

NIAMS IRPartners

Summer 2006



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

Inside This Issue

- From the Scientific & Clinical Directors..... 2
- Autoinflammatory Conference a Success 3
- Did You Know?..... 4
- Pediatric CD-ROM4
- Research Updates: CIAS1-Associated Syndromes..... 5
- Alasdair Steven, Ph.D., Chief, Laboratory of Structural Biology Research 7
- IRP Welcomes Two New Directors9
- Dr. Katz Wins Award 10
- Free Health Information 10



U.S. Department of Health and Human Services



National Institutes of Health



National Institute of Arthritis and Musculoskeletal and Skin Diseases

Cultural Relevance: Finding the Tools for Better Health Promotion

By Kelli L. Carrington

In a small room with nothing more than an exam table and medical supply cabinets, a Hispanic woman aged 50 talks about her experience with rheumatoid arthritis. She's had it for over a decade. What resonates in her conversation is how much pain she endures daily and what little control she has over it. In the same room, about an hour later, an African American man who's in his 60s talks about living with osteoarthritis. He too has had it for many years. His biggest challenge is the uncontrollable pain that comes with his condition. These are just two experiences captured as part of a study to find better ways to educate and empower patients from minority communities by designing culturally relevant health interventions.



Katherine Jackson, post-baccalaureate fellow, interviews Ana Celiz Alvarez about health beliefs and behaviors.

While most of today's health messages, programs and even medical services address the needs of many, few address the cultural diversity, financial status, reading levels and languages of our population with tailored interventions that are relevant to the cultural practices and lifestyles of various racial and ethnic communities.

According to health behavior research, some interventions have been found to change a person's attitudes about and behaviors toward health and health care. The same research calls for changes in the current health promotion practices. Federal initiatives such as Healthy People 2010, which outlines the nation's health objectives, recommend more research on culturally appropriate health communication and tailored community health programs, including medical services.

From the Scientific and Clinical Directors . . .

We are pleased to bring you the Summer 2006 issue of *IRPartners*, our first since accepting our new appointments at NIAMS.

This issue begins with a story about researchers at our Community Health Center who are attempting to identify the cultural influences on health perceptions and practices of patients with arthritis and other rheumatic diseases.

Then we'll update you on the clinical research being done on some rare diseases known as CIAS1-associated syndromes. These diseases are

*John O'Shea, M.D.
Scientific Director
Intramural Research Program
National Institute of Arthritis and
Musculoskeletal and Skin Diseases,
National Institutes of Health*



autoinflammatory, a topic covered during a recent conference called "FMF and Beyond," which we'll briefly describe.

You'll also meet Dr. Alasdair Steven, chief of the Laboratory of Structural Biology Research, a long-time employee of NIAMS who was born in Scotland. And we've included a short article about the new National Cancer Institute guidelines encouraging everyone to eat more fruits and vegetables.

We hope you enjoy this issue, and we look forward to bringing you many more.

*Daniel Kastner, M.D., Ph.D.
Clinical Director
Intramural Research Program
National Institute of Arthritis and
Musculoskeletal and Skin Diseases,
National Institutes of Health*



CULTURAL RELEVANCE, *continued from page 1*

Studying Health Beliefs and Behaviors

Gwenyth Wallen, R.N., Ph.D., and her colleagues in the Department of Nursing at the National Institutes of Health Clinical Center are responding to the recommendations by identifying some of the cultural influences on health perceptions and practices of patients with arthritis and other rheumatic diseases. Their study, "Health Beliefs and Health Behavior Practices Among Minorities With Rheumatic Diseases," is conducted out of the

NIAMS Community Health Center in Washington, D.C. The study is a collaboration between the Department of Nursing and NIAMS. The research project also explores patients' use of complementary and alternative medicines and improvement in patients' health status after treatment.

