

- Mindfulness program reminds staff to care for themselves
- Healthy volunteers endure mosquito bites to advance research



## Hospital honored for support to patients



Clinical Center Intensive Care Unit staff proudly display the award. The trophy circulated throughout the hospital for staff to enjoy the honor and be photographed.

The National Research Corporation (NRC) Health selected the NIH Clinical Center as a recipient of its 2017 Excellence Award. The Clinical Center earned the highest ratings in overall satisfaction by patients and their families in the category of Emotional Support, among 426 eligible facilities. Each year, NRC Health recognizes top-performing hospitals and health systems that have exhibited an exceptional commitment to understanding each individual patient's complete care journey.

"Compassion for our patients and their families is one of our guiding principles," said NIH Clinical Center CEO Dr. James K. Gilman. "Our staff understand that as a world class research facility we must provide the very best in safe, high quality patient-centric care and support. This is a particularly meaningful award in which every Clinical Center employee will take great pride."

The Excellence Awards recognized the CC, along with 29 other facilities, for receiving the highest ratings in overall satisfaction by patients and their families in a variety of categories from April 2016 - March 2017. The CC accepted the award in August at the 23rd Annual NRC Health Symposium for Patient-Centered Care in Boston.

Word of the CC receiving the award was met with applause on the hospital's popular Facebook page (<https://www.facebook.com/NIHClinicalCenter/>). Comments in response included "The emotional support our family received was outstanding," and "I give it an A+ for the care I got there."

More details: <https://go.usa.gov/xRA32>

## Robotic exoskeleton offers potential new approach to alleviating crouch gait in children with cerebral palsy

With a motor, sensors and electronic-technology-powered brace wrapped around their legs, several pediatric patients participating in a Rehabilitation Medicine clinical trial looked like characters from the movies *Iron Man* or *Transformers* – and more importantly, they felt like the superheroes they resembled. The patients, all of whom have cerebral palsy, walked with crouch gait, or excessive bending of the knees. In order to improve their walking, researchers led by staff scientist Dr. Thomas Bulea, created the first robotic exoskeleton specifically designed to treat crouch gait in children with cerebral palsy by providing powered knee extension assistance at key points during the walking cycle.

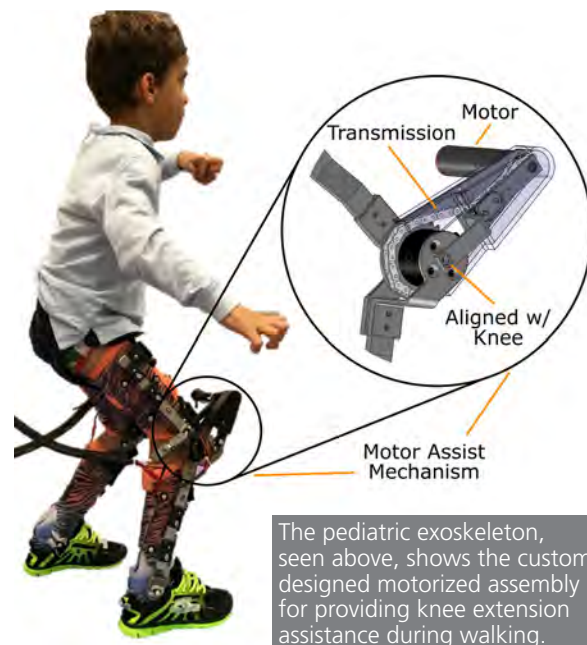
Crouch gait is a common and debilitating condition in children with cerebral palsy. Despite conventional treatments (including muscle injections, surgery, physical therapy and orthotics), crouch gait can lead to a progressive degeneration of walking function, ultimately resulting in the loss of walking ability in roughly half of adults with the disorder.

Bulea and his team are among the first to create a device like this for children.

"To date most wearable exoskeletons are intended for adults with paralysis, with the exoskeleton replacing the lost function of the user's muscles to restore walking ability. Rather than restoring lost function, our exoskeleton was designed to change the way children with crouch gait from cerebral palsy walk."

