

- Survey shows staff satisfaction with work, desire for additional resources & more leadership support
- CC employee chases dream, changes career

Gallin appointed to new leadership position

Duties designed to strengthen strategic planning, prioritization, scientific review

For more than two decades, while under the leadership of director Dr. John I. Gallin, the NIH Clinical Center achieved scientific advances that are saving hundreds of thousands of lives, pioneered countless patient-centered initiatives and trained the next generation of clinician-scientists. This January, Gallin will complete a transition from hospital director to a newly created role as NIH Associate Director for Clinical Research and Chief Scientific Officer for the Clinical Center, where he can leverage his unparalleled experience to tackle a number of emergent challenges facing both the hospital and the Intramural Research Program.

As a world renowned research institution, a regular host to presidential visits, and the only hospital to ever receive a prestigious Lasker Award, the Clinical Center's record of success with Gallin at the helm is perhaps too long to list here, but some key institutional milestones include; overseeing the design and activation of the Clinical Research Center; the establishment of a curriculum for clinical research training that is replicated around the globe; and the development of information systems for biomedical translational and clinical research. All the while, the Clinical Center remained at the vanguard of fighting the world's most vexing public health crises, from AIDS to Zika.

Last August, Gallin began transitioning to his new job even while continuing as director of the Clinical Center. He will complete the transition once the new Clinical Center Chief Executive Officer, Major General James K. Gilman, M.D., U.S. Army (Retired), begins in early 2017 (see coverage in upcoming January *CC News*).

NIH Director Dr. Francis Collins decided to alter the Clinical Center's longstanding leadership structure in response to recommendations in the Red Team Report. The report was developed by external members of an NIH working group in hopes to better reduce risk and promote patient safety in the hospital.

Notably, in his newly created position, Gallin will play a major role in developing a systematic approach to distributing resources within the Clinical Center. His

specific duties will include:

- managing the scientific review process for clinical protocols conducted within the 18 institutes and centers that utilize the hospital within the NIH Intramural Program;
- setting priorities for clinical research across institutes and centers to ensure stewardship of the scarce resources within the Clinical Center;
- reviewing institutes and center directors new oversight responsibilities of their clinical directors;
- supervising the independent research programs of Clinical Center investigators;
- overseeing the strategic planning process for Intramural Clinical Research;
- developing strategic partnerships with the extramural community to expand and foster new collaborations; and
- overseeing clinical research training programs at NIH.

The Clinical Center's Office of Protocol Services and the Biomedical Translational Research Information System (BTRIS), as well as the Bench-to-Bedside grants program, will be under the purview of Gallin's new office.

Gallin, who is a rare disease expert and member of the National Academy of Medicine, will report to the NIH director and will interact closely with the institute and center directors throughout the Intramural Research Program. Gallin is expected to maintain offices in both Building 1 and the Clinical Center.

Collins said in a staff-wide email in August that Gallin's new position "is essential to ensuring that NIH continue its record of extraordinary scientific accomplishments in a world-class clinical research setting."

In September, Gallin, who still operates a research lab at the Clinical Center, spoke at an NIH Town Hall about the pending leadership changes.

"I look forward to how we can improve our clinical research here at the Clinical Center, and I want to thank you again for all you have done to make this place so special," Gallin said. "I look forward to pursuing this new adventure with you, and I hope to be able to count on your continued support."



Dr. John I. Gallin (second, from left) accepts the Lasker ~ Bloomberg award Sept. 23, 2011, on behalf of the Clinical Center and the NIH. More details: <http://go.usa.gov/x8vgK>



Dr. John I. Gallin (right) welcomes patient Marcos Arrieta to the pediatrics unit in the new Hatfield Clinical Research Center April 2, 2005. More details: <http://go.usa.gov/x8v2q>



On Aug. 5, 1995, President Bill Clinton (center) takes a tour of the NIH Clinical Center with Dr. John I. Gallin (right). More details: <http://go.usa.gov/x8vjim>

The sweet smell of gingerbread houses fill the atrium



From left: World-renowned cellist Yo-Yo Ma, who visited Building 10 to present the Annual J. Edward Rall Cultural Lecture, enjoys the Cancer Moonshot themed gingerbread house with NIH Director Dr. Francis S. Collins, as CC Director Dr. John I. Gallin looks on; the Star Wars Ewok Christmas Dogs N-Cats entry; the Dog Genome Project entry.

Fifty-five entries in the 13th Annual Gingerbread House Decorating Contest are on display in the Clinical Center atrium. Created by NIH staff, the houses were judged by employees, patients and visitors with paper ballots and on Facebook (<http://bit.ly/2gE2nd3>). The National Human Genome Research Institute Dog Genome Project en-

try (above, center) was the first place paper ballot winner and the Ewok Christmas Dogs N-Cats by a team from the National Center for Advancing Translational Science (above, right) was the first place Facebook winner.

