July 2011

Clinical Center

In this issue:
MIS celebrates 35th anniversary
Baron presents Decker Lecture
NIH Races for the Cure

Recreation Therapy Section celebrates 50th anniversary

The Clinical Center Rehabilitation Medicine Department's Recreation Therapy Section celebrated a milestone in May. The section, which has known several different names during its tenure, celebrated its 50th anniversary this year.

Celebrations included a visit from the section's first ever employee and supervisor Arnold Sperling. Sperling recalled his 14th floor space in the Magnuson Center, prior to the Hatfield Building's construction, and his work establishing relationships with nurses and social workers to spread the word about recreation therapy and how it benefits patients. According to Sperling, the typical stay for patients was much longer during his time as supervisor. "I realized that a happy patient was a good research volunteer," he said.

The Recreation Therapy Section will continue the celebration of its anniversary during National Therapeutic Recreation Week July 10-16. The section has planned a larger reunion with previous staff members from the last half century to help celebrate this milestone.

Therapeutic intervention

For the past 50 years, the Recreation Therapy Section has worked to help patients cope with the stress of hospitalization, function at their highest possible level, and maintain their quality of life through interventional treatment and recreational activities. The section currently offers general recreation drop-in programs open to all patients and their families and guests, as well as individualized treatment plans which requires an order from the patient's doctor. The therapeutic recreation offered by the section involves an evaluation of the

continued on page 4



Project SEARCH interns and their mentors marked the interns' graduation and successful completion of the program in June. The group included (from left) Adam Russell; Donna Scott-Harper, Pharmacy Department technician; Amethyst Thornton; Aamer Khan; and Jim Schlick, Pharmacy Department Inpatient Section chief

NIH and Project SEARCH celebrate successful pilot with intern graduation

Interns, family members, mentors, staff, and administrative partners gathered to celebrate the graduation of 12 important Clinical Center community members in June.

The graduation honored the success of the NIH-Project SEARCH interns who completed a 30-week unpaid internship in various departments throughout the CC. The internship was offered in collaboration with Project SEARCH, an international organization that works with hospitals and businesses to provide employment opportunities and experience for young adults with disabilities; the lyymount School's Post High School Program, a communityfocused life skills program that prepares students ages 18-21 for a successful transition from school to employment and adult life; and SEEC, a local nonprofit that provides community-based employment support to transitioning youth and adults.

During the 30-week pilot, lyymount and SEEC's on-site staff members provided personalized vocational support for the

interns and were instrumental in dealing with challenges and creating a positive environment.

"I can't tell the graduates and their families how privileged we feel that we have been able to get to know these graduates on a personal basis and to really see the work that you've all accomplished," said CC Director Dr. John I. Gallin at the ceremony. "It has really enriched the Clinical Center. It's made the Clinical Center a better place, operationally and as a community."

This is the first Project SEARCH internship program for CC. It launched last year as a pilot under the management of Denise Ford, chief of Hospitality Services, and as part of the CC Volunteer Program. Ford said the program isn't about just getting interns jobs; it is about starting their careers.

"They came to us with a yearning for independence, for the opportunity to work and to work hard ... With all of our

continued on page 3

Group of emergency physicians visit CC

During a recent trip to the nation's capitol, members of the American College of Emergency Physicians (ACEP) visited the Clinical Center to learn more about NIH, the clinical research hospital, and the CC's sabbatical in clinical research management.

The CC Office of Clinical Research Training and Medical Education (OCRT-ME) hosted the group on May 25. The 25 attendees came from across the United States and included practicing emergency physicians and residents, and medical students interested in emergency medicine careers.

The visitors met with Dr. Lawrence Tabak, NIH principal deputy director, and Dr. John I. Gallin, CC director, to discuss future directions in clinical and translational research. The group also learned about the bedside electronic medical record recently implemented in the intensive care unit. Dr. Patricia Sengstack, CC deputy chief information officer, described the new system.

ACEP members heard more about the sabbatical in clinical research management, a program open to experienced physicians, other health-care providers, and hospital administrators seeking additional knowledge and experience in the skills necessary to lead a clinical research enterprise.

Dr. Sandra Schneider from the University of Rochester and current ACEP president, as well as future sabbatical participant, led the visiting group. This was the first CC visit for Schneider since being accepted into the sabbatical program earlier this year. She will begin at the CC in February 2012 and plans to focus on fostering the development of emergency care research networks.

