

Clinical Center



(from left) Shirley Winford, Floride Canter, Harry Canter, and CC patient Clenton Winford visit over coffee and cookies from the Red Cross hospitality cart.

'Irreplaceable' Canter family goes home after 25 years of volunteer service to CC

On Monday, Nov. 5, the outpatient clinic waiting rooms throughout the Clinical Center became a little quieter. That's because the Friday before, Floride, Harry, and Susan Canter—a family that has given more than 25 years of service and friendship to CC patients and staff—spent their last day volunteering before their Nov. 9 move to Harrisonburg, Va.

Floride, American Red Cross chairwoman at the CC, serves a continental breakfast to the phlebotomy patients each morning before making rounds with a hospitality cart. Her husband, Harry, a 14-year volunteer, worked at NIH for 43 years before retiring as chief of the research, analysis, and evaluation branch in NCI's Division of Extramural Activities.

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IOM selects Rehabilitation Medicine chief

The Institute of Medicine elected Dr. Leighton Chan, chief of the Clinical Center Rehabilitation Medicine Department, as one of 65 new members in October.

IOM membership, now totaling 1,538, is one of the highest honors in the fields of medicine and health. The criteria for election are: distinguished professional achievement in a field related to medicine and health; demonstrated and continued involvement with the issues of health care, prevention of disease, education, or research; skills and resources likely to contribute to the Institute's tasks of assessing

current knowledge, conducting studies, and considering policy issues; and willingness to be an active IOM participant.

Unique for its structure as both an honorific membership and advisory organization, IOM was established in 1970 by the National Academy of Sciences and is recognized as a resource for independent, scientifically informed analysis and health recommendations. With their election, members make a commitment to devote a significant amount of volunteer time as members of IOM committees, which engage in studies on health policy issues. ■

Gallin named 2007 Clinical Teacher

Clinical Center Director Dr. John I. Gallin received the 2007 Distinguished Clinical Teacher's Award, the highest honor bestowed on an NIH senior clinician, staff clinician, or tenure-track clinical investigator by the NIH Clinical Fellows. The award was presented Oct. 24 at Grand Rounds. Recipients of the award, given annually since 1985, are recognized for their excellence as a mentor and teacher and their contributions to clinical research.

Dr. Brian Porter, who chaired this year's award committee, noted that they had a record 16 nominees this year. Reading a few comments from fellows during the introduction, Porter called Gallin "one of the strongest mentors and advocates of clinical fellows at NIH."

As the 2007 DCTA award recipient, Gallin will deliver the annual John Laws Decker Memorial Lecture during a CC Grand Rounds in June 2008.

The finalists for the 2007 DCTA award were Dr. Richard Childs, NHLBI Hematology Branch, and Dr. Roberto Machado, NHLBI Pulmonary and Vascular Medicine Branch.



Dr. Michael Gottesman (at left), NIH deputy director for intramural research, and Dr. Brian Porter (at right), 2007 award committee chair, present the award to Clinical Center Director Dr. John I. Gallin.

“Let food be your medicine and your medicine be your food.”

Not every Clinical Center patient can eat meals with utensils. Some patients must be fed with IVs or tubes, can't eat solid foods, or need special ways of receiving nutrition because of digestive issues.

Sara Bergerson, clinical nutrition support dietitian in the Nutrition Department, specializes in finding unique solutions to ensure CC patients' proper nourishment, comfort, and tolerance of treatment side effects. “Food is so



Sara Bergerson

Job: Clinical nutrition support dietitian in the Nutrition Department, at the CC for 28 years.

important to us all. It's a quality of life issue,” Bergerson said. Her role in the Pain and Palliative Care Service reflects her commitment to these issues. The team's chief Dr. Ann Berger notes that “Sara goes above and beyond to get anything for every patient. When all a teenage patient would eat was noodles, Sara made sure to provide them.”