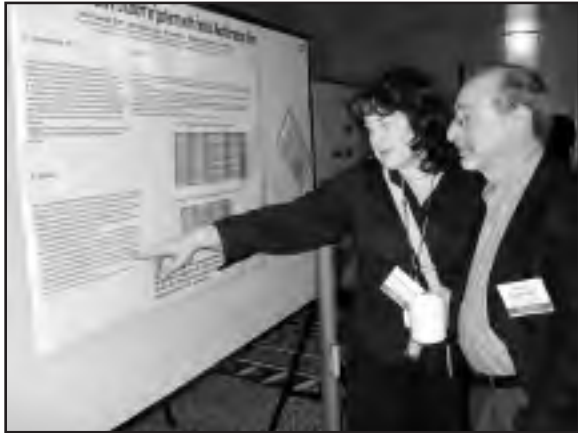
Through an existing natural history study of rheumatic diseases at the health center, Dr. Wallen is recruiting patients mostly representing local African American and Hispanic/Latino communities. Study



Nicole Schuett (standing), health educator at NIAMS, gave a presentation on the Patient Liaison Program at the January 26 meeting of the community partners, after which attendees discussed strategies to improve minority access to health care and clinical trials. These community partners helped NIAMS create the Health Partnership Program (HPP), a community-based research initiative, and helped establish the Community Health Center in Washington, D.C., the clinic where this study on health beliefs and behaviors takes place. The partners provide the HPP with insight into the community's needs and concerns about health care and research. They also share resources to help the HPP operate effectively in the community.

NIAMS-Sponsored Autoinflammatory Conference a Success

A team of 30 international researchers, led by NIAMS Clinical Director Daniel L. Kastner, M.D., Ph.D., hosted scores of scientists at the November 6-9, 2005, Fourth International Congress on Systemic Autoinflammatory Diseases, at North Bethesda's Marriott Conference Center. The comprehensive meeting, dubbed "FMF and Beyond," was deemed a huge success. In addition to NIAMS, co-sponsors included the National Human Genome Research Institute, the National Institute of Allergy and Infectious Diseases, the National Institute



Nurit Tweezer-Zaks, M.D., of the Heller Institute in Tel Hashomer, Israel, and Stephen Goldfinger, M.D., of Massachusetts General Hospital, review her poster on familial Mediterranean fever (FMF) and liver disorders.

on Deafness and Other Communication Disorders, the National Institute of Diabetes and Digestive and Kidney Diseases, the NIH Office of Rare Diseases and the Foundation for the National Institutes of Health.

"In planning the agenda of presentations, workshops and posters," said Dr. Kastner, "the organizing group aimed for balance among the disciplines, planning sessions in basic and clinical science, genetics and treatment of inherited disorders of inflammation."

These illnesses, termed systemic autoinflammatory diseases, are characterized by episodes of seemingly unprovoked inflammation. Many of the autoinflammatory diseases discussed at the meeting are inherited as Mendelian traits, which means they are produced by a single gene. The diseases include:

- Familial Mediterranean fever (FMF)
- TNF receptor-associated periodic syndrome (TRAPS)
- Hyperimmunoglobulinemia D with periodic fever syndrome (HIDS)
- Neonatal-onset multisystem inflammatory disease (NOMID; also known as chronic infantile neurologic, cutaneous, and articular syndrome, or CINCA)

- Familial cold autoinflammatory syndrome (FCAS)
- Muckle-Wells syndrome (MWS)
- The syndrome of pyogenic arthritis with pyoderma gangrenosum and acne (PAPA)
- Blau syndrome.

[See the text box on page 6 for more about autoinflammatory diseases and how they are different from autoimmune diseases.]

Other inflammatory disorders, such as Juvenile Idiopathic Arthritis, Adult-onset Still's Disease, Crohn's Disease and Behçet's Disease, were conference topics as well.

Approximately 220 scientists representing over 20 countries convened for the transdisciplinary conference. Over 100 research projects were presented in poster sessions. One tangible outcome of the conference, said Dr. Kastner, was that "Researchers are putting in place mechanisms to develop a DNA repository—a DNA exchange system that will help with genetic testing quality control and more accurate diagnosis of many of the autoinflammatory diseases."

