December 2012

Clinical Center news

In this issue:
Children's School bids director goodbye
New Grand Rounds series kicks off
Clinical research course taught in India

NIH...Turning Discovery Into Health®

Recreation therapist Kathy Elokdah readies painting and collage materials for a session with a patient who is on infection control isolation. The patient said painting has helped with his anxiety.

Therapists address feelings of isolation that can arise with infection control precautions

Every sad ballad will tell you: you can feel alone with others around you. Lying in a hospital bed with nurses and doctors flurrying about, even with your loved ones by your side, you can be set apart by an illness.

When an infection limits your activities outside your room, and everyone who enters is outfitted in a gown and gloves, feelings of anxiety and depression can be amplified.

The Clinical Center Recreation Therapy Section works with patients on infection control isolation to offset some of those negative feelings and improve quality-of-life, perceived control and motivation through individualized therapy.

"One day I was really anxious, and just putting paint to paper helped me. It really calmed me down," said one patient. "It also helped pass the time, and not focus on the fact that I'm stuck in a room by myself."

Patient isolation helps control the transmission of infection. The hospital implements varying degrees of isolation, depending on the severity of the infection and its likelihood of transmission. The most stringent infection precautions restrict patient activity outside the room and require visitors to wear personal protective equipment (gloves, gown, mask, etc.).

"Some patients are colonized with multidrug-resistant bacteria that persist for months, and are contagious as long as they are colonized," said Amanda Heath of the Hospital Epidemiology Service. "When we reviewed our data, we saw that often after a patient tested negative for colonization and we discontinued isolation, the patient would test positive again soon thereafter. For this reason we are keeping more patients on isolation for longer times."

Patients can suffer depression, restlessness and loss of hope when their interactions with the outside world are limited. The Recreation Therapy Section, part of the Rehabilitation Medicine Department, is collaborating with the Hospital Epidemiology Service to work with patients on a tailored plan to meet their physical, cognitive, emotional and psychosocial needs while adhering to the infection control guidelines.

continued on page 4

Finding meaning in the dying experience

Imagine facing a serious life threatening disease. Imagine facing such before you have a chance to start a family or even graduate high school.

This is the unfortunate situation of many young adults. Dr. Lori Wiener, director of the National Cancer Institute Pediatric Psychosocial Support and Research Program, led the development of a resource for these patients and their families to help them communicate about and plan for this difficult time. *Voicing My CHOICES* is the first advance-care planning guide created specifically for adolescents and young adults.

Wiener and her colleagues evaluated how an advance directive document could act as a bridge for communicating during this difficult time. They worked with patients to understand what mattered most to them.

"This is an excellent example of what clinical research is all about," Wiener said. "We were able to create something by and for patients living with life-threatening diseases."

The patient accounts Wiener's study collected inspired the researchers. More than concerns about life-saving measures, the study's participants expressed an importance in feeling they lived a purposeful life, being remembered, leaving a legacy and spending quality time with family and friends. Another popular theme was how their families would carry on after they were gone.

From this feedback, Wiener and her co-authors from the NCI and the National Institute of Mental Health designed *Voicing My CHOICES* to offer adolescent and young adult patients the opportunity to have their voice heard and feel a sense of control in a formidable situation.

"If teens can use this resource to find meaning in the dying experience, then we have been successful," Wiener remarked.

New lecture series highlights collaboration on complex clinical cases

Dr. Steven Holland was one of four presenters at the inaugural Clinicopathogenic Grand Rounds lecture.

A new quarterly Clinical Center Grand Rounds lecture series kicked off on Oct. 31. A team of an infectious diseases specialist, a radiologist, a pathologist and a microbiologist presented the observations and conclusions that led to the identification of a new mold: *Aspergillus tanneri*.

"The aims of these Clinicopathogenic Grand Rounds are to illustrate complex medical cases that advance medical education and also highlight the patient care, and clinical and translational research that is ongoing here at the Clinical Center," said Dr. Aradhana Venkatesan, staff clinician in CC Radiology and Imaging Sciences, who is leading the new series.

Dr. Steven Holland, chief of the Laboratory of Clinical Infectious Diseases (LCID) in the National Institute of Allergy and Infectious Diseases, presented the case of a young man with chronic gramulomatous disease and an additional chromosomal abnormality. The patient died, despite aggressive antifungal therapy, from a mold that was subsequently identified by the LCID Molecular Microbiology Section as an entirely new species.

