

April 2000

# Clinical Center News

## In this issue:

- Volunteers interpret
- Retirements
- Diversity conference

## “A soothing place of respite...”

### *Plans move ahead for a Family Lodge near Clinical Center*

Emma\* was just 21 years old when her sister, Jane\*, was diagnosed with bone cancer. Since her parents were elderly, it was difficult for them to make the 70-mile trip to Bethesda to support and care for Jane during her participation in a clinical trial. “So I came to the hospital every three

weeks—or sometimes more frequently—during her yearlong treatment,” said Emma.

Emma’s accommodations during these stays were patchwork at best. “I could stay in her room some nights. I was lucky enough to have a family friend in the area where I could stay if need be. One night I

slept in my car.”

Paula\*, who lives 400 miles away, in Ohio, is a participant in a cancer vaccine protocol. She’ll come to the CC several times in the next few months. Her 23-year-old daughter wanted to come with her for a recent visit, but “I told her no,

*\*Not their real names.*

See **Family Lodge**, page two



Dr. Douglas Shaffer, center, was the first student to receive his Master of Health Sciences in Clinical Research through the NIH-Duke Training Program in Clinical Research. Pictured with him are, left, Dr. John Gallin, CC director, and, right, Dr. William Wilkinson, Duke program director.

### **First graduate of NIH-Duke program**

The NIH-Duke Training Program in Clinical Research (TPCR) has its first graduate, Dr. Douglas Shaffer, a fellow with the Division of Epidemiology and Clinical Applications of NHLBI.

Reflecting on his achievement, Dr. Shaffer said, “This has been a remarkable experience. The TPCR goals of providing formal training in quantitative and methodological principles of clinical research have been exceeded. Not only am I better prepared to conduct clinical research, I feel I’m a better clinician as well.”

See **graduate**, page five

## ...Family Lodge project moves forward

continued from page one

because I didn't want her to stay alone in a hotel," Paula said.

To help prevent such situations, the Clinical Center is working diligently with the Foundation for the National Institutes of Health and private donors to bring a Family Lodge to campus.

"The NIH Family Lodge will provide housing for the families and loved ones of Clinical Research Center adult inpatients," said CC Director Dr. John Gallin.

The goal is to build a 35-unit facility with a comfortable, homelike atmosphere, common areas for recreation and relaxation, and a telecommuting center, which would allow family members to keep in touch with their jobs or family back home. Individual units will have a bedroom, sitting room, and possibly a kitchenette.

The concept has two NIH precedents: the Children's Inn and the pilot NIH Guest House, which opened in 1996 in the old Apartment House (Bldg. 20). With the demolition in 1998 of Bldg. 20 to make way for the new Clinical Research Center (CRC), the 6-unit Guest House moved to a nearby apartment building on Battery Lane in Bethesda. As nice as that facility is, it doesn't provide quite the added convenience to families that planners feel is crucial to its mission.

The proposed site for the new Family Lodge is an area between the

Clinical Center and the Cloister. "We want to make it easy for caregivers to walk back and forth between the Lodge and the CRC so that they can get respite when needed, and get quickly back to the CRC to be with their loved one," said Jan Weymouth, project manager. "We also hope the Lodge will provide a setting where caregivers can meet and interact with others who are going through a similar event."

Emma agrees that proximity to the CC is crucial. "There were nights when I would have opted to stay with [Jane] in her room, but when that was not possible, a lodge just across the street would have been wonderful. Also, in this part of the country sometimes the weather makes it difficult to get to the hospital even if you're staying a few miles away."

Private funds built the Children's Inn, and a similar arrangement is in the works for the Family Lodge. Dr. Constance Battle is the executive director of the Foundation for the National Institutes of Health, the organization tasked with raising the estimated \$9 million to design and construct the facility. The Foundation was created by Congress to provide support in areas not traditionally funded by the government.

Half of the projected funds have already been raised thanks to gifts of \$1.5 million each from The Merck Foundation, Bristol-Myers Squibb Foundation, and Glaxo Wellcome, Inc., according to Dr. Battle.