Researchers are making great progress in unveiling the mysteries of the immune system and opening new doors to better treatments. While much work remains



Anna Simon, M.D., (r) from Radboud University, Nijmegen, Netherlands, discusses a poster about her research on immunoglobulins with meeting participants.

to be done, this research has implications for other common diseases involving inflammation, such as stroke, atherosclerosis and heart attack.

A gala dinner and awards ceremony was held at the Corcoran Gallery of Art on the last evening of the conference. The next meeting is tentatively scheduled for Spring 2008 and is being arranged by the International Society for the Study of Autoinflammatory Diseases. ▲

Did You Know...Eating Five Fruits and Vegetables a Day is Not Enough?

The National Cancer Institute (NCI) has modified its recommendations to eat more fruits and vegetables. It still recommends eating them, but instead of its former five a day for good health, it now suggests you eat five to nine a day. NCI says most people need to double the amount of fruits and vegetables they eat to ward off illnesses like certain types of cancer, diabetes and heart disease. A serving is often smaller than people think, and one serving will usually fit in the palm of your hand.

Men should try for nine fruits and vegetables a day, while women should strive to eat seven. To find out more about what they recommend and why, visit <http://www.5aday.gov>.

What's the connection between this information and the NIAMS? Many of our publications talk about the importance of eating right, exercising and maintaining a healthy weight, in order to help you feel good in the face of chronic problems, or to prevent problems. (Studies have shown, for example, that overweight women who lost an average of only 11 pounds reduced the risk of developing osteoarthritis in their knees.)

But if you find it's hard to change your eating habits, maybe some new recipes will help jazz up the menu and entice you to try some more varieties of good-for-you foods. *IRPartners* found a few Web sites maintained by the federal government containing recipes using nutritious foods.

The NCI's "Eat 5 to 9 A Day for Better Health" Web site contains a nutritional analysis per serving for each recipe, including amounts of calories, fat and carbohydrates. Visit the recipe database: <http://www.5aday.gov/recipes/index.html>.

The Centers for Disease Control and Prevention (CDC) also has a recipe file. Start on this page which lists the Fruit and Vegetable of the Month: <http://www.cdc.gov/nccdphp/dnpa/5aday/month/index.htm>.

Pick one from here or scroll down the page to see all fruits and vegetables. Choose one for a wealth of information about it and its benefits, and scroll further down the page to see featured recipes.

The U.S. Department of Agriculture has a page on its site also: <http://schoolmeals.nal.usda.gov/Resource/5adayrecipes.html>. The links go off-site to other organizations, and they are not all consistent about providing the nutritional analysis, but each page does provide more options.

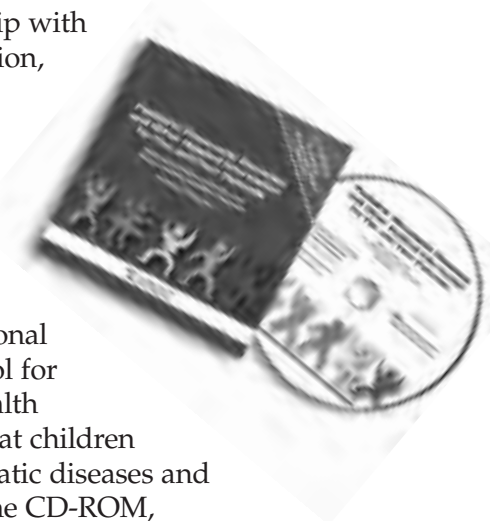
For even more choices, go onto the Web and do your own search for "5 a day recipes."

Other institutes at NIH have recipes to help you get and stay healthy. Visit some of these:

- The National Heart, Lung and Blood Institute has heart-healthy recipes at <http://www.nhlbi.nih.gov/health/index.htm#recipes> (including a bilingual recipe booklet for Latinos and one for cooking in an African American style).
- The National Institute of Diabetes and Digestive and Kidney Diseases has a recipe and meal planner guide (also available in Spanish) to help people manage diabetes: http://ndep.nih.gov/diabetes/M mealPlanner/en_intro.htm. ▲

