Director's Annual Report
NIH Clinical Center

PROFILE 2006

U. S. DEPARTMENT OF HEALTH AND HUMAN SERVICES • National Institutes of Health

Cast in metal on the elevator doors outside Masur Auditorium are images symbolically depicting advances important to medical history. Some of those images, created by architect Vincent Glinsky and installed in 1953, were recently translated into wall hangings for the P1 lobby of the Hatfield Center (see page 13 for more information).

front cover
(top left to right)
DOROTHEA LYNDE DIX (1802–1887), an American crusader, pioneered in providing humane treatment for the mentally ill. Here, a student nurse is taught how to care for a child.

HIPPOCRATES (c. 460–c. 375 B.C.), a Greek who is often called the “father of medicine,” rejected the superstitious magic of primitive medicine and laid the foundations for medicine as a branch of science. Here he is shown writing the oath of professional behavior attributed to him.

(bottom left to right)
SIGMUND FREUD (1856–1939), born in Moravia, founded the psychoanalytical school of psychology, based on his theory that unconscious motives determine behavior. Here, the doctor literally “pushes the clouds” from a patient’s mind.

WILHELM CONRAD ROENTGEN (1845–1923), a German physicist, in 1895 produced and detected electromagnetic radiation in a wavelength known today as X-rays, or roentgen rays. Here a patient is X-rayed.

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PROFILE 2006

OUR VISION

The NIH Clinical Center will serve as the nation's premier research hospital for conducting clinical research to improve the health of humankind. It will also serve as a national resource for clinical research by developing diagnostic and therapeutic interventions; enhancing systems to ensure the safe, efficient, and ethical conduct of clinical research; training clinical researchers; and leading the response to the nation's public health needs.

OUR MISSION

As the nation's clinical research center, the NIH Clinical Center is dedicated to improving human health by providing an outstanding environment that facilitates:

- Development of diagnostic and therapeutic interventions
- Training of clinical researchers
- Development of processes to ensure the safe, efficient, and ethical conduct of clinical research.

The Clinical Center achieves this mission through a culture that fosters collaboration, innovation, diversity, and the highest ethical standards.

GROWTH AND TEAMWORK

Many patients with poor prognoses—patients told they had a limited life expectancy, or a health problem for which medical science had not yet found solutions—are alive today because they participated in clinical research at the Clinical Center. As the largest hospital in the world totally dedicated to clinical research, the NIH Clinical Center provides hope both for the patients who come here from every state in the union and for many more, around the world and not yet born, who will benefit from the medical advances made here.

Chief among the partnerships that make groundbreaking research possible at the NIH Clinical Center is that between patients, researchers, and caregivers. In 2005, a year of significant progress and change, two landmark achievements made patients' participation in such research much, much easier. In April we moved patients from a hospital built 52 years ago into our new research hospital, the Mark O. Hatfield Clinical Research Center. And in June we opened the Edmond J. Safra Family Lodge, which is located just steps away from the new hospital. To undertake two such major initiatives required both years of planning and implementation and the unwavering commitment of staff members and volunteers willing to work long hours to make things happen.

That staff commitment to the health and welfare of others was demonstrated powerfully again in September, when Hurricane Katrina hit the Gulf Coast, in the nation's worst natural disaster ever. In a unique partnership between a federal public health research agency, a military hospital, and a private health care facility, the Clinical Center had been developing mutual support plans for disaster responses with two neighboring health-care facilities, Suburban Hospital and the National Naval Medical Center. Emergency preparedness planning and drills developed in response to the threat of terror strengthened our ability to respond with a strong clinical presence. Members of the NIH community and our colleagues across the nation quickly and compassionately answered the call for help when Katrina, and then Rita, hit the Gulf Coast. We learned how resilient—and yet how fragile—the national emergency health care system is.

I want here to recognize and deeply thank the many employees, contractors, and volunteers—especially patient volunteers—who have made this clinical research enterprise a beacon of hope for patients everywhere. Your commitment, enthusiasm, and consistent efforts have enabled us not only to strengthen our research capabilities at home but also to reach out and help those in crisis elsewhere.

John I. Gallin, MD
Director, NIH Clinical Center

RECENT CLINICAL CENTER ACHIEVEMENTS

In 2005 we:

Moved patients into the Mark O. Hatfield Clinical Research Center. In a spacious new hospital fully dedicated to clinical research, our patient census routinely hit peak occupancy, and in many ways we improved the environment both for clinical research and for patient care.

Opened the Edmond J. Safra Family Lodge at NIH. Its 34 guest rooms provide a comforting home away from home for families and caregivers of patients who participate in clinical research. The lodge has reached full capacity several times and averages 80 percent occupancy.

Strengthened emergency preparedness. Back-to-back hurricanes (Katrina and Rita) on the Gulf Coast produced the worst natural disaster in U.S. history. In a powerful demonstration of their commitment to public health, Clinical Center and NIH employees worked with staff from other agencies in timely, well-coordinated emergency relief efforts.

In response to Hurricane Katrina, a 60-member team of volunteers from NIH and Duke University Medical Center deployed to set up a 500-bed field hospital in Meridian, Mississippi—an effort that produced valuable lessons for future disaster responses. A call center providing a national coordination and referral network for medical consultations logged 446 calls in an around-the-clock operation that began September 3 and lasted nearly four weeks.

In addition, we created surge capacity to accept up to 100 patients and family members from the Gulf Coast region. Working with partners developed through the Association of American Medical Colleges, NIH physicians contacted colleagues in academia and professional organizations such as the Society of Critical Care Medicine, and those partners stood ready to support any needs that arose.

Improved patient services. Providing excellent patient care is essential if research patients are expected to comply with the regimens of clinical research studies—which is essential for the successful conduct of clinical research. The Clinical Center consistently scores outstanding ratings from patients in a national database of academic medical centers. In 2005 we implemented several new services to improve patient safety and the quality of patient care.


ONE WAY

MOVE TO THE MARK O. HATFIELD CLINICAL RESEARCH CENTER

MARCH 4, 2005: THE REHEARSAL

Through years of practice, staff in the "old" hospital had routines and contingencies down pat. To practice how things would work when the new hospital was activated, on March 4 the staff practiced real-life scenarios in a four-hour "day in the life" exercise.

For months leading up to the day patients would be moved from the old hospital to the new, employees participated in a series of tests, drills, and exercises to prepare them for any situation that might arise on the move date and in the days following. The relocation task force led practice walks through various routes from the Magnuson to Hatfield building many times, looking for anything that might interfere with the movement of patient beds and determining the best path for efficiently moving patients.

For the March 4 exercise, planners had developed scripts and scenarios featuring everything from missing patients and unruly visitors to STAT (urgent) pharmacy orders and routine meal delivery. Fire alarms were tested and building evacuation simulated. Staff from throughout the Clinical Center participated enthusiastically in the exercise, testing how everything would work in the new environment.

(right) Nurse Ann Marie Matlock and Tam Cillie, respiratory therapist, set up oxygen for model patient Amy Garner-Obrien in the ICU.

(below) Admissions staffer Steve Yen greets model patient Darice Stephenson as she arrives in admissions. This scenario tested the routine admission process and the staff's ability to provide clear directions to inpatient units.

APRIL 2, 2005: MOVE DAY

The lobby of the Mark O. Hatfield Clinical Research Center was quiet early that Saturday morning. A few people lingered at the café tables by the fountain, while others prepared for the day ahead—wiping countertops, sweeping hallways, and turning on computers. Just after 9 a.m., the general stillness was broken by the muffled sound of wheels rolling across tile floors somewhere on the south end of the first floor.

Over a radio came the alert: "The patient is on his way!" Those who had been answering phones, mopping floors, scrubbing desks, or checking files stopped what they were doing, walked into the lobby, and waited with curiosity and welcoming smiles. Doctors, nurses, hospitality staff, housekeepers, construction workers, and visitors all strained for a glimpse of the historic group heading toward the new patient care unit for pediatric patients. The unit's first patient, Marcos Arrieta, lying on his bed, was escorted from the Warren Grant Magnuson building to the bright new rooms of the Hatfield Center by his mother, Maria, and a crew of nurses, volunteers, and other staff. CC Director Dr. John I. Gallin warmly welcomed the boy. Marcos smiled shyly as Gallin shook his hand and pointed out such features in the boy's room as the flat-screen television that doubles as a computer monitor and the glow-in-the-dark animal footprints on the ceiling.

Four more pediatric patients arrived at their rooms: Derek Aldona Reyes, Valeria Rivero, Kathryn Yokoyama, and Nicole Hofhine. Through the night a couple of them had asked, with excitement, "Can we go now?"

"Look at this view!" said Nicole's mother, Michelle, gazing out the room's large window. "You can see the Children's Inn right across the street!" Nicole and her mother had been coming to the Clinical Center for almost ten years. They had been there for the groundbreaking and were happy to finally see the inside of the new hospital.

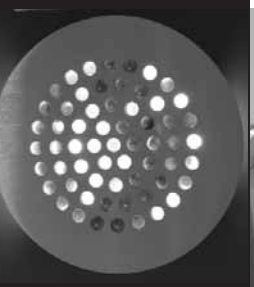
(above) Neurology unit staff welcome their first patient, Erias Hyman, with a ribbon-cutting ceremony. Charley McGarvey, Rehabilitation Medicine Department (center), joins Hyman's family members (right) for the mini-celebration.

(left) Housekeeping and Fabric Care team members Ayida Atsibiha, Woine Hagos, Zerfe Agraw, and Precious Moko put final touches on a new unit.

(below) Dr. John I. Gallin welcomes patient Marcos Arrieta, the first pediatric patient to make the move into the new building.

