

April 2013

Clinical Center

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NIH...Turning Discovery Into Health®

Dr. Harvey Alter selected to receive 2013 Canada Gairdner International Award

Dr. Harvey J. Alter, infectious disease researcher and clinician, chief of clinical studies and associate director of research in the Department of Transfusion Medicine at the Clinical Center, has been selected to receive the prestigious Canada Gairdner International Award for 2013. The award, which will be presented in Toronto in October, is given to individuals who have demonstrated outstanding leadership in medicine and medical science, and whose work has contributed significantly to improving the quality of human life.

"Dr. Alter's career-long achievements in blood safety have done much to advance the cause of human health. We are thrilled that he is being recognized with this prestigious international honor," says NIH Director Dr. Francis S. Collins. "Dr. Alter's research achievements in hepatitis have been transformative for public health practice in the U.S. and abroad," adds CC Director and NIH Associate Director for Clinical Research Dr. John I. Gallin. "We are proud of his prominence in the field of biomedical research and the path he is laying for the next generation of researchers."

Hepatitis means inflammation of the liver and also refers to a group of viral infections that affect the liver. An estimated 4.4 million Americans are living with chronic hepatitis; most do not know they are infected. Thirty years ago, about a third of transfused people received tainted blood, which later inflamed their livers, producing hepatitis (also called viral hepatitis), the leading cause of cirrhosis and liver cancer, and the most common reason for liver transplantation. Alter was the principal investigator on studies that identified non-A, non-B hepatitis, now called hepatitis C. His work was instrumental in providing the scientific basis for instituting blood donor screening programs that have decreased the incidence of transfusion-transmitted hepatitis to near zero.

Alter shares the award with Daniel Bradley, Ph.D., consultant at the Centers for Disease Control and Prevention, and



Dr. Harvey J. Alter was selected to receive the 2013 Canada Gairdner International Award.

Michael Houghton, Ph.D., researcher and professor at the University of Alberta, for their critical contributions to the discovery and isolation of the hepatitis C virus, which has led to development of new diagnostic and therapeutic agents. When asked how he felt about receiving this award, Alter responded, with characteristic humility, "If my studies to improve blood safety have helped patients and also reflect well on NIH, then I am doubly gratified to have won this award."

The Gairdner National Program is a 10-day celebration of science excellence across Canada. Since they were instituted in 1959, the Canada Gairdner Awards have become Canada's foremost international awards. Five honorees are selected each year after rigorous review by a medical review panel made up of active

BTRIS: Your e-Research Assistant

The BTRIS clinical research data repository is a key e-research tool for clinical researchers across the intramural program. Imagine sitting at your own computer, and within minutes, retrieving all of the laboratory data or medication administration records for your protocol subjects. Since 2009, BTRIS has added 38 data sources, providing users with close to five billion rows of data. New data domains are added on a regular basis to support varied research interests.

BTRIS provides data from Clinical Center and Institute research systems. In addition to labs and medication data, users can run protocol-specific reports on demographics, diagnoses, clinical documents, PDF's such as signed consents, vital signs and radiology reports with images, as well as other domains.

Do you have to file reports with ClinicalTrials.gov (CT.gov)? Users can populate required fields with data from BTRIS and upload their own data on study arms and adverse events using spreadsheet templates. BTRIS User Support is ready to assist researchers and study support staff meet this mandatory reporting requirement.

BTRIS has released a new version of the De-Identified Data application. Available to intramural researchers, this tool allows users to pose "what if" queries to develop research hypotheses, verify potential sample size of a population based on a diagnosis, labs or medications, and to find potential collaborators. Betty Marciano (NIAID), an inaugural user of the new application, notes that this application has the potential to compare data between populations using, for example, labs, toxicities or medication effects.

For additional information on BTRIS see <http://btris.nih.gov> or contact BTRIS Customer Support at BTRISsupport@nih.gov or 301-827-8270. Dr. Jim Cimino will host two sessions on using the BTRIS De-Identified Data Application for research in room 4-2551 April 2 at 2:00 p.m. and April 10 at 4:00 p.m.



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2013 Rare Disease Day at NIH brings together research groups from community



ORDR Director Dr. Stephen Groft gave the opening remarks at Rare Disease Day 2013.

The National Center for Advancing Translational Sciences Office of Rare Diseases Research and the Clinical Center organized NIH's third annual observation of Rare Disease Day, bringing together research groups from NIH institutes and centers, partner federal agencies, as well as others from across the rare disease community for a symposium held in Natcher Conference Center February 28-March 1.

In opening remarks, ORDR Director Dr. Stephen Groft spoke of the importance of collaborative efforts between patient advocacy groups, scientists at federal agencies, academic researchers and industry in addressing the treatment of rare diseases, and NCATS Director Dr. Christopher P. Austin noted that "Translation is a team sport, and has to be approached that way."

Highlighting the importance of rare disease research for general medicine, in his remarks Dr. John I. Gallin, CC Director and NIH Associate Director for Clinical Research, quoted the 17th century British physician, William Harvey, who wrote, "... nor is there any better way to advance the

proper practice of medicine than to give our minds to the discovery of the usual law of nature, by careful investigation of cases of rarer forms of disease."