Bergerson thinks working at the CC is the “most exciting and dynamic way to be a dietitian” because of the close team work required. She interacts with doctors, nurses, and pharmacists to review patients' nutritional status, which can change significantly during treatment. Bergerson is responsible for the nutrition of critically ill patients, including those in the ICU, radiation oncology, and hematology units.

Dr. Margaret Bevans, senior nurse specialist with nursing's Research and Practice and Development Service, calls Bergerson a team player with a clear focus on patients' nutritional outcomes. After rounds, Bergerson frequently remains with the patient and family to discuss the nutritional implications of their treatment at the CC. She is a strong advocate in ensuring that not

only patients' physiological nutrition needs, but also their psychological and emotional needs, for food are met.

She is always challenging teams to consider creative strategies to dovetail patient preferences with clinical needs. When a new nutritional supplement for cancer patients was introduced, Bergerson provided samples for staff to try before using it with patients.

Madeline Michael, chief of clinical nutrition services for the Nutrition Department at the CC, said Bergerson embodies Hippocrates' saying, “Let food be your medicine and medicine be your food.” She demonstrates during her interactions with patients how important nutrition and food are in healing and recovery and recognizes the special significance that food holds for those who are ill and for their families. “What sets Sara apart is that rare combination of excellence in clinical care, commitment to duty, and her dedication to the whole patient,” Michael said.

“The patients give to me as much as I give to the patients,” Bergerson said. “I have a lot of fond memories and amazing experiences I would never have had anywhere else.” ■

Dancing with the NIH Stars for the Combined Federal Campaign



ORS Director Dr. Alfred Johnson (at left) won the first—and possibly last—Combined Federal Campaign dance championship trophy on Oct. 18 for his rendition of the cowboy boogie during a country line dance competition in front of Building 1. NIH Director Dr. Elias Zerhouni took second place and NINDS Director Dr. Story Landis (far right) came in third. The event was part of this year's CFC campaign with the theme, “Have a heart, be a star,” hosted by NHLBI Director Dr. Elizabeth Nabel (center). For more information, see <http://cfc.nih.gov/cfc>. ■

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CC News reserves the right to edit story submissions for length and appropriateness.

MIS, first CC electronic medical record system, has left Building 10

On Sept. 21, the Clinical Center surplused the Medical Information System (MIS) mainframe, which had served the hospital since June 1976. The CC was the nation's fifth hospital to install the system and the first to configure and enhance it to support protocol-based clinical research. MIS allowed physician order entry, result reporting, medication administration, and nursing documentation long before others began using electronic medical records—and provided access to patient data at rates difficult to match even after 30 years.

CRIS replaced most of MIS in 2005. MIS continued to be used for patient registration and for managing admission, discharge, and transfers until last November.

Dr. Jon McKeeby, CC CIO, marked the historic transition by lauding the enduring efforts of Dr. Thomas Lewis—the “heart and soul of MIS” since the beginning. Lewis, former associate director of information systems and currently a consultant to DCRI, led the original MIS selection and implementation team.

“As you might imagine,” said Lewis, “the step from a billing-oriented, community hospital to the complex research-oriented CC environment was large and with significant risk.” It was a risk work taking. Lewis credits staff involved in clinical programs—even for brief peri-



DCRI's Tim Maloney and Susan Houston stand behind a palette stacked with 128 disk drives from MIS.

ods—during MIS's lifespan who “worked hard to use, contribute to, critique, explore, and expand the use and advancement of information technology for better patient care and clinical research. This is a group of thousands of people, many of whom may not even realize how much