"WE HAVE MADE HISTORY IN THIS HOUSE OF HOPE."

– Dr. John I. Gallin



(photo above) The Medical Board Room served as move day's communications and coordination hub.

Nicole arranged two stuffed dogs beside her in bed and smiled at the sight of her very own computer keyboard.

The weekend roster of patients had purposely been kept low, so only 89 patients had to be moved from the old hospital (six of them from intensive care). Hundreds of staff, movers, and volunteers were on hand to coordinate their transport. Wearing bright blue "Follow Me to the CRC" T-shirts, the moving-day crew moved furniture, cleaned new work stations, stocked pharmacy shelves, prepared patients' meals, translated for non-English-speaking families, reassured people, or communicated updates from move headquarters in the Medical Board Room upstairs. In addition to moving patients they moved support services for day hospitals, the pharmacy, nutrition, rehabilitation medicine, and spiritual ministry.

"Getting to this point has been an adventure—like climbing Mt. Everest," said Dr. Gallin to those gathered to kick off moving day events. "It's been a 12-year hike, and this last thrust may be short, but we'll reach an awesome goal."

The most challenging part of the move was completing it in one day, which was the only realistic option. "Logistically, we could not split our patient services between two locations," said Laura Chisholm, a leader of the relocation task force. We had to move all of our equipment and patients at the same time. Thankfully, we had a great team working together, so it made the whole move go exceptionally well."

The move was completed ahead of schedule, at 3:38 p.m., but not without problems. "The facilities staff did an amazing job," said Chisholm. "Throughout the day, they fixed a broken elevator, tended to two small floods, built a ramp to allow beds to travel over a path that had a bump in it, took care of door access issues, and finished last minute housekeeping needs."

Despite the day's challenges, the mood among staff, patients, and their families was one of positive excitement. Family members joined doctors and nurses as they all snapped photos of loved ones moving into the sparkling new facilities. Patients shook hands with the movers who had pushed their beds, and smiled and waved to staff as their beds progressed down the hallways.

It was also a memorable day for those present, and a historic day for NIH. "Watching this enterprise move forward, watching what you do so well," said Dr. Gallin, "we have made history in this house of hope."

photos oposite page
(top right) Phyllis Davis of Barre, Vt., was the first patient admitted to the new hospital. With her are Dr. Constantine A. Stratakis, NICHD, her attending physician; Dr. John I. Gallin, CC director; Dr. Stephen G. Kaler, NICHD clinical director; Dr. Owen M. Rennert, NICHD scientific director; and Mary Haughey, Davis's primary nurse.

(bottom right) The move route included atrium walkways.

"WHAT THE DOCTORS LEARN WILL MAKE IT EASIER FOR OTHERS." – **Phyllis Davis, the hospital's first new patient**

APRIL 3, 2005

FIRST NEW PATIENT ADMITTED

A Vermont resident devoted to helping others was the first new patient admitted to the newly opened Mark O. Hatfield Clinical Research Center. Phyllis Davis of Barre arrived in admissions at 12:04 p.m. on Sunday, April 3.

Davis was participating in a protocol led by Dr. Constantine Stratakis, a clinical investigator with the National Institute of Child Health and Human Development. Stratakis is studying adrenal tumors and a group of rare and sometimes difficult to diagnose conditions known collectively as Carney Complex. More than 500 patient volunteers have participated in the clinical trial since it started in 1994. The goal is to confirm the diagnosis and map the inherited factors involved. Both aspects of the study, Stratakis explains, can help patients and their physicians better address potential health problems. Serious complications include a variety of tumors, including tumors of the heart. Davis spent a week at the NIH Clinical Center. The protocol involves numerous blood draws, MRIs, and other tests. She'll come back for follow up annually. "I'm doing this for a good reason," Davis says. "What the doctors learn will make it easier for others."

"THIS IS JUST LIKE A NEW HOME,"... AND IT IS A NEW HOME FOR ALL OF US." – **Ashley's mother, Donna Appell**

WHAT THE PATIENTS APPRECIATE MOST

During her stay in a sunny room on 5 West—on the south side overlooking the courtyard—Phyllis Davis had a chance to explore the hospital, including the new chapel and the recreation therapy facilities. She had started a project called Precious Gifts of Love, to provide stuffed animals to children who survived the 2004 tsunami in Indonesia. "I love working with my hands and have really enjoyed the arts and crafts. It's a beautiful building—roomy and airy."

What all of the patients wanted to keep from the old building was the sense of community, of the shared memories of generations of patients, of being less lonely because there are other people who know what you are going through. Many patients like the beauty of the building and gardens and the presence of so many beautiful nooks, crannies, and open areas to hang out in when you aren't in appointments. Pediatric patients and their parents welcome the cheerful décor of the pediatric ward, the safe and imaginative playground outside, and the fact that the Children's Inn is a short walk away. Adult patients like the wood-like floors, which appear clean and make patient rooms look less like hospital rooms. Everyone loves the bedside computers, which double as a television screen, so that you can switch from e-mail to TV and back without getting out of bed.

To the extent that a building affects camaraderie, most of the patients agree that the Hatfield building seems physically brighter, warmer, and more cheerful than the old hospital, with courtyards and other gathering places to facilitate getting together between tests and appointments with medical staff. Being able to meet and socialize with patients with different health problems, from different walks of life and parts of the country, feels like part of the therapy to many of the patients.

Patients who have stayed in the old hospital and the new are struck, on their first visit to the Hatfield Center, with the spaciousness and natural light. "It's great that the rooms are larger,' said Ashley Appell, a long-term patient with Hermansky-Pudlak syndrome, who will soon outgrow the pediatric ward. "This is just like a new home," said Ashley's mother, Donna, "and it is a new home for all of us."

Marybeth Krummenacker, whose college-age daughter Laura has been a patient at the Clinical Center since she was three, visited the old hospital the same day she saw the new one for the first time, "I hadn't realized how crowded and small those rooms are. There seems to be more space in the new patient rooms. They seem so open, and I couldn't get over how cheerful and bright and sunny it was, anywhere we went—in the labs, in the patient rooms, even the intensive care units."

"Better not to be sick," says Dinora Hernandez, a cancer patient from Maryland who spent difficult time in the old ICU. "But if you're sick, better for everyone to be in a spacious room. The new hospital is wonderful."

"The CRC feels more spacious than the old hospital—especially in the patient kitchen area on each floor," says Ellen Berty, a diabetes patient. "In the old hospital the space was so small—like a small closet—that you had to close the door in order to move around. You could take maybe one step, and that that was only if you had small feet! Now that area is so much bigger and luxurious. And having the many different conversational areas and the outside garden is especially nice."

(above) Patients have enjoyed seeing the new hospital. Among those touring after the dedication ceremony were, left to right, front row: patient and NIH employee Wanda White, with her hand on the shoulder of patient Ellen Berty; Ashley Appell, patient; Laura Krummenacker, patient; Marybeth Krummenacker, Laura's mother. Back row: Tammie Bell (peeking over Berty's shoulder), NCI employee who gave her kidney to Wanda White; Donna Appell, Ashley's mother; Pat McNees, author of *Building 10 at Fifty*; Heidi Hughes, patient; and Heidi's mother, Carol Hughes.

(opposite) Patient rooms, including those in the ICU, were built for flexibility and adaptability.

"I FEEL SO CONFIDENT IN THE EXPERTISE HERE."

– Leigh Johnson

EXPERTISE AND PATIENT CARE VALUED MOST

It isn't the physical hospital itself that patients value so much as the patient care.

"I feel so confident in the expertise here," says Leigh Johnson, a retired schoolteacher from Indianapolis, who came to the Clinical Center for a stem cell transplant—with stem cells from her brother—as treatment for acute myelogenous leukemia (AML). "I'm neutropenic, so I have to stay away from germs. Here they keep the doors closed and there's a big sign on the door, 'If you have a cold or the flu, do not enter.'

"My sense is they are very careful here," says Johnson. "I'm in a place that knows more about my disease than any place anywhere, which is so comforting. And the nursing care is wonderful."

Todd Wesanen, whose husband Dick was treated for an aggressive form of prostate cancer, concurs. "When we got to NIH," she says, "I could have stayed in my husband's room and taken care of him if I had wanted, but there was no need. You push a button and before the buzzer stops they are on the speaker or they are there, and they come in periodically, to see what you need. The nurses are totally involved with each patient. They tell you that once they work at the Clinical Center they don't want to work anywhere else, because they can actually give the kind of care that, when they go to nursing school, they like to think they are going to provide. It's not like being in the hospital anywhere else in the country.

"I've seen a lot of health care around the world," says Wesanen, "and at the NIH our dollars are being spent where they should be spent, and a lot of good is coming from it. I wish that both domestically and around the world people could understand what's going on in the Clinical Center, because everyone is benefiting from it."

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Patient gateway provides security and hospitality

A special entrance to the NIH campus opened for patients and their visitors at the intersection of West Cedar Lane and West Drive, near the Children's Inn. Located just north of the Hatfield Center, the friendly new entrance was built to simplify and ease patients' access to NIH. Hospitality staff stationed in the 780-square-foot visitor processing center provide directions, answer questions, and generally help ease the transition onto campus. The facility's security booth and two vehicle inspection lanes enable one-stop security screening. The new visitors' entrance is open from 7 a.m. until 3 p.m. weekdays (except holidays). At other times visitors enter through the NIH Gateway Center at Metro, which is located at Rockville Pike and South Drive.