At the Oct. 31 Grand Rounds Venkatesan presented the patient's diagnostic imaging illustrating the course of disease progression while a patient at the CC. Dr. Greg Riedlinger of the National Cancer Institute Laboratory of Pathology went over findings from the patient's autopsy. Dr. June Kwon-Chung, chief of the LCID Molecular Microbiology Section, described how her group identified and characterized the mold that had been isolated in the CC Department of Laboratory Microbiology Service. The new species of mold took the life of this patient and, it was determined, an earlier CC patient.

"We've done our best to turn his tragedy into something we can do good with," Holland said of the young man.

Those interested in presenting a case for future Clinicopathogenic Grand Rounds can contact Venkatesan at venkatesana@cc.nih.gov.

Caregiver event offers respite and resources

National Family Caregivers Month in November is nationally recognized as a time to support and empower family caregivers. On Nov 13, the NIH Clinical Center hosted the third annual Family Caregiver's Day, providing respite, resources and recognition for caregivers supporting a family member or friend with a serious health illness.

More than 65 million people provide care for a chronically ill or aged family member or friend each year. Studies have shown that stress of caregiving for people with dementia affects the caregiver's immune system. Thus caring for a loved one with an illness can increase one's own risk of developing a chronic illness.

"The annual caregiver event aims to raise awareness of the emotional and physical effects of caregiving and highlight resources available to manage challenges faced while serving as a caregiver," said Dr. Margaret Bevans, clinical nurse scientist and co-organizer of the event.

To learn more about the CC's caregiver resources, visit clinicalcenter.nih.gov/wecare.

Andrew Liang, with the National Library of Medicine, provides health information and resources to CC health care providers.

***Clinical Center News* online:**

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

news

Maggie McGuire, 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: 301-594-5789 Fax: 301-480-2984

Published monthly for Clinical Center employees by the Office of Communications and Media Relations.

News, article ideas, calendar events, letters, and photos are welcome.

Submissions may be edited.

New application for ultrasound guides neurological treatment

Dr. Katharine Alter, a clinician in the Functional and Applied Biomechanics Section of the Rehabilitation Medicine Department, has pioneered the use of ultrasound technology – emission of sound waves used for imaging as in obstetrics and cardiology – for a new and promising purpose.

Nine years ago Alter began using ultrasound to guide the injection of chemical nerve blocks. This technique, called chemodenervation, introduces a chemical compound to silence the nerve and relax the overactive or spastic muscles of patients with neurological diseases such as cerebral palsy, dystonia or stroke.

"At that time I was one of the first clinicians in the United States to use ultrasound for this purpose," Alter said. She discovered that using ultrasound gives a doctor an exquisitely detailed view of the therapy target as well as all of the structures adjacent to the target that should be avoided.

In current practice doctors palpitate or activate the muscle by moving the limb, or they may use electromyography (EMG) or electrical stimulation to locate the muscle. These methods can be inaccurate and sometimes require a response from the patient, which may be difficult to impossible.

"Once you learn to read the muscles and recognize their ultrasound pattern, you can be extremely accurate in targeting the muscle," Alter said.

Alter and her colleagues from the National Institute of Neurological Disorders and Stroke will publish a much-anticipated first textbook, "Ultrasound-Guided Chemodenervation Procedures," next month. The comprehensive textbook covers ultrasound technology, imaging planes and machine settings, along with the multitude of applications for botulinum neurotoxin (one chemical compound used to treat muscle spasms).

It is the authors' hope that this textbook will inform a new standard for clinical practitioners and serve as a reference manual.

Astute Clinician Lecture examines neurogenetic riddles

Dr. Huda Y. Zoghbi

Dr. Huda Y. Zoghbi, presented the 15th annual Astute Clinician Lecture as part of the Wednesday Afternoon Lecture Series on Nov. 7.

In his opening remarks, NIH Director Dr. Francis S. Collins called Zoghbi "a cutting-edge, top of the pile neurogeneticist." She is a Howard Hughes Medical Institute investigator, professor at Baylor College of Medicine, and director of the Jan and Dan Duncan Neurological Research Institute at Texas Children's Hospital.

Zoghbi's lecture was "The Value of Clinical Clues in Solving Neurogenetic Riddles."

The Astute Clinician Lecture Series was established through a gift from the late Dr. Robert W. Miller and his wife, Haruko. It honors a U.S. scientist who has observed an unusual clinical occurrence, and by investigating it, has opened an important new avenue of research.

NIH faculty bring research course to India

The Clinical Center and the Clinical Development Services Agency (CDSA), a component of the Indian government's Department of Biotechnology, collaborated to bring an abbreviated version of the CC course Introduction to the Principles and Practice of Clinical Research (IPPCR) to 126 attendees from across India from Oct. 29 – Nov. 3 in New Delhi.