For more information on the sabbatical and other training programs offered by the CC, visit the OCRTME website at http://clinicalcenter.nih.gov/training/ index.html.



CC patients and budding professional musicians Bennett and Mina Burnside performed a set of instrumental jazz, funk, and folk to listeners in the atirum in June.

CC patients bring jazz to the atrium

Brother and sister duo and Clinical Center patients Bennett and Mina Burnside brought a delightful variation to the typical atrium concert fare in June when they performed a set of instrumental jazz, funk, and folk music as part of the CC Concert Series.

The Burnsides have been patients at the CC for more than 13 years, and as they played their sound check their mother Jeni Burnside recalled watching them run down the halls as toddlers. "I am so happy they had the opportunity to do this," she said.

The pair has been playing music together since 2005, and while both young adults play a variety of different instruments, Bennett performed on the guitar and Mina on the bass.

The pair has already started making

names for themselves within the music industry. Bennett, at age 17, has written songs for use in computer games and hopes to write music for movies, television shows, and radio as well.

Fifteen-year-old Mina was recently chosen to be one of nine teenage "Got Milk?" spokespersons, and will be pictured in an advertisement in Seventeen magazine in September.

In addition to playing with each other, they each perform with a variety of bands and other musical groups in their hometown of Nashville.

Bennett and Mina attend the Nashville School of the Arts and regularly perform at local music venues in Nashville. They hope to study music in the future.

Clinical Center News online:

www.cc.nih.gov/about/news/newsletter.html

Nicole Martino, editor

Clinical Center News National Institutes of Health **Department of Health and Human Services** Building 10, 10 Center Drive, Room 12C440 Bethesda, MD 20892-1504

Tel: 301-496-6787 Fax: 301-480-2984

Published monthly for Clinical Center employees by the Office of Communications, Patient Recruit-

photos are welcome.

Submissions may be edited.

NIH-Project SEARCH interns graduate from 30-week program

continued from page 1

partners, we put together this opportunity for the interns to succeed in this transitional school-to-workplace training," Ford said. "We put the opportunity out there, but they stepped up and seized the opportunity. That is what made this successful.'

New graduate Ricky Day, who worked in Hospitality Services, said his internship was challenging yet rewarding. "We really earned it every day," he said.

Rebecca VanGilder, the interns' instructor, explained that the NIH-Project SEARCH team tried to challenge and encourage the young adults by placing shy, reserved interns in social or verbal roles to teach communication skills and by placing outgoing individuals in calm environments to teach professional discipline and appropriate workplace behaviors.

"There are not enough words to describe the immense growth that each intern experienced because they were treated as any other employee here at the Clinical Center," she said. VanGilder saw both the interns and the CC community grow throughout the program's term. "I think we all see that much more than any disability, these young adults have unique abilities that exceed what someone else could do or provide," she said.

Eight of the new graduates will go on to fill permanent positions within the CC. All will take away career skills, though, such as how to use public transportation and how to use aids like an alarm to remember appointments.

Chauncey Buford, a supervisor in the Housekeeping and Fabric Care Department, worked with intern Chane Wade-Goodwin for the entire 30-week internship and was excited for the opportunity to help Chane build skills of all kinds. "Since the beginning of the program I think Chane is more positive. He went from being unsure to sure. He built confidence and started talking about his ambitions."

According to Steve Blanks, director of vocational and day supports at SEEC and part of the NIH-Project SEARCH team, similar initiatives in other organizations do not have such a high success rate. "For eight out of 12 students to be hired, that is an unbelievable success," he said. "These guys have learned new

I can't tell the graduates and their families how privileged we feel that we have been able to get to know these graduates ... It's made the Clinical Center a better place, operationally and as a community.

- Dr. John I. Gallin, Clinical Center director

skills, met new friends, and learned things that they will carry with them for the rest of their lives."

Ford said she hopes to continue the program next year and expand it to

other NIH institutes and centers, embracing the president's goal of increasing the employment rate of workers with disabilities.

Ford added, "They have opened people's minds to look beyond the wheelchair—past the appearance of the physical disability— to see that bright young person who can contribute in an extremely meaningful way to the mission of the NIH."