Kiosks help visitors find their way

The family group finding its way from the new hospital to the Blood Bank at the far end of the Clinical Center can now stop at the nearest visitors kiosk to get directions and a map of the route to take. The new steel and granite kiosks feature a touch-screen computer and mapping software to help patients and visitors find their way through the Clinical Center. After locating the desired destination on screen, the family can print out a map showing them how to get from that kiosk to the Blood Bank, or wherever else they need to go that day. They can also pick up a courtesy phone, which automatically dials hospitality staff who are available 6 a.m.-5 p.m. weekdays for assistance.

Business center provides an office away from home

The five computers in the Clinical Center's new business center help patients and their families keep up with work and personal responsibilities, which is especially useful during long hospital stays. Available are Internet connections, telephones, and a combination printer/copier/FAX.

Located in just inside the front door of the Hatfield Center, the business center is open Monday through Friday, from 8 to 5. Hospitality staff and volunteers stationed in the main north lobby of the Hatfield Center provide access to the center.

The healing arts

The Clinical Center's art galleries are popular among patients, visitors, and staff. That a hospital values such art reflects a shift in thinking about art's role in healing. The chief aim of hospital décor in 1953, when the original Clinical Center opened, was to convey how clean and sterile the facilities were. That view began to shift in the mid-1980s.

Works of original art are displayed in eight exhibit spaces throughout the Clinical Center. Many of the pieces are by local artists. Their work is available for purchase, with 20 percent of the sale proceeds donated to the Patient Emergency Fund. Original works are also commissioned. Figuring out which art to commission for which space is not always easy. Finding the right artwork for the curved walls of the P1 lobby in the new hospital (pictured above) was a particular challenge.

Art program staff took advantage of the metal castings installed on the main elevator doors (outside Masur Auditorium) when the original Clinical Center first opened. Designed by Russian-American artist Vincent Glinksy, the images depicting symbolic moments in medical progress had been an important piece of NIH history since 1953. The dilemma was how to translate those images into something large enough to fill the lobby walls without being too dark or gothic. A wall covering was the final product, incorporating warm colors and three-dimensional images. The printed wall covering subtly links the old and new buildings.

The Oasis, commissioned for the atrium, also has special meaning for the hospital. A "Bethesda pool" at the northern entrance of the original Clinical Center echoed the symbolism of Bethesda as a healing place. The original Bethesda pool was removed in 1984 when the Ambulatory Care Center (the glass cube) was built on that site. The artist who designed the "Oasis" fountain on the ground floor of the atrium had the same biblical image in mind. The bridge near the fountain represents one of the five porches described in John V of the New Testament, the fountain represents the healing pool, and the palm trees echo the biblical theme.

During the summer, the Clinical Center added to its arts repertoire a lunchtime music program, headquartered in the atrium.

PATIENT ADVISORY GROUP PROVIDES INVALUABLE ADVICE

As representatives of the Clinical Center's key partners in research, members of the Patient Advisory Group offer frank feedback on major Clinical Center initiatives. In preparation for the move into the Mark O. Hatfield Clinical Research Center and the opening of the Edmond J. Safra Family Lodge, they provided especially useful recommendations about signage, privacy needs, computer requirements, handicap access, and food. During 2005, they strongly recommended improving scheduling and shortening wait-times for outpatient services. They urged fuller patient access to personal medical information and suggested ways to improve patient access to pharmacy services. They encouraged and fully endorsed the bereavement program proposed (and now established) by the Pain and Palliative Care Service (see next page for program details). Their comments on the development of electronic informed-consent documents for clinical research protocols were very helpful. They helped develop a patient survey to assess patient perceptions of the physical aspects of the old and new hospital buildings and had suggestions for the pilot program testing biometrics, such as fingerprints, facial geometry, iris or retina patterns, for patient identification.

Courtyard garden of the new hospital.

QUALITY-OF-LIFE TEAM DEVELOPS BEREAVEMENT PROGRAM FOR SURVIVORS

© Alan Karchmer

The chapel in the new hospital.

The Pain and Palliative Care consult service celebrated its fifth year of improving the quality of life for Clinical Center patients by adding a new bereavement program to help survivors of those patients who succumb to their health problems.

"We weren't doing as well as we could with support for bereavement," says Dr. Ann Berger, chief of the department. In providing palliative care, Berger's staff works with resources all over the Clinical Center, from social workers and volunteers to therapists with the recreation department—but there has been no coordinated effort to provide support for bereavement.

Some departments make an effort. They send a card at the time of a patient's death, they call the family at various critical times during the first year of bereavement, and especially a year after the death. "But these groups are on overload," said Berger. "There was a clear need to centralize the process." Berger's department will provide bereavement support and outreach both to families and to other patients affected by a patient's death.

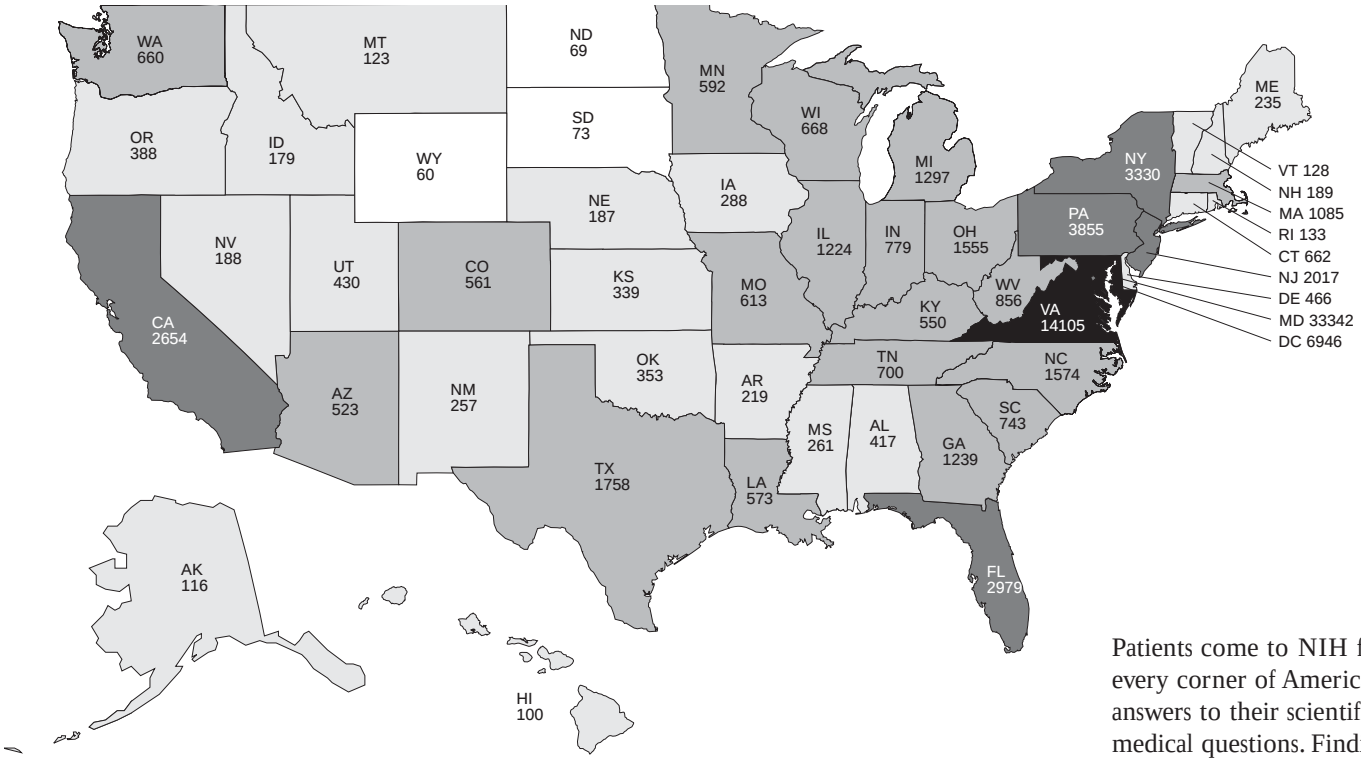
It is three to six months after a death that the grief often hits, said Berger, and those hit by grief often don't know how to recognize or deal with it. The Clinical Center's bereavement program will be coordinated by Diane St. Germaine, of the palliative care department, and staffed by trained volunteers. The training will be provided by Tina Levin, a social worker with the HIV team, and Jacques Bolle, a nurse with a doctorate in thanatology.

Bereavement support can be provided only if a bereavement consultation is requested by the principal investigator on a protocol. "We can come in only if called," explains Berger.

Once the consultation has been requested, a volunteer assigned to the family will arrange for a card to be signed by everyone who cared for the patient and sent to the family, because families seem to appreciate that connection with the staff. If after six months there seems to be a risk of complicated grief, the volunteer will try to help the family member find a bereavement support group in the community. A call will be made on the one-year anniversary of the death.

The palliative care service will also provide staff education about death, dying, and bereavement. Patients stay long enough at the Clinical Center that they develop friendships with each other and with their caregivers. No one is immune from feelings of grief and loss and almost anyone might need help dealing with those feelings. Yearly memorial services will continue to be held, one conducted by pediatric oncology staff and one by pain and palliative care staff.

HOME STATES OF ALL ACTIVE CLINICAL CENTER PATIENTS



Patients come to NIH from every corner of America seeking answers to their scientific and medical questions. Finding these answers through leading-edge clinical research is the sole mission of the NIH Clinical Center, guiding all of its activity.