A sick child's need to be near his

or her parents makes a poignant fundraising pitch. But, Dr. Battle points out, "90 percent of the patients at the Clinical Center are adults. They have the very same family-centered needs that children have. While any family member is receiving medical treatment, there is a great deal of stress on other family members to be present with the patient and to support them, yet meet the home obligations and their own needs as well."

Emma agrees. "A lodge would be very important because it gives the caregiver a chance to rest emotionally and physically so they can give the best care they possibly can for their loved one."

Although Emma was happy to help her sister through her illness, "it was very tiring, very draining emotionally. There were a lot of tears and questions and mixed emotions. It was financially challenging to be there every time. A family lodge would relieve not only the financial strain of trying to find a place to stay, but also some of the emotional strain, because [where to stay] is just one more question, one more problem to deal with. If you can eliminate that from the pile of other worries, that's one burden less."

According to Dr. Gallin, "The Family Lodge will also provide transitional housing for patients and their family caregivers after hospital discharge while they are learning the skills needed to sustain care at home.

continued on page eight

Clinical Center  
**News**

Editor: Sue Kendall

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## Take child to work

“Take Your Child to Work Day” is April 27. The NIH purpose is to introduce school children to the vital public services their parents provide and to encourage children to consider careers in medical research and the many supporting career fields. With supervisor approval, employees are encouraged to bring their children, ages 8 to 15, to participate in the planned events from 9 a.m. to 4 p.m. Activities include hands-on labs, workshops, and demonstrations. Preregistration is required for some activities. Parents should accompany their children to all activities. Contact Gary Morin at 6-4628 to request reasonable accommodations. Check the website at <http://www.cc.nih.gov/ccc/work/2000.html> for the current list of events. For more information, contact Brenda Robertson at 3-0913 or Joyce Starks at 2-6068.

## “CC News” online

Just a reminder that “Clinical Center News” is available online at <http://www.cc.nih.gov/ccc/ccnews/current/>.

## Healthier snacks

Looking for a healthier way to snack? Premiering this month will be healthier food choices in vending machines in the 2nd floor cafeteria. The machines, located on a wall visible from the cash registers, will be available 24 hours a day for a 3-month trial basis. Machines will offer fruit juices and water, coffee/cappuccino, yogurt, microwave items, including soups, dinners, and health entrees. But not to fret, in case you

have a junk food attack, chips, sodas, cookies, and candy will still be available in the vending machines near the back entrance of the cafeteria. The new vending machines are brought to you by the CC Quality of Worklife Council, the Nurses Retention Team, and the Wellness Subgroup.

## Construction info

Construction got you confused? If you need help figuring out what’s going on with the new Clinical Research Center, and why it’s happening, check out the following website for the latest information and photos: <http://www.cc.nih.gov/ccc/crcnews/updates.html>.

## “Protomechanics” available

The third edition of “Protomechanics: A Guide to Preparing and Conducting a Clinical Research Study” is available from Clinical Center Communications, 6-2563, or on the web at <http://www.cc.nih.gov/ccc/>

## Brain study

NIMH researchers seek children ages 6–13 years for a study of how the brain controls finger movements. Children may be healthy volunteers or those with a diagnosis of Attention Deficit and Hyperactivity Disorder (ADHD). The study takes 3 hours and involves a neurological examination, ADHD assessment, and noninvasive tests. Compensation provided. Call Dr. Marjorie Garvey at 6-5323 for details.

## “Change” class

The Education and Training Section of OHRM presents “Managing Change,” May 31 from 9 a.m. to 4 p.m., at 6100 Executive Blvd., Suite 3E01. Presenter Synde Kalet will teach you how to react positively and professionally when change is thrust upon you, find the hidden opportunities in even the most unwelcome exchange, and go from “panic” to “plan” within minutes of hearing unexpected news. Call 6-1618 to register.

## Stutter study

NINDS seeks adults and children age 5 or older who stutter or have familial speech disorders for an experimental study of the causes of speech disorders. The study includes speech, voice, and language testing. There are no study-related costs to participants, and NIH provides payment for those who take part. For details, call 1-800-411-1222.

