



Doing the honors at a ribbon-cutting at the new Special Clinical Studies Unit on April 16 were (from left) Stewart Simonson, former HHS assistant secretary for public health emergency preparedness; Dr. (Col. US Army) Mark Kortepeter, deputy director of the Infectious Diseases Clinical Research Program at the Uniformed Services University of the Health Sciences; CC Director Dr. John I. Gallin; and NIAID Director Dr. Anthony Fauci. After the ceremony they toured the new facility.

New unit provides unique support for research

A ribbon-cutting for NIAID's new Special Clinical Studies Unit at the Clinical Center was held on April 14. The new seven-bed unit, which is in the 5NE-S corridor of the Hatfield Building, affords state-of-the-art isolation capabilities.

"This new unit is another example of the Clinical Center's ability to adapt to emergency situations," said CC Director Dr. John I. Gallin at the ceremony.

During the event, NIAID Director Dr. Anthony Fauci presented a special award to Stewart Simonson, former HHS assistant secretary for public health emergency preparedness, who was instrumental in the creation and development of the unit. "He promised it would happen, and here it is," Fauci said. Simonson applauded NIH staff for the ability to "use their imagination, try to anticipate problems, and create solutions before they happen."

Inpatient healthy volunteers and low-acuity patients in clinical trials will typically

spend extended periods of time on the unit. The facility, designed as a mini-apartment to make the time spent more comfortable, includes one single room (with an anteroom), three double inpatient rooms, a common area for dining, a kitchenette, an exercise area, and laundry space.

The entire unit is also capable of functioning as an isolation suite of rooms and can be used to house patients with known or suspected infections with especially virulent infectious agents. It will be available for use by investigators whose patients are suspected of having a highly contagious condition.

When patient isolation is needed, all four patient rooms and their connecting corridor will be kept under negative pressure at a high rate of air exchange and with HEPA-filtered exhaust. When isolation is mandated, access to the unit will be restricted to the unit staff with state-of-

continued on page 6

Undiagnosed Diseases Program meets expectations and earns attention

Success means different things to different people. When the NIH Undiagnosed Diseases Program (UDP) launched two years ago, its leaders weren't sure how to measure the program's progress. The magnitude of families looking for answers has offered one sure yardstick—more than 3,000 people have sought to participate in the program.

"The goal of NIH's Undiagnosed Diseases Program is two-pronged: to improve disease management for individual patients and to advance medical knowledge in general," then-NIH Director Dr. Elias Zerhouni said at a press conference announcing the new program on May 19, 2008. A partnership involving the Clinical Center, the National Human Genome Research Institute, and the NIH Office of Rare Diseases Research, the UDP welcomes applications from referring physicians of patients who have eluded diagnosis to help find them cures or therapies and to take what they learn for further application.

"To a certain extent, simply making a diagnosis is a help to patients," said UDP Director Dr. William Gahl. "Some certitude in their lives, some expectation, some prognosis that's associated with a diagnosis is comforting, even when you think it might not be comforting because it's a dire prognosis."

The program has received more than 1,100 medical records from interested parties and accepted around 290 patients into the program. Those are welcomed to the CC for a visit to meet the UDP team for days of tests and consultations to explore the symptoms and possible causes of the patients' varied disorders. The team's initial goal was to diagnosis 10 to 15

continued on page 7

Art project educates on imaging with Barbies, burgers

Computed tomography (CT) scans usually show disease, or hopefully lack of such, in patients. Visitors to Clinical Center Radiology and Imaging Sciences (RIS) now can see how toys, electronics, and even food look through the imaging equipment.

The Radiology Art project from former art professor and current Weill Cornell Medical College student Satre Stuelke sends inanimate objects through a CT scanner. The time on the Cornell machine is donated by the medical college's Citigroup Biomedical Imaging Center. Colors are assigned to densities, and contrast and balance are manipulated to create the neon still-lives.