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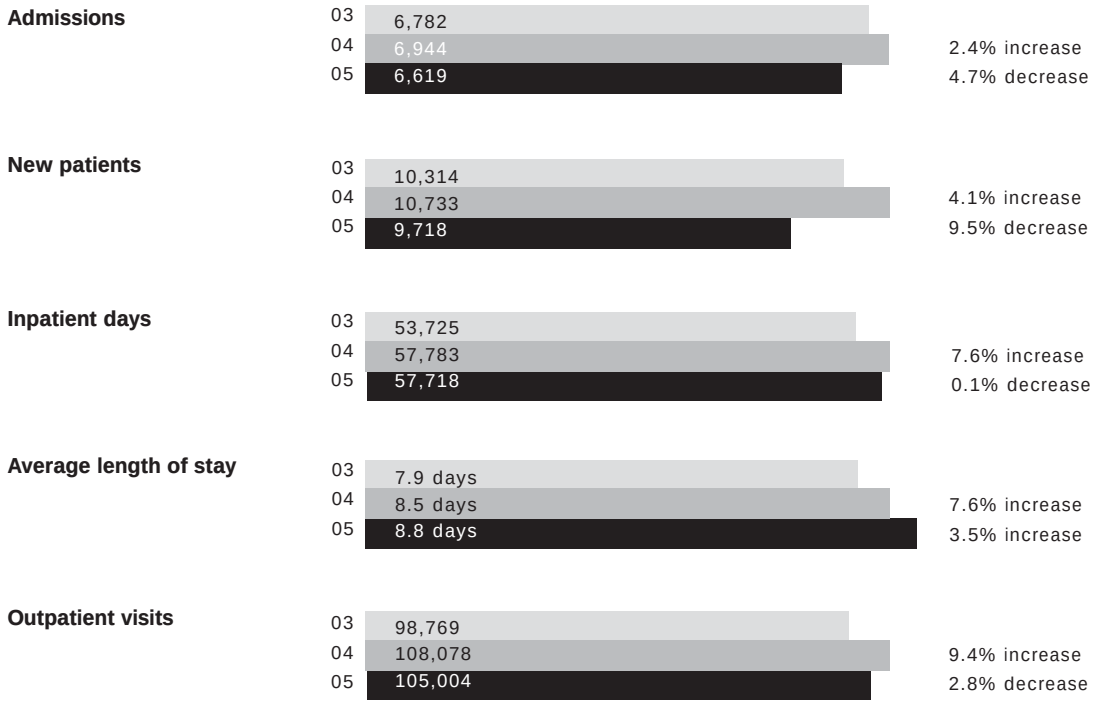
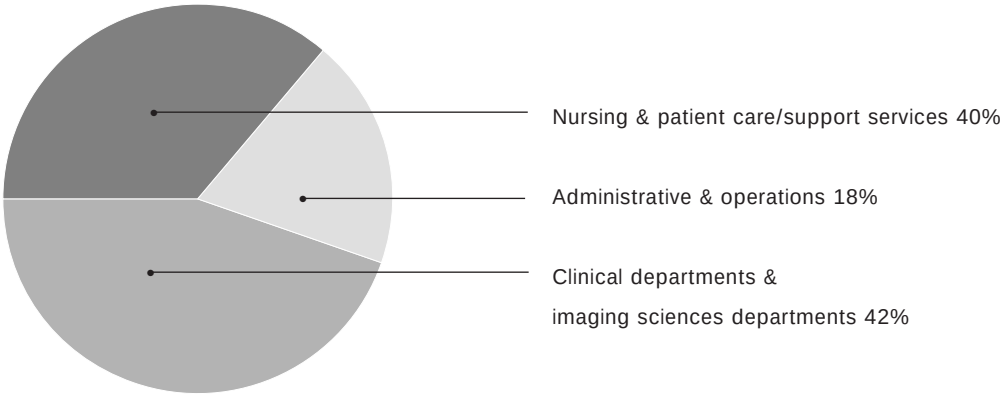
- 100-499
- 500-1,999
- 2,000-9,999
- 10,000 +

PATIENT ACTIVITY



WORKFORCE DISTRIBUTION

The Clinical Center has a staff of about 2,000. Roughly 80% of the Clinical Center's employees work with patients, as the following exhibit shows. Another 18% work in administration and operations.



EDMOND J. SAFRA FAMILY LODGE OPENS

LODGE OFFERS HOME-LIKE RETREAT

The Edmond J. Safra Family Lodge at NIH—a home away from home for families and caregivers of patients receiving care at the Clinical Center—opened for guests on June 1. A major project of the Foundation for the National Institutes of Health, the lodge represents the culmination of a decade-long dream of Clinical Center employees. "Each day we are privileged to work with the extraordinary guests of the lodge. It has become a home to many guests who have forged lasting friendships and a retreat to those who need a quite place to rest," said Jan Weymouth, the lodge's executive director. The lodge has provided a much-needed home for those in need and financial relief for families, who stay in the lodge at no cost. It is especially important for patients whose protocols require longer stays at NIH.

Ground was broken on October 29, 2002, and construction on the lodge began in 2003. Contributions of $5 million from The Edmond J. Safra Philanthropic Foundation helped fund the Family Lodge and gardens. Other contributors included the Merck Company foundation, the Bristol-Myers Squibb Foundation, GlaxoSmithKline, and The Harry and Jeanette Weinberg Foundation, along with many other corporations, foundations, and individuals.

Built in the English Arts and Crafts style, the Safra Family Lodge provides a home-like retreat, offering space for solitude, family meetings, and supportive fellowship. The lodge features—in addition to 34 guest rooms—a library, a business and telecommuting center, a fitness center, a

spacious kitchen in which to cook homemade meals, and comfortable social and sitting areas—including quiet places in the garden.

Opening ceremonies

At a dedication and opening ceremonies held May 26, celebrities, politicians, donors, and NIH administrators and staff gathered to mark the formal dedication and opening of the lodge. Barbara Harrison, news anchor for WRC-TV NBC 4, moderated the ceremony. Speakers were Dr. Charles A. Sanders, chairman of the board of directors for the Foundation for the NIH; Dr. Elias Zerhouni, director of NIH; Hon. Paul G. Rogers; Mrs. Lily Safra; and Dr. John I. Gallin.

"The Clinical Center had a dream," said Gallin, explaining how the Safra Lodge developed from plan to reality. "The dream was to create a refuge for patient families—to relieve the stress of dealing with a severely ill loved one far from home." In response to a growing need for guest quarters for the families of patients, the Foundation for the National Institutes of Health coordinated the project. Families of Clinical Center patients had been staying in family homes or hotels while they waited for a loved one to complete treatment, but the distance and cost took its toll on families. The idea of an on-campus guesthouse was proposed and put into action in 1996 in the form of six apartments in an NIH campus building (which was soon torn down to make way for the Hatfield Center). "The guest house was an instant success. It was fully occupied and proved the need for a home away from home for patients and their families. This place represents a powerful statement of our renewed commitment to our patients."

"From personal experience, when a loved one becomes sick, the world narrows," said Mrs. Lily Safra, widow of financier and philanthropist Edmond J. Safra, who suffered from Parkinson's disease. "Caring for them becomes not the most important goal, but the only goal. The lodge will help us ensure that every patient at NIH will feel loved and cared for by the most important people in the world—their families."

"How graceful, welcoming, and reassuring to have this building here," said the Honorable Paul G. Rogers, a former Florida congressman (1955-1978) who is well known for his support of government funding for scientific research. Rogers praised the public/private partnership

(above) Mrs. Lily Safra at the dedication ceremony. With her are the Honorable Paul Rogers, who served in Congress for 24 years, and Dr. Elias A. Zerhouni, NIH director.

(left) A quiet corner of the garden.

(opposite page) The Safra Family Lodge provides space for family meetings and supportive fellowship.

(top) The lodge includes a kitchen for families.

(above) The lodge is built in the English Arts and Crafts style.

(right) Families have a place to relax together.

that made construction of the lodge possible. "When you need solitude, you will find it at the Safra Lodge," said Zerhouni. "When you need to gather with others who share your pain, you will be able to do it at the Safra Lodge."

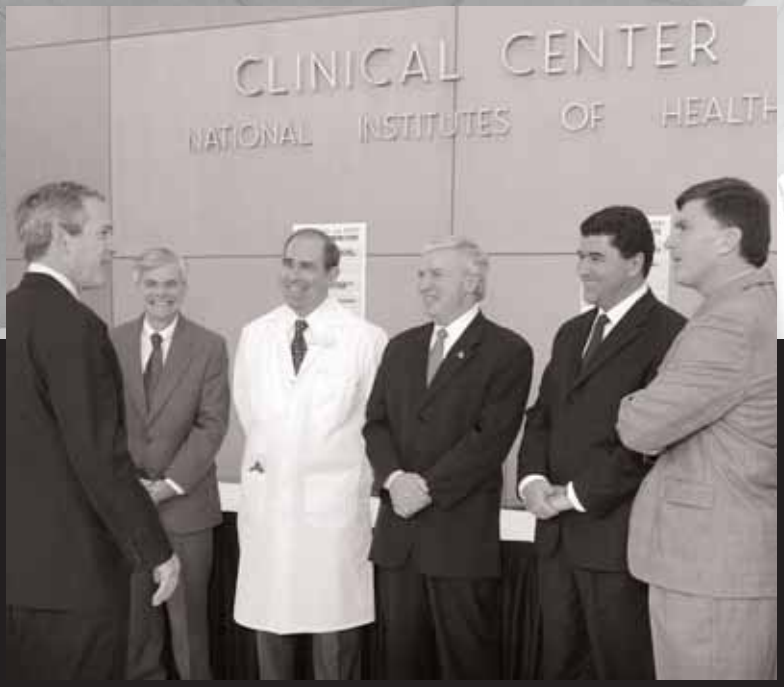
"This project had a heart," says Jan Weymouth, executive director of the lodge. "It is not just a building, but a living, breathing place." For many, the construction and opening of the lodge became a labor of love. "For all of us, it was an opportunity to build something important—a place with longevity and an important mission."