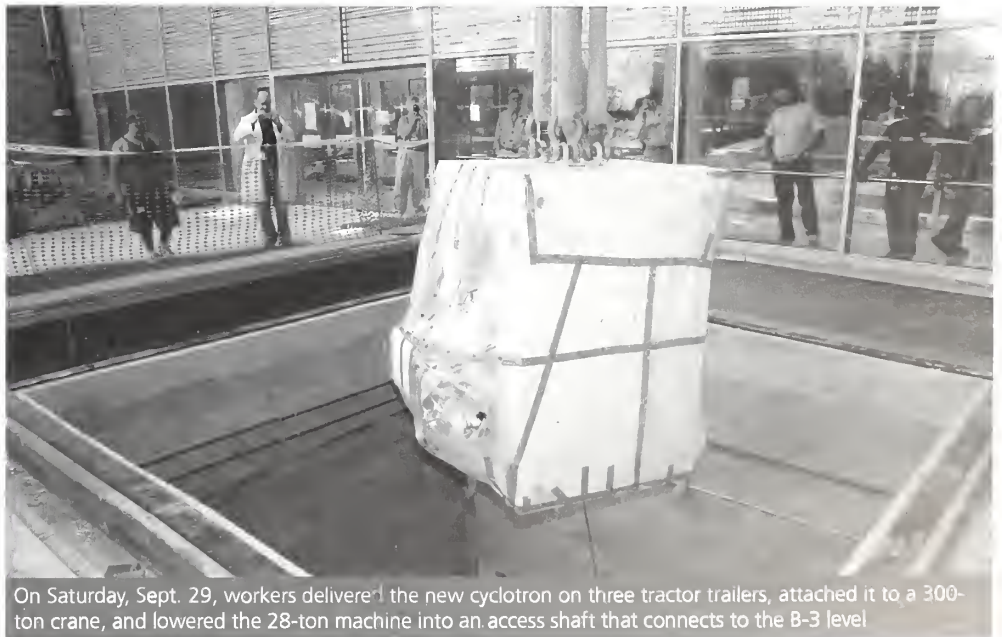
they contributed, to patients, the CC, the NIH, and beyond.” Other DCRI staff involved in retiring the historic mainframe included Steve Bergstrom, John Franco, Susan Houston, John Kocher, Murali Kumar, Tim Maloney, and Steve Moore. ■

Out with the old, in with the new ... cyclotron

The children's playground and ground-level glass door passageway on the west side of the Hatfield building were closed for a few days in late September during the preparation for and delivery of a new PET trace cyclotron to the Clinical Center.

The new cyclotron weighs about half as much as the old JSW-1710 machine and is computer-controlled rather than manually operated. It is identical to a machine installed in 2002 and complements the remaining large CS-30 cyclotron installed in 1985.

Staff conducted soil compression tests to ensure that the soil between the playground and the CC could support the weight of the crane and the trucks used to move the machines. ■



On Saturday, Sept. 29, workers delivered the new cyclotron on three tractor trailers, attached it to a 300-ton crane, and lowered the 28-ton machine into an access shaft that connects to the B-3 level

Conference unmasks pheochromocytoma, 'the great mimic'

Medical professionals, patients, and their families gathered in Bethesda Sept. 28 and 29 for the world's second conference on pheochromocytoma, or pheo for short, a rare neuroendocrine tumor that can be lethal if not identified and treated promptly.

Some call pheo "the great mimic" because its symptoms resemble many other conditions. It's so misunderstood and underdiagnosed that it was the subject of an episode of the TV show "House." Pheos are tumors of the chromaffin cells, which produce, store, metabolize, and secrete catecholamines, such as norepinephrine or epinephrine. The diagnosis depends on evidence that the tumor is overproducing catecholamine.

Although the disease's signs and symptoms can include bouts of rage, more common are anxiety, headache, severe hypertension, and nausea. Symptoms, caused by the body's response to catecholamine secreted by pheos, may last from few minutes to several hours and may occur daily or once every few months.

Presentations at the conference, hosted by NICHD, were a collaborative effort between NIH institutes and centers to pull together the entire spectrum of care involved in the rare disease.

CC contributions included Dr. James Reynolds, chief of the Clinical Studies Section of the Nuclear Medicine Department, who discussed internal radiation as a treatment for pheo; Dr. Brad Wood, chief of interventional radiology research in the CC Diagnostic Radiology Department, who discussed the potential application of tumor ablation; and Dr. Jacques Bolle, clinical thanatologist—a specialist who helps people live a fuller life and maintain meaning as they face serious illnesses that could lead to death—with the CC Pain and Palliative Care Service, who discussed the emotional impact of a life-challenging illness.