The interns were: Crystal Battle, Ashton Bell, Van Berg, Ricky

Day, Scott Gladstone, Justin Haynes, Aamer Khan, Alex Lightfoot, Adam Russell, Lindsey Schaufelberger, Amethyst Thornton, and Chane Wade-Goodwin.



Maureen Gormley, CC chief operating officer, and Dr. John I. Gallin, CC director, congratulated the Project SEARCH interns, including Ricky Day.



The 1SE patio was filled with cheers of congratulations from families, coworkers, and friends for the 12 NIH-Project SEARCH interns who graduated on June 10 after 30 weeks spent in various CC departments

Recreation Therapy Section celebrates a half decade milestone

continued from page 1

patient's physical, cognitive, behavioral, social, and emotional domains and treatment through a variety of modalities, like engaging a pediatric patient in medical play or using other meaningful activities to achieve functional outcomes.

"We want our patients and their families to have a well balanced experience while they are here, and to the extent possible, support and enhance their quality of life," said Donna Gregory, chief of the Recreation Therapy Section.

Members of her team work with patients to understand what is of meaning to them, access available resources, and utilize therapeutic interventions to accomplish the patient's goals.

Sometimes an illness might affect a patient's ability to participate in meaningful activities. "In that case, the recreation therapist would establish a treatment plan focused on functional improvement, use of adapted equipment, or modifying the activity so that the patient has the opportunity to participate and can continue to enjoy it," said Gregory. "For example, if a patient has balance problems and they love to golf, we would have them swing a golf club or play wii golf as a way to address that functional goal," she said.

Immediately upon his arrival to the United States from Jordan, CC patient Mohammad Akramawi was impressed with American food. Akramawi and his recreation therapist Emily Lawrence have swapped stories about the best burgers and milk shakes in town, and in June—22 days into his stay at the CC-Lawrence brought a special surprise to their session together.

On a visit with a friend before checking in to the CC as an inpatient, Akramawi watched a server make fresh guacamole at a restaurant and was immediately hooked. He even explained the ingredients to his mother in Jordan over the phone so that she too could share the experience of this new, delicious food. When Akramawi reported a craving and the desire to try the recipe himself, Lawrence brought everything they could need to make the tasty dip together as a team.

They collaborated in deciding best proportions of each ingredient, and what they thought would taste the best.

Although Akramawi's illness prohibited him from making the movement

necessary to cut the vegetables, Lawrence did the chopping and Akramawi helped stir and gave her directions.

Akramawi was thrilled with the opportunity to make quacamole with Lawrence. "She is the one who puts the smile on my face all the time," he said. He expressed hope for the future as a result of his recreation therapy sessions with Lawrence. "I am not here just to finish my treatment," he said. "When I arrived here, my life started."

Welcoming new playmates

In addition to celebrating 50 years at the CC in May, the Recreation Therapy Section also celebrated the addition of four new playmates to the Main Playroom: guinea pigs Twix, Oreo, Kit Kat, and Peanut.

According to Karen Perkins, a

Recreation Therapy Section supervisor, interaction with the guinea pigs can be an important motivation tool for patients in rehabilitation. She recalled a time when a young child with cerebral palsy whose goal was to increase the amount of time she could stand apart from her walker was motivated to stand while interacting with the guinea pig and a recreation therapist.

"When interacting with the guinea pigs, children with behavioral health issues have the opportunity to practice impulse control, planning, and decision-making skills," Perkins added.

She also explained that when the section's last guinea pig began to show signs of illness, the children could relate to her

CC patient Mohammad Akramawi and his recreation therapist Emily Lawrence made Akramawi's favorite, guacamole, at their last session together.



cine Department's Recreation Therapy Section team: Peanut and Twix, two of the section's four new guinea pigs.

hair loss and experience with veterinary tests. "The children told her about similar medical tests they had experienced explaining what would happen to her and attempting to calm the guinea pig's imagined fears and concerns about medical procedures," Perkins said.

The guinea pigs were named by the CC's pediatric patients. They could nominate a set of names for the four new members of the team, and then voted for the names that they liked the best. Twix, Oreo, Kit Kat, and Peanuts are available for patients, their siblings, and children of patients to visit in the Main Playroom, Monday through Friday from 10 am-12 noon and 1-3 pm.

