

Back to: [Clinical Center Home Page](#) > [About the Clinical Center](#) > [News and Events](#)

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Clinical Center News

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[past issues](#)

May 2002

[Family Lodge at NIH dedicated](#)

[Breaking ground for new Children's Inn wing](#)

[Changing gears to fight AIDS](#)

[Laboratory Medicine receives high review marks](#)

[Caring is key: pediatric nursing program wins journal award](#)

[New protocol services office established](#)

[Customer-friendly employee badges make debut](#)

[New continental breakfast responds to patient's needs](#)

[News briefs](#)

Family Lodge at NIH dedicated



Personal stories can have a positive public impact. Such as in the case of the family lodge planned for NIH.

A ceremony marking the naming of the facility was held Wednesday, April 17, at the Russell Senate Office Building in Washington, D.C. The Foundation for the NIH formally accepted a \$3 million donation from The Edmond J. Safra

Philanthropic Foundation and announced the dedication of the Edmond J. Safra Family Lodge at NIH.

It was a personal story that caught the eye of Lily Safra, wife of the late Edmond Safra, who passed away in 1999. In the Foundation's annual report, she read the account of a patient with metastatic kidney cancer whose local doctor had told him nothing more could be done, but that the NIH was conducting a clinical study that might help. The patient would undergo an experimental bone marrow transplant at NIH Clinical Center, which required he and his wife remain nearby for several months.

When that story drew Mrs. Safra's attention, she stepped forward with a contribution to the Foundation's Family Lodge Campaign. Her husband had suffered from Parkinson's Disease, so she knew firsthand about the challenges of being a daily caregiver. Unlike many families dealing with illness, however, she possessed the financial resources to ease the burden. It was her empathy for patients and their families in their most dire moments that inspired Mrs. Safra's gift.

At a mid-day ceremony in the Senate Caucus Room, Mrs. Safra related that the Lodge reflects "the spirit and values" of her late husband. "When my husband became ill, my world narrowed quickly. Helping Edmond was not my most important goal; it was my only goal," she said.

The lodge is planned as a temporary residence for caregivers of patients taking part in clinical trials. In his remarks Dr.

John Gallin, director, NIH Clinical Center, told the audience that patients come from every state in the union, traveling great distances because of the hope that NIH provides - hope that "our research will save their lives, or improve the lives of family members, or the lives of others who have their disease." He noted that patients frequently spend months in the Clinical Center and that it becomes their home away from home. Despite special amenities such as recreation rooms, a gym, and a complete school, he said there was more that could be done.

Dr. Gallin expressed concern about two things in particular. "The stress of chronic and severe illness is enormous, especially when far away from home and too many families fracture. What is missing is a convenient place near the hospital to take a break and get a moment of solitude, or take a nap, or get a good night's sleep," he said. "And following intensive therapy, patients and family members need a facility where they can transition to home. They need a place where they can gain confidence in home care procedures in order to gain independence from the hospital."

Offering thanks to Lily Safra and the Safra Foundation, as well as partners in industry, for their generous gifts Dr. Gallin said the lodge would be a much needed refuge to welcome and comfort patient caregivers. He predicts the facility will become an important model for other clinical research centers.

NBC's Barbara Harrison moderated the event. The program also included Foundation for NIH Board of Directors Chairman Dr. Charles Sanders, actor and patient advocate Michael J. Fox (who also suffers from Parkinson's Disease), Ohio Congressman Ralph Regula, Massachusetts Senator Edward Kennedy, and Dr. Patricia Grady, director, National Institute of Nursing Research.

Grateful sentiment for the Safra donation was expressed: "This is what the American people are all about, helping people help others. As people committed to giving, Lily we thank you." –Dr. Sanders.

"Mrs. Safra, the Edmond J. Safra Family Lodge will stand as a monument for years. Those who will never know you will realize that your gift says there are those who care." –Mr. Regula.

"I want to thank Lily Safra for the work she does. Her gift here represents the high standard she brings to everything she does." –Mr. Fox.

Both Senator Kennedy and Dr. Grady agreed with Dr. Gallin that the Lodge might become a model for others to follow. "Patients get better more quickly when they have a family member nearby and their treatments are more effective," said Kennedy, adding that he hoped news of the Safra Family Lodge would soon "echo forth, causing it to be replicated throughout the country and world."