"THIS PROJECT HAD A HEART." – **Jan Weymouth**

VISITORS SEE THE NIH CLINICAL CENTER

Visitors from all over the world and from all walks of life come to tour Mark O. Hatfield Clinical Research Center, a global model for bench-to-bedside medical research. In the last year alone, more than 1,700 people participated in 116 tours of the NIH Clinical Center. A cadre of volunteer ambassadors from throughout the CC help lead the tours, which are typically coordinated by Hospitality Services, in the CC Office of Workforce Planning and Organizational Development.

(top, right) Prince Charles and his wife, the Duchess of Cornwall, visited last fall for a briefing on osteoporosis. The Duchess, who heads Britain's National Osteoporosis Society, said her "mother and grandmother died as a result of this devastating disease." An enthusiastic crowd of patients, visitors, and staff warmly welcomed the royal couple. Greeting them are Surgeon General Richard H. Carmona (left) and CC Director Dr. John I. Gallin (right).



(left) President George W. Bush was at the Clinical Center early in 2005 to conduct a discussion of health-care alternatives. With the President are Dr. Michael Gottesman, NIH deputy director of intramural research; Dr. John I. Gallin, CC director; Dr. Andrew von Eschenbach, NCI director; Dr. Elias Zerhouni, NIH director; and Maryland Gov. Robert L. Ehrlich, Jr.

(opposite page, center) Students and staff from the Arthur Ashe Academy (Brooklyn) came to learn more about careers in science and medicine.

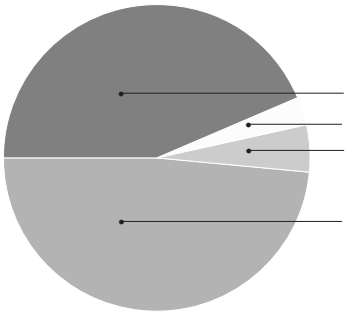
(opposite page, bottom) Legendary composer Marvin Hamlisch gave a special holiday performance at the Edmond J. Safra Family Lodge in December. "Opening this lodge is one of the best ideas and most beneficial projects I could imagine," said Hamlisch.

(left) The Maryland Terrapins baseball team with pediatric patients Amy Knopfmacher (left) and Valeria Rivero, on one of their CC visits.

(right) Author Kay Redfield Jamison spoke during an author-patient dialogue presented by the Patient Library. Dr. Jamison shared candid stories from her personal battle with depression.

PROTOCOLS BY RESEARCH TYPE

(onsite intramural protocols, fiscal year 2005)



Total active protocols: 1,357

Clinical trials: 593 (44%)

Training: 34 (2%)

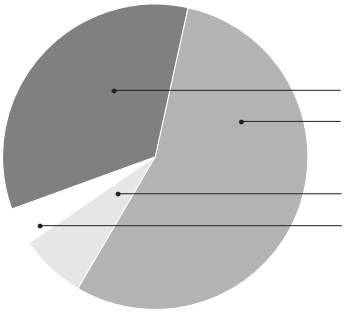
Screening: 64 (4%)

Natural history (disease pathogenesis): 660 (49%)

Note: Six protocols (1%) are for NIH specimens only

Clinical studies are medical research studies (or protocols) in which human volunteers participate. *Clinical trials* are studies developing or investigating new treatments and medications for diseases and conditions. *Natural history studies* investigate normal human biology and the development of a particular disease. *Screening studies* determine if individuals may be suitable candidates for inclusion in a particular study. *Training studies* provide an opportunity for staff physicians and other healthcare professionals to follow particular types of patients.

Breakdown of clinical trials



Total clinical trials: 593

Phase I: 203 (34%)

Phase II: 324 (55%)

Phase III: 44 (7%)

Phase IV: 22 (4%)

Clinical trials proceed through four phases

Phase I: Researchers test a new drug or treatment for the first time in a small group (20–80) of people to evaluate its safety, determine a safe dosage range, and identify side effects.

Phase II: The study drug or treatment is given to a larger group (100–300) of people to see if it is effective and to further evaluate its safety.

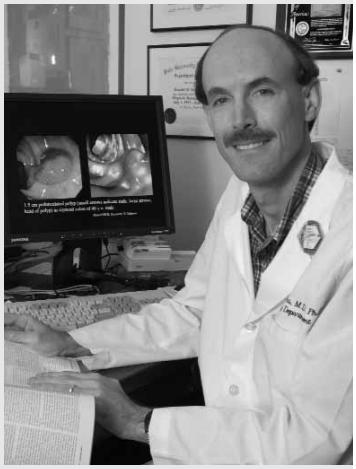
Phase III: The study drug or treatment is given to large groups of people (3,000 or more) to confirm its effectiveness, monitor side effects, compare it with commonly used treatments, and collect information that will ensure safe usage.

Phase IV: These studies are done after the drug or treatment has been marketed. Researchers continue to collect information about the effect of the drug or treatment in various populations and to determine any side effects from long-term use.

CLINICAL CENTER LEADS STUDY OF VIRTUAL COLONOSCOPY

Computer-aided detection software, in conjunction with a procedure commonly called virtual colonoscopy, can deliver results comparable to conventional colonoscopy for detecting the most worrisome types of polyps, according to a study led by Dr. Ronald M. Summers, senior investigator and staff radiologist in the Clinical Center's diagnostic radiology department. Published in *Gastroenterology* (December 2005), the study was presented at the November 2005 annual meeting of the Radiological Society of North America.

A minimally invasive radiological procedure, virtual colonoscopy, uses a CT scan to create two- and three-dimensional images of the colon, so there is no need for sedation or insertion of a colonoscope, although a full bowel prep is still required. The process produces 600 to 1,000 images, which a radiologist interprets. Computer-aided polyp detection software serves as a second set of eyes, identifying sites that warrant closer inspection. The radiologist reviews these sites before making a final diagnosis. Initial studies with computer-aided detection are very encouraging. "The fact that this worked so well on a large number of patients indicates that this is a robust technique," says Dr. Summers. "We believe it will work well in clinical practice, but more testing in the clinical environment still is needed."



Dr. Ronald M. Summers led a multi-site study of virtual colonoscopy.

MINORITY INVOLVEMENT A MATTER OF ACCESS, NOT ATTITUDE

It is widely claimed that racial and ethnic minorities are less willing than others to participate in health research, partly out of distrust based on past research abuses. Notable among such abuses was the 1932-1972 Tuskegee syphilis study, funded by the Public Health Service, in which hundreds of poor African American men in Alabama were followed for decades without being told they had syphilis and without being given penicillin to treat it.

But a new study led by researchers in the Clinical Center's department of clinical bioethics shows that when minorities are given the opportunity to participate in health research, they do so at the same rate as non-Hispanic whites. "The main barrier probably is not the attitudes of African Americans and other minorities," says Dr. Ezekiel Emanuel, chair of the department and an author of the report. "The main barrier is access, knowledge that these studies exist, eligibility criteria that ensure minorities can participate, and overcoming logistical barriers," such as the location of the study or the need for child care.

These findings counter the widely held notion that minorities are less willing to participate and led the researchers to suggest that minority involvement is more a matter of access than attitude. The study was published online December 6, 2005, in the medical journal *PLoS Medicine*, published by the Public Library of Science.

Dr. Ezekiel Emanuel co-authored a study that produced surprising findings about minorities and health research.

AWARDS FOR IMPROVING OUTREACH TO HISPANIC PATIENTS

José Rosado-Santiago, of the social work department, and Dinora Dominguez, of the patient recruitment and public liaison office, were two of seven recipients of the NIH Hispanic Health Communications Initiative Award given by the NIH Office of Communications and Public Liaison. The two were recognized for their longtime volunteer service to the Hispanic Health Communications Initiative. Implemented in 1997, the initiative is designed to promote health and reduce health disparities in underserved Hispanic communities.

Rosado-Santiago had represented NIH at a series of Hispanic health fairs, distributing NIH and Clinical Center health education materials and speaking with Hispanic families. Dominguez was honored for her participation in a series of local and national radio broadcasts held annually, in which she has informed listeners about the importance of Hispanics participating in clinical trials. "I am glad to work in an agency that is continually striving to excel in the production of high-quality Spanish-language materials and in reaching out to minorities," says Rosado-Santiago.

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AWARD FOR CHAMPIONING PATIENT SAFETY

The Clinical Center presented its first Patient Safety Champion Award to the nursing and patient care staff of 3 East. The award will be given annually to individuals or teams demonstrating a sustained commitment to creating and maintaining a safe environment for patients.

The 3 East unit uses a philosophy of "supportive care" to help children throughout the research process in the acute care pediatric behavioral health program. As a result of the staff's actions, injuries to both patients and staff, and incidents that resulted in placing patients in seclusion or restraints, were reduced by 70 percent over the course of six months. Dr. John I. Gallin presented the award on March 10, as part of the Clinical Center's observance of National Patient Safety Week.

Front row: Teachers Ann Davidson and Susan Job and nurses Patricia Evans, Julia Mitchell, Danielle Gabrielle, and Diane Lawrence.
Back row: Dr. Julia Tossell, Ann Mulqueen, Christian Mbulu, Dr. Gallin, Georganne Kuberski, Andre Caple, Tom Houston, Dr. Ken Towbin, and Camille Grigg. Mulqueen, Kuberski, Houston, and Grigg are nurses. Nbulu and Caple are behavior health technicians. Drs. Tossell and Towbin are with NIMH.