## Sleep study

NIMH researchers seek male and female volunteers, ages 20–35, who routinely sleep 9 hours or more per night or 6 hours or less per night. (Employees of NIMH are ineligible for participation.) Volunteers must have no sleep disturbances or insomnia, no history of mental illness, and be in good general health and not taking any medications or birth control pills. The study requires a 4-day stay on the research unit. Compensation is available. For details call 6-5831.

## Volunteers break down language barriers

Imagine being a sick little boy in a place where nobody spoke your language and you didn't speak theirs. It could be pretty scary.

But then, someone finally shows up who does speak your language. And suddenly you aren't so scared anymore.

This situation is commonplace at the Clinical Center. And the people who make it happen are the volunteer language interpreters.

Andrea Rander, director, Volunteer Services and Language Interpreters Program, recalls one such volunteer, Gerti Tashko, a premed student at the University of Maryland.

"He called me to see if there were any lab placements available. I said I didn't have anything at the moment. He then asked me if I needed a volunteer who spoke Albanian. I couldn't believe it, because just the day before, I'd had a request for an interpreter for an Albanian boy who spoke absolutely no English. It was like a miracle. Gerti was so valuable to the patient and his family. He worked with them during his summer break, and he even worked with another volunteer, a former teacher, to help the boy with his education."

Two more volunteer interpreters recently joined the CC. Amina Gaber is from Egypt. She speaks Arabic and some French. She's new to the area, having moved here from Michigan with her husband, who works here. She picked up "CCNews" to learn more about the place, saw a piece about interpreting, and contacted Rander.

"I am enjoying it to the utmost," she said. "I'm glad that I'm helping people as much as I can." Gaber is also helping out in the Patient Representative Office.

Some of the Clinical Center's volunteers. From left to right, Anne Belton, Harry Canter, Susan Stevens, and Josephine Diur.



Josephine Diur is from the Democratic Republic of Congo, and speaks French and Swahili. She also helps out in the Rehabilitation Medicine Department. Asked why she volunteers, she replied, "This country has given me a lot and helped me a lot. Now I want to give back."

Interpreting is just one of many ways volunteers give of their time. Anne Belton, a retired teacher, started at the CC last fall. She is one of the Hospitality Services Program volunteers who greet and assist newcomers to the hospital. She decided to volunteer after a visit to the CC with a group of patients. "I was extremely impressed by the caring and sensitive staff. What I see now is what I saw then. The people are wonderful and friendly, and I meet people from all over. I love it."

Susan Stevens has been volunteering Mondays and Fridays for about a year. She brings an assortment of magazines to patients' rooms. "It is very rewarding to me because I have that one-on-one relationship with some of the patients," she said. "Some start a conversation,

some don't. I'm there to talk to and provide companionship if I am asked." She also helps out with paperwork in one of the clinics.

Harry Canter is a fixture around the CC. He volunteers almost every day, and he and his wife Floride run the flower shop. He has been with NIH since 1951 and worked as a biologist for NCI. He retired in 1993, but couldn't stay away from the place; after all, his wife chairs the Red Cross volunteer desk. He also pitches in wherever and whenever he's needed, from assisting with lecture receptions, or checking audiovisual equipment in the auditorium, or proofreading a lecture agenda.

Why does he volunteer?

"It's not the money," he joked. "It's the fringe benefits. It's the nice people. I see a lot of friends from the old work days too. I thought I'd give a little back for what I got."

*National Volunteer Week is April 9-15. Take a moment to say "Thank you" to some of the dedicated people who give their time and talents to make the Clinical Center tick.*

*-by Sue Kendall*



## **After 20 years, volunteer retires**

Once the volunteer bug bites some people, they're hooked. Such is the case for Joan Uhrig.

She began volunteering at the Clinical Center in 1980, and has been here ever since. She spent most of her time with the Patient Representative office, but she feels the time has come to hang up that familiar red jacket and retire.

Uhrig, a native of New Zealand, began her career as a pediatric nurse. She traveled to jobs in Australia, England, and Canada. Then she and her husband came to the United States when he took a position with the World Bank. "We were supposed to stay 4 or 5 years, and that's turned into 35 years," she said.