Entry themes ranged from recent movies, such as Trolls and Zootopia, to medical-related messages, such as the importance of

diversity in the sciences and mental health.

Kari Wheeler, a clinical research nurse and gingerbread house entry contributor, said, "This was a huge group effort! While it was a challenge, it was nothing compared to the challenge our patients face with their illnesses. I hope the house brings them and others visiting joy and comfort."

Clinical Center employee chases dream, changes career

After 18 years of working at NIH, Lisa Krueger has just accomplished what many only dream of – she has earned a college education by attending school part-time over the past five years and has made a dramatic career change from an administrative assistant to a nurse resident in the NIH Clinical Center.

Krueger, a former assistant for Dr. David Henderson, the CC deputy director for clinical care and associate director for hospital Epidemiology and Quality Improvement, is now a nurse resident on 5SE. On the unit, she cares for patients with infectious diseases, rheumatologic and immune disorders as well as patients with sickle cell disease and pulmonary disorders. She began working at the NIH with the Student Temporary Employment Program in the National Human Genome Research Institute while she took college courses and also worked in the NIH Clinical Center's Critical Care Medicine Department with Dr. Henry Masur.

"I was unsure of what I wanted to do, so I eventually stopped taking classes altogether. After working with the Office of the Deputy Director for Clinical Care for a few years, I was inspired by Dr. Henderson, Laura Lee (director of the Office of Patient

Safety and Clinical Quality) and other nurses to go back to school, to become a nurse and to have a hands on role in patient care," she said. "I started at community college and then moved on to the University of Maryland School of Nursing."

She graduated with a degree in nursing in December 2015 and was hired in the CC Nursing Department in October 2016. As a new graduate of a nursing program, she was also selected to participate in the Clinical Research Nursing Residency Program (see related photo/caption on page 6).

"Working toward this degree was the biggest challenge of my life. It was very difficult at times to balance work, classes, clinical hours, studying and my family life," she said. "Now, to have the amazing opportunity to continue my work here at the Clinical Center as a nurse resident, I am beyond thrilled and honored to be a part of the Nursing Department."

Krueger went on to say she could not picture herself working as a nurse anywhere else besides the CC.

"I wanted to turn my job into a career, focusing on patient care and patient safety. My first day working on the unit was a bit

of a culture shock. I was always aware I worked in a hospital, but it didn't really sink in until I was actually on a patient care unit and in a patient room. I felt a great sense of accomplishment that my work over the years at NIH and in nursing school, were finally coming together as one."

While pursuing this degree took hard work, Krueger recommends other staff follow their dreams if they're thinking of a career change.

"My advice to anyone thinking about pursuing a drastic career change would be to not doubt yourself or your abilities, to lean on friends, family and colleagues when you need to, and to persevere!"



Lisa Krueger, a new nurse in the NIH Clinical Center, conducts a neurology exam to test the strength of patient Nathan Swaney's extremities.

Read more online! Scan the barcode or visit www.cc.nih.gov/about/news/newsletter.html



- A celebration of Nurse Practitioners, who are a crucial part of the patient care team
- California radiogenomic expert presented annual Doppman Memorial Lecture

Use a downloaded app on a smartphone or tablet to scan the Quick Response (QR) barcode. You will be directed to the CC News online.

Clinical Center News

Editor: Molly Freimuth

Contributors: Cindy Fisher, Donovan Kuehn, Maria Maslennikov, Rachel Wolf

National Institutes of Health Clinical Center
10 Center Drive, Room 6-2551
Bethesda, MD 20892-1504

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Contact: 301-594-5789
Molly.Freimuth@nih.gov



Dr. Paul Farmer, founder of Partners in Health, speaks at NIH on global health equity, visits pediatric patient from Peru



Dr. Paul Farmer (center on bed), guest speaker at the 2016 Barmes Global Health Lecture, visits pediatric patient Melva Fernandez Quispe (left on bed) and her father Carlos Fernandez Suni (right on bed). Farmer was joined by Dr. Francis Collins, director of NIH (standing second from right) as well as staff from NIH and Partners In Health.

In late November, 7-year-old pediatric patient Melva Fernandez Quispe and her father, Carlos Fernandez Suni, received a special visit in their NIH Clinical Center room from Dr. Paul Farmer, co-founder and chief strategist of Partners In Health (PIH). PIH, a non-profit organization that delivers health care in low-resource settings, helped to treat Melva at home in Peru, and PIH care providers reached out to NIH doctors to see if Melva could participate in a clinical trial (<http://go.usa.gov/x8ReE>).