NIAMS Launches Pediatric CD-ROM

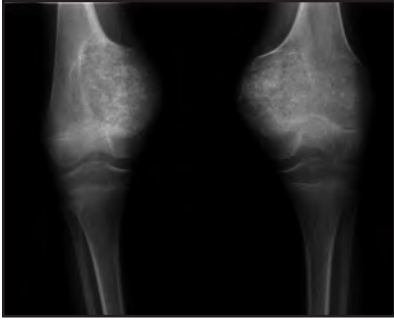
NIAMS, in partnership with the Arthritis Foundation, recently launched the *Pediatric Rheumatic Diseases and Other Related Information for You and Your Patients CD-ROM*, a comprehensive and cost-effective educational and informational tool for doctors and other health professionals who treat children with pediatric rheumatic diseases and related conditions. The CD-ROM, introduced in November at the annual meeting of the American College of Rheumatology in San Diego, is a resource for health professionals and patients about childhood diseases such as juvenile rheumatoid arthritis, osteogenesis imperfecta and juvenile osteoporosis. The CD-ROM includes print-friendly PDF files of selected patient education brochures, professional education resources and links to useful resources from the NIH and other federal and nonprofit organizations. To order a free copy of the CD-ROM, contact the NIAMS Clearinghouse at 1-877-22-NIAMS (1-877-226-4267) (free of charge), niamsinfo@mail.nih.gov or <http://catalog.niams.nih.gov>. ▲



Research Updates: CIAS1-Associated Syndromes

NIAMS researchers are conducting clinical trials with three patient groups, trying to find better treatments for some autoinflammatory diseases known as *CIAS1*-associated syndromes.

Autoinflammatory diseases occur when the body's immune system causes inflammation (normally one of the body's defense mechanisms, often causing swelling, pain, redness and heat) without the presence of harmful intruders such as viruses and bacteria, or without tissue death. Since



An X-ray showing the characteristic enlargement of the knees in a NOMID patient.

there aren't a lot of people with these diseases, researching the syndromes is complicated. But NIAMS researchers like Raphaela Goldbach-Mansky, M.D., have enlisted a critical number of these patients, and are making headway studying these rare syndromes in three different protocols.

The Syndromes

These syndromes are called *CIAS1*-associated syndromes because the *CIAS1* gene, located at chromosome 1q44, sometimes contains a mutation. "Although not everyone who develops these syndromes has a mutation in this gene," says Dr. Goldbach-Mansky, "those with and without mutations experience the same symptoms, which suggests that the underlying disease mechanism is the same in patients with and without *CIAS1* mutations." Researchers classify patients experiencing these symptoms as having *CIAS1*-associated syndromes whether a gene mutation is present or not. Studying this gene has allowed researchers to learn more about the process that leads to the disease.

CIAS1-associated syndromes are characterized as mild, moderate and severe. Familial cold autoinflammatory syndrome (FCAS) is considered least severe, characterized by episodes of fever and a rash that appears only when the patient becomes cold. Muckle-Wells syndrome (MWS) is considered more severe, characterized by episodes of fever and a rash that can occur at any time, as well as progressive hearing loss and, in some patients, kidney failure. The

most severe form is neonatal-onset multisystem inflammatory disease (NOMID), also known as chronic infantile neurologic cutaneous and articular (CINCA) syndrome. In this illness, most patients have no history of *CIAS1* mutations in their families. This disease appears in children, and the first symptom is usually a rash within the first weeks of life which affects the entire body. Other symptoms include frequent episodes of fever, arthritis leading to joint malformations, brain inflammation, eye problems which can lead to blindness, and nervous system problems including chronic meningitis, brain atrophy, seizures, mental retardation, migraine headaches and hearing loss. Musculoskeletal problems characteristic of NOMID include enlargement of bones or joints, mainly in the knees. NOMID is associated with early mortality.