Much of Bolle's presentation about the emotional responses to pheo pertains to life with any chronic or life-challenging disease, especially those that are rare (see related story on next page). The multiple complex emotions experienced by pheochromocytoma patients include: uncertainty, fear, powerless-



Dr. Jacques Bolle, clinical thanatologist with the CC Pain and Palliative Care Service, gives a presentation at the conference.

ness, depression, and anger. Bolle also shared his "pearls of wisdom" for how to cope with illness: pace your day according to your biological clock; lose the word "should," which leaves little room for flexibility; restrict how large a part of your life the disease becomes in relation to other aspects of your identity; ask care providers questions and consider them partners in your treatment; share feelings with loved ones; and use humor and laughter.

Several conference participants with pheo advocated becoming proactive in learning about and seeking support for their disease. After the initial astonishment of wondering, "How can something this rare happen to me?" one woman expressed her frustration when, after multiple misdiagnoses, her instincts that

something was wrong with her turned out to be correct. Others described difficulties responding to questions about a disease with few external signs and symptoms that mimic other conditions.

Some participants found comfort in the universality of health concerns. "Everyone has "something" in their lives, whether it's heart disease, diabetes, Parkinson's, or cancer," said one. "Mine happens to be pheo, which is rare and new. But the development of treatments gives us some hope. Life isn't always fair and you have to decide how you are going to deal with it." Bolle quoted the title of an article one physician wrote about his own illness: "We are all patients. Some of us also become physicians as well." ■

NEWS BRIEFS

Functional genomics symposium

The fifth annual Symposium on the Functional Genomics of Critical Illness and Injury, "Forging a Critical Alliance: Are We Meeting the Need?" will be held at Natcher Conference Center on Nov. 14 and 15. The event will assemble multidisciplinary acute and critical care specialists, microbiologists, immunologists, cell biologists, molecular biologists, experts in high-throughput technolo-

gies, and computational scientists to discuss the application of functional genomic approaches to critical illness and injury. The Clinical Center's Critical Care Medicine Department is one of the symposium's sponsors, and CCMD's Drs. Robert Danner and Anthony Suffredini served on the organizing committee. For more information, visit www.strategicresults.com/fg5. ■

'We are all patients': One physician's story of life with pheo

Conference attendees (see related story on page 4) heard an unusual perspective on pheochromocytoma from Dr. Edward Kauffman. He's a physician with the disease who didn't recognize it in himself.

Many physicians don't think of checking for pheo when their patients describe these symptoms and prescribe medications appropriate to the symptoms but not the underlying condition while the potentially fatal metastatic disease goes unchecked, according to Kauffman. Because death from hypertension and heart attacks are common and usually don't trigger autopsies, studies indicate that up to 50 percent of all cases remain undiagnosed until death, he said.

Kauffman experienced anxiety, night sweats, and heart palpitations. His wife noticed personality changes and angry episodes that could be triggered by anything, and kept escalating.

Eventually, Kauffman's son, who is also a physician, put his father on a path that led him to Dr. Karel Pacak, head of NICHD's unit on clinical neuroendocrinology, and an expert on the condition. About 2,000 patients are diagnosed with pheo in the U.S. every year.

Pacak, together with NINDS' Drs. David Goldstein and Graeme Eisenhofer, developed a biochemical diagnosis for the

disease using plasma-free metanephrines that changed the method of diagnosis worldwide. They also developed the use of 18F-fluorodopamine positron emission tomography to successfully take images of tumors. "Hope at NIH comes from the research. It's not just about doing the clinical work, but also incorporating research into daily clinical practice through better ways of diagnosing and treating patients," Pacak said.

regardless of family or clinical history.

