

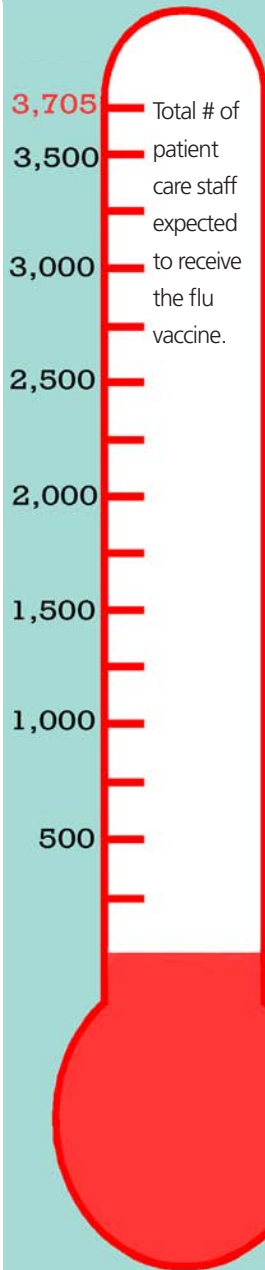
- Registration now open for clinical research introductory course
- Leaders from Africa visit the NIH, discuss advancements, future of health research
- Students sharpen career, research skills

Clinical Center

NIH...Turning Discovery Into Health®

Patient care providers and staff help raise the ...

Anti-Flu-O-Meter



Beginning Sept. 15, the NIH Office of Research Services and the Clinical Center will offer free flu shots to anyone with an NIH identification badge. Vaccinations will be available through Oct. 25.

This year, the flu immunization clinic will open at 6 a.m. during the first week of operation: Sept. 15-19. The on-site clinic will be located on the east side of the seventh floor of the Clinical Research Center.

Over 3,700 staff members who have patient contact, employees and contractors are required to get the flu vaccine each year. The shot is available but not required of all other NIH staff. Staff age 65 and older can receive a higher dose vaccine. Details on this flu shot: <http://go.usa.gov/PAUY>

The Occupational Medical Service will provide a certificate of immunization by email.

Questions? Call 301-496-2209. View additional information: www.foitheflu.nih.gov

Enhancements to NIH database provide more ways for intramural collaboration

A powerful tool to advance research has been improved to help better connect investigators with study participant data.

The Biomedical Translational Research Information System (BTRIS), pronounced BEE-triss, is a catalogue of clinical research data dating back to 1976. The system can only be seen and used by intramural scientists or internal NIH staff who conduct research on the Bethesda campus or an NIH facility. BTRIS provides access to information contributed by over 500,000 people who've participated in a study. Those contributions make up five billion dis-

tinct data points that can be assessed to advance current research.

Over the past several months, the Clinical Center Laboratory for Informatics Development, which maintains BTRIS, enhanced its usability and worked to ensure that current data use is communicated more effectively to the original investigators who collected the information. The improvements also allow the system's administrators to monitor how employees approach the data in order to provide continuous enhancements to the system.

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Exploratory study broadens understanding of international family's needs at the CC

Parents of pediatric patients share experience during treatment

Social worker Rachel Margolis says her involvement in a recent study has greatly improved her ability to support international families of pediatric patients at the Clinical Center.

The study, titled "An Exploratory Study of the Characteristics of and Challenges for International Families Seeking Medical Care in the United States," allowed Margolis the opportunity to conduct qualitative interviews with 22 caregivers of pediatric patients. The National Institute of Mental Health (NIMH) study included patients from several different institutes. It was managed by Principal Investigator Dr. Maryland Pao, NIMH, and Lead Associate Investigator Dr. Lori Wiener, National Cancer Institute. Additional NIH staff also helped conduct interviews.

Researchers hope to better understand the barriers and challenges that international families face when seeking treatment at NIH and to develop greater support for them. With families from abroad, the stresses and challenges of seeking treatment in the U.S. are complex. There can be language barriers, cultural barriers, financial is-



Rachel Margolis, bilingual in Spanish, has been with the Social Work Department for five years. She works with the families of the Center's youngest patients in the Pediatric Inpatient Unit, Day Hospital and the Pediatric Clinic.

suess and stress from being separated from community supports and other children who remain back at home. While at NIH, families have to adapt to a research medical environment and to living in a foreign country.

The families who participated in the study, many of whom spoke Spanish or English, came from places around the globe including the Dominican Republic, Honduras, Greece, the Middle East, Great Britain and Jamaica.

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Can we meet the October 25th deadline?

Scan the barcode with a smart device for more details

Upcoming Events

View most lectures online at
<http://videocast.nih.gov>

Clinical Center Grand Rounds Lecture Contemporary Clinical Medicine Great Teachers Lecture; Medical Mistakes: Why Do They Happen and How Can We Prevent Them?

Sept. 10, 2014; Noon - 1:00 p.m.