The event focused on new technologies, such as the NCATS Tissue Chip program; new rare disease patient registry efforts; and the value of incorporating patient-reported information in clinical study results.

A panel discussion featuring Jessica Wapner (author of *The Philadelphia Chromosome: A Mutant Gene and the Quest to Cure Cancer at the Genetic Level*), and Susannah M. Cahalan (*Brain on Fire: My Month of Madness*) was followed by a screening of the film *Here. Us. Now*.

The Genetic and Rare Diseases Information Center (GARD), a joint initiative of the NCATS ORDR and the National Human Genome Research Institute (NHGRI) was highlighted at one of the exhibit booths. At GARD, trained information specialists and genetics counselors are available to help those seeking to learn about rare diseases, with information provided in "patient-friendly language." Information is available here: <http://rarediseases.info.nih.gov/GARD> or at 888-205-2311.

A video of the event is available for the first day at <http://1.usa.gov/Y6PDNg>, and the second day at <http://1.usa.gov/ZxffQb>.

Did you know...

- Nearly 7,000 rare diseases affect approximately 25 million Americans.
- It is estimated that about half of all rare diseases affect children.
- What researchers learn by studying rare diseases often adds to our basic understanding of common diseases.



Dr. Juan Lertora

Dr. Juan Lertora receives PhRMA Foundation Award

Dr. Juan J. L. Lertora, director of the Clinical Pharmacology Program at the NIH Clinical Center, is the 2013 recipient of the Pharmaceutical Research and Manufacturers of America Foundation Award in Excellence in Clinical Pharmacology.

Since 2006, Lertora has managed the NIH Principles of Clinical Pharmacology course for NIH trainees, staff scientists and national and international distance learning partners. He also oversees special training programs in clinical pharmacology for postdoctoral fellows, residents and medical students, and serves as a consultant for NIH investigators implementing clinical drug development trials.

In 2008, Lertora received the NIH Clinical Center Director's Award for Teaching and Training in recognition of his management of the Principles of Clinical Pharmacology course, as well as his efforts to establish elective rotations at the FDA, introducing NIH clinical research trainees to the regulatory sciences. In July 2010, Lertora was recognized by the NIH Director with the Ruth L. Kirschstein Mentoring Award.

The PhRMA Foundation advances drug discovery and health care by supporting the careers of pharmaceutical scientists, educators and physicians. The award program honors former Foundation grant recipients for outstanding career achievements.

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NIH Director Dr. Francis S. Collins presents Rita Dove with the J. Edward Rall Cultural Lecture certificate for outstanding cultural accomplishments and lecture.

Dr. Alter honored

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Canadian scientists in mid-career and a medical advisory board composed of 24 senior scientists from across Canada, the U.S., Europe, Australia, and Japan. To date there have been 313 awardees, of whom 80 have gone on to win a Nobel Prize in Medicine.

Alter earned his medical degree at the University of Rochester Medical School and trained in internal medicine at Strong Memorial Hospital, Rochester, and at the University Hospitals of Seattle. He came to the NIH Clinical Center as a senior investigator in 1969. In 2000, he received the prestigious Lasker Award for clinical medical research, and in 2002 he became the first Clinical Center scientist elected to the National Academy of Sciences and the Institute of Medicine in the same year. Only a small number of scientists nationally are elected to both of these prestigious scientific societies.

To view a video of Dr. Alter describing his work in hepatitis research, visit the NIH YouTube channel at <http://youtube.com/user/NIHOD>. For education and research information on hepatitis <http://digestive.niddk.nih.gov/ddiseases/pubs/viralhepatitis/>. For information on treatment practice, prevention, and surveillance <http://www.cdc.gov/hepatitis/>.

Poet Laureate Rita Dove visits Clinical Center

On March 13, Rita Dove, author of nine books of poetry, visited the Clinical Center and spoke at the annual J. Edward Rall Cultural Lecture. After being introduced by NIH Director Dr. Francis S. Collins, Dove read selections from her newest work, *Sonata Mulattica*, a poetic treatise on the life of 19th-century Afro-European violinist George Polgreen Bridgetower. Dove has served as U.S. Poet Laureate (1993-1995), and she received the 1987 Pulitzer Prize in poetry.

Lecture explores a medical mystery: what caused Mozart's death?

What caused the untimely death of one of the greatest musical geniuses who has ever lived? This was the fascinating question explored at the Contemporary Clinical Medicine: Great Teachers lecture on March 13.

Ever since Mozart died in 1791, there has been a lively controversy surrounding the cause of his death. After a performance of the first movement of Mozart's String Quartet #19 by the NIH Philharmonia String Quartet, the invited lecturer, Dr. Philip A. Mackowiak, chief of the Medical Care Clinical Care Center at the VA Maryland Health Care System and professor and vice chairman of the Department of Medicine at the University of Maryland School of Medicine, told the story of how he had explored this more than 200-year-old mystery.