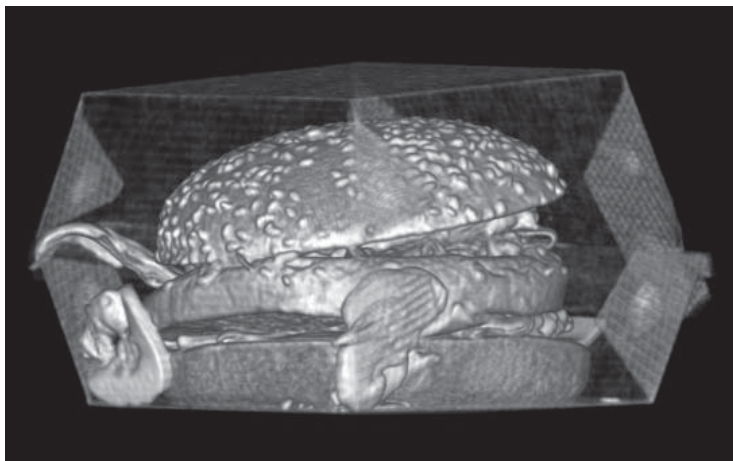
A new monitor display running on screens in the RIS waiting area and near staff offices will loop a selection of Stuelke's works through the month of May. Other slides are of publication abstracts, staff profiles, and department announcements.

"This exhibit illustrates the 3-dimensional nature achieved by state-of-the-art radiology techniques that are currently in use. The 3D images of familiar objects are easier to understand than complex medical anatomy," said Dr. David Bluemke, RIS director.

Stuelke has a master of fine arts from the School of the Art Institute in Chicago and taught at the School of Visual Arts in Manhattan before going back to school to pursue a medical degree. His project examines the connection between objects that humans form a connection to—stuffed animals, cell phones, and fast food—by revealing their make-up.

"Take the Barbie doll," the artist's website (<http://radiologyart.com>) states, "she has leg bones, joints, and even a skull, just like you and me."

"The works bring patients—already in a vulnerable and scary



Satre Stuelke's Radiology Art project sends everyday objects, like a McDonald's Big Mac, through a CT scanner to show how the technology works.

position, about to go into a giant machine—a little closer to how a radiologist might approach an image of their bodies," Stuelke said. "If patients are already familiar with a common everyday object I've scanned, then the CT scan of that object is going to reveal to them a structure that they can more readily understand and reconstruct in their minds as it relates to the entire object."

RIS fellows Genevieve Jacobs and Faezeh Razjouyan are coordinating the monitors' display. Of their choice to include the Radiology Art project, Jacobs said, "We wanted to create something fun, but also informative."

"This is a positive way to see how a CT scan works," Razjouyan said.

CC offers educational fun on Take Your Child to Work Day



The Clinical Center hosted multiple events on Take Your Child to Work Day on April 22, including an inside look at imaging, veterinary services and anesthesia.

Department of Laboratory Medicine staffer Tor Moore (at right in photo) led youth on a "Fantastic Voyage Through the DLM" where visitors dressed up like medical technologists; performed laboratory tests; used microscopes to view microorganisms, parasites, and blood cells; learned how to collect specimens; and practiced using different laboratory equipment. The DLM main laboratory hosted a tour for parents and chaperons while the children were busy at work.

Clinical Center News online:

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

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Published monthly for Clinical Center employees by the Office of Communications, Patient Recruitment, and Public Liaison, Sara Byars, chief.

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

Submissions may be edited.

International field physician draws a crowd in Lipsett

Reflecting on the lessons learned and challenges faced in the field with international medical humanitarian organization Doctors Without Borders/Médecins Sans Frontières (MSF), Dr. Jean-Hervé Bradol spoke to a packed Lipsett Auditorium on April 16.

Director of research at the MSF Center for Reflection on Humanitarian Action & Knowledge, Bradol has extensive field experience with MSF including in refugee camps in Thailand and in Rwanda during the early 1990s. He also served as president of MSF-France for eight years and is a former board member of MSF-USA.

Dr. Christine Grady, acting chief of the Clinical Center Department of Bioethics, introduced Bradol, calling him a “widely respected humanitarian.”

The MSF leader shared his experience with Burmese refugees in Thailand suffering from advanced malaria. A patient told him that he had resorted to smuggled drugs from China because the MSF drugs were not working. Bradol’s team obtained the other pharmaceuticals and started investigating their safety and efficacy.

“But setting up trials in those environments is not that easy,” Bradol said. The refugee community was not initially receptive to using a Chinese drug not registered in their country, and ethical concerns were rampant in conducting research with such a patient population.