Lipsett Amphitheater

Presented by Frederick S. Southwick, MD,
University of Florida College of Medicine.

Clinical Center Grand Rounds Lecture Screening for Suicide Risk in Medi- cal Settings: Time to Ask Questions; New Insights into the Neurobiology of Suicide and Rapid-Acting Treatment

Sept. 17, 2014; Noon - 1:00 p.m.

Lipsett Amphitheater

Presented by Lisa Horowitz, PhD, NIMH
and Carlos A. Zarate, Jr., MD, NIMH.

National Symphony Orchestra

Sept. 17, 2014; 2:00 p.m. – 3:00 p.m.

Hatfield Building, North Atrium

A concert performance, co-presented
by the FAES and the Clinical Center.

NIH Director's Wednesday Afternoon Lecture Series; The Neurogenetics of Innate Behaviors

Sept. 17, 2014; 3:00 p.m. - 4:00 p.m.

Masur Auditorium

Presented by Leslie B. Vosshall, PhD,
The Rockefeller University.

Thirty-Third Annual Symposium: Immunology and Blood Transfusion

Sept. 18, 2014; 8:25 a.m. – 3:30 p.m.

Masur Auditorium

Learn about recent developments,
current practices, controversies and
laboratory management issues relative
to transfusion medicine. Free and open
to the public. <http://go.usa.gov/Pdhx>

NIH Research Festival

Sept. 22-24, 2014

Building 10

Celebrate the NIH intramural research
community and learn about new ef-
forts. <http://researchfestival.nih.gov> or
email researchfest@mail.nih.gov.

Clinical Center News online:

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

news

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The goals of the BTRIS upgrade were to advance research by letting scientists explore data in an uninhibited way and providing researchers with the flexibility to analyze different data sets.

BTRIS is unique to NIH. It allows the information collected from almost 40 years of studies to be used to its utmost potential. The “self-service” tool provides users with access to data within their own active protocols and to obtain limited data sets across both current and past protocols. Study participant data in BTRIS can be provided either in an identified format (with personally identifiable information) or a limited data set (with no personally identifiable information). The limited data set application has four types of data: demographic, laboratory, medication and diagnosis. The identified-data application has many more data types.

All of the data are related to research protocols so when people access the statistics, the original researchers are made aware that other NIH investigators are reviewing the information, fostering a collaborative environment where current researchers connect with past investigators in assessing and using data to better protect human health.

“We hope this will spur collaboration between the user and previous investigators,” said Dr. James J. Cimino, chief of the Laboratory for Informatics Development. He also emphasized, “We owe it to our



Dr. James J. Cimino, chief of the Laboratory for Informatics Development, presenting at the 2013 BTRIS Town Hall.

[patients], who have literally given their blood, sweat and tears, to make the maximum use of this data.”

While this round of updates to the six-year-old BTRIS is complete, there are long-term plans to add access to full text documents in de-identified form to expand the information available to researchers. Eventually, NIH intramural investigators would be able to access items like pathology reports, discharge summaries and x-ray details which would allow them to better understand the significant factors in a study participant’s treatment and the outcomes of the studies.

There will be a symposium on the BTRIS system at the NIH Research Festival Sept. 22-26: <http://researchfestival.nih.gov>. A Town Hall meeting on BTRIS and data sharing will occur Oct. 30: <http://btris.nih.gov>.

Registration open for enhanced introduction to clinical research course for health professionals

Scientists, physicians, medical students and other health professionals can now register for a free NIH training course to expand their knowledge in clinical research. This year’s Introduction to the Principles and Practice of Clinical Research course has an enhanced curriculum and additional lectures that provide more comprehensive content on clinical research infrastructure.

Registration is open through Oct. 6. The course will be held Monday and Tuesday nights, 5:00 p.m. – 6:30 p.m. Oct. 14, 2014

through March 9, 2015. Participants can attend the class in person at the Clinical Center or view it online at any time.

Last year, nearly 2,100 participants registered for the course including 480 at NIH, 677 in the U.S. and 902 internationally.

View the schedule of NIH, HHS and other teachers who will present throughout the six-month course and register online: <http://go.usa.gov/EFDW>. Contact course coordinator, Daniel McAnally at 301-496-9425, daniel.mcanally@nih.gov.

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Clinical Center

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"We interviewed caregivers of patients, who had been here for at least three months, about their experiences," Margolis said. "These were semi-structured interviews with twelve open-ended questions and the leeway to ask follow up questions."

The participants were asked the following questions about their time at the hospital: What was helpful? What were problem areas? How did you find out about NIH? Before you got here, how much information did you have on your child's medical condition? What were your experiences upon arrival? How have you grown from this experience?

Of the caregivers Margolis interviewed, not one regretted the decision to come to NIH for treatment. The caregivers she talked with said they experienced personal growth. Having to adapt to the situation and then being successful at it made them feel competent and good about themselves.

Just as families reported benefiting from the experience, so did Margolis.