The Anakinra Study

One study NIAMS is undertaking is called *Anakinra to Treat Patients with Neonatal-Onset Multisystem Inflammatory Disease*. The study involves children, and evaluates the safety and effectiveness of anakinra, a drug approved by the Food and Drug Administration for treating rheumatoid arthritis in adults. The study looks at patients two years of age and older with NOMID whose disease symptoms appeared by at least six months of age. After three months of treatment with anakinra, the symptoms of all eighteen patients enrolled in the study improved. Researchers admitted the first eleven patients to the hospital, where they stopped giving the patients anakinra and observed them. Upon drug withdrawal, the patients' conditions got worse, and the researchers restarted the drug. All study participants receive follow-up visits and testing at the NIH Clinical Center. This study has completed recruitment.

Researchers want to test drugs like anakinra to see if they are better than existing treatments. "Corticosteroids and other very potent immune-suppressing medicines are commonly used to treat NOMID," says Dr. Goldbach-Mansky, "but they have only modest effects in suppressing disease symptoms, even if used for a long time and in high doses, which often can cause harmful side effects." Anakinra works by blocking interleukin-1 (IL-1beta), a protein produced by a variety of cells including white blood cells. Anakinra is called an IL-1 receptor antagonist, which means it binds to the IL-1 receptor, a tiny structure on the surface of a cell, so that IL-1 can't bind to any tissues and cause the immune response. Dr. Goldbach-Mansky points out that IL-1beta

is a potent stimulator of an inflammatory response, and was initially discovered because of its ability to cause fever and flu-like symptoms at low concentrations.

The Natural History Study

Promising results from the first study have changed the course of another study, *The Natural History and Cause of Neonatal-Onset Multisystem Inflammatory Disease*, begun in April 2003. In this study, researchers originally intended to examine and test children with NOMID to learn about the cause and course of the syndrome. The goal was to evaluate affected children receiving the current standard of treatment to better characterize the problems caused by the disease and develop a comprehensive treatment approach.

However, the anakinra treatment being used in the first study proved to be so effective at treating the symptoms of NOMID — reducing the number of fever episodes, eliminating the rash in all treated children and significantly reducing brain inflammation — that anakinra is now being given to the patients enrolled in the natural history study. These patients will continue to receive anakinra and will be followed over time. “Results with the anakinra study have been so promising, we are hopeful that anakinra can prevent progression of hearing and vision loss in patients who have already developed ear and eye damage,” says Dr. Goldbach-Mansky. More studies will be needed to see if anakinra is safe and effective in these patients as a long-term treatment.

The Experimental Drug Study

A third study, being conducted in an adult population, tests an experimental drug on patients with the other two syndromes associated with the *CIAS1* mutation. This drug, IL-1 Trap, is called experimental because it is not approved by the Food and Drug Administration as treatment for any condition, but researchers are allowed to study its effects in clinical trials. The study *Interleukin-1 Trap to Treat Autoinflammatory Disease*, in adults with FCAS or MWS, is currently recruiting patients. People with similar autoinflammatory diseases thought to be caused by other gene mutations, like familial Mediterranean fever (characterized by abdominal pain, fevers and arthritis) or adult Still’s disease (characterized by fevers, rashes and arthritis) are also eligible for this study. Begun in October 2004, the study examines the safety and effectiveness of IL-1 Trap. It works like anakinra in blocking IL-1, but it is a long-acting IL-1 inhibitor and can be administered weekly by an injection into the fat under the skin, while anakinra has to be given daily. Thus, IL-1 Trap may provide improved dosing convenience, potential for fewer injection site reactions, and improved effectiveness over current treatments. Participants are admitted to the NIH Clinical Center for a baseline evaluation and treatment.

As NIAMS scientists and researchers learn more about the causes, symptoms and effective treatments for autoinflammatory diseases, the prognosis should improve for those affected by these complex diseases. Information regarding NIH Clinical Trials can be found at <http://clinicaltrials.gov/>. ▲

Autoimmune or Autoinflammatory?

IRPartners often talks about **autoimmune** diseases, like rheumatoid arthritis and lupus, which are caused by autoantibodies. These are different from **autoinflammatory** * diseases.