Unable to work in the U.S. as a nurse because of different training requirements, she began to look for other meaningful work. That search led her to the Red Cross. They suggested she try volunteering at NIH.

At first, Uhrig provided support and assistance to families in the waiting rooms. She later joined the Patient Representative Office. "The Patient Representative service is very important," she said. "Families need that support. They really appreciate it."

Looking back on her years here, Uhrig says "What amazes me is the strength of the patients and families during what they go through. The nurses and people who work here are

## **...First graduate of NIH-Duke program**

continued from page one

The program, which began in 1998, is a collaboration between the Clinical Center and Duke University, in Durham, N.C. It uses distance-learning to strengthen training opportunities in clinical research. The program is designed primarily for clinical fellows and other health professionals training for careers in clinical research. Courses include research design, statistical analysis, health economics, research ethics, and research management. NIH participants complete coursework primarily through videoconferences with faculty at Duke. NIH staff teach other courses as Duke adjunct faculty.

Dr. Shaffer cites the dedication of the faculty as an important factor for the success of the program. "There was always consistent, unequivocal support here and in Durham. About halfway through the first semester, many in our group hit a point of overall uncertainty," he said. Anxious feelings centered on the magnitude of the commitment they had undertaken. "Our statistics instructor from Durham, Dr. Sandra Stinnett, came to Bethesda to meet with us not only as a group, but individually as well. That speaks to the quality and dedication behind this program." He says this same instructor would notice whenever the Bethesda group became too quiet during a lecture. "She could sense uncertainty on our end, and always quickly intervened."

special too—the families tell me that. Some people don't want to go back to their own hospital and doctors because they are treated like family here."

Laura Cearnal, head of the Patient Representative Office said of Uhrig, "Joan's work on behalf of CC patients and families has been a

The Duke University School of Medicine, which established its program in 1986, awards a Master of Health Sciences in Clinical Research for successful completion of the TPCR. The program can be completed in two 16-week semesters; participants typically spread course work over two years, an approach that Dr. Shaffer recommends. Due to time constraints related to his fellowship, he completed the coursework in one year. "It's not optimum," he said. "You need to think carefully about the best way to manage your time and complete your regular work as well." He recommends having a research project in mind before beginning the program, and he credits supportive mentors, Drs. Larry Friedman and Peter Savage, for allowing him flexibility in matching his work with his educational goals.

Unfortunately, Dr. Shaffer has to miss the formal commencement ceremony, to be held in Durham in May. But as he prepares to move on in his career, he said of the TPCR, "It was the highlight of my experience here. Was it hard? Yes. Bumpy? At times. However, it was well worth the effort."

*For details on this and other educational programs, consult the Clinical Center's web site at <http://www.cc.nih.gov>, and click on "Medical and Scientific Education."*

model of excellence in volunteer service. Her leadership and commitment have been outstanding. She will be missed."

Uhrig says she's leaving the door open to come back. But for now she looks forward to spending more time with her husband and her two Corgi dogs, Sam and Morgan.

## Roger Mack retires after 34 years with CC

It was in the spring of 1966 when Roger Mack first arrived at the Clinical Center, and the NIH Police still drove Studebaker cars, he recalls. Now, 34 years later, Mack looks forward to restoring a couple of Studebakers during his retirement, which began last month.

Mack joined the CC in the Inhalation Therapy Section of the Anesthesiology Department, and became section chief approximately one year later. Now called respiratory therapy, the specialty provides breathing support to patients. In the 1960's the specialty was relatively new.

Under Mack's leadership, the section grew from 3 to 13 people. He published articles in the "Journal of the American Association for Inhalation Therapy," and worked with scientists and inventors to develop respiratory therapy equipment, including a nebulizer used for patients with cystic fibrosis. He also was commended by the Joint Commission for his

voluminous and accurate chart documentation with the then new MIS system.

Mack was also one of the original members of the Disaster Medical Assistance Team (DMAT), which travels to disaster sites and pitches in with medical help and relief supplies.