EXPANDING CRIS

During its first year in operation, CRIS, the Clinical Center's powerful new Clinical Research Information System, has been invaluable in supporting patient care. A 2006 upgrade of this core system will provide new options for organizing and viewing data and expanded capability for clinical documentation. CRIS's next phase includes creation of a data warehouse to improve the availability of clinical information for research.

Numerous smaller systems feed information to CRIS, and work has continued on those components. A new web-based scheduling system was introduced in December. The clinical laboratory system has been significantly enhanced, a project that involved the Departments of Laboratory Medicine, Transfusion Medicine, and Anatomic Pathology. Work is under way on new surgical and pharmacy systems.

PARTNERS TEAMS

The move to the Hatfield Center reduced the number of patient care units from 22 to 13. Partners Teams consisting of a nurse manager, at least one institute clinical leader, and a hospital administrative officer were created to manage governance for each patient care unit. The Partners Teams planned final facility and equipment changes, clinical operations for the new units, and hospital activation. Teams also assisted in the move of patients from the old hospital to the new. Partners Teams will continue to manage operations, patient care, and interdisciplinary functions within the patient care units now that we have moved. In addition, a relocation task force analyzed all clinical and support department operations to identify possible impacts of the move and produced new concept of operations plans for each department.

Emergency response to Gulf Coast hurricanes

Back-to-back hurricanes (Katrina and Rita) on the nation's Gulf Coast in August and September produced the worst natural disaster in U.S. history. Even before the true extent of destruction was known, Clinical Center staff were lining up to help in any way possible and played major roles in implementing NIH responses.

A hospital in Mississippi

Sixty volunteers from across NIH and the Clinical Center, plus a contingent from Duke University, were deployed to set up a 500-bed federal medical contingency station (FMCS) in the airplane hangar of the Air National Guard in Meridian, Mississippi.

The volunteers included medical, logistical, information technology, facility management, and security personnel. "The volunteers were enthusiastic and ready to commit," said Dr. Pierre Noel, chief of Laboratory Medicine's hematology service and the group's medical director. "Our hospital's goal was to provide care for patients who are actively sick or acutely injured." The challenge was to set up a hospital containing 500 beds in 24 hours. "This could not have been done without the dedication and support of the combined staff of 180," said CAPT Elaine Ayres, team leader and the Clinical Center's assistant director for ethics and technology development. The FMCS in Meridian was staffed by the NIH/Duke team and three other teams of PHS officers, some from NIH.

The need for the hospital in Meridian didn't materialize, because hospitals in the region were getting back up and running, so most volunteers headed home September 10. But the deployment to Mississippi "gave us the opportunity to better understand how best to use this type of resource in the future," said Ayres. "We learned many lessons, so the exercise was instructive," said Ayres. The Clinical Center has a supply team and a system for routinely putting supplies away, for example, but in that hangar the volunteers had to create a system for storing and keeping track of supplies.

"We also had a chance to look at staffing models in an emergency operation, which is different from running a hospital day to day," said Ayres. "We got a sense of the different kinds of people we would need. Frankly, many of the patients the Meridian station was going to take were not as ill as the patients we take here but we also had to figure out what to do with the family members who come with the patients. So we worked out issues in the field that we might one day have here."

Surge capacity

In addition to efforts in the Gulf region, the Clinical Center created capacity to accept up to 100 patients and their family members from the affected areas. In addition, working through the Association of American Medical Colleges, NIH Director Dr. Elias Zerhouni got in touch with medical school deans across the country, and 201 institutions identified more than 1,000 potential volunteers. NIH physicians contacted colleagues in academia and professional organizations such as the Infectious Diseases Society of America and the Society of Critical Care Medicine, and those partners stood ready to support any needs that arose.

(above) Volunteers from NIH and Duke set up a field hospital in a hangar in Meridian, Miss.

(below) NIH director Dr. Elias Zerhouni and CC director Dr. John Gallin (center) met with the NIH group that left Sept. 4 to set up the Mississippi hospital.

Call Center for medical support

The Clinical Center established an around-the-clock call center for medical consultation and referrals, which was available 7 days a week. Between September 3 and September 28, it handled 446 calls. Dozens of staff volunteers answered and triaged calls to medical experts from throughout NIH. Often the callers were patients and family members from Louisiana and Mississippi devastated first by Katrina and then by Rita. Staff volunteers worked tirelessly to provide information and assistance to callers with nowhere else to turn.

"Most people were amazed to get a real human being on the phone," said nurse-practitioner Kathie Bronson of her experience in the call center. "They were so grateful for anything we were able to do to help. It's nice to know that you can reach out from here at NIH and help in a meaningful way."

Corps deployments

On Sunday afternoon, August 28, as Katrina developed into a category-four storm heading for the southern coast, ADM John Babb of the Commissioned Corps' Office of Forced Readiness and Deployment called for deployment of the first team from the Commissioned Corps of the U.S. Public Health Service. The corps maintains a heavy presence at NIH with 400 NIH commissioned officers, 111 of them Clinical Center employees. Before the storm hit, members of Team Alpha—30 local members of the corps plus eight employees of the Center for Disease Control in Atlanta—traveled directly into the hurricane's path so they would be on the ground and ready to help when and where they were needed most.

Local partners in emergency preparedness

In September 2005, Dr. John I. Gallin, director of the Clinical Center, Rear Admiral Adam Robinson, Jr., commander of the National Naval Medical Center, and Brian Gragnolati, president and chief executive officer of Suburban Hospital Healthcare System, signed a memorandum of understanding that military, federal, and private-sector hospitals would streamline and integrate their responses to disasters.

The partners have developed streamlined communications procedures, strategies for resource sharing, and the ability to free up beds to accommodate patients from Suburban and Navy. Preparedness drills provide the opportunity to test, under fairly realistic circumstances, how well these newly designed processes actually work. More than 4,000 people participated in the 2005 drill.

(above) CC staff answering and triaging calls in the NIH Call Center included Dinora Dominguez, Laura Lee, Dora Bell, Nancy Jenkins, Debra Byram, Dr. Fred Gill, and Kathie Bronson.

(below) A volunteer-victim who has arrived at the Clinical Center is comforted by nurse Maureen Kennedy during the 2005 disaster drill.

Bench-to-bedside awards encourage intramural-extramural collaboration

Consistent with campuswide efforts to foster collaboration in research, the bench-to-bedside awards program is being expanded to include for the first time extramural partners. Intramural investigators local to the NIH campus are encouraged to identify a university-based extramural researcher with an NIH grant related to the general subject of the bench-to-bedside proposal. If the clinical investigator is from the intramural program, the basic science investigator could be from extramural NIH (or vice versa). Projects with intramural and extramural partners will have priority as a result of this new opportunity.

Support for these awards is $3.1 million from the NIH Office of Rare Diseases, the Office of AIDS Research, the Office of Research on Women's Health, the National Center on Minority and Health Disparities, and the National Center for Research Resources.

Online system for reporting medical errors

Finding ways to monitor and strengthen patient safety is especially important in clinical research. Because of its mission, the Clinical Center has a robust infrastructure that makes it an appealing "laboratory" in which to study the processes of patient care and clinical research. So it was a logical place to evaluate the efficacy of a Web-based occurrence reporting system for detecting and managing medical errors.

"The occurrence reporting system lets us know what is happening in the hospital in real-time," says Laura Lee, special assistant to the deputy director for clinical care. "A great example of how this system helps us to identify problems happened when we started using a new device to draw blood. The product had a design flaw and the nurses used the ORS to report this problem. Within one day we had received so many reports that we knew something was wrong and took immediate action to correct the problem. If the nurses hadn't had this tool to report what was happening it might have taken us a week to know about and act on the situation. We also use the system to recognize staff who provide outstanding service and care. Staff are encouraged to report these 'occurrences of kindness.'"

Redesign of the system brought about a significant, sustained increase in event reporting. Users found it much easier to have an interactive system, with immediate online access to event status and immediate access to follow-up information. Reporting soared from 500 reports each year to over 5,000 reports annually. And the Clinical Center was able to identify nearly 20 epidemiological clusters of adverse events related to medications and prescriptions, new devices, and care-delivery processes. Performance improvement teams intervened and follow-up data showed significant improvement in all the clusters and only one instance of an event recurring during six months of follow up. This is a great new tool for reducing medical errors.

Disseminating ProtoType

ProtoType, the new Web-based tool introduced in 2004 to help author and manage protocols, provides clinical investigators with a standard protocol structure, online help, and cassettes of suggested language. This helps investigators put their ideas for new protocols into the proper format for satisfying regulations and facilitating review. Enhancements to ProtoType in 2005 included greatly improved reference management and better capability for cutting and pasting text from word processing documents. The Informed Consent Steering Committee used ProtoType to create a question-based tool for helping to write protocol consent documents. ProtoType is now used in several institutes and several others are considering its use. The tool could eventually become a standard for writing protocol consents in NIH's intramural program.

REHAB MEDICINE INAUGURATES MOVEMENT ANALYSIS LAB

Patient Brianne Schwantes (center) helps celebrate the opening of the new lab with Dr. Steven Stanhope, Dr. John I. Gallin, Karen Siegel, and Dr. Lynn Gerber.

Many of today's movies include cast members made of pixels and digital data. The digital technology that makes such animation possible is also changing the lives of real human beings. And it is helping the Clinical Center take the lead in an important area of clinical research: movement analysis, the study of how a person's body moves in performing daily activities such as walking or climbing stairs.