"A doctor that is involved with Partners in Health contacted me to see if we could help her. She has a rare immunodeficiency that predisposes her to mycobacterial infections," said Dr. Alexandra Freeman, a National Institute of Allergy and Infectious Diseases pediatric infectious disease specialist caring for Melva. "Dr. Farmer just lit up being able to interact with the patient and her father

and discussing with the group, the child's treatment."

Farmer was at the NIH Clinical Center to present the 2016 David E. Barmes Global Health Lecture in Masur Auditorium. His lecture, titled "Against Balkanization: Research + Training + Care = Global Health Equity", drew more than 500 attendees. Farmer discussed HIV/AIDS therapy treatment and its cost, specifically in rural Haiti, and the spread of Ebola and emergency response.

"When you have the staff, stuff, space and systems that you need, not only can you do better research to find out what's going on, you can actually make a great difference in people's lives," Farmer stated.

The lecture series honors the late David Edward Barmes, special expert for international health at the National Institute of Dental and Craniofacial Research (NIDCR). View the lecture, sponsored by the NIDCR and the Fogarty International Center: <http://go.usa.gov/x8ReA>

Annual government survey shows staff satisfaction with work, desire for additional resources and more leadership support

According to the 2016 Federal Employee Viewpoint Survey (FEVS), administered by the U.S. Office of Personnel Management in May, NIH Clinical Center employees enjoy their work but say they need more resources and leadership support. Over 700 CC federal employees participated in the FEVS survey this year. It is a key tool used to measure Federal Government employees' perceptions about their work experiences, organizations and leaders. The survey was sent to full- and part-time permanent federal employees.

The FEVS had some questions that were similar to the CC Employee Survey, administered to employees in February 2016. But the two surveys are very different feedback mechanisms. The FEVS is a broadly written survey sent annually to all federal employees. The CC Employee Survey was written specifically for CC staff in Building 10 and compared its results to U.S. hospital employees and other U.S. employees.

Compared to the 2015 survey results, this year's survey showed a 6% improvement in how satisfied CC employees are with their pay. In addition, 9% more

participants than last year believe that the CC has prepared employees for potential security threats. Since the 2015 survey, there have been areas in which employee satisfaction decreased by 5% or more. These areas include: the workforce has the job-relevant knowledge and skills necessary to accomplish organizational goals, high level of respect for the organization's senior leaders, sufficient resources to get the job done and employees are protected from health and safety hazards on the job.

Less than half of CC employees who responded to the survey believe that the results will be used to make their agency a better place to work, similar to the results of the CC Employee Survey. In an effort to mitigate this concern, Dr. John I. Gallin, director of the NIH CC, will share the results with the new Chief Executive Officer, expected to be announced and in position in 2017, to assist in developing strategic and operational planning. In addition, the CC's Office of Workforce Management and Development will provide each CC department head with a copy of their individual survey results to help encourage discussions and action.

Federal Employee Viewpoint Survey Highlights

(Percentage listed are respondents who agree with the statement)

Successes

- When needed, I am willing to put in the extra effort to get the job done (97%)
- The work I do is important (94%)
- I know how my work relates to the agency's goals & priorities (87%)
- I like the kind of work I do (87%)

Areas for Improvement

- Pay raises depend on how well employees perform their jobs (30%)
- Promotions in my work units are based on merit (36%)
- In my work unit, steps are taken to deal with a poor performer who cannot or will not improve (37%)
- Similar to the CC Employee Survey, employees expressed some dissatisfaction with their opportunities to get a better job in their organization (37% are satisfied)

Survey details, including detailed CC results (Staff Only): <http://go.usa.gov/x8UPH>

Five NIH grants awarded for collaborative research in the CC, across the U.S.

Five new innovative research projects, recently funded by the NIH, will soon bring together NIH intramural researchers with researchers from institutions across the nation. Collaboratively, these top scientists will conduct promising new protocols within the NIH Clinical Center, jointly utilizing some of the broad resources the research hospital can offer.

The research projects are an outcome of the third round of awards given through the granting mechanism Opportunities for Collaborative Research at the NIH Clinical Center (U01). The five collaborative projects will broaden and strengthen the scope of clinical research beyond the work of separate, individual institutions. Ten awards were made in 2014 (<http://go.usa.gov/xkeGq>), and an additional 10 in 2015 (<http://go.usa.gov/xkefh>).

These three-year, renewable grants allow for up to \$500,000 in direct costs per year. The partnerships will ensure full access to NIH Clinical Center's innovative facilities, equipment and technology.