When the immune system is working properly, foreign antigens (proteins that don’t belong in the body) provoke an immune response. Antibodies are proteins that attach to these antigens so that the immune system can detect and destroy them. However, when these antibodies attach to the body’s own healthy tissues by mistake and signal the body to destroy them, they are called autoantibodies, and they cause **autoimmune** diseases. The part of the immune system which orchestrates all of this develops as a person grows, and is known as the acquired immune system. It “remembers” foreign antigens, or proteins, so that

it can fight them if they come back. It employs white blood cells called lymphocytes.

But the body also has an innate (inborn) immune system which is more primitive. It employs types of white blood cells called granulocytes and monocytes to destroy harmful substances. In **autoinflammatory** diseases, this innate immune system causes inflammation for unknown reasons. It reacts, even though it has never encountered autoantibodies or antigens in the body. Autoinflammatory diseases are characterized by intense episodes of inflammation, such as fever, rash or joint swelling.

* The term “autoinflammatory” was coined by NIAMS researcher Daniel L. Kastner, M.D., Ph.D., based on his research with familial Mediterranean fever and TNF receptor-associated periodic fever syndrome.

Alasdair Steven, Ph.D., Chief, Laboratory of Structural Biology Research

Growing up in Wigtown, a small country village in Scotland, Dr. Alasdair Steven notes that even though his local school had only 30 students in the graduating class, he was fortunate to have had an excellent group of teachers there. Medicine was a family interest: both of his parents were medical doctors, two of his three brothers also entered this profession, the third is a veterinarian, and one of Dr. Steven's own sons recently graduated from Tulane University and is now a physician. Dr. Steven is a biomedical researcher but came into this career through science rather than clinical training.

Dr. Steven received his first degree, an M.A. in mathematics and physics, from the University of Edinburgh and went on to receive a Ph.D. in theoretical physics from the University of Cambridge. Upon receiving his doctorate, he had an opportunity to go to Switzerland as a postdoctoral fellow to work with the late Professor Eduard Kellenberger at the University of Basel. Dr. Steven says, "I remember him as a very lively, creative, and somewhat idiosyncratic person." Professor Kellenberger also initially trained in physics, but by this time was mainly concerned with molecular genetics and biological electron microscopy. Dr. Steven spent five years with Professor Kellenberger, who became his mentor. During his stay there in the early 1970s, many research opportunities in molecular bioscience were just beginning. His first research assignment in Basel was to try to visualize conformational changes in protein assemblies after they were treated with an enzyme. This was a very exciting project, and he succeeded in demonstrating that a specific viral protease triggered a large structural change that propagated across the assembly. This was the first time that such an effect had been observed, with biochemical and genetic analysis complementing the electron microscopy and image processing, and Dr. Steven continues to work on this project today. His time in Basel was made even more enjoyable and exciting by the many other young scientists who were there at the same time and who have gone on to make their careers in front-line research.

Asked how he came to enter science as a career, he says, "No one person inspired me to go into science — it was a natural progression." Progressing through

graduate school, he found that he liked research and wanted to stay with it, so he switched to research on molecular biology, earning a Swiss Certificate in molecular biology. One of the most influential books in his life was the first edition of *Molecular Biology of the Gene* by James D. Watson, who won the Nobel Prize for his part in discovering the structure of DNA and served as the director of the National Center for Human Genome Research, which later became the National Human Genome Research Institute.

Watson's book, together with Albert L. Lehninger's book *Biochemistry*, helped him make the transition from theoretical physics into experimental biology.

In 1978, Dr. Steven was recruited by the late Richard Podolsky, Ph.D. — then chief of the Laboratory of Physical Biology at the National Institute of Arthritis, Metabolic and Digestive Diseases (NIAMDD) — to the NIH, where he was appointed to a tenure-track position. That institute later split to become the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and NIAMS. In this division, Dr. Steven was assigned to NIDDK as a section chief in the laboratory headed by the late

Robert Simpson, M.D., but a few years later, Henry Metzger, M.D., then scientific director of NIAMS, gave him the opportunity to come to NIAMS as chief of the newly created Laboratory of Structural Biology Research.