"Patients are often discharged from a hospital without knowing how to cope with their conditions," said Dr. Grady. "Their caregivers are challenged, too. Caregivers need special knowledge to deal with many challenging issues and attend to their own health as well. An NIH program to address these issues for Safra Family Lodge residents would provide lasting benefits as they return home and pick up their caregiving responsibilities again. The program could become a model for other research and care organizations to follow."

The Edmond J. Safra Family Lodge is designed to provide "a home away from home" on the NIH campus for caregivers of Clinical Center patients. Residents will find amenities that reflect the comforts of home as well as the support and companionship of others facing similar challenges. Groundbreaking for the lodge will occur this summer with completion projected for 2003.



Foundation for NIH Board of Directors Chairman Dr. Charles Sanders (left) and NIH Clinical Center Director Dr. John Gallin (right) with Mrs. Lily Safra at The Edmond J. Safra Family Lodge dedication ceremony in the Senate Caucus Room.

-by Dianne Needham

[Back to Top](#)

Breaking ground for new Children's Inn wing



Breaking ground for the new wing of The Children's Inn are (left to right): John Taylor, executive director, Merck Company Foundation; Lori Wiener, president, Board of Directors, The Children's Inn; four inn children residents and a parent; NIH Acting Director Dr. Ruth Kirschstein; Tony Morella, inn board member and congressional spouse; Mark Raabe, inn board member and Merck rep; Chris Downey, inn board member; and NIH Clinical Center Director Dr. John Gallin. Looking on from behind are inn board members and congressional spouses Jane Gephardt (left) and Cecile Tausin (right).

No longer will The Children's Inn have to say, "there is no room at The Inn." That according to Lori Wiener, Ph.D., president, The Children's Inn at NIH, is the reason a new wing will be built on to the existing facility.

"We often find ourselves overbooked, having to bump children back to hotels," she said. Wiener pointed out that during a 2-year period from the summers of 1998-2001, families were turned away on nearly 500 occasions due to space limitations.

On April 24, a formal groundbreaking ceremony was held to mark the start of the wing's construction. Wiener remarked to those in attendance, "I'm not sure if it is harder for the staff member who has to share the news or for the child to hear the news that there's no room for them to stay at the inn. I think you can all imagine how difficult it is to add this burden onto an already stressed child and family."

Before moving forward with the inn's expansion data collection a review was conducted on the inn's usage, institute protocols and

future pediatric research plans. Based on this data, the inn's Board of Directors decided that in order to continue to support NIH pediatric research a new wing was justified. Twelve years have gone by since the original groundbreaking for the Children's Inn.

When the wing opens in 2003, the Children's Inn will have the ability to provide a "place like home" for another 18 seriously ill children and their families during their visits to NIH, increasing the inn's capacity from 37 to 55 families. It will be a two-level addition that will blend and connect with the original structure, and will include features on the ground level that will enhance the overall homelike environment.

[Back to Top](#)

Changing gears to fight AIDS

A trio of NIH security officers is looking for support in the fight to find a cure for AIDS.

Officers Dwayne Taylor, Kendrick Robinson and Ron West will travel to Europe next month where they will cycle 500 miles from Amsterdam to Paris in the first annual European AIDS Vaccine Ride.

"This is a really good cause and we want to show people that we're not just here working in the Clinical Center, but that we're in the community trying to make a difference," said Taylor, captain of the NIH Team American Health.

The European AIDS Vaccine Ride, sponsored by the firm, AOL Time Warner, helps raise funds to benefit the work of scientists at



Left to right, Kendrick Robinson, Dwayne Taylor and Ron West will participate in the first-ever European AIDS Vaccine Ride. Although this is the first time this event has been sponsored, similar events produced by Pallotta Team Works, a private event enterprise based in California, have raised more than \$222 million and attracted more than 124,000 people worldwide.

the University of California at Los Angeles AIDS Institute and the Emory Vaccine Center in Atlanta, Ga. According to the European AIDS Vaccine Ride website, the organization raises money to help free scientists from the tether of grant writing so that they can remain in their laboratories, test new ideas and get to work immediately on the approaches they feel are most promising.

Beginning June 30, the cyclists will ride for seven days through the Netherlands, Belgium, and Germany. The tour will be completed in France. Each team is asked to raise at least \$5,000 for AIDS research. NIH Team American Health aims to raise a minimum of \$8,000. "We don't want to put a limit on the maximum amount that we want to raise," said West, team co-captain. "The sky is the limit."