In introducing Mackowiak, Dr. Theo Heller (NIDDK) noted the numerous awards and honors Mackowiak has received, including many for his teaching and mentoring activities. Mackowiak is also the author of several books: *Fever: Basic Mechanisms and Management*; *Post-Mortem: Solving History's Great Medical Mysteries*; and *Di-*

agnosing Giants: Solving the Medical Mysteries of Thirteen Patients Who Changed the World, soon to be published by Oxford University Press.

Many theories as to what caused Mozart's final illness have been advanced, among them poisoning, syphilis, acute rheumatic fever, and trichinosis. Mack-

owiak explained how he used his medical knowledge to systematically rule out each of these theories, and how he arrived at his own: poststreptococcal glomerulonephritis.

The music and lecture were recorded and can be seen on the NIH videocast website at <http://videocast.nih.gov>.



Before learning about "Mozart's Fatal Anasarca," listeners were treated to a rendition of the first movement of Mozart's String Quartet #19 in C Major ("Dissonance"), performed by the NIH Philharmonia string quartet (Richard Siegel, sr. investigator, NIAMS, violin; Marijean Miller, assoc. prof., Pediatric Ophthalmology, Children's National Medical Center, violin; Mark Little, sr. investigator, NCI, viola; and Jeffrey Pier, program officer, National Science Foundation, cello).



MRSP conducts interviews with future fellows

March 4, 2013—The National Institutes of Health Medical Research Scholars Program conducted interviews with 91 potential candidates from 49 U.S. accredited universities for 2013-2014. MRSP is a comprehensive, year-long research enrichment program designed to attract the most creative, research-oriented medical, dental, and veterinary students to the intramural campus of NIH in Bethesda, Md.

The 2012-2013 MRSP year-end scientific presentations will occur May 13 and 14 in Lipsett Auditorium. Visit <http://clinicalcenter.nih.gov/training/mrsp/index.html> for more information.

NIH Information Security & Privacy Awareness refresher courses to be launched in April 2013

There is a direct relationship between the privacy and security controls necessary to safeguard Personally Identifiable Information and Sensitive Information. As a biomedical research organization that provides patient care in the Clinical Center, NIH staff must be informed of some of the provisions of the Health Insurance Portability and Accountability Act, or HIPAA, which requires that we safeguard Protected-Health Information. NIH cannot have an effective privacy policy without a basic foundation of information security.

To help educate staff on how to properly secure NIH information resources and protect the privacy of individuals to whom data pertains, the FY13 Annual Security and Privacy Refresher courses are being launched together. These two courses reside on the same website and some staff members have commented that because the courses are similar, they become confused as to whether they have completed the proper course. Additionally, privacy awareness training has now been provisioned in the same way in which security awareness training is set up, which means it is required prior to the creation of an Active Domain account, and annually thereafter.

Completion of the annual NIH Information Security and Privacy Awareness Refresher courses will provide valuable knowledge of your responsibility to secure NIH resources and protect all forms of personal information, whether it belongs to you, a member of the public, a grant applicant, research study participant or patient of the NIH Clinical Center.

In April, staff will be notified by the CC Information Systems Security Officer and Privacy Officer that training must be completed by June 15. Staff who have significant IT security responsibilities may also be asked to take—or certify they have taken—appropriate role-based security training.

For questions concerning the mandatory online training requirements for either annual privacy or security awareness training, please contact:

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Phone: 301-402-6201
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Upcoming Events

April 22 is Earth Day

Think RECYCLE on Earth Day and every day! Hint #1: Many items previously not recyclable—like yogurt containers (rinsed) and plastic bags—can now be recycled as “Commingled Goods.” Hint #2: Toner cartridges have their very own recycling container—look for them, and use them. (NIH Charities get \$1 for each toner cartridge placed for recycling!)

Let’s all join in and work a little harder to recycle, shall we? More information is available at <http://nems.nih.gov>.

Take Your Child to Work Day

April 25, 2013

9:00 a.m. – 4:00 p.m.

The NIH will host its 18th annual Take Your Child to Work Day. NIH staff are invited to bring school-aged children grades 1-12 to the NIH campus, and engage them in a day of healthy discovery. Registration is required. This is your opportunity to showcase what you do, as well as the shared mission of the nation’s medical research agency. For more information e-mail: Take-Your-Child-To-Work@nih.gov.

I ♥ Clean Hands Day!

Information Fair & Expo

May 21, 2013

10:00 a.m. – 1:00 p.m.

Join in for the second annual “I ♥ Clean Hands Day!” at North Atrium Hall in the Hatfield Building.

Event sponsors, the Clinical Center Epidemiology Department and the Clinical Center Hand Hygiene Isolation Innovation Team, are holding the event to encourage infection control best practices among staff members, patients, and their families. Come learn more about when, where, why and how to fight disease through proper hand hygiene.

New autism study on toddlers

Researchers are conducting a study on language delays in toddlers 10 to 20 months old. This study seeks to learn the risk factors for autism by studying the behavior and brain functioning of toddlers with early communication delays as well as typically developing toddlers. Toddlers from 10 to 20 months with limited vocalizations or words and typically developing toddlers may be eligible to participate. Please call 1-866-444-2214 (TTY-1-866-411-1010). www.clinicaltrials.gov and refer to study 11-M-0144.