This year's awards will support the following research (<http://go.usa.gov/xkeG2>):

- Exploring a new therapy for cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL), a neurological disease that can lead to migraines, dementia or death
- Assessing if short-term antibiotic use will affect the healthy bacteria found in the body as well as the subjects' metabolism and immunity
- Analyzing the effectiveness of Prostavac, a cancer vaccine, to help men who have recurrent prostate cancer
- Understanding Lymphangi leiomyomatosis (LAM), a destructive multi-system disease in women, to create better treatments
- Developing new therapies for patients with Neurofibromatosis type 1 (NF1) and malignant peripheral nerve sheath tumors (MPNST),

which are highly aggressive and can spread throughout the body

In early 2017, the NIH will announce recipients of the fourth set of awards within the U01 program. This cohort will receive awards that are, for the first time, four-year renewable grants. Previously, they were renewable over three years. In addition, applicants from both domestic and foreign institutions were eligible to apply.

Cycle 5 applications are due April 11, 2017. Interested applicants can visit: <http://go.usa.gov/xkefJ> or contact ClinicalCtrPartner@mail.nih.gov. More on the U01 program: <http://go.usa.gov/xkeGx>



Left, intramural researchers from the National Cancer Institute (from left to right) Drs. Bill Dahut, James Gulley, Peter Choyke, Jeff Schlom, Ravi Madan and Baris Turkbey gather near a PET scanner used in the NIH Clinical Center to measure the effects of immunotherapy on recurrent prostate cancer. Their project is funded by the U01 program at the NIH Clinical Center and is done in collaboration with, pictured on the right, Drs. Gwo-Sho Mary Lee, Ying Mazzu, Kazumasa Komura, Philip Kantoff, Goutam Chakraborty and Shin-Yi Du, from the Dana Farber Cancer Institute.



Drs. Martin Blaser, Tom Battaglia, Guillermo Perez and Lama Nazzal work in their New York University School of Medicine laboratory studying the effects of antibiotics on the healthy bacteria in the human body. Their project, funded by a U01 grant by the NIH, is done in collaboration with Drs. Steven Holland and Emilia Falcone, National Institute on Allergy and Infectious Diseases intramural researchers who work in the Clinical Center. Photo credit: Troi Santos

Hooray for Caregiver's Day! NIH celebrates people who provide patient support



Candace Campbell, who's participating in a clinical trial at the CC, and her husband and caregiver Eric Campbell, pose in the caregiver day photo booth.

In recognition of National Family Caregiver Month, the NIH Clinical Center held the 7th Annual Family Caregiver Day Nov. 15. CC departments and outside organizations shared resources, services and hosted a variety of interactive workshops for family caregivers. In addition, caregivers and patients, including Candace Campbell and her husband/caregiver Eric Campbell (seen left), posed in a photo booth and held up a white board to display what caregiving means to them.

Capt. Dr. Margaret Bevans, a clinical nurse scientist within the

Nursing Department who helped organize the event said, "We served approximately 150 individuals, the majority of whom were caregivers of patients at the CC as well as staff who serve as family caregivers. The wellness activities, including stress reduction services, were most attended. It is common for family caregivers to report feeling stressed and overwhelmed and the music-filled space provided a temporary sanctuary albeit for a brief moment in their day!"

Caregiver resources: <http://go.usa.gov/x8FJc>. Caregiver Facebook page: <http://bit.ly/2gEEH4L>

Travel Office connects patients with cures

Imagine you've been diagnosed with a rare disease that doctors see in one out of 200,000 patients. Your physician has reached out to the NIH Clinical Center in Bethesda, Md., and you have been accepted into a clinical trial at one of the world's most prestigious research hospitals. You're feeling a mix of emotions: relief, anxiety and curiosity. But the next big question is, "How do I get there?"

If you live close to the Clinical Center, the answer is easy: hop into your car or onto the transit system that connects Maryland, Virginia and the District of Columbia. But if you aren't nearby – like almost 10,000 patients in the 2016 fiscal year – getting to the hospital for treatment may be a challenge.

Fortunately, patients don't have to figure out travel details on their own. The Clinical Center has an onsite Travel Office located on the first floor, near Admissions, that works with patients. Contracted through Omega World Travel, the office has four full-time travel agents and one supervisor who serves as a backup travel agent. One member of the team is fluent in Spanish, reflecting the needs of an increasingly diverse patient population. With over 19,000 trips booked in fiscal year 2016, the office is busy.

The office can arrange airline and Amtrak rail travel for patients and authorized medical guardians. Hotel reservations are not in the purview of Omega Travel's patient services.