"I thought I had a death sentence," Kauffman recalled. "Now I know pheo is treatable, although not cureable." The tumors may never go away, but for a third of patients, they won't grow and might even shrink. Pacak and his team are still seeking other therapeutic options for patients with metastatic tumors who don't respond to current treatments. Curiously, Pacak says patients

When you have a rare disease, you think you're alone. The Clinical Center provides a feeling of security, knowing there's a place that deals with this problem on a routine basis.

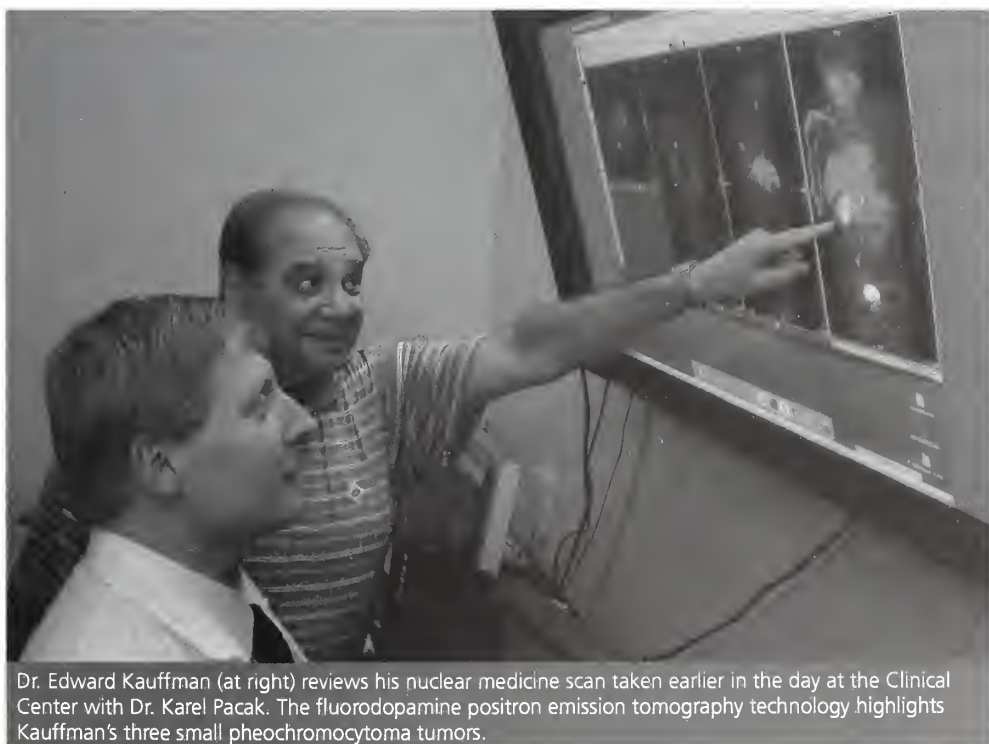
—Dr. Edward Kauffman
Clinical Center patient

Pacak says another "huge breakthrough" in the disease came with the discovery that pheo susceptibility is associated with mutations of the succinate dehydrogenase (SDH) gene family. As between 30 to 35 percent of tumors have a hereditary basis, he now recommends that all patients with identified tumors be tested for the presence of possible underlying genetic mutations,

with minimal symptoms often have an extensive, aggressive form of pheo that requires a different treatment than those with differentiated tumors and more symptoms.

At NICHD's first worldwide conference last year, Kauffman met other patients, most of whom are enrolled in Pacak's protocols, and learned that what he experienced was common. "When you have a rare disease, you think you're alone. There are no local support groups for pheo." Instead, email contact with fellow patients across the country provides a lifeline on new information and advances. Kauffman said the care he and others receive at the CC provides "feeling of security, knowing there's a place that deals with this problem on a routine basis."

For Kauffman, who was first a physician and then a patient, moderating a session at the conference about patient and family dynamics is his way of adapting to his condition and giving back to the pheo community and NIH. "I thank my lucky stars that I found NIH," Kauffman said. ■



Dr. Edward Kauffman (at right) reviews his nuclear medicine scan earlier in the day at the Clinical Center with Dr. Karel Pacak. The fluorodopamine positron emission tomography technology highlights Kauffman's three small pheochromocytoma tumors.