The Centers for Disease Control and Prevention reports that there were approximately 21.8 million HIV/AIDS-associated deaths worldwide through 2000. Of those, about 17.5 million were adults and 4.3 million were children under the age of 15.

"We're not just doing this for AIDS research, but for cancer and all the other diseases that have no cure yet," said West. "We are doing this for the doctors and scientists, as well as the people they care for." Currently, the team is seeking funding from NIH departments, local businesses and the community for equipment and travel expenses. They are also looking for more people to participate in the event. "We want others who work in the Clinical Center and NIH to know that they have a voice and can make a difference, too," said Robinson. "Little things and little people can have a big voice in this world."

To support NIH Team American Health, contact Dwayne Taylor at teamah@hotmail.com, or call 202-321-4964.

[Back to Top](#)

Laboratory Medicine receives high review marks

The College of American Pathologists (CAP) accredited the department of Laboratory Medicine last month "with distinction."

The inspection, conducted every two years as part of the CAP's Commission on Laboratory Accreditation, took place in February. Beginning this year, the commission added the terms "With Distinction" to mark laboratories that passed the rigorous criteria with especially high marks.

"We were very pleased at the outcome of the inspection," said Department Director Dr. Thomas Fleisher. "The inspectors' comments were extraordinarily complimentary to both our personnel and operations, as well as the excellence of services being provided."

The Clinical Center's Department of Laboratory Medicine is one of more than 6,000 nationwide CAP-accredited laboratories. The accreditation program began in the early 1960s and is recognized by the federal government as being

equal to, or more stringent than, its own inspection program. During the off year between accreditation cycles the lab conducts a self-inspection comprised of a "fairly extensive review of operations" said Fleisher.

Laboratory Manager Peggy Spina said the fact that peers conduct CAP inspections and not regulators is a plus.

"We've opted to take part in the CAP program because it is an inspection by our peers—others who actively run and work in similar environments. These are people thoroughly familiar with all the issues and questions that come up." As part of a reciprocal agreement, laboratory staff from the Clinical Center also act as inspectors for other participating labs. CAP is a medical society serving nearly 16,000 physician members and the laboratory community throughout the world.

[Back to Top](#)

Caring is key: pediatric nursing program wins journal award



Pictured are some members of the Nursing Pediatric Program of Care winning team: Back row standing on bench (left to right): Donna Gwyer, Myra Woolery-Antill, Brandi Hobbs, Kara Leddy, Debbie Rawson, Chantal Mouw, Marie Weskamp, Shannon Kruk, Patty McGinley, Cindy Hahn; standing (left to right): Kathy Obunse, Holly Villepique, Charlotte Bosmans, Kathleen Beville, Barb Corey, Lt. Blondell Hill, David Draper, Linda Ellison, Kimberly Elenberg, Katie Mullin; and front row (with knees bent, left to right): Christine Spalding, Lt. Commander Felicia Andrews, and Donna Gaskins.

Children. Illness. Hospital. To some people, these words might mean suffering. To the Pediatric Nursing Program of Care team nurses, they mean commitment to a patient care model that treats patients as family, and colleagues as partners. The team, a group of 61 nurses and two clinical research support assistants, works on 9-West, 9-West Day Hospital, 13-West, and Outpatient-13. Four clerical research support assistants also support the team. They have proven that patients from many institutes can be cared for together, with excellence and sensitivity without compromising quality care or clinical research.

This accomplishment has not gone unnoticed. *Advance for Nurses*, a professional nursing journal, holds an annual Best Nursing Team competition in recognition of superior nursing practice. This year, the Pediatric Nursing Program of Care placed third in the Advance For Nurses Fourth Annual Best Nursing Team 2002 Contest, Baltimore/Washington, D.C., metro area. Deborah Merke, M.D., the Clinical Center

pediatrician for the program, is clearly impressed. "I feel privileged to work with these nurses daily. They meet and exceed the challenge of providing excellent patient care to children with varied needs, while providing superior clinical research support to clinical investigators. It's wonderful that their skills are being recognized."