In his laboratory now, Dr. Steven does fundamental structural research, using state-of-the-art electron microscopes and computational technology combined with a gamut of other biophysical and biochemical approaches to understand the organization of some of the smallest substances and the parts they play in human health. Projects in his lab are quite diverse, with scientists studying:

- a variety of systems at the molecular and supramolecular level, such as viruses
- the huge enzymes that recycle targeted proteins inside cells
- amyloid filaments that are made of misfolded proteins and are associated with diseases such as Parkinson's disease, diabetes and rheumatoid arthritis



Dr. Steven holds the medal awarded him by Charles University.

participants spend an hour sharing details about their experiences with arthritis, including discussions on pain, physical abilities or limitations, mental health, personal empowerment and treatment. They also discuss values and lifestyle patterns. Some of these lifestyle patterns may tie in closely with their native cultures, while others may be more similar to the general cultural practices in the U.S. “Arthritis patients live with a great deal of pain,” said Dr. Wallen. “Learning how this patient group perceives their illness and treatment and what they’re doing to control the related pain and disability is key to designing culturally relevant strategies for better health outcomes,” she continued.

The patients participating in the study have illnesses such as osteoarthritis, characterized by the wear and tear of joint tissue causing bone-on-bone



Juan Mendoza, clinical research technician, and Babbie Babilonia-Ayukawa, R.N., clinical research nurse, employees of the NIH clinical center, review interview questions.

friction; rheumatoid arthritis, with its symptoms of joint inflammation and swelling; systemic lupus erythematosus (or lupus), with its symptoms of painful or swollen joints, fever and extreme fatigue; and fibromyalgia, marked by chronic muscular pain and prolonged fatigue. The prevailing symptom in all these conditions is pain. And the dominant effect can often be disability: restrictions in carrying out daily living activities such as walking, dressing and cooking. For many, going to work can seem an enormous, if not impossible, challenge.

Current health interventions commonly concentrate on the segment of our population with access to conventional resources, such as foods in the general American diet and exercise facilities like swimming pools, gyms and even well-maintained walking paths, as well as access to standard health care. However, these “mainstream” resources either are not useful or are inaccessible to other portions of the population, particularly people from minority communities. A healthy-eating message that encourages people to “cut out the fat” in their diet, for example, while suggesting foods that are not in their normal diet, is not a health message that’s relevant to everyone. Thus, a segment of the population may not act on the health message they need to improve their health behaviors.

Creating Tools for Better Health

So how do we improve upon current health interventions? How do we ensure they address the needs of everyone? “First, we need to have patients involved in designing tools for better health,” says Dr. Wallen. “During this study, we found that people were eager to talk about their health and interventions.” For example, patients had ideas about places where exercise activities could be held other than a costly gym: a recreation center, for example, or a church facility. Dr. Wallen further explained that in addition to having a program that is culturally appropriate based on ethnicity, it should be age-appropriate as well. An older person with osteoarthritis, for example, may be interested in exercises different from those for a younger patient with lupus. Both may have differing emotional and social needs as well based upon their ages.

Finding the tools for better health is not hard; it just takes time and real commitment, suggests Migdalia Rivera-Goba, R.N., Ph.D., co-investigator on the health beliefs and behavior study. “We have to go to the [minority] communities, ask them how we can best serve them, and be prepared to listen and incorporate what they say into our interventions,” says Dr. Rivera-Goba. She recalls a male patient and his wife who both have a form of arthritis. Neither has health insurance and between them they have at least three jobs. Medical expenses are \$1,100 a month for this family in the low- to middle-income range.

What is their idea of health interventions that meet their needs? “A health care facility that is located in

their neighborhood, with staff resembling their ethnicity, and treatment that's affordable," says Dr. Rivera-Goba, "so they don't have to choose between getting medical care and paying rent." Through this study, the investigators are learning about cultural practices that can help them tailor interventions like this couple's ideal medical facility.

Looking ahead to the study's outcomes, Dr. Wallen and her colleagues foresee new health promotion tools based on patients' feedback. For example, Dr. Wallen notes, "If we find the levels of depression are high among this patient group, that may indicate we need to develop a tailored mental health program." Likewise, she explains, "If we find that their physical abilities are very limited, we'll consider a specialized exercise program."