Canter family led by example *continued from page 1*

Their daughter Susan has volunteered at NIH for about 15 years.

The family began volunteering when Floride saw an ad in the *Washington Post* seeking volunteers to do filing work at a CC dental clinic. By the time her application was processed, the position had already been filled. But hospitality help was also needed, which turned out to be Floride's talent. "Very few people can greet anyone, anywhere better than Floride," Harry said. "She can open her heart to everyone. It's the best part of her personality." Monica Sullivan, a volunteer Spanish interpreter at the CC since 1988, agreed that Floride's friendliness and kindness are her greatest gifts to patients, volunteers, and staff. "She always has something nice to say about everybody and tries to help in any way possible," Sullivan said.

Andrea Rander, director of volunteer services and language interpreters programs at the CC, called the Canters "the epitome of volunteerism" and an inspiration to her, as well as volunteers and staff. "I cannot convey enough thanks for all the hours they have devoted to

and minds of many of us at the CC for what they have given to the organization, patients, their families, and staff."

"The Canters have provided a steady beacon of support, kindness, and compassion throughout the Clinical Center," said Dr. John I. Gallin, CC director. "Their graciousness has touched the lives of thousands."

"The Canters have been selfless in their love for and service to the patients. In the hierarchy of Clinical Center angels, the Canters are right at the top," said Marie Riordan Kaplan of the NIH patient library.

Therese Clemens, treasurer and a former executive director of the Friends of the Clinical Center, shared office space with the Red Cross volunteers, led by the Canters. She remembers how the Canter family accepted her into the fold, sharing the common goal of serving CC patients. "Leading by example, their dedication to service inspired many of us who came to know them. They selflessly and quietly carried out actions of compassion every day, and I was privileged to witness it, to be a part of it."

"Sometimes seeing someone with an

The Canters approach every task with a can-do attitude and a willingness to do whatever it takes. They are an inspiration.

—Laura Cearnal
Clinical Center patient representative

our volunteer program: Floride more than 27,000; Harry 15,000. Rarely has either Floride or Harry said 'no' to any chore asked of them. They have passed along this spirit of service to their daughter Susan, who also added to the beauty of volunteer services at the Clinical Center. I will miss them individually and as a family. They are irreplaceable."

Dr. Adrienne Farrar, chief of the Social Work Department, agreed that the Canters will be sorely missed. "Nothing compares to their level of generosity and commitment. There is a very special place in heaven for the Canters and a very special place in the hearts

older face can be reassuring," Floride said, noting that she lets those she meets decide what they want to chat about. "Some would rather talk about anything other than their condition." She tells the story of a young man who was preparing to go in for a treatment. "He said to me, 'You remind me so much of my grandmother,' and asked for a hug." According to Harry, Floride is an adopted grandmother to many people within the CC, in addition to their five biological grandchildren.

Margo Bradford, Edmond J. Safra Family Lodge operations manager, said that the art of bringing genuine concern to the CC experience "reached its zenith" in Floride



Susan Canter at the March 2007 Social Work Department open house. Susan shared her parents' commitment to volunteering at the CC.

with her "encyclopedic knowledge" of the hospital and willingness to help someone in distress solve a problem. "There are legions whose anxiety has been calmed by the soft Southern lilt of her voice and her innate hospitality," she said.

One of the many long-time bonds the Canters developed is with CC patient Clenton Winford and his mother, Shirley, who have come to the CC from Texas for more than 20 years to participate in clinical research. They make a point of seeing the Canters on every trip. "It won't be the same without them," Winford says.

CC and Red Cross staff feel the same way. "I cannot imagine more generous people," said CC patient representative Laura Cearnal. "Perhaps even more important than the many services they've provided to CC patients and families is the spirit in which their service is offered. They approach every task with a can-do attitude and a willingness to do whatever it takes. They are an inspiration and so steady."