“How can a refugee give consent when the question is asked by the very organization that provides their basic survival? The person is not really in a position to say no,” Bradol said. He reported that with advance treatments and preventive mea-



Dr. Jean Hervé-Bradol spoke to a full Lipsett Auditorium on April 16 about the challenges his teams faced on international humanitarian medical missions with Doctors Without Borders/Médecins Sans Frontières.

asures such as mosquito nets, malaria is no longer a major public health issue in that area.

His lecture coincided with the release of the MSF collection *Medical Innovation in Humanitarian Situations: The Work of Médecins Sans Frontières*, which illustrates 10 examples of the complexities of introducing medical innovations in the midst of difficult humanitarian crises.

Patient performs in piano concert series

Clifford Smith is grateful that the NIH shared its gifts with him and will return to share his artistic gifts when he performs a concert piano recital on May 19. Smith will perform his own internationally acclaimed piano compositions at 1 pm in the Hatfield atrium to reciprocate the benefits he received here in diagnosis, treatment, and remission of his life-threatening cancer.

“Music is probably the most complicated invention given to man,” said Smith. “Its potentials are endless, and the mysterious workings of music perform their interventions to charge a person—it uplifts, comforts, inspires.”

With suspicion of prostate cancer, Smith entered an NCI protocol in 2005. He credits the advanced imaging equipment here for finding his cancer and has been on hormonal therapy since the condition was confirmed. His prostate-specific antigen has been nearly undetectable for years. He shows no signs of metastasis. “You could call me fairly clean of cancer,” said Smith, who returns here periodically for follow-up. “It’s been

very helpful to have NIH as an anchor and guiding beacon. I truly believe the NIH facility saved my life.”

That life has been focused on the piano since age 12, when Smith first began working seriously at the instrument. He was composing his own works the following year, and debuted that year in Chicago. He continued to publicly perform his works, as well as many works by other composers, arousing the sustained audience and critical accolades that continue to follow him today. He went on to attend the Interlochen Arts Academy for gifted youth and the University of Michigan, majoring in piano and composition.

Smith, who performs internationally to great critical acclaim, is typically known to perform benefit concerts for worthy causes, amid his regular concert itinerary, and strongly feels the need to dutifully share the gifts he has been given to benefit others. “The strong message is hope. You have to muster everything within yourself and be of positive mental attitude, and share the message with others,” he said.

Kirschstein tribute

Inspiring the best in others

Join the NIH community on May 17 to highlight the accomplishments of Dr. Ruth L. Kirschstein, former NIH deputy director and twice acting director who died October 6, 2009.

The events will begin at 9 am in Natcher Auditorium, Building 45, in remembrance of Kirschstein’s life-long dedication to inspire the best in others. Current and former members of the NIH and Congress will be on hand to help celebrate her legacy. Speakers will include Dr. Laurie Boyer, Massachusetts Institute of Technology; Dr. Howard Chang, Stanford University; and Dr. Francis Lee, Weill Cornell Medical College.

The day will continue with a look forward as Ruth L. Kirschstein National Research Service Award recipients deliver scientific presentations and reflect on their own inspiration in the strive for excellence. The tribute will conclude with a poster session and reception from 5 to 7 pm.

A live videocast of the day’s events will be available at <http://videocast.nih.gov>. Contact Sarah Freeman at sarah.freeman@nih.gov with any questions.

Updates and awards for Bench-to-Bedside program announced

Clinical Center Director Dr. John I. Gallin spoke on "The Pipeline of Clinical Research from Bench to Bedside and Back" at a lecture in Lipsett Auditorium on April 26 cosponsored by the NIH Translational Research Interest Group and the NIH Clinical and Translational Science Awards (CTSA) program. Gallin provided an overview of the CC's contributions to turning "innovation into implementation."

A major cog in that machine is the Bench-to-Bedside Awards program, which supports projects to speed the work of basic and clinical scientists.

The call for FY2011 projects will go out in August. This year, CTSA and extramural researchers can initiate partnerships on proposals with intramural investigators. Previously, intramural researchers were required to serve as project leaders.