Five faculty from the NIH and the Department of Health and Human Services (HHS) joined Indian experts in tuberculosis clinical trials, community participatory research and research ethics to augment the core course topics. The course trains participants on how to effectively conduct clinical research by highlighting such areas as study design, protocol preparation, patient monitoring and quality assurance. IPPCR is taught annually at the CC and to thousands around the world through long-distance learning technology.

"Our goal was for each attendee to go back to his or her home institution and feel empowered to train others in the process of conducting clinical research," said Dr. Frederick P. Ognibene, CC deputy director for strategic partnerships and educational affairs. Ognibene co-led the planning for IPPCR's debut in India with Dr. Harmeet Sidhu from the CDSA.

In addition to Ognibene, Dr. John I. Gallin, CC director; Dr. Jerry A, Menikoff, director of the HHS Office for Human Research Protections; Dr. Pamela Shaw, statistician with the National Institute of Allergy and Infectious Diseases; and Dr. Laura Lee Johnson, statistician with the National Center for Complementary and Alternative Medicine, traveled to India to teach the course.

Faculty (middle standing from left to right) Dr. Jerry A. Menikoff, Dr. Pamela Shaw, Dr. Frederick P. Ognibene, Dr. John I. Gallin and Dr. Laura Lee Johnson presented the Introduction to the Principles and Practice of Clinical Research course in India with the country's Clinical Development Services Agency.

NIH Children's School says goodbye to beloved director

Clinical Center pediatric and young adult patients – not to mention staff – bid farewell to a true friend and teacher when long-time director of the NIH Children's School Helen Mays retired in September.

Mays joined the NIH in 1969 after she began her career teaching in Detroit and Kentucky and in France and Germany with the U.S. Army. The NIH Children's School – provided by a contract with the Montgomery County Public Schools Home and Hospital Teaching Program – aims to maintain continuity of education while students are at the CC to participate in clinical trials. Five part-time teachers work with patients in the school and at the bedside.

"It's about making life as normal as possible in a place where they're pricked, prodded and poked," Mays told The Bethesda Gazette last year.

Her retirement celebration pulled friends from around the hospital.

"I'd like to say don't leave us, but that would be selfish," said Dr. Alan Wayne of the National Cancer Institute Pediatric Oncology Branch.

"Don't, because I'll stay," Mays said.

CC Director Dr. John I. Gallin thanked Mays for her years of service (even more than him, which he noted is hard to come by). "We see in the eyes of the parents and the kids how special this school has been. We are very appreciative of what you have done and what you have brought to this place," he said.

"Long may it continue," said Mays.

Helen Mays holds court at her retirement party with guests including Dr. Alan Wayne (left), Dr. John Gallin (third from right), and her husband Bob (second from right).

Patients treated to a Halloween event

Goblins, ghouls and princesses roamed the halls of the Clinical Center on Halloween searching for treats not tricks. The Recreation Therapy Section organized two groups of pediatric patients and patient siblings for a holiday excursion.

Rec therapy works with isolation patients

continued from page 1

"You are at the mercy of the research, of your medical issue, and having some ability to have influence over your own situation is an important balance," said Donna Gregory, chief of the Recreation Therapy Section.

In addition to in-room therapy including creative expression like painting and adapted physical activities like golf putting, therapists bring patients on social outings off the NIH campus to give them a break from the monotony of the hospital and allow them to practice community reintegration skills with the guidance of a therapist.

"We educate the patient and his or her family on how to manage infection precautions – such as wiping down public seats after sitting or wearing a face mask – so they feel confident doing so when off on their own," Gregory said.

"Through teaching there can be a reduction in the fear that they will contaminate others and the patients can express confidence in their interactions with others who may not be familiar with the infection precautions," said social worker Marilyn Innis.

Pediatric patients can attend social events, too, under the careful eye of a therapist. Two isolation patients went trick-or-treating around the hospital for Halloween. "It's even harder for kids," said Gregory, "because their life role is to play, and they're being kept by themselves."

Another important therapeutic tactic for pediatric patients is medical play where they are introduced to the equipment and process of a new medical procedure before they undergo the real thing. The empowerment to ask questions and familiarization can reduce anxiety and promote a sense of control, which are very important during isolation, Gregory said.

Testing their approaches, the Recreation Therapy Section has started collecting quantitative data on its outreach to pediatric isolation patients and hopes to gather qualitative data on the impact of their treatment.