Decker Lecture addresses childhood growth and development

The Eighth Annual John Laws Decker Memorial Lecture on June 8 highlighted the work of Dr. Jeffrey Baron, chief of the National Institute of Child Health and Human Development's Section on Growth and Development.

Baron, who was chosen as the recipient of the NIH Fellows Committee's 2010 Distinguished Clinical Teacher Award, presented the lecture titled "Childhood Growth: New Concepts, New Treatments."

The annual lecture honors the legacy of former CC Director Dr. John Laws Decker, who died in 2000. He served as director of the CC and as NIH associate director for clinical care from 1983 until 1990, after which he was named scientist emeritus.

Among the major advances that occurred during his tenure are the development of the PET program, the clinical use of MRI, and the introduction of the CC's popular arts program. Decker's children, Dr. Megan Molaro and David Decker, and

> his grandson Ian attended the lecture.

Baron presented his research on the cellular and molecular mechanisms governing childhood growth and development, how to use these factors to understand childhood growth failure, and current and potential treatments.

Prior to his lecture he recognized the fellows in the



Dr. Jeffrey Baron, chief of the NICHD's Section on Growth and Development and recipient of the 2010 Distinguished Clinical Teacher Award

pediatric endocrinology training program who nominated him. "It is one of the great pleasures of this job, to teach you, to learn with you, and to take care of patients together," said Baron.

A videocast of Baron's lecture is available in the Grand Rounds archives at http://videocast.nih.gov.

ter) at Decker's namesake lecture on June 8. In attendance were (from left) Decker's son-in-law James Malaro, daughter Dr. Megan Malaro, daughter-inlaw Lisa Greenlees, son David Decker, and grandson lan.

Faces around the CC: Student gains experience and insight

Clinical research relies on informed decisions. Andrew Richardson, a student employee with Nursing and Patient Care Services, makes life choices with the same thoughtful approach.

Originally pursuing a career in information technology, Richardson began to question his career choice. He spoke with professionals in the field and professionals in health care, which he always had an interest in. Richardson decided medicine was a more stable and long-lasting choice, so he redirected his studies. He is now a pre-nursing major at Montgomery County Community

With no experience in health care, Richardson turned to the NIH, which he knew about from previous technology work with other federal agencies. He searched for opportunities for students and found the Student Temporary Experience Program that gives students' valuable work experience while they finish their education.

"I hope to leave here with my head



CC Nursing and Care Services

full. Experience is the best teacher," Richardson said.

He serves as an assistant to Dr. Cheryl Fisher, director of professional development in NPCS, full-time during the summer and about 24 hours a week around his class schedule during the school year.

One of his favorite experiences was observing patient care while collecting data on the intensive care unit around use of the new bedside electronic health records. For more insight into health care, Richardson participated in clinical studies himself as a healthy volunteer and approached nurses for informational interviews.

"Having a student in the office like Andrew is a win-win situation. We continuously think of educational opportunities to expose our students to, while having the benefit of them providing administrative and research support for the office," Fisher said. "Andrew is energetic and eager to learn, which he will find is certainly to his benefit in the future."

Richardson appreciates how welcoming and helpful the Clinical Center staff have been. "No one is selfish with what they know. Knowledge is abundant and accessible," he said. While he knows he wants to be a registered nurse. Richardson does not yet have a specialty in mind. "I'm not going to rush it."

News briefs

Conference addresses using innovative technology

Clinical Center staff members are invited to join colleagues from the Clinical and Translational Science Award institutions to explore the dynamic intersection of community engagement and health information technology in August.

On August 30-31 the Duke Translational Medicine Institute will present "Using IT to Improve Community Health: How Health Care Reform Supports Innovation." The conference, which is funded by the NIH's National Center for Research Resources, will be held at the Bethesda North Marriott Hotel and Conference Center.

Leading health information and technology specialists and community engagement experts will discuss the latest successes in applying IT to community health at the federal, state, and local levels, including patient portals such as those used at the CC.

For more information, visit www. dtmi.duke.edu/ce-workshop or contact Barbara Gregory at barbara.gregory@duke.edu.

NIDA presents on addiction

On August 5 the National Institute of Drug Abuse will present the Addiction Performance Project in Lipsett Amphitheater from 10-11 am.

NIDA launched this free CME program to help break down the stigma associated with addiction and provide a forum for health-care professionals to discuss challenges in and strategies for addressing this issue in their practices.