"What's most amazing about the Canters is that they work as a family, which is very rare," said Red Cross volunteer Saroja Kanesa-Thasan, who joined the Red Cross volunteers at NIH at the same time as Floride, about 25 years ago. "They are a very unified family, supporting and complementing each other very

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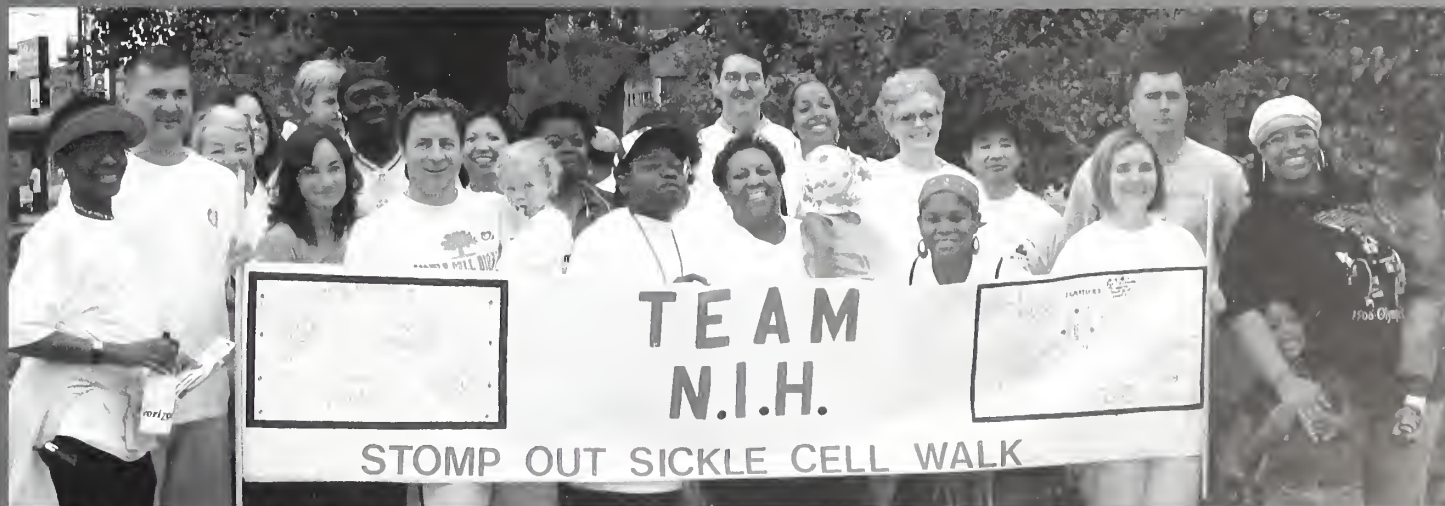
Clinical Center staff, patients unite for sickle cell month events



(from left) NHLBI's Eleni Footman; Steven Mosley; Ihsan Rogers of the CC Social Work Department; Althea Burey; Erika Fonseca; Emily Hershenson, also from SWD; NHLBI's Nona Coles; Alexander Gibson; and Curtis Robinson work on the Team NIH banner for the Stomp Out Sickle Cell (SOS) Walk during a sickle cell support group meeting at the Clinical Center. Rogers said that the CC sickle cell support group members' enthusiasm for the SOS Walk spread to CC staff and motivated them to participate. "Patients want people to know what it's like to live with sickle cell and how severely underfunded it is compared to other chronic illnesses. They also want to encourage genetic testing so people will know if they carry the sickle cell trait," Rogers said.



CC respiratory therapist Kevin Cole meets Gabriel George, the Sickle Cell Disease Association of America's 2007-2009 sickle cell poster child, at the organization's 35th annual conference. The event, which was sponsored by NHLBI in September, focused on sharing information and building partnerships between medical, scientific, and public health professionals with the ultimate goals of finding a cure and improving the quality of life for patients living with sickle cell disease.