"The more I did these interviews, the more it changed the way I worked with

the families. It made me more aware of what they need," she said. "I found that it was critical for the research teams to alert me ahead of time that an international family is coming, because it's very important to communicate with them before they arrive. It allows me to assess their needs earlier and help prepare them for what to expect. Once they get here, it allows them to feel more comfortable that they already know someone."

Upon arrival, Margolis quickly meets with the families to orient them to the building and show them the non-medical essential areas such as the cafeteria, interpreter program, patient library, chapel, fitness room and other support services.

"I typically try to do this orientation with just the caregiver, without the child, as it gives them a respite and helps build that relationship between me as the social worker and them," Margolis said. "This also allows the family member to talk about their fears because coming here can be very intense and overwhelming. If you help them through it, there can be positive elements to the experience of being here."

The study found that caregivers were impressed with the staff's commitment and by support from facilities like the Children's Inn. Read more about the study: <http://go.usa.gov/PhHd>. View a recent journal article: <http://go.usa.gov/Ph63>

The social work department

The Clinical Center Social Work Department has 25 social workers, eight of whom are bilingual. They screen both inpatients and sometimes outpatients to determine what psychosocial needs they have. The psychosocial assessment helps determine how patients and families are coping emotionally and psychologically with an illness, the social impact on the family and the family's ability to utilize community resources as needed.

In addition to interdisciplinary involvement, the social work staff provide counseling, advocate for patient needs, help facilitate communication between the patient and the medical team and connect people to resources within the Clinical Center and in their local communities.

African heads of state and government participating in the 2014 US-Africa Leaders Summit visit NIH hospital



NIH officials met with the Presidents, ambassadors and other government officials from Tanzania and the Republic of the Congo in the Clinical Center Aug. 2.

The President of Tanzania, Jakaya Mrisho Kikwete, the President of the Republic of the Congo, Dennis Sassou Nguesso, the President of Mali, Ibrahim Boubacar Keita, the Zambian Vice President, Guy Scott, and other ambassadors and government officials from Africa visited the NIH Clinical Center Aug. 2 and Aug. 7. These leaders, along with over 45 additional African heads of state and government, were in the Nation's Capital for the U.S.-Africa Leaders Summit. During their visit,

Dr. Francis S. Collins, NIH director, Dr. John I. Gallin, Clinical Center director, and other NIH leaders showcased the NIH-supported research in African countries and discussed how these investments are making a difference in the lives of Africans and Americans. NIH directors presented research advancement and specific opportunities for future research investment. The leaders were invited to NIH by the Fogarty International Center.

Students sharpen career, research skills at the Clinical Center

Clinical Center Summer Internship Program



For eight weeks, the Clinical Center hosted students enrolled in high school, college and graduate schools to participate in their yearly Summer Internship Program. Nearly 40 students worked with mentors who are researchers and health professionals and attended weekly lectures presented by Clinical Center investigators and administrators. The students also participated in the annual NIH Summer Poster Day and shared their research with the NIH community. The closing reception was held Aug. 8 where three students were awarded for best posters. Best intern and best mentor awards were also presented. Above, the students gather with their mentors.

Clinical & Translational Research Course for Ph.D. Students



Twenty eight graduate students participated in the Clinical and Translational Research Course for Ph.D. Students in the Clinical Center July 7-18. During the two week intensive course, participants learned the process of clinical and translational research from concept to implementation, including study design, ethical and scientific review, protocol logistics and drug development. The 2014 class of students represented 22 institutions from 14 states and the District of Columbia. During the first week of the course, as seen above, students met with NIH investigators to discuss their research.

Clinical Fellows Program



A welcome reception was held in July for 70 clinical fellows who joined NIH to develop competence as medical, surgical or dental specialists. The fellows networked with graduate medical education training program directors, institute and center directors, scientific and clinical directors and other NIH medical and administrative staff. While at NIH, they will conduct cutting-edge patient-oriented research as they actively participate in a variety of investigational protocols at the Clinical Center.

Community College Summer Enrichment Program



Bobby Pourier, a high school student from South Dakota, interned in the Nursing Department as part of the NIH Community College Summer Enrichment Program. Pourier worked alongside postdoctoral fellows and graduate students to better understand research. He says his summer was a success due to his mentor, Alyssa Todor Brooks (left) and Dr. Gwenyth Wallen (right). "[They] were so friendly," Pourier said. "I came through the gates of the NIH so nervous and unsure, and I'm leaving with a plan, a new set of goals and a whole new outlook about my future."

Medical Research Scholars Program



With books, comforters and dorm room apparel in hand, more than 40 students headed to the NIH campus to live, learn and participate in the yearlong Medical Research Scholars Program. The students moved in throughout the summer and will now engage in a mentored basic, clinical or translational research project on campus that matches their interests and career goals. The 2014-2015 class represents 34 institutions, 39 medical students, three dental students and one veterinary student.