For eligible participants, travel is paid for as a part of the research protocol in which the patient is enrolled. The research team may determine that a medical escort

is also required to accompany the patient. The office works with families to also ensure that they can coordinate and travel together.

"We are committed to booking the lowest government fare available while also trying to help families travel together. A lot of the people coming to the Clinical Center are very sick and need assistance as they travel to the hospital," said Barbara Stevenson, Omega World Travel's manager of the patient travel office at NIH.

The office also helps figure out many health-related details unfamiliar to most travel agencies. Many people travel with service animals, but commercial airlines only allow one assistance animal per plane; airlines have guidelines that govern the use and transportation of oxygen canisters; many patients have impaired mobility and need assistance to get around airports and on and off of the plane.

Staff at the office often share travel tips about the local airports (Washington National, Dulles and Baltimore Washington International) and work hard to make arrivals and departures coordinate seamlessly with the NIH shuttle connections that run to the local airports.

The staff strive to be flexible. Since patients enrolled in clinical studies are often facing their last hope for treatment, it isn't always possible to predict how someone who is ill will respond to a medical procedure or new medication. The staff respond dynamically to patient needs and shifting schedules and can accommodate last-minute adjustments that often result from patients' medical care. If patients

end up with unexpected long-term stays, they can be connected with resources available from the Social Work Department.

Patients appreciate the important work of the office, and the staff have a sense of connection as many patients return for follow-up care. Staff require poise and thoughtfulness since they deal with patients at different stages of their illness: new diagnoses, ongoing treatment and discharge.

Robert Richardson, who is participating in a prostate cancer trial, greatly relies on the services of the

9/11 survivor discusses challenges, inclusion



On Nov. 14, the Clinical Center hosted 9/11 survivor Michael Hingson, in an event sponsored by the NIH Section 508 Program in partnership with the independent blind and low-vision resource sharing group, 3 Blind Mice. Hingson, who has been blind since birth, was working in the World Trade Center Building One, on Sept. 11, 2001. He walked down 78 flights of stairs with his guide dog Roselle and escaped the worst terror attack on American soil. He discussed his experiences on that day, along with the power and potential of people who have disabilities and the need to avoid making assumptions about people's capabilities. Hingson is pictured with his current guide dog, Africa, above. View the videocast (HHS staff only): <http://go.usa.gov/x8mJc>

Travel Office.

"I've been coming up so much – every three weeks – for six and a half years. You get to know [the staff here, over time.] It's...like family."

As a token of his appreciation, Richardson bought brownies for the office.

Stevenson, who has been with Omega Travel at the NIH since 2002, recalled one family who went through a gamut of emotions. The husband came in for cancer treatment with his wife serving as caregiver. Treatments led to his eventual cure. Then he and his wife reversed their roles of caregiver and patient when his wife subsequently developed lung cancer and was enrolled in a different protocol.

Stevenson summarized her experiences: "It's an incredibly rewarding job. The best feeling is when someone comes into your office and says, 'I'm cured.'"



Gabby Nadjimbadi, with Omega Travel, assists Robert Richardson with his flight to Panama City, Fla. Robertson's appointment in November marked his 114th visit to the Clinical Center as a part of a prostate cancer trial.

Dr. Nicholas Patronas, CC neuroradiology section chief, retires

Dr. Nicholas Patronas, chief of the Section of Neuroradiology in the NIH Clinical Center Radiology and Imaging Sciences Department, retired Sept. 30. Patronas is a distinguished leader in the neuroradiology field for three decades.

Patronas arrived at NIH in 1981. Initially, he worked as a fellow in the National Institutes of Neurologic Disorders and Stroke on the new imaging modality at the time called Positron Emission Tomography (PET). He has served as a staff radiologist at the CC and as a professor of radiology at Georgetown University. He returned to NIH, as a contact radiologist and then became a federal employee in 1996.

At the CC, he was key in the creation of the section of neuroradiology, and, jointly with Georgetown University and George Washington University, he helped establish a neuroradiology training program. Throughout his career, Patronas taught medical students, residents and fellows and advanced medical knowledge.

He authored or co-authored over 250 papers in peer reviewed journals and in book chapters. His work has been cited over 22,000 times. Among his most commonly cited publications are the original observations that PET imaging plays an important role in the diagnosis and grading of tumors. Commonly cited work also includes observations related to PET scanning in Alzheimer's disease and in epilepsy. The publications related to diffusion and perfusion magnetic resonance imaging (MRI) are significant contributions pointing to the value of these MRI modalities in the study of various diseases in the central nervous system.

At a retirement celebration in October, Patronas expressed his thankfulness for the opportunity to work and participate in the research effort of many other scientists.