Projects funded for FY2010 are:

AIDS: Projects funded by Office of AIDS Research (OAR)

■ **New bioinformatic approach to determine HIV incidence:** NCI: F. Maldarelli, M. Kearney, W. Shao; NIAID: R. Dewar; Johns Hopkins University, Bloomberg School of Public Health: J. Margolick; Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center (LA BioMed): E. Daar

■ **Role of gut-associated lymphoid tissue in HIV-1 persistence:** NCI: F. Maldarelli, M. Kearney; University of Pittsburgh: D. McMahon; National Naval Medical Center: A. Ganesan

■ **Multiplex microarray chip-based diagnosis of respiratory infections in HIV:** CC: J. Kovacs, A. Suffredini, P. Murray; NIAID: S. Holland, J. Cuellar-Rodriguez; NCI: J. Gea-Banacloche, R. Lempicki; Washington Hospital Center: M. Smith

BEHAVIORAL & SOCIAL SCIENCES: Project funded by Office of Behavioral & Social Sciences Research (OBSSR)

■ **Antibody identification and IVIG treatment of PANDAS:** NIMH: S. Swedo; Yale University: J. Leckman; Oklahoma University Health Sciences Center: M. Cunningham

WOMEN'S HEALTH: Project funded by Office of Research on Women's Health (ORWH)

■ **Adrenal hyperplasia among adolescent patients polycystic ovarian syndrome:** NICHD: C. Stratakis; SUNY: S. Ten

MINORITY HEALTH: Projects co-funded by National Center for Minority Health & Health Disparities (NCMHD) and ICs

■ **Control of XMRV replication in PBMCs and prostate carcinomas:** NCI: V. Pathak, A. Rein, W. S. Hu, F. Maldarelli; University of California, Davis: R. deVere White, H.J. Kung

■ **In vitro fucosylation to augment cord blood stem cell engraftment:** NHLBI: R. Childs, J. Pantin; CC (Transfusion Medicine): D. Stroncek

■ **Biochemical mechanisms of the etiology of sickle cell pain:** NIDDK: A. Schechter; NINR: R. Dionne; CC (Transfusion Medicine): D. Stroncek, W. Smith; Beth Israel Medical Center: R. Portenoy, R. Cruciani

GENERAL: Projects co-funded by National Center for Research Resources (NCRR) and ICs

■ **Optical guidance for improved prostate cancer surgery:** CC (Radiology and Imaging Sciences): B. Wood, M. Dreher, A. Kapoor; NCI: P. Pinto, W. Linehan; Massachusetts General Hospital: U. Mahmood



■ **Imaging CXCR4-expressing cancer using 64CuAMD:** NIAID: J. Farber, I. Weiss; NIBIB: X. Chen, O. Jacobson; NCI: P. Choyke; Georgetown University: C. Isaacs

PHARMACOGENOMICS: Project funded by Food & Drug Administration (FDA)

■ **Mechanism of response to Anti-TNF therapy in inflammatory bowel disease:** NIAID: M. Yao, W. Strober, I. Fuss; University of MD: R. Cross, M. Flasar

RARE DISEASES: Projects co-funded by Office of Rare Diseases Research (ORDR) and ICs

■ **Targeting antigen-antibody responses in Systemic Capillary Leak Syndrome:** NIAID: K. Druey, T. Myers, S. Porcella; NCI: O. Landgren; NIBIB: A. Gorbach; University of Minnesota: A. Dudek; Mayo College of Medicine: P. Greipp

■ **Sympathetic innervation & myocardial injury in acute stress cardiomyopathy:** CC, Radiology and Imaging Sciences: C. Sibley, D. Bluemke; NINDS: D. Goldstein; NHLBI: D. Rosing; Johns Hopkins: I. Wittstein, F. Bengel, J. Mudd, J. Lima

■ **Preclinical testing of targeted agents for clinical development in NF1:** NCI: A. Kim, B.

Widemann, E. Dombi; Children's Hospital Medical Center: N. Ratner, J. Wu

■ **The DICER1-related pleuropulmonary blastoma cancer predisposition Syndrome:** NCI: C. Kratz, B. Alter, P. Rosenberg; National Children's Medical Center: A. Hill; Children's Hospital & Clinics of MN: Y. Messinger, K. Schulz

■ **Brain development in children with Williams syndrome and the LIMK1 Gene:** NIMH: K. Berman, J. Kleinman; University of Louisville: C. Mervis

■ **The role of EGFR in endolymphatic sac tumors:** NCI: P. Dennis; Yale University: A. Vortmeyer

RARE DISEASES DRUG DEVELOPMENT: Projects co-funded by Therapeutics for Rare and Neglected Diseases (TRND) Program and ICs