Team NIH at the Stomp Out Sickle Cell Walk on Sept. 22 included (front row, from left):

Ijeuru Uzoma; Jim Nichols, head research nurse; Carole Tremonti, former CC nurse; Dr. Mark Gladwin of CC's Critical Care Medicine Department

and NHLBI's Vascular Medicine Branch, holding his son Rowan; Dietrich Ames; Darlene Allen, medical technologist, holding her granddaughter Kennedy; Ayana Rowley, ambulatory care and pharmacotherapeutics research fellow; Carissa Haney, CRNP; and Ihsan Rogers holding her daughters, Faith and Amirah.

(back row, from left) Monica Tremonti, Tammy Gladwin, holding her son Brenden; Victor Doherty; Amy Chi, CCMD senior clinical research nurse; Annie Brown; Dr. James Taylor; Eleni Footman; Mary Hall, CCMD protocol manager; Chris Chi; and Sean Haney.

Upcoming Events

Clinical Center Grand Rounds and Great Teachers Lectures

November 7, 2007

No Grand Rounds
Astute Clinician Lecture at Masur Auditorium, 3 p.m.
From the Rivers of Babylon to the Coronary Blood Stream
Barry S. Collier, M.D., David Rockefeller Professor of Medicine
Head, Laboratory of Blood and Vascular Biology, The Rockefeller University Hospital
For more information visit www.cc.nih.gov/researchers/lectures/astuteclin07.shtml

November 14, 2007 Great Teachers

Contemporary Clinical Medicine: Great Teachers
Contemporary Management of Acute Coronary Syndromes
Eugene Braunwald, M.D.
Distinguished Hersey Professor of Medicine
Harvard Medical School
Chairman, TIMI Study Group, Brigham and Women's Hospital

Lecture will be videocast, <http://videocast.nih.gov>

November 21, 2007

No Grand Rounds

November 28, 2007

Myeloid Leukemia Antigens and the Development of Vaccines
John Barrett, M.D.
Chief, Stem Cell Allotransplantation Section, Hematology Branch
NHLBI

Katayoun Rezvani, M.D., Ph.D.
Fogarty Visiting Fellow, Stem Cell Allotransplantation Section, Hematology Branch
NHLBI

Canters left a legacy of kindness and caring at CC *continued from page 6*

strongly. Harry has a very quiet manner, and whatever Floride can't do, he will take over. Susan is also very friendly."

Louise Gorman, a Red Cross volunteer at the CC who worked with Floride for at least 10 years, said the family is "very dedicated. They have time for everyone and everything. I've never known anyone to devote that much time. They're very good, kind people."

The Canters also provided behind-the-scenes contributions to facilitate clinical research. Marilyn Kelly, NIDCR research nurse and former NIAID study coordinator, said the family was instrumental in the success of the shingles prevention study from 1999 to 2001. The Canters assembled thousands of recruitment letters and discharge folders for participants.

In spite of their many friendships here,

the appeal of Floride and Harry's hometown of Harrisonburg and the family they have there is strong. It's where they grew up and met 60 years ago. When asked what they'll do in their new town, Floride immediately responds, "We're going to volunteer! Most likely at the new hospital." Susan will work in a cafeteria of one of the colleges in the area. James Madison University encourages seniors to audit their courses and both Floride and Harry plan to attend some classes.

"There's vitality here. We're going to miss seeing everyone and being a part of it," Floride said.

And the CC will miss them too. "They have been a foundation stone of service to the patients, anticipating and responding to patient needs that others didn't even know existed—from cookies and coffee to weary arrivals in phlebotomy, warm winter clothing for patients from southern climes, to suitcases for departing behavioral health patients. I fear it will be only after they have left that we will appreciate all of the unheralded things they do for patients and their families," said Kaplan. Added Bradford, "I'm hoping we've all learned enough from her example that her legacy of kindness and caring will be found throughout the CC for a very long time." ■



Floride Canter receives a token of gratitude for her service from Andrea Rander, director of volunteer services and language interpreters programs, during the April 2007 volunteer awards ceremony during National Volunteer Week.