When respiratory therapy was one of the areas set to be contracted out in the early 1980's, Mack left clinical care for administration. He became a hospital administrative officer (HAO), providing administrative support to the intensive care and mental health units. He received a special commendation from NHLBI for his contribution to the 1993 design and construction of the 2 West bone marrow transplantation unit. That project was one of the last he completed as an HAO.

The past few years have found Mack helping out the Materials Management Department, where his familiarity with medical equipment has been invaluable.



Roger Mack

In addition to restoring antique cars, Mack's plans for retirement might include a move to either Florida or to his wife's family farm in northwestern Pennsylvania.

Reflecting on his years at the CC, he said, "It's been a very productive and satisfying career. I've especially enjoyed the opportunity to work closely with patients, some of whom you see years later. They tell you how much they appreciated all you did for them, and that's a good feeling."

## Ed Davis retires after 23 years with CC

"I've seen miracles happen here," said Edward H. Davis of his 23-year career with the Clinical Center.

Davis retired in February and celebrated with friends and co-workers at a reception last month in the Visitor Information Center.

In 1977, after spending 22 years in the Army, Davis was hired as a respiratory therapist by Roger Mack (see story above). The two men then led roughly parallel careers and became good friends.

Davis, like Mack, was an original member of the Disaster Medical Assistance Team (DMAT), and also left respiratory therapy to pursue a career in hospital administration.

But his fondest memories are of

the care he was able to provide to CC patients. He recalls a patient from the 1970's who'd had open heart surgery and was on a ventilator while in a coma for about 8 months. Her mother said the rosary daily. The patient moved her eyelids one night while Davis was checking her ventilator. Soon after, she woke up completely. Davis saw her about 3 years ago in the CC cafeteria, and says she is now married and doing well.

But as medicine changed, so did the nature of care. Patient stays shortened, and computers took over some of the functions therapists performed.

Even during his years in administration, Davis would still see former patients, one of whom spoke at the



Edward H. Davis

groundbreaking ceremony for the Clinical Research Center.

For Davis, his second retirement still doesn't mean stopping work. He continues to work with DMAT, doing what he likes best: helping others.

## Radiology's Ron Norman retires

Ronald A. Norman, a technologist with the Computed Tomography (CT) Section of the Diagnostic Radiology Department, retires this month after almost 20 years with the Clinical Center. He joined the Radiology Department in October 1980. Prior to coming to NIH, he worked at Suburban Hospital for 20 years.

Norman arrived in the D.C. Metropolitan area in April 1958, where he served in the United States Army at Walter Reed Army Medical Center. Although he is a native Texan, he is a true Washington Redskins fan. He still holds a place in his heart for the Dallas Cowboys, as long as they are not playing the Redskins.

Norman is a team player who worked together with his colleagues to provide quality patient care in the CT scan section. He is widely admired by his peers. Arguably one

of his most significant accomplishments has been his almost perfect attendance record.

Norman has made an enormous contribution to NIH through the wonderful example he has provided to everyone he has come in contact with. He is an exceptionally bright, talented, friendly, and straightforward individual who truly cared for the patients and went out of his way to do everything possible for them.

His plans for retirement include a variety of activities. Recently he has become a member of the "Model T Club." One of his retirement goals is to restore his own Model T. He would also like to travel the world. When not traveling or working on his Model T, Norman will be spending lots of time with his grandchildren. His enthusiasm for baseball may lead him to return to coaching Little League baseball.



Ronald A. Norman

Ron's sincerity, compassion, and friendship will be missed by all.

—by Nina Carter

*Nina Carter is a colleague and friend of Ron Norman.*

## CC'ers take part in diversity conference

A DHHS Conference on Diversity was held on March 1 and 2, at the Hubert Humphrey Building, downtown. The Clinical Center, along with other IC's at NIH and other Operational Divisions within DHHS, nominated staff to attend this conference. Pictured are CC participants: Standing, left to right, Rona Buchbinder, Walter Jones, and Deborah Gardner. Seated, left to right, Jerry Garmany, Adrienne Farrar, and Nicole Butler.