■ **A novel therapy to treat acid lipase deficiency by LCAT inhibition:** NHLBI: A. Remaley, K. Vickers, R. Shamburek; Cincinnati Children's Hospital Medical Center - Research Foundation: G. Grabowski, H. Du

■ **Development of combination therapy for Niemann-Pick Disease, type C:** NICHD: F. Porter, A. Yergey, S. Bianconi; NHGRI: W. Pavan; Washington University: D. Ory

■ **Gene therapy clinical trial for LAD-1 using a foamy viral vector:** NCI: D. Hickstein; University of Washington Medical Center: D. Russell; Cincinnati Children's Hospital Medical Center: P. Malik

■ **BH3 mimetics for the treatment of autoimmune lymphoproliferative syndrome:** CC (Laboratory Medicine): J. Oliveira Filho, T. Fleisher; NIAID: V. Rao, K. Dowdell; NIDDK: D. Appella

■ **Preventing aortic dilation in women with Turner syndrome:** NICHD: C. Bondy, V. Bakalov, J. Zhou; NHLBI: A. Arai, D. Rosing, M. Boehm, V. Sachdev; Johns Hopkins University: J. Van Eyk, Q. Fu

■ **Immunogenicity and leishmania vaccine potential of sandfly saliva in humans:** NIAID: J. Valenzuela, S. Kamhawi; Uniformed Services University of the Health Sciences/Walter Reed Army Medical Center: N. Aronson; George Washington University: M. Bottazzi

IC-FUNDED: Project funded by the National Institute of Child Health and Human Development (NICHD)

■ **The role of BDNF in autism spectrum disorder and cognitive function:** NICHD: J. Han, C. Pierpaoli; NIMH: K. Martinowich, D. Weinberger, C. Golden Williams, S. Swedo, A. Thurm; NCI: L. Tessarollo; Uniformed Services University of the Health Sciences/Walter Reed Army Medical Center: S. Sharp; GlaxoSmithKline Pharmaceuticals: B. Lu

Specialized iron majors connect with the Clinical Center

Members of the Army Medical Specialist Corps (dietitians, physical therapists, occupational therapists, and a physician assistant) visited the Clinical Center April 1 as part of their time in the Washington, DC, area for Iron Majors Week, a leadership and skill-building experience. During their stop at the CC, the group toured the hospital, spoke with NIH peers in their specialties, and learned about continuing education and grant opportunities.

Director of the NIH Dietetic Internship and supervisory metabolic dietitian LCDR Merel Kozlosky (front row, second from right) hosted (back row, from left) MAJ David Bauder, MAJ Rob Montz, CPT Tamara Osgood, MAJ Charles Quick, MAJ Jesse Ortel, and (front row) MAJ Reva Rogers, CPT(P) Mark Lester, and LTC Joanna Reagan.



Ognibene elected into association

The Association of American Physicians—a nonprofit organization founded in 1885 for “the advancement of scientific and practical medicine”—elected Dr. Frederick P. Ognibene, Clinical Center deputy director for educational affairs and strategic partnerships, as a member this year. The association is composed of about 1200 active members and approximately 550 emeritus and honorary members, and election is an honor bestowed annually to only approximately 60 individuals.

The goals of the association include the pursuit of medical knowledge and the advancement through experimentation and discovery of basic and clinical science and their application to clinical medicine. Each year, individuals having attained excellence in achieving these goals are recognized by nomination for membership by the council of the association.

Also among the 59 members elected in 2010 is Dr. Mark Udey, chief of the Dermatology Branch and deputy director in the National Cancer Institute Center for Cancer Research.



CTSA visitors see latest from the CC

The Clinical Movement Analysis Lab in the Clinical Center Rehabilitation Medicine Department Functional & Applied Biomechanics Section was one stop for a group of visiting fellows from the Clinical and Translational Science Award (CTSA) consortium on April 7. Launched in 2006, the CTSA program—led by the NIH National Center for Research Resources—creates academic homes for clinical and translational science at research institutions across the country.

In the Washington, DC, area for the 2010 Clinical and Translational Research and Education Meeting, sponsored by the Association for Clinical Research Training and the Society for Clinical and Translational Science, about 75 CTSA representatives from academia around the country—such as Morehouse School of Medicine, Washington University in St. Louis, and Weill Cornell Medical College—toured the CC after an overview of the hospital from CC Deputy Director of Educational Affairs and Strategic Partnerships Dr. Frederick Ognibene.