"This is a great institution because we have made a lot of contributions to the management of patients and in promoting the field of imaging," he said. "Results cannot be done by one person. You have to have a team that is dedicated and works together."

He acknowledged technologists and administrative staff for their support. He also thanked Dr. John I. Gallin, director of the CC, and Dr. David Bluemke, director of the Radiology and Imaging Sciences Department.

In retirement, Patronas serves as a special volunteer helping to analyze imaging data.

Five recent graduates of nursing school complete Clinical Research Nursing Residency Program



On Oct. 19, the Clinical Center Nursing Department celebrated the graduation of the Clinical Research Nursing Residency Program's third cohort of trainees. Pictured above, from left to right, trainees Debbie York, Faith Gill, Sayaka Simmons, Joe Shadrick and Lonice Carter with Rachel Perkins, program coordinator. The yearlong residency program will commence its fourth class in December. Successful residents graduate from the program with the skills, experience and knowledge required to provide high-quality care to research participants in the clinical research setting.

Over \$2,500 raised for charity at CFC bake sale



The seventh annual CC Combined Federal Campaign (CFC) bake sale took place Oct. 19 and collected around \$2,700 for charity. The event raised awareness about the CFC, which allows federal workers, retirees and government contractors the opportunity to donate to charity through December. Above, Kenny Williams (left) from the Office of Clinical Research Training and Medical Education purchases baked goods from Peter Conway and Meredith Beck from the Office of Administrative Management. Treats were baked and sold by staff from 26 different areas of the hospital. In addition, a baking competition was conducted.

Experts from NIH and the Middle East cure patient with rare tumor

In November 2015, Jumana, a teenage patient, arrived at the NIH seeking a cure for a rare disease that made her bones so fragile and muscles so weak that she was confined to her bed, barely able to lift her legs. Earlier this year, after a medical collaboration by NIH researchers and others around the world, Jumana was cured and is able to walk again.

The patient, who traveled nearly 6,000 miles from her home in the Palestinian territories to the Clinical Center, had a disease called tumor-induced osteomalacia (TIO). TIO is caused by a rare endocrine tumor that secretes FGF23, a hormone that regulates phosphate absorption and active vitamin D production. In high levels, as is seen in TIO, it causes low blood phosphate levels that leads to muscle weakness, bone pain and fractures.

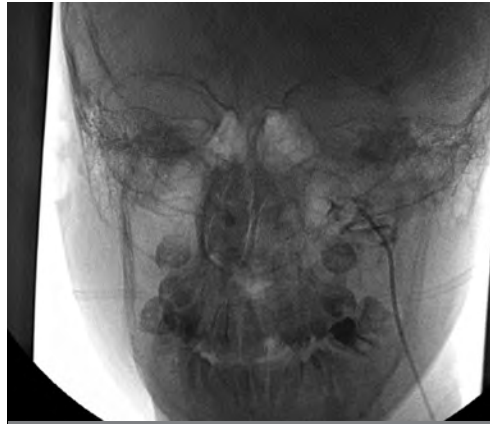
There are only a few places in the world with expertise in diagnosing and treating TIO. When clinicians in Israel diagnosed the condition in this patient, but couldn't find the tumor, they called Dr. Michael Collins, chief of the Skeletal Clinical Studies Unit for the National Institute of Dental and Craniofacial Research (NIDCR). Collins and his team took on the challenge of finding the tumor.

Other disorders caused by FGF23 disruption are the result of genetic glitches and usually reveal themselves early in life. The symptoms of TIO typically begin between the ages of 30 and 40, which means that when a teenager shows up with TIO, it can often be confused with the genetic form. The only way to make a sure diagnosis of whether high FGF23 is the result of a genetic glitch or acquired, which is what TIO would be considered, is to find the tumor. That, according to Dr. Collins, is akin to finding the proverbial needle in a haystack.

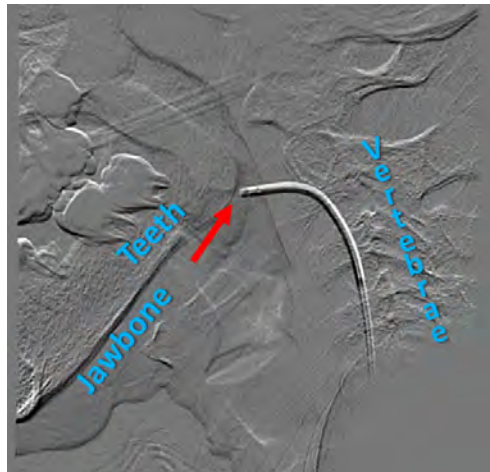
"Most of the tumors that cause TIO are about the size of a pea," says Dr. Collins, "and they can be in bone or soft tissue anywhere in the body – from head to toe. The fact that they can be anywhere and that they're small compounds is the difficulty in finding them."