The proposed health programs bring good news to the health center's patients, who can look forward to promising programs that fit into their cultural practices and lifestyles. And for patients like the middle-aged Hispanic woman who shared her story of arthritis with researchers, the study brings forth an immediate outcome expressed in her satisfaction that someone cared to ask about her experience with the disease, and that her participation in the study could help improve another patient's quality of life. ▲

Intramural Research Program Welcomes Two New Directors

In December, NIAMS welcomed two new directors into the Intramural Research Program.

John O'Shea, M.D., was appointed as NIAMS scientific director. He has been the chief of the Molecular Immunology and Inflammation Branch at NIAMS since 2002.

Daniel Kastner, M.D., Ph.D., was appointed as NIAMS clinical director. He has been the chief of the Genetics and Genomics Branch at NIAMS since 2003.

IRPartners will bring you more about these new directors in future issues. ▲

- the components that make up skin and muscle tissues.

His hope is that the basic structural observations made in the course of these studies will have practical applications that will prove helpful in the treatment of human disease, such as the devising of new vaccines or antiviral drugs.

Dr. Steven was recently honored for his accomplishments. He was awarded the prestigious Medal of the 1st Faculty of Medicine by the Institute of Cellular Biology and Pathology of the Czech Republic's Charles

Dr. Steven was recently awarded the prestigious Medal of the 1st Faculty of Medicine by the Institute of Cellular Biology and Pathology of the Czech Republic's Charles University in Prague.

University in Prague. The honor recognized mainly his contributions to basic biomedical research, but also his support of Czech science, and his enhancing the international image of the

Charles University. The Charles University tradition of faculty medals is centuries old, and this medal is the University's highest honor. The list of awardees is short, numbering only 106 in the 20th century.

Much has changed in the years since Dr. Steven went to school in that small town in Scotland. He remarks that "There have been many differences between my own experiences and those of my children growing up here in the United States." Along the way, he has mentored many scientists, some of whom have gone on to establish their own research programs, a fact of which he is very proud. He also cherishes his professional collaborative relationships, working with talented scientists here at the NIH and also at institutions elsewhere in the country. Asked what he expects to be doing five or ten years hence, Dr. Steven says, "I hope to still be working here with the great people at NIAMS and the rest of the NIH." ▲

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.osteoo.org. ▲

National Institute of Arthritis
and Musculoskeletal and
Skin Diseases/NIH
Building 31, Room 4C02
31 Center Drive, MSC 2350
Bethesda, MD 20892-2350

Produced by the National Institute of Arthritis
and Musculoskeletal and Skin Diseases/NIH

Office of Communications and Public Liaison

Building 31 • Room 4C02
31 Center Drive
Bethesda, MD 20892
Phone: 301-496-8190
Fax: 301-480-2814
E-mail: bettends@mail.nih.gov
Web site: www.niams.nih.gov

Stephen I. Katz, M.D., Ph.D., Director

John O'Shea, M.D., Scientific Director

Daniel Kastner, M.D., Ph.D., Clinical Director

Ray Fleming, Editor

Susan Bettendorf, Associate Editor

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 Community Health Center.

Call 202-673-0000 for information.

Questions To Consider Before Joining a Study

- What is the purpose of the study?
- What is required of me?
- Will the study benefit me or others?
- Are there risks? If so, what are they and what are the chances that they will occur?
- What discomforts are involved?
- How long will the study last?
- What will happen if I decide to leave the study?

Dr. Katz Wins Award



NIAMS Director Stephen I. Katz,
M.D., Ph.D.

NIAMS Director Stephen I. Katz, M.D., Ph.D., has been awarded the prestigious Harvey J. Bullock, Jr. Award for Equal Opportunity Achievement by the National Institutes of Health for his "extraordinary leadership in many scientific, programmatic and administrative arenas, and exemplary leadership

through his clear commitment to equal employment opportunity." In his more-than-a-decade tenure as director, Dr. Katz has provided unwavering support for NIH and Public Health Service EEO programs, and facilitated and enhanced the recruitment, career development and advancement opportunities of minorities, women and persons with disabilities. ▲