Movement analysis helps digital artists design characters for video games. Analyzing how a baseball player throws a ball can help improve his pitch; analyzing how a tennis player controls his muscles can help improve his swing. At the Clinical Center, the technology helps adults and children who have problems that affect joint motion or their muscles' ability to control movement.

The Physical Disabilities Branch, a joint venture between the Clinical Center and the National Institute of Child Health and Human Development (NICHD), houses the clinical movement analysis laboratory used for this specialized research. The lab is designed for three things: conducting research, conducting clinical trials that help a patient or health-care provider develop a rehabilitation plan, and educating other clinicians about how to apply this science and technology to their own studies.

Constructed specifically for movement analysis, the movement analysis lab on the first floor of the Hatfield Center contains both sophisticated equipment (including infrared video cameras and powerful computers) and a specialized floor with built-in force plates that enable computer enhanced analysis of movement.

When a patient steps on the force plate, it records the force that the foot exerts on the ground, allowing researchers to study the relationship between force and movement. "This technology is unique to the world," says Dr. Steven Stanhope, director of the Physical Disabilities Branch.

Adding the patient's force measurements to the data from the camera recordings gives researchers a complete picture of the patient's movement. "The possibilities for how we can put this technology to good use are endless," says Karen Siegel, a senior staff specialist in the rehab medicine department. "We can study the effects of cancer when a bone has been removed or a muscle has been damaged, we can learn more about rheumatoid arthritis or post-polio conditions." With braces or prosthetics, it used to be trial and error—trying first one, then another, to see which worked best. "Now we can skip all of that and recommend the ideal treatment from the beginning," she says.

CLINICAL INVESTIGATOR STUDENT TRAINEE FORUM

(from left) With Dr. John I. Gallin, CC director, are Albert Einstein College of Medicine students Kristen Thorstenson, Ashley Holder, and Daniel Schreeder, and Dr. Frederick P. Ognibene, director of the CC Office of Clinical Research Training and Medical Education.

2005 was the third year of the Clinical Investigator Trainee (CIST) Forum. The forum is designed to inform medical and dental students who have expressed an interest in clinical research about both the excitement and the realities of clinical research—and to encourage them to become the next generation of clinical researchers. About 250 students in a mentored clinical or translational research program attended the November 2005 forum. There they learned, among other things, how mid-career and well-known panelists established their careers and balance their personal lives with the profession's demands.

Participants included Howard Hughes Medical Institute scholars (Cloister) and fellows (non-Cloister); Doris Duke Clinical Research Program medical students; National Center for Research Resources/GRC students in year-long research programs; Sarnoff Endowment for Cardiovascular science fellows; Fogarty International Center-Ellison Foundation fellows; and fellows in the NIH Clinical Research Training Program for medical and dental students.

National Institute of Child Health and Human Development researcher Dr. Lynnette Nieman was named the 2005 Distinguished Clinical Teacher. She was recognized as an exemplary clinical mentor and outstanding teacher who played an important role in the professional development of clinical fellows.

Training a clinical research workforce

Training in clinical research is important if the nation is to build the workforce needed to explore opportunities for medical advances. By building an infrastructure for clinical research training on NIH's main campus, the Clinical Center has helped not only to train its own clinician-scientists but also to address the nationwide shortage of training opportunities for medical and dental students, physicians in formal residency and fellowship training programs, nurses, pharmacists, and allied health professionals. It is a top Clinical Center priority to train clinical researchers in the responsibilities of planning and conducting clinical research and to increase the pool of clinical researchers with expertise in various specialties.

The Clinical Center's Office of Clinical Research Training and Medical Education, established in May 2003 and directed by Dr. Frederick Ognibene, is responsible for developing, administering, and evaluating clinical research training and medical education initiatives. Through distance education, the NIH Clinical Center increasingly exports its clinical research training programs throughout the United States and the world. Students in a convenient time zone can participate through live teleconferencing. Students also participate in the courses through archived content—available through a Webcast or a DVD—from as far away as Singapore, Seoul (South Korea), Bergen (Norway), and Rabat (Morocco, our newest partnership). The courses offered in the curriculum include:

- Introduction to the principles and practice of clinical research
- Ethical and regulatory aspects of clinical research
- Clinical research training, and
- Principles of clinical pharmacology

In 2005, 4,542 students participated in the courses, with 3,388 students using distance-learning technology.

THOMAS HONORED WITH HHS AWARD

Clifford Thomas with the NIH director.

Rockville Pike was just a three-lane road in 1955, when housekeeping aid Clifford Thomas began working at NIH after being honorably discharged from the Army as a member of the infantry at Ft. Meade. "I used to drive by and see NIH and I wondered if I could get a job there," says Thomas, now 75.

He was offered a job as a housekeeping aid, and has worked in various places across NIH ever since. In May 2005, he received his 50-year pin and a handshake from HHS Secretary Michael Leavitt and NIH Director Dr. Elias Zerhouni on May 25, at the HHS Secretary's Departmental Honor Awards.

"Mr. Thomas is a very rare person," says Henry D. Primas, chief of the Clinical Center's Housekeeping & Fabric Care Department. "He's very dependable, having a large cache of sick leave that he seldom uses, and if he says he's going to do something, he does it. He gets along with everyone, puts in a full day's work, and is very pleasant and courteous."

Thomas, who is assigned to on the Clinical Center director's floor, was asked by the director's staff to follow them to the Hatfield Center. "Mr. Clifford is one of those exceptional people who distinguish themselves through their actions and reliability," says Dr. John I. Gallin. "He's remarkably dedicated, efficient, and pleasant. His work ethic and values are greatly appreciated."

Glad that he has a job and is able to work, Thomas has no plans to retire. "I never even think about it."

WILSON NAMED NEW CHIEF OF PHARMACY

Dr. Andrew Wilson came to the CC in October.

The Clinical Center named Dr. Andrew Wilson chief of the pharmacy department in October. Wilson had directed pharmacy services at the Medical College of Virginia Hospitals (MCV) in Richmond since 1998. At MCV Wilson led the professional, clinical, operational, and administrative pharmacy for a 700-bed teaching hospital, including its ambulatory clinics, a home-infusion and specialty-services pharmacy, and four large outpatient pharmacies. He managed a staff of 160, an expense budget of $53 million, and a revenue budget of $116.5 million.

"When you think of what this job entails, it's a 360-degree approach," he says of the Clinical Center position. "There's patient care, research, and customer service. It's about meeting a professional standard that is second to none. It's also about becoming part of the most prestigious group of medical researchers, practitioners, and caregivers in the world. Am I excited? Yes, I wouldn't be here if I weren't!"

In 1996, Wilson was named a fellow of the American Society of Health System Pharmacists. He maintains an active interest in the education and training of pharmacists, serving on editorial boards for several national pharmacy publications. He had also served as associate dean for institutional programs and associate professor of pharmacy practice in the Virginia Commonwealth University School of Pharmacy. Before his MCV appointment, he served 10 years as the director of pharmacy services at Saint Louis University Hospital in Missouri.

"Everything I've done has involved a multifaceted approach," he said. "Cost-containment strategies, the implementation of new pharmacy electronic information systems, and, with the implementation of automation and robotics—are all significant technical advances with which I have had experience. But that's only part of it. These technologies all have to be integrated with the basic recognition that the ultimate driver is people. And NIH clinical care, which is people-based, has always been a step above the rest."

Dr. Lynn Gerber

LYNN GERBER, RETIRING FULL SPEED AHEAD

Naomi Lynn Hurwitz Gerber, MD, has a single-spaced 19-page curriculum vitae, "and there is not a bit of fluff to it," said her colleague CAPT Charles McGarvey at her retirement party. Gerber's distinguished medical career and 30-year tenure at NIH have made her an internationally recognized researcher in rehabilitation science and chronic illness.

Gerber first came to NIH in 1962, as a summer research fellow in the lab of Nobel Prize winner Marshall Nirenberg. "I was working with the who's who of biomedical research," she says. "It was one wonder after another! After that life-changing experience I decided, 'I have to do something with my life. I have to fashion my life in such a way that I can, in one way or another, work in an exciting area.' Coming to NIH was the fulfillment of a dream. Not only when I arrived, but every step along the way."

She earned an undergraduate degree from Smith College and a medical degree from Tufts University School of Medicine and did her residency at the New England Medical Center, before joining NIH as a clinical associate in the arthritis and rheumatism branch of the National Institute of Arthritis, Metabolism and Digestive Diseases (now the National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIAMS). In 1973, she completed her fellowship in rheumatology.

One of many at NIH who noticed her hard work and tenacity was Roger Black, acting director of the Clinical Center. He was looking for someone to be chief of rehabilitation medicine and asked Gerber if she wanted to give it a try. She began a residency in physical medicine and rehabilitation at George Washington University Medical Center in 1975 and stepped into the role of chief in 1976.

She changed the way the department of rehabilitation medicine interacted with other departments and with clinical studies. For one thing, she developed new ways to measure a patient's quality of life after diagnosis or treatment. She asked, "What makes a treatment successful?" at a time when many scientists defined the answer by whether the patient died or lived. Gerber proposed judging success not just by whether the patient lived but with what quality of life and function, even if measured subjectively.

At the time, Dr. Steven Rosenberg, chief of surgical oncology in the National Cancer Institute, was studying sarcoma, a solid tumor of the extremities. "He was trying to determine which treatment—amputation or a limb-sparing procedure—would result in a better prognosis," says Gerber. "My question was, how could one decide without measuring functional parameters? We helped them assess function (limb swelling, insensitivity, time to return to usual activity), which helped realign their original surgical plan."

