public administration," says Mr. Miranda. "It helped me diversify my options. To me it's a perfect marriage, working in a communications office for a governmental organization."

Today, Mr. Miranda builds relations with the Spanish-speaking community and professional organizations through the NIAMS Health Partnership Program, and he also translates health information from English into Spanish. Since the recent anniversary celebration at the NIAMS Community Health Center, he's helped bring media attention to the center.

It's easy to see from Mr. Miranda's outgoing personality that the job suits him. A native Spanish speaker, he is obviously comfortable writing for and talking to the Spanish-speaking community. When asked about his goals, he says, "Now I need to keep working on my *English* writing skills." ▲