Kevin Thurm, deputy secretary of DHHS, and the DHHS Union-Management Partnership Council, composed of senior managers and union representatives, provide oversight for the quality-of-worklife programs within DHHS. One quality-of-worklife initiative is to improve man-



agement of diversity across DHHS, with the specific objective of making diversity a source of performance excellence.

The Conference on Diversity in the Workplace was one step in this initiative. The goals of the conference

were to develop a vision for DHHS diversity as a source of equity, inclusion, and performance excellence, and to make recommendations to achieve that vision.

—by Nicole Butler

If space is available, patients who travel to NIH from long distances, but do not require hospitalization (and their families) may use the facility.”

That feature would be a big help to a patient such as Paula, who stays with a cousin during visits that don't require an inpatient admission.

“It is too hard to get [to NIH] from Alexandria at 7:30 in the morning without a car,” she said. On her last visit, she stayed in a nearby

hotel, but reimbursement only covered half the hotel fee. “A family lodge would be really nice.”

The project is a priority, and fundraising efforts are in high gear. The Foundation has released some funds to begin the design process. Several architectural firms will present their design concepts and qualifications this month.

“We'll be talking to patients and their families and the medical team to get as many ideas as possible for

the Lodge,” said Dr. Battle. “It's not a complicated building, but we want it to be right. We want it to be a soothing place of respite and be accessible to the hospital.”

*For further information on the Family Lodge project, contact Jan Weymouth at 6-2925. For information on fundraising efforts, contact Dr. Battle at 2-5311.*

—by Sue Kendall

## a p r i l

**5** **Ethics Grand Rounds**  
noon - 1 p.m.  
Lipsett Amphitheater

*Disclosing Life-threatening Diagnosis to Minors: Who Should Decide?* Ronald Bayer, Ph.D., Columbia University, New York, guest discussant; Lauren Wood, M.D., NCI, presenter; Robert Wittes, M.D., NCI, moderator

**Wednesday Afternoon**  
**Lecture**  
3 p.m.  
Masur Auditorium

*Protein Localization and Cell Differentiation During the Cell Cycle*, Lucy Shapiro, Ph.D., Stanford University School of Medicine

**12** **Grand Rounds**  
noon - 1 p.m.  
Lipsett Amphitheater

*Bench to Bedside: Treatment of Leukemia With Recombinant Immunotoxins*, Ira Pastan, M.D., NCI; Robert J. Kreitman, M.D., NCI

**Wednesday Afternoon**  
**Lecture**  
3 p.m.  
Masur Auditorium

*New Technology as a Two-Edged Sword: Bone Densitometry and Prevention of Osteoporotic Fractures*, Steven R. Cummings, M.D., University of California, San Francisco

**19** **Grand Rounds**  
noon - 1 p.m.  
Lipsett Amphitheater

*Birt-Hogg-Dube Syndrome: A Novel Marker of Kidney Neoplasia*, Jorge R. Toro, M.D., NIAMS

*Endocrine Secretion from an Exocrine Gland: Harnessing a “Minor” Physiological Pathway for Gene Therapeutics*, Bruce Baum, M.D., Ph.D., NIDCR

**Wednesday Afternoon**  
**Lecture**  
3 p.m.  
Masur Auditorium

*A Fibronectin-FAK Signaling Axis: How Special Is It?* Caroline H. Damsky, Ph.D., University of California, San Francisco

**26** **Clinical Staff Conference**  
noon - 1 p.m.  
Lipsett Amphitheater

*Paying Research Subjects*, Christine Grady, Ph.D., CC, moderator

**Wednesday Afternoon**  
**Lecture**  
3 p.m.  
Masur Auditorium

*Cancer Cytogenetics: Is It Passé?* Janet D. Rowley, M.D., D.Sc., University of Chicago

**28** **Clinical Center RoundTable**  
noon - 1 p.m.  
Lipsett Amphitheater

*MRI in the ER*, Robert Balaban, M.D., NHLBI, panel leader; Steven Warach, M.D., NINDS; Andrew Arai, M.D., NHLBI; Wayne Olan, M.D., Suburban Hospital, panelists

*A live broadcast featuring physicians and scientists from NIH and other prestigious institutions discussing current research activities and issues in depth.*