Collins and his team, however, had developed a procedure under a NIDCR clinical trial that used a technique known as selective venous sampling (SVS) to measure levels of FGF23 in the small veins surrounding a potential TIO-causing tumor. As one gets close to the tumor, the levels of FGF23 in the veins gets higher, confirming that the suspected lesion is the tumor. Functional and anatomical imaging studies could turn up likely spots, but only SVS could make a positive identification.

According to Collins, there are only a few



NIH experts conduct selective venous sampling in the interventional radiology section of the hospital to identify the location of the TIO-causing tumor in the patient's upper jaw.



A tomographic x-ray, seen above, from the sampling procedure shows the patient's teeth, jawbone and vertebrae, along with the catheter which allows sampling from the patient's deep veins (the pterygoid plexus).

places in the world where venous sampling can be done for TIO.

"One of the limiting factors," he says, "is the need for an interventional radiologist who is skillful enough to guide a catheter about the size of a thread through the tiny veins that surround the tumor. Luckily, NIH has Dr. Richard Chang [from the NIH Clinical Center Radiology and Imaging Sciences Department] who can do that."

Once SVS had positively identified a tumor in Jumana's upper jaw bone, Collins and his clinical team began to explore what needed to happen next. Surgery would remove a large portion of her jaw, and a palatal obturator, a device used to cover the surgical opening to allow eating and drinking while the area healed, would have to be inserted.

After surgery, she would also require several months of reconstruction to rebuild her jaw, physical therapy to help her walk again and endocrinological follow-up to make sure that her levels of FGF23 return to normal.

Swiftly, Collins pulled together a multidisciplinary team of experts, centered at NIDCR, to review Jumana's case and its special requirements. Under the direction of Dr. Janice S. Lee, clinical director of NIDCR, Collins arranged a videoconference amongst NIDCR physicians, post-doctoral scholars and other clinicians to analyze the patient's case.

"Sometimes experts for these conferences are pulled in from outside NIH," said Lee. "When Dr. Collins came to us with this case, we already had the videoconferencing capacity so that everyone involved could see the imaging studies, records and whatever else we had to look through."

The review of Jumana's case involved experts around the world, including surgical and medical teams from Haifa and Nablus, the largest city in the Palestinian territories on the West Bank, Dr. John van Aalst, a plastic surgeon from Cincinnati Children's Hospital who already had ties to the region from regularly donating his surgical services to a hospital in Haifa, and additional NIDCR and NIH doctors who had experience with head and neck surgery. Together, the multinational group systematically thought through the entire process to identify areas of expertise and the procedures needed for surgical removal of the tumor and rehabilitation.

During this time, Jumana's family, who had traveled with her to the Clinical Center, explained that they had to get back home. Her father was the sole breadwinner in the family and couldn't afford to stay away from his job much longer. Help was provided to them by the United Palestinian Appeal, a Washington and members of St. Aphraim Syriac Orthodox church.

In January 2016, the family traveled back to Israel, and shortly thereafter a team of fifteen doctors from Israel and the Palestinian territories, including Aalst, performed the 90-minute surgery. Within a week of removing the tumor, Jumana was standing and several weeks after that she was walking again. She periodically sends videos to Collins to show him her progress.

"Once you take out the tumor that causes TIO, you've cured the disease," said Collins. "For patients with TIO and their doctors, it's extremely satisfying. We don't often get the chance to really cure."

For Lee, the case is a gratifying example of NIDCR's global presence.

"What happens around the world, also helps our patients here in the U.S." said Lee. "Our clinical team understands that these diseases have no boundaries; a rare tumor like this can be found anywhere in the world."

Former NIH trainee returns to lecture on leading cause of pediatric acquired heart disease

Dr. Adriana Tremoulet, alum of the NIH Clinical Research Training Program, came back to the NIH Clinical Center Nov. 9 as a guest speaker for the Contemporary Clinical Medicine: Great Teachers lecture.

Tremoulet, who completed the training program in 1999, now called the Medical Research Scholars Program (MRSP), is an associate professor and associate director at the Kawasaki Disease Research Center at the University of California San Diego Rady Children's Hospital.

"I used to sit in this auditorium as an MRSP fellow, and it's an absolute honor to be on this side of the podium today," she said.