Engineers Christopher Stanley (in front) and Lindsey Bellini demonstrated the capabilities of the newly updated Clinical Movement Analysis Lab. CTSA fellows also visited the new CC Pharmacy Department Pharmaceutical Development Section facility, and the National Heart, Lung, and Blood Institute Vascular Biology area.

Deputy director gives SHEA lecture



CC Deputy Director for Clinical Care Dr. David Henderson

Clinical Center Deputy Director for Clinical Care Dr. David Henderson gave the Society for Healthcare Epidemiology of America (SHEA) Lecture on March 20 at the Fifth Decennial

International Conference on Healthcare-Associated Outcomes.

A member of SHEA for the last two decades, Henderson was chosen by the society's board of trustees. "I felt really honored to join the distinguished individuals on the list of former recipients of the lectureship," Henderson said.

The SHEA Lectureship recognizes the career contributions of one senior investigator in infection prevention and control and health-care epidemiology each year. Henderson's presentation "Opportunities and Opportunities" reviewed his 30 years as a hospital epidemiologist at the CC and commented on options for and barriers to the society's success.

Former recipients of the SHEA Annual Lectureship include such distinguished hospital epidemiologists as Dr. Robert Weinstein of Rush Medical College; Dr. Dennis Maki of the University of Wisconsin; Dr. Didier Pittet from Geneva, Switzerland; Dr. Richard Wenzel of the Medical College of Virginia; and Dr. Glen Mayhall from the University of Texas.

In addition to his lecture, Henderson gave three platform presentations at the conference, including an opening plenary talk titled "Charting the Course for the Future of Science in Healthcare Epidemiology", and a symposium presentation about managing providers infected with bloodborne pathogens, and conducted a workshop on Occupational Health.

The Atlanta conference gathered thousands for five days of panel discussions, poster presentations, and lectures. Co-sponsors were SHEA; the Centers for Disease Control and Prevention; the Association for Professionals in Infection Control and Epidemiology, Inc.; and the Infectious Diseases Society of America.



Volunteers Mark and Michelle Cohen (middle) were honored by CC Volunteer Program coordinator Courtney Duncan for their efforts with animal-assisted therapy. "I am glad that we can help.; it's so nice to see someone who is having a tough time light up when we visit," Mark said.

Volunteer Program honors outstanding service to the Clinical Center mission

The Clinical Center Social Work Department honored hospital volunteers April 19 to 25 as part of National Volunteer Week, a celebration of ordinary people doing extraordinary things to improve communities across the country.

The 17th annual CC volunteer appreciation event on April 22 included presentation of special recognition awards to nine volunteers based on consistency, reliability, hours spent, or "general overall wonderfulness," as CC Volunteer Program coordinator Courtney Duncan said. Out of the 280 volunteers from the last year (currently 197 on board), honored were: Mark and Michelle Cohen, animal-assisted therapy program; Eileen De Santillana, Language Interpreters Program; Joanne Hill, Patient Ambassador Program; Saroja Kanesa-Thanan, Red Cross; Cynthia Kim, Patient Ambassador Program; Janet Logan, volunteering on OP 12 for 14 years; Monica Sullivan, Language Interpreters Program; and Armen Thomasian, Patient Ambassador Program.

In the celebration's welcome, CC Chief Operating Officer Maureen Gormley thanked the volunteers for their contribution to the CC's healing environment.

CC and NIAID open new unit

continued from page 1 the-art infection control procedures in place. Point-of-care laboratory testing and telemetry monitoring are additional capabilities of the unit.

Staffing the access-protected Special Clinical Studies Unit requires a new process, too, said Ann Marie Matlock, nurse manager. While new to the CC, all 10 nurses hired to staff the unit came with clinical experience and a professional interest in infectious diseases.

Specific training is being developed and implemented to deal with infectious pathogens staff could potentially encounter despite the expected rarity of these types of occupational exposures or exotic infections, Matlock said.

Former mystery, Mandy Young *Where is she now?*

Present at the NIH Undiagnosed Diseases Program launch in May 2008 was a representative of the patient population the new endeavor hoped to serve and learn from.