The program will include an expert panel with Dr. Nora Volkow, NIDA director; and a dramatic reading of Act III of Eugene O'Neill's Long Day's Journey into Night featuring Debra Winger and Arliss Howard.

This event is free and open to the public. Registration is recommended. Visit www.drugabuse.gov/nidamed/ app or email nidamed@nida.nih.gov for more information.



Friends of the CC dedicate new display

The Friends of the Clinical Center unveiled a new display in Admissions on the first floor of the Hatfield Building on June 9. The display honors CC patient Patrick Harris and also recognizes the volunteers, sponsors, and other donors who support the CC and its patients and their family members. The FOCC is a private, nonprofit, charitable organization.

In his remarks, FOCC board member Jeff Vigne described what he believes is the wonderful thing about supporting the CC's patients and their families. "It is an investment not only into an individual's life, but it is also an investment into the good work of clinical trials for all of our lives," he said. "Every day progress is made, it not only benefits the individual, but it benefits all of us."

MIS celebrates 35th anniversary

The Clinical Center celebrated the 35th anniversary of the launch of the center's first computerized hospital information system on June 14.

The day marks the first time the medical information system, known as the MIS, began live installation in 1976.

"You would order in one system and results would come back in one system. That was a very new idea at that time," said Dr. Jon McKeeby, CC chief information officer.

The MIS was a pioneer in the use of this type of technology. At the time, less than 10 hospitals in the country had some kind of medical information system and the MIS was the first applied to clinical research.

The system enabled CC staff and physicians to collect, transmit, and store information about patients quickly and efficiently. It's capabilities included complete physician order entry, results reporting, medication administration tracking, and nursing documentation at a time when few facilities had computerized order entry at all. At the CC by the 1980s, 90 percent

of computerized orders were entered by the physicians themselves, McKeeby said.

"We needed one master system that could communicate with other systems around the Clinical Center," said Gerald Macks, a now-retired management analyst and one of the overseers of the original project. "It still seems pertinent to stop for a minute to contemplate how far we all have come since that memorable day."

Macks explained what he found most significant on this anniversary, "A nurse reporting for duty on 5-West on June 14 in 1976 potentially could work for 30 years, an entire career, and retire never having to deal with a manual system," he said.

To keep up with evolving technology, the Department of Clinical Research Informatics began planning for the replacement of the MIS with the current system, the Clinical Research Information System (CRIS) which launched in 2004.

Patient advocate and nurse leader retires

After 50 years of nursing and more than 25 years at the Clinical Center, 7SE clinical nurse manager Sybil Barnaby will retire in July. Friends, family, and current and former staff members gathered to celebrate Barnaby's contribution to the CC at a special event on June 22.

Barnaby's colleague from 7SE Roger Brenholtz was met with laughter when he announced, "We decided that the



Dr. Clare Hastings (center) and Tannia Cartledge (right) congratulated 7SE clinical nurse manager Sybil Barnaby on her retirement.

best way to do this is to use a format that we are familiar with, and that is a community meeting." The celebration mimicked the same sort of discharge planning meetings Barnaby and her team use for patients when they are leaving the CC. "We are discharging you after over 28 years of research," he said. At the meeting, many individuals spoke, thanking Barnaby for her guidance and direction as a mentor, something she said came naturally to her.

"Anyone who wants to be a leader can look to Sybil, and learn how to be a leader both as a nurse and as a patient advocate," said Dr. Clare Hastings, CC chief nursing

Although Barnaby reports that she will miss her colleagues and patients greatly, she is looking forward to playing piano, gardening, and spending time with her husband and her new Pomeranian puppy named Bing.

Volunteers bring flowers to the courtyards



A group of volunteers brought May flowers to the Clinical Center's courtyards on May 21. Helping out were (top row, from left) Elizabeth Sweet, Bekah Geiger, Dr. David Henderson, Peter Cramer, Debby Haynes, Gregory Holcombe, Lynn Mueller, (seated, from left) Dr. John I. Gallin, Mengfei

The group spent the Saturday afternoon planting more than 20 flats of impatient flowers and several perennial daylilies in the healing gardens. These new flowers will bring vibrant color and beautiful flowers to the courtyards themselves as well as the view from the patient rooms with windows that overlook the gardens.