The Advance for Nurses award caps many achievements by these dedicated caregivers:

- Development of "Teddy Bear Rules," guidelines in the form of frequently asked questions that help patients move smoothly from unit to unit and "Elephant Rules" that do the same for visitors to outpatient clinics
- Coordinated admission planning between all pediatric areas
- Expansion of the pediatric units' abilities to care for new institute patients and protocols
- Revising competencies to encompass the pediatric program
- Providing support and expertise for pediatrics to the organization One hallmark of the program is that patients, parents, and staff members have a close relationship, almost like family, when they are together. Primary nurses greet returning patients by their first names, an informality that patients appreciate. The mother of a 7-year-old child who was discharged after a 9-month hospitalization stay, speaks for many patients and their relatives when she said that leaving the unit was "like leaving your family behind." Staff members have also helped patients and their loved ones celebrate important life events—both happy and sad.

To help staff cope with the grief that comes when patients die the program holds an annual bereavement service to commemorate the lives of children who have passed away.

Since 1998, the Nursing Pediatric Program of Care has met many daunting patient care challenges: the merging of three inpatient pediatric units to two, and the expansion of the pediatric day hospital to include patients from all institutes. When the new Mark O. Hatfield Clinical Research Center opens, the program will have merged all pediatric services into one unit and a combined pediatric clinic. For pediatric patients and families, these changes will be seamless. The Nursing Pediatric Program of Care will continue to exemplify the can-do spirit that Clinical Center staffers make their daily credo.

"We are so proud of our team for winning this award. It is so gratifying to see our nursing staff acknowledged for their expertise and teamwork. They are truly a wonderful group to work with," says Barbara Corey, nurse manager. Myra Woolery-Antill, program CNS agrees. "They make it happen," she said.

-by Wendy Schubert

[Back to Top](#)

New protocol services office established

Dr. Robert B. Nussenblatt, chief, Laboratory of Immunology, National Eye Institute (NEI), also became chief of the new NIH Office of Protocol Services in January. "The conduct of clinical research on campus is something I've been interested in for years," he said, "not only as a user, but as scientific director of the NEI," a job he held until last year.

After discussing various approaches to clinical care with Clinical Center Director Dr. John Gallin, Dr. Nussenblatt said it became clear to both of them that they shared the same vision and goals. Dr. Gallin asked Dr. Nussenblatt to take the lead position for the newly designed Office of Protocol Services, formerly known as the Protocol Coordination Center.

"In theory, 20 percent of my time was to be devoted to the new job," Dr. Nussenblatt laughed. "But the way it works out, I spend five days a week in the Eye Institute and four days at the Clinical Center."

Dr. Nussenblatt is enthusiastic about the progress that the new Protocol Services effort is making. "A lot depends on the people who help you, and there are some very creative and dedicated people here," he said. One of the most promising projects is a web-based protocol-writing assistance tool currently known as ProtoType. Within a few months, the tool, which formalizes and simplifies the writing of complex medical research protocols, was created and then presented to the Medical Executive Committee. Designed to be interactive, ProtoType offers both uniformity and flexibility to the protocol writing process.



"It makes it easier for more junior investigators to follow all the rules and regulations, while at the same time providing them with common language that can be inserted into a template that has already been developed and accepted," Dr. Nussenblatt explained.

The writer can easily and automatically insert procedural language that exists and is explained in other protocols or, if preferred, the writer can create entirely new language. Thus, the template can be as rigorous or as flexible as desired.

As an added bonus, Dr. Nussenblatt believes ProtoType will result in better patient safety and follow up because each protocol will be standardized and allow principal investigators to "map" the progress of investigations and track when patients should have certain tests.

Dr. Nussenblatt relies on his experience as an investigator user to help make ProtoType work. In 1977, he came to NIH as a clinical associate and knows what new researchers need. He also knows that under the present system, investigators have to peruse paper charts and maintain their own records, a time consuming and inefficient use of resources given today's computerized technology.

"The ultimate goal," he said, "is that this will be the first step to entering the Clinical Research Information System, and that it will progress into a paperless operation." By year's end Nussenblatt expects 20 to 25 percent of all protocols to be written using ProtoType. The tracking of protocols, including the proper regulatory requirements and reminding users of protocol renewals are among the other features that will eventually be added to ProtoType to make it an even stronger protocol services tool.

"It will be an ongoing process, but I'm sure that as it evolves, it will be like a living document. It will constantly develop as conditions and regulations change." In the meantime, Dr. Nussenblatt remains busy. "We're still in the honeymoon stage, but amazingly, we haven't run into any major problems. I'm sure, though, that we'll see some redundancies, problems and things we've forgotten, but to date, everyone's been very positive about the new Office of Protocol Services as well as ProtoType."