Amanda Young suffered from spinal meningitis, gas gangrene, salmonella poisoning of the sinuses, and an abdominal abscess before age 20, with no explanation why. She came to the Clinical Center in 1990 for the first of many visits in hopes that CC Director Dr. John I. Gallin could figure out what was ravaging her young body. Young remembers down to the minute when she learned that she had an IRAK-4 deficiency, an extremely rare genetic mutation that affects her body's ability to create a protein needed to fight bacteria, leaving her vulnerable to life-threatening infections.

In 2008 it seemed that Young's condition was improving, and she has had no major health situations since. Still, she visits the CC once a year, and was here last in February. Research continues into the cause, treatment, and cure for IRAK-4 deficiency, a condition a handful of others (all younger, so there is no historical reference) around the world suffer from—though none with Young's exact mutation.

Her samples also may be used to learn about the immune system related to lupus, certain types of cancer, arthritis, and heart disease, said Young, who is honored to help. "Just from what my body is doing, it's helping learn about diseases that millions suffer from," she said, sounding astonished.

Young shares her story as a motivational speaker in and around her hometown of Conyers, Ga., recalling her path through "medical chaos"—as she calls it—and her emergence on the other side with a smile to boot.

Read more about Young's journey and diagnosis in the June 2008 issue of *CCNews*, available at <http://cc.nih.gov>.



Patient Mandy Young has been doing well since her IRAK-4 deficiency, which caused serious illness to crop up without warning, was diagnosed.

UDP marks two years

continued from page 1 percent of applicants, and they have reached that with expectations to improve in the future, Gahl said.

"When the UDP started, I could not predict the number of applicants, their specific undiagnosed problems, or the number we would admit to the program," said UDP attending physician Dr. Fred Gill, chief of the CC Internal Medicine Consult Service. "There was also little precedent to anticipate the extent of the evaluation they would require at the Clinical Center, regarding laboratory testing, imaging, genetic testing, and specialty consultations from multiple institutes."

Louise Bengé knows what UDP patients go through. She and her sister were enrolled in the program in early 2009, suffering from unexplained vascular disease due to calcification. NIH researchers found that their condition was tied to a genetic factor. Though the UDP team couldn't stop their symptoms, they recommended therapies to ease their stiffness and pain.

"We were glad to find out what was causing it, and we just hope that they can find a cure for us. But if they can't find one for us, maybe sometime down the road they can help other people," said Bengé, whose four other siblings and parents have all visited the UDP for further sampling. Their story was featured on CNN's *Vital Signs* in May 2009.

The UDP team also hopes that their success in Bengé's case will mean diagnosis for others. "New genetic findings have already been discovered in a small number of patients. We anticipate that these findings will be useful for evaluation and diagnosis of future patients with similar undiagnosed clinical manifestations," said Gill.

Such progress has taken hard work from the expanding UDP team. Originally, Gahl led a scheduler, two nurse practitioners, and a squad of physicians volunteering from their primary posts. Two years later, the UDP team has welcomed a deputy clinical director and full-time neurologist, as well as additional nurse practitioners, part-time physicians, a physician's assistant, and administrative personnel.

"More than 50 senior attending physicians from throughout NIH have carved out time for UDP cases," Gahl reported. That varied expertise is key to the program—which sees many patients with conditions involving multiple systems—and unique to a collaborative environment such as the CC, the director said. Experts in fields including neurology; genome research; allergy and infectious diseases; arthritis, musculoskeletal and skin diseases; child health and human development; and dental and craniofacial disorders—to name just a few—work together under one roof. UDP patients could see specialists from many of these concentrations in the same day.

As patients must return to their hometowns and original caregivers, the UDP team sends their findings to the referring physician, who usually appreciates the report, even when it does not include a diagnosis. "When we report that the UDP team and consultants have not discovered a unified diagnosis, it is interesting that the referring doctor often indicates that the lack of diagnosis after evaluation at NIH helps their confidence in continuing care for their patient," Gill said.

Upcoming Lectures

All will be videocast at <http://videocast.nih.gov>.