CC loses employee

Ann McNemar, a nurse consultant in the Department of Clinical Research Informatics, former pediatric nurse, and longtime federal employee, passed away on June 25. McNemar, 66, died after a fall at her home.

McNemar began working in her most recent position in the DCRI in 2001, and Dr. Jon McKeeby, CC chief information officer, reported that she was essential to the design, planning, and development of clinical documentation within the clinical research information system. "She provided vision, knowledge, and skill to her work and friendship and compassion to her colleagues," McKeeby said.

A native of Wilmington, Ohio, McNemar received her bachelor's of science from the University of Cincinnati College of Nursing in 1967, and earned a master's degree in pediatric nursing from the University of Pittsburgh in 1970. She was a pediatric nurse at the CC for more than 25 years and was honored for 40 years of government service in May 2011.

McNemar took pleasure in her involvement within the equestrian world. She enjoyed riding her beloved horse "Barbie;" working as a volunteer scorer at many horse events, including the Olympics in Atlanta in 1996; and sharing the fun and fellowship of her fellow equestrians.

McNemar's life was celebrated at the CC's chapel on June 22.

Help the CC go green!

The Clinical Center Green Team is developing new strategies to help our community become more environmentally friendly. Have you noticed a way in which the CC could be a better environmental steward? Do you have a bright idea that could help the CC go green? Let the CC Green Team know! Email your green ideas to:

ccgreenteam@mail.nih.gov.

Teams NIH and USPHS race for the cure

NIH staff members and their families met on the National Mall on June 4 to walk and run in support of breast cancer research. The five-kilometer Susan G. Komen Global Race for the Cure united survivors and activists on a sunny summer dav.

This year, US Public Health Service officers also joined together to form the team PHS Races for the Cure. The team consisted of 46 officers, coworkers, as well as family and friends. RADM Christopher Halliday, chief of staff of the Office of the Surgeon General, attended the event in support of the team.

PHS Races for the Cure raised more than \$3,000 and were honored as the top fundraiser team in the US government agency division.

Team captains LCDR Jill Hammond and LCDR Shayna Wilborn began organizing the event in March. CDR Vicky Borders-Hemphill, LCDR Latonia Ford, LCDR Aline Moukhtara, and LCDR Loan Nguyen rounded out the planning committee.





The US Public Health Service officers team, including many CC employees and their families, was the top fundraiser in the US government agency division at the Global Race for the Cure on June 4.

NEW CLINICAL RESEARCH PROTOCOLS

The following new clinical research protocols were approved in May:

- The Natural History of Liver Disease in a Cohort of Participants with Hepatitis B and/or Hepatitis C with or without HIV Infection; 11-CC-0152; Dr. Shyamasundaran Kottilil; CC
- A Pilot Study of Pentostatin Plus Cyclophosphamide Immune Depletion to Decrease Immunogenicity of SS1P in Patients with Mesothelioma; 11-C-0160; Dr. Raffit Hassan; NCI
- A Phase I/II Study of IL-15 Administration Following a Non-Myeloablative Lymphocyte Depleting Chemotherapy Regimen and Autologous Lymphocyte Transfer in Metastatic Melanoma; 11-C-0170; Dr. Steven A. Rosenberg; NCI
- A Phase 1 Study of the Mitogen Activated Protein Kinase Kinase (MEK) 1 Inhibitor AZD6244 Hydrogen Sulfate (Selumetinib Sulfate) in Children with Neurofibromatosis Type 1 (NF1) and Inoperable Plexiform Neurofibromas (PN); 11-C-0161; Dr. Brigitte C. Widemann;
- Phase II Study of Tumor Infiltrating Lymphocytes Generated with Engineered Cells for Costimulation Enhancement in Patients with Metastatic Following Lymphodepletion; 11-C-0163; Dr. Steven A. Rosenberg; NCI
- The Natural History of Ocular Graft-Versus Host Disease: 11-El-0173; Dr. Rachel J. Bishop; NEI
- Bisphosphonate Users Radiographic Characteristics of the Hip (BURCH) Study; 11-AR-0156; Dr. Michael M. Ward; NIAMS
- Effect of Functional Exercise in Patients with Spinal and Bulbar Muscular Atrophy; 11-N-0171; Dr. Kenneth H. Fischbeck; NINDS