-by John Iler

[Back to Top](#)

Customer-friendly employee badges make debut

Some employees are now sporting the new NIH employee identification badge. The new badge improves security at NIH, but according to Dr. Michele Evans, Clinical Center safety officer, it will also be customer-friendly for patients and their families.

"In short, the Clinical Center customized the government badge so that it is easier to read and tells you who people are," said Evans.

The customized badge has a wide black horizontal stripe with large white letters identifying some 20 employment designations. The letter character font and colors are read easily from six feet away—a realistic distance that helps patients when they are talking with their health care provider, said Evans.

Clinical Center employees, as well as all medically privileged and affiliated health care workers in the institutes, will have the black stripe and a descriptive designation. All new NIH badges have a magnetic strip that will, in the future, grant and record access to secured areas via a proximity reader.

Employees also no longer need to go to Building 31 for their new badge. For better employee convenience, portable kiosks or "badging stations" will be set up throughout the Clinical Center. Workers in the kiosks will access an employee's personal information from the NIH Enterprise Directory (NED) only. Employees are encouraged to review their current NED records with administrative officers to ensure their names and employee information are correct.

"Once you are at the kiosk, the badge workers cannot change the information in the NED," Evans said. Each Institute has a NED coordinator and employees should check with their administrative officer for assistance.

[Back to Top](#)

New continental breakfast responds to patient's needs

Recently it came to light in a discussion with Clinical Center patients that there may be a patient need for a continental breakfast. Just this month, the Nutrition Department began a pilot program that provides continental breakfasts to patients each weekday from 7-10 a.m. During this pilot program the times may be adjusted to accommodate patients' requests.

"Primarily, it's for patients who have early morning blood work," said Alberta Bourn, chief of the Nutrition Department. "But it's open to any patient who wants to take advantage of it."

Before implementing the program, patients complained those hours of fasting before blood draws had made them hungry. They wanted some form of nourishment once the procedures were over. Some patients, who had regular early morning tests, had begun bringing bagged food. This came to Clinical Center Director Dr. John Gallin's attention during a meeting of the Patient Advisory Group and a decision was made to find a solution.

Now, each weekday morning in the Admissions area of Building 10, patients are treated to coffee and tea, hot chocolate, fruit juices, fresh fruit, and an assortment of pastries, muffins, granola bars, and bagels.

"Patients are very enthusiastic in their response," said Bourn. "We've been told this was something that was very much needed and we were happy to respond."

[Back to Top](#)

briefs

Your Voice Counts- Take the CC Employee Survey

- Influence the future of the Clinical Center
- Participate in the 2002 Employee Survey
- April 22 through May 20
- Mailed to employees at home
- Complete it promptly and return it in the postage-paid envelope

Race for the Cure

Join Team NIH in the 2002 Komen National Race for the Cure on Saturday, June 1. Those who registered at the Clinical Center in April may obtain their race packets May 28-29 from 11 a.m.-2 p.m. at the second floor cafeteria. Registration is available until race day. Find full race and registration details at

<http://www.nationalraceforthecure.org/registration.html> or contact Clinical Center reps: Pat Piringner, 301-402-2435, Dianne Needham, dneedham@cc.nih.gov; and Georgi Cusack, 301-594-8128, gcusack@cc.nih.gov .

GM cancer conference

The 2002 General Motors Cancer Research Foundation Annual Scientific Conference (GMCRF) will be held June 4-5 in Masur Auditorium. The NIH Director's Wednesday Afternoon Lecture Series on June 5 will host presentations by each of the 2002 GMCRF winners. The event starts at 8:15 a.m. No registration. Visit <http://www4.od.nih.gov/gmcrf>, email ruemk001@surgeytrials.duke.edu or call 919-668-8018.

NIH Clinical Teacher's Award

The NIH Distinguished Clinical Teacher's Award is the highest honor bestowed collectively on an NIH senior clinician, staff clinician or tenure-track/tenured clinical investigator by the NIH clinical fellows. The deadline for nominees for the next award is June 1. Point of contact for further information is John Paul SanGiovanni, who can be reached via e-mail at jpsangio@nei.nih.gov.

Primary care updates

Join the Clinical Center Nursing Department for its third primary care update seminar on June 19, 3-4 p.m. in Lipsett Amphitheater. Angelo Taveira-Dasilva, M.D., Ph.D., Pulmonary Critical Care Medicine Branch, NHLBI, will present the topic, "The Interpretation and Clinical Application of Pulmonary Function Tests."

[Back to Top](#)

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