CC Grand Rounds

Lipsett Amphitheater, 12 noon

May 5, 2010

Lecture held in Masur Auditorium The Role of Oral Microbiome in the Prevention of Ventilator-Associated Pneumonia

Nancy J. Ames, RN, PhD, CCRN
Critical Care Clinical Nurse Specialist,
Nursing and Patient Care Services, CC

Patrick R. Murray, PhD
Chief, Microbiology Service, Department
of Laboratory Medicine, CC

Naomi O'Grady, MD
Staff Clinician, Critical Care Medicine
Department, CC

CANCELLED

May 12, 2010

Contemporary Clinical Medicine: Great Teachers Medicine and the New Science of Thinking

Jerome E. Groopman, MD
Recanati Professor of Medicine, Harvard
Medical School

May 19, 2010

Ethics Rounds Who Can Appoint a Research Surrogate?

Presenter: David S. Wendler, MA, PhD
Head, Unit on Vulnerable Populations,
Department of Bioethics, CC

Discussant: Scott Kim, MD, PhD
Associate Professor of Psychiatry, Bioethics
Program, and Investigator, Center for
Behavioral and Decision Sciences in
Medicine, University of Michigan

May 26, 2010

Roles for STAT3 in Human Immune Responses and Atopy

Joshua D. Milner, MD
Tenure-Track Investigator and Chief,
Allergic Inflammation Unit, Laboratory of
Allergic Diseases, NIAID

Disrupted Airway Defenses and Environmental Infection Susceptibility

Kenneth N. Olivier, MD, MPH
Staff Clinician, Immunopathogenesis
Section, Laboratory of Clinical Infectious
Diseases, NIAID

Wednesday Afternoon Lecture Series

Masur Auditorium, 3 pm

May 5, 2010

Annual Robert S. Gordon, Jr., Lecture What Do We Do When Studies Disagree?

Julie Buring, ScD
Professor of Medicine, Harvard Medical
School
Deputy Director, Division of Preventive
Medicine, Brigham and Women's Hospital

May 12, 2010

Clock Genes and Clock Cells: A New View

Joseph Takahashi, PhD
Professor and Chair, Department of
Neuroscience, and Lloyd B. Sands
Distinguished Chair in Neuroscience,
University of Texas Southwestern Medical
Center
Investigator, Howard Hughes Medical
Institute

May 19, 2010

Control of Tumor Promotion and Metastatic Progression by Inflammatory Signaling

Michael Karin, PhD
Professor of Pharmacology, University of
California, San Diego
American Cancer Society Research
Professor

May 20, 2010

Special Thursday Lecture From Rare Gases to Ribosomes: Mass Spectrometry for Structural Biology

Carol Robinson, PhD
Royal Society Research Professor,
Department of Physical and Theoretical
Chemistry, University of Oxford

May 26, 2010

Interrogating Circulating Tumor Cells to Direct Targeted Cancer Therapies

Daniel Haber, MD, PhD
Director, Massachusetts General Hospital
Cancer Center
Isselbacher/Schwartz Professor, Harvard
Medical School
Investigator, Howard Hughes Medical
Institute

News Briefs

Explore the Science of Community Engagement

On May 13 and 14 the Clinical and Translational Science Awards (CTSA) consortium will conduct its third annual conference on community engagement, "Partnering to Improve Health: The Science of Community Engagement," at the Sheraton National Hotel in Arlington, Va. The event is free and open to the public.

This year's conference will emphasize how to identify and secure local and regional resources.

The CTSA's are funded by the NIH National Center for Research Resources. Register by May 10 to attend the conference at www.aptrweb.org/prof_dev/ce_registration.html. For more information, contact Donna Jo McCloskey at mccloskd@mail.nih.gov.

Race for a cure with Team NIH

Join Team NIH at the Susan G. Komen Global Race for the Cure 5K on June 5 on the National Mall in Washington, DC. Walk or run to support breast cancer research; no fundraising is required. Visit http://globalrace.info-komen.org/site/TR/GlobalRaceForTheCure/GlobalRace?fr_id=1370&pg=entry and choose "Join a Team."

Meet at the Archives-Navy Memorial Metro station the morning of the race. Contact Maggie McGuire at mcguirema@mail.nih.gov for more information.

Trial recruiting volunteers

Healthy volunteers are needed to participate in a National Institute of Diabetes and Digestive and Kidney Diseases study for comparison to individuals with narcolepsy, a sleep disorder. You may be eligible to participate if you are between 18 and 55 years of age, do not smoke, do not take any prescription medications, and do not take any hormonal contraceptives. The study requires a one-week stay at the Clinical Center, and compensation is provided.

Interested volunteers may call 1-866-444-2214 and reference study, 06-DK-0079.