Because of her collaborations with various institutes, they provided support for something she never expected—her own clinical laboratory. In the mid-1980s rehab medicine installed a biomechanics lab to study human motion. An even more sophisticated lab for measuring muscle strength, mobility, and effectiveness in everyday activities opened recently on the first floor of the Hatfield Center (see story on page 31).

In 1995 she started a foot clinic, bringing together several specialists who would meet with one patient at a time, analyze the problem, and brainstorm for remedies.

"Dr. Gerber listens carefully to what patients have to say," says Karen Siegel, a senior staff specialist in rehab medicine. "Her patients feel that their functional level and quality of life are the result of the care she has provided them."

Gerber and her colleagues treat many patients with chronic conditions, which means they often form lifelong friendships. Many of her osteogenesis imperfecta patients have been coming to Gerber's lab since they were infants. She knows them by name and talks of their accomplishments like a proud mother. "The best rewards of my work are when you see people not just surviving, but surviving well," says Gerber. "I don't focus on treating the disease. I am concerned with their potential for restoring function. We rehabilitationists believe there is much we can do to help patients solve problems so that they can do more—and do more of what they would like. We add life to years."

Gerber also applies the rehab philosophy to herself. A former patient became her tennis instructor, getting Gerber back in the game after years of not picking up a racket, and she now plays competitively in the local circuit. "I believe in rehabilitation medicine because I see what people can do for themselves. As you age, accelerate. Don't slow down."

She clearly has no intention of doing so. She leaves NIH to develop George Mason University's new Center for Chronic Illness and Disability.

ART ATKINSON RETIRES

Dr. Art Atkinson

Dr. Arthur J. Atkinson, senior advisor in clinical pharmacology, retired after eight years at the Clinical Center. His relationship with NIH dates back to 1965, when he worked in NIAID as a clinical associate. In 1997, as an expert consultant for the National Institute of General Medical Sciences, he was charged with assessing NIH's proposed intramural training program in clinical pharmacology. After completing his study, he was offered the position from which he retired, directing the ClinPRAT postdoctoral training program and the Clinical Center course on Principles of Clinical Pharmacology.

"I wanted trainees to have the same wonderful experience I had as a clinical associate," said Atkinson. Under his leadership, enrollment increased from 180 students to 500, 34 lectures were given, and a website was created to provide access to syllabus materials and videotapes of the lectures. The program is broadcast in classrooms at UCLA, Indiana University, and University of Texas Southwestern Medical Center.

In March Atkinson was awarded the Oscar B. Hunter Memorial Award in Therapeutics from the American Society for Clinical Pharmacology and Therapeutics (ASCPT) for his work applying mathematical principles to individual drug therapy and dosage.

He studied chemistry at Harvard College, got his medical degree from Cornell University, and interned and took residency training at Massachusetts General Hospital. He did postdoctoral training in clinical pharmacology at the University of Cincinnati before taking a post as visiting scientist in the Department of Toxicology of the Karolinska Institute in Sweden. In 1970, he started the program in clinical pharmacology at Northwestern University Medical School, before leaving to be corporate vice president for Clinical Development and Medical Affairs at the pharmaceutical giant, Upjohn Company.

RADM Romano with the Surgeon General at her promotion ceremony.

CAROL ROMANO NAMED ASSISTANT SURGEON GENERAL

Clinical Center employees know her best through her work in clinical informatics—first helping design and implement the Clinical Center's first electronic medical information system (MIS, in 1976) and currently as deputy chief information officer, directing clinical operations for CRIS, the clinical research information system that replaced MIS last year.

Effective November 1, 2005, however, she is also Rear Admiral (RADM) Carol A. Romano, Assistant Surgeon General and Chief Nurse Officer in the U.S. Public Health Service.

That she had already risen in the ranks is evident from the credentials after her name: PhD, RN, BC, CNAA, FAAN. Her new duties are to lead and coordinate PHS nursing professional affairs for the Office of the Surgeon General and the Department of Health and Human Services (DHHS). She will represent the surgeon general and the PHS in contacts with state, national, and international groups and with professional societies concerned with nursing issues. She will guide and advise the surgeon general and the Nurse Professional Advisory Committee (N-PAC) on such matters as standards, recruitment, retention, readiness, and career development of PHS nurses.

Romano earned a diploma in nursing (1971) from the Geisinger Medical Center in Danville, Pennsylvia, and a baccalaureate degree in nursing (1977), an MS (1985), and a PhD (1993) from the University of Maryland. She completed the Senior Managers in Government Training Program at Harvard University School of Government (1997) and the Interagency Federal Health Care Executive training program at George Washington University (1993). She is board certified by the American Nurse's Credentialing Center in nursing informatics and advance nursing administration.

She began her civil service career at the Clinical Center in 1971, as a clinical research nurse. She was appointed to the Commissioned Corps in 1986 and assimilated as a Regular Corps Officer in 1993. Over 34 years she has worked as an associate investigator, clinical research nurse, nurse educator, nursing information systems specialist, director of marketing & recruitment, and director of clinical informatics & quality assessment. She has published studies on informatics education, the confidentiality of clinical records, and the adoption of innovations.

She was a co-architect of the world's first graduate curriculum in nursing informatics at the University of Maryland. She has been a mentor to numerous students, written more than 50 papers, edited two books, served on three editorial boards, given many presentations, and held several adjunct faculty appointments. She was chair of the Commission on Certification (1997-1998) for the American Nurses Credentialing Center, a member of the Advisory Board on Therapeutic Information Management (1995-2000) for the US Pharmacopeia's Drug Index, and co-chair of the Maryland State Board of Nursing Task Force on Standards of Practice in 2001. She has been advisor to WHO and other organizations. She codeveloped the NIH nurse scientist training program and helped lead the emergency response to Hurricane Katrina, creating the federal call center manned by volunteers. She has received many, many awards from the PHS as well as an NIH Director's award, a Clinical Center Director's Award, and two DHHS Quality of Life Awards.

NIH CLINICAL CENTER

Organization Chart

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Elaine J. Ayres, MS, RD

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        - Veterinary Care Program
          Lisa Portenoy, VMD

A broader role for governance

Clinical Center governance changed in FY 2004, as part of an effort to promote the NIH intramural program as a model for interdisciplinary research. As recommended by the NIH Director's Blue Ribbon Panel on the Future of Intramural Clinical Research, the former Clinical Center Board of Governors assumed a new and larger identity, becoming the NIH Advisory Board for Clinical Research. The Board will oversee all intramural clinical research, while continuing its oversight of Clinical Center resources, planning, and operations. It will play a key role in guiding the development of trans-NIH strategic planning and priority setting for intramural clinical research through the integration of Institute/Center strategic visions and agendas. The Board's responsibilities extend only to the intramural clinical research program, but it will also be open to new opportunities for clinical research, including high-risk, high-impact research, research in rare diseases, and interactions between intramural and extramural clinical research programs.

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MEDICAL EXECUTIVE COMMITTEE MEMBERS

NIH Clinical Center

The Medical Executive Committee is made up of clinical directors of the NIH intramural clinical research programs and other senior medical and administrative staff.

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National Cancer Institute

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National Institute of Mental Health

Carter Van Waes, MD, PhD
National Institute on Deafness and Other Communication Disorders

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National Institute on Aging

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Deputy NIH Legal Advisor

Richard G. Wyatt, MD
Office of the Director, NIH

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NIH Clinical Center

(the institutes, in alphabetical order)

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National Eye Institute (NEI)
National Heart, Lung, and Blood Institute (NHLBI)
National Human Genome Research Institute (NHGRI)
National Institute on Aging (NIA)
National Institute on Alcohol Abuse and Alcoholism (NIAAA)
National Institute of Allergy and Infectious Diseases (NIAID)
National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
National Institute of Biomedical Imaging and Bioengineering (NIBIB)
National Institute of Child Health and Human Development (NICHD)
National Institute on Deafness and Other Communication Disorders (NIDCD)
National Institute of Dental and Craniofacial Research (NIDCR)
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
National Institute on Drug Abuse (NIDA)
National Institute of Environmental Health Sciences (NIEHS)
National Institute of General Medical Sciences (NIGMS)
National Institute of Mental Health (NIMH)
National Institute of Neurological Disorders and Stroke (NINDS)
National Institute of Nursing Research (NINR)
National Library of Medicine (NLM)

(the centers, in alphabetical order)

Center for Information Technology (CIT)
Center for Scientific Review (CSR)
John E. Fogarty International Center (FIC)
National Center for Complementary and Alternative Medicine (NCCAM)
National Center for Minority Health and Health Disparities
National Center for Research Resources (NCRR)
NIH Clinical Center (CC)
Mark O. Hatfield Clinical Research Center
Warren Grant Magnuson Clinical Center

back cover

(top left to right)
MARIE SKLODOWSKA CURIE (1867–1934), a Polish-born chemist and physicist in France, co-discovered the elements radium and polonium and did pioneering work on radioactivity, including its medical uses. Mme. Curie is shown here at work in her laboratory.

ASCLEPIADES OF BITHYNIA (c.124–c. 40 B.C.), a Greek physician who practiced in Rome, advocated humane treatment for the mentally ill and taught that diseases occur because of an imbalance in the body's natural harmony. Here he revives a dying man.

(bottom left to right)
CRAWFORD WILLIAMSON LONG (1815–1878), an American physician considered first to perform surgery using ether-induced general anesthesia. Here the pulse of the anesthetized patient is being checked.

WALTER REED (1851–1902), an American Army surgeon, proved that yellow fever is transmitted by mosquitoes. Subsequent steps drastically reduced mortality rates from the disease and made possible completion of the Panama Canal.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
NIH Clinical Center
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For administrative use
January 2006