Tremoulet spoke on Kawasaki Disease (<http://go.usa.gov/x8Rvu>), a childhood disease that's a form of vasculitis. The disease causes inflammation of blood vessels such as the arteries, veins, capillaries and even the coronary arteries – which can lead to serious heart problems. It occurs predominately in children of Pacific Island and Asian descent.

"It's often labeled as a rare disease but it is the most common cause of acquired heart disease not only here in the U.S. and Japan, but across the world," she said. "Our job as scientists and the family's job as parents is to make sure we do everything possible so that [patients] don't suffer."

Tremoulet presented a case on a 4-month-old patient with a rash and fever. The patient's mom had been told by numerous medical providers that he had a shellfish allergy, but "when you look closely [at his photo], you see red eyes, red lips – he had classic Kawasaki Disease," Tremoulet said.

She then discussed additional patient cases, diagnosis strategies and future treatment possibilities. Videocast: <http://go.usa.gov/x8RCS>

UNC professor presents Astute Clinician Lecture on autoimmune swelling of blood vessels

Dr. Ronald Falk presented the annual NIH Astute Clinician Lecture in early November in the NIH Clinical Center. Falk was introduced by Dr. Francis Collins, director of the NIH, who reflected on his experience learning alongside Falk in medical school.

"I found out during the four years of medical school Ron Falk was an exceptionally intelligent, thoughtful, hard-working, dedicated guy who was going to be undoubtedly a leading physician in the nation. And that turned out to be true," said Collins.

Falk is the chair of the Department of Medicine and a Nan and Hugh Cullman eminent professor at the University of North Carolina Chapel Hill. Through his lecture, "Perspective on Autoimmunity: A View from the ANCA Vasculitis Looking Glass," Falk discussed Anti-Neutrophil Cytoplasmic Autoantibodies (ANCA) vasculitis, a type of autoimmune swelling caused by autoantibodies. A person's immune system helps to fight germs by using normal antibodies in the blood. But some people have abnormal antibodies, known as autoantibodies that attack their cells and tissues instead

of protecting them. More specifically, ANCA autoantibodies attack a white blood cell known as a neutrophil. When this attack takes place, vasculitis, or the swelling of blood vessels, can occur in many different parts of the body.

"ANCA, which started as a biomarker of disease, is now the name of the disease. And it's resulting in earlier diagnosis, more prompt therapy and much better long-term results," Falk said. He added, "I want to thank the patients who have helped us. Patients can tell you three months ahead of time whether they are going to flare, whether they are flaring or whether they are in remission. They know. And that's the next huge question, what do they know that we can't find a biomarker to tell them?"

Videocast: <http://go.usa.gov/x8NVb>



The 2016 NIH Astute Clinician Lecturer Dr. Ronald Falk from the University of North Carolina Chapel Hill, talks about the importance of patients in the scientific process on Nov. 2.

Upcoming Events *View lectures online: <http://videocast.nih.gov>*

Hurry! Combined Federal Campaign

(CFC) is extended to Dec. 31, 2016. Visit the CC News online (<http://go.usa.gov/x9CNw>) to see the lengths Pharmacy deputy director Dr. Barry Goldspiel went to inspire participation: shaving his legendary moustache and dying his hair pink.

Neuroimmune Interactions in Health and Disease Seminar

Jan. 10, 2017, Noon – 1:30 p.m.

Lipsett Amphitheater

Presented by Dr. Jony Kipnis, University of Virginia School of Medicine. Sponsored by the Inflammatory Disease Interest Group.

Inflammation and Gene Regulation in Arthritis Seminar

Jan. 24, 2017, Noon – 1:30 p.m.

Lipsett Amphitheater

Presented by Dr. Lionel Ivashkiv, Weill Cornell Medicine.

The Various Roles of Nanoscale AMPA Receptor Dynamics in Synaptic Plasticity Seminar

Feb. 6, 2017, Noon – 1 p.m.

Lipsett Amphitheater

Presented by Daniel Choquet, University of Bordeaux.

Host-Microbiota Interactions in the Gastrointestinal Tract Seminar

Feb. 7, 2016, Noon – 1:30 p.m.

Lipsett Amphitheater

Presented by Dr. Wendy Garrett, Harvard School of Public Health.

Rare Disease Day at NIH

Feb. 27, 2017,
8:30 a.m. – 3:30 p.m.
Masur Auditorium

Sponsored by the NIH National Center for Advancing Translational Sciences and Clinical Center, Rare Disease Day raises awareness about rare diseases, affected patients and research collaborations addressing rare disease challenges. Event will feature presentations, posters, exhibits and an art show.



Aging and Inflammation Seminar

Feb. 28, 2017, Noon – 1:30 p.m.

Lipsett Amphitheater

Presented by Connie Weyand, Stanford Medicine.