The exoskeleton helps children with crouch by tracking the natural movement patterns of their limbs and supplying motorized assistance for knee extension at the appropriate times of the walking cycle.

The majority of the children, ages 5 to 19, were able to improve their knee extension by up to 37 degrees while wearing the brace. According to Bulea, it was the first time in their life some of the parents had



The pediatric exoskeleton, seen above, shows the custom designed motorized assembly for providing knee extension assistance during walking.

seen their kids walk while standing that tall.

"Our results show that the exoskeleton can safely and effectively change the posture of a child while they wear it. The exciting part is that the children's muscle activity was preserved when they walked in this new way with the exoskeleton, suggesting that long-term use of this device might be a viable way to train a new walking pattern in this population."

Like all the research done at the NIH Clinical Center, the team in the Rehabilitation Medicine Department hopes that after the proper validation of the science, the technology will move out of the lab and into clinics amongst the general public.

"Ultimately, our goal is to have this device reach as many children who can benefit as possible," Bulea concluded. "We are also planning studies in children with more severe gait deficits from cerebral palsy who are therefore at elevated risk for declining mobility, as well as in other disorders such as spina bifida or muscular dystrophy."

Bulea's research was published in August in the academic journal, *Science and Translational Medicine*: <http://stm.sciencemag.org/content/9/404/eaam9145>  
More details: <https://go.usa.gov/xRA3c>

# NIH Clinical Center bids farewell to long-time employees this fall



**Frederick Ognibene**

After more than three decades at the Clinical Center, Dr. Frederick P. Ognibene, deputy director for Educational Affairs and Strategic Partnerships, and Director, Office of Clinical Research Training and Medical Education (OCRTME) retired Sept. 29.

Ognibene came to the NIH as a clinical fellow and was an active clinical investigator focusing on pulmonary complications of immunosuppressed patients as a tenured senior investigator and member of the senior staff in the CC's Critical Care Medicine Department. In

2003, he became director of the CC OCRTME and in 2009 expanded his portfolio as Clinical Center deputy director for educational affairs and strategic partnerships.

At a time when the number of clinician-scientists is declining, Ognibene focused the CC's efforts to support research-oriented medical and dental students through yearlong mentored research experiences, first through the NIH Clinical Research Training Program and then through its successor, the Medical Research Scholars Program. Research recently published in *Academic Medicine* (<https://tinyurl.com/ybsmmxxs>) showed that nearly two-thirds of scholars who had fully completed formal training were now conducting research for some percentage of their time as opposed to entering entirely into full-time practice of medicine.

One of Ognibene's final projects was to help initiate a still developing collaboration

between the NIH Intramural Research Program, the Walter Reed National Military Medical Center and the Uniformed Services University of the Health Sciences to share cutting edge medical care facilities and other resources while improving patient care, supporting collaborative research and expanding training opportunities.

"Well beyond half of my life has been spent here, so I don't leave in a lighthearted manner. I leave fulfilled, gratified, and very thankful," Ognibene said. "I never thought 35 years ago that my coming to the NIH as a fellow for a couple of years would turn into a career. I had the very good fortune to be in an environment where I was able to achieve excellent clinical training and gain excellent clinical skills as a critical care physician, while learning what my strengths are in research and taking those things collectively into my passion for education and training."

## Margaret Bevans

Dr. Margaret Bevans, clinical nurse scientist with the Nursing Department, has accepted a position in the NIH Office of the Director in the Office of Research on Women's Health where she will serve as associate director for Clinical Research.

Bevans will help implement the NIH Strategic Plan for Women's Health Research. She will oversee the clinical research portfolio, as well as develop strategies to enhance sex and gender considerations in clinical research at an NIH-wide level.

Bevans has served the Nursing Department since 1988. Over the last decade, she has dedicated herself to clinical research and specifically the area of family caregivers and patient reported outcomes.

"Although it is a difficult decision to leave the Clinical Center after 29 years, I am excited about the new opportunities," said Bevans.

## Upcoming Events <https://clinicalcenter.nih.gov/locmr/events.html>

### NIH Staff Influenza Vaccine Clinic

October 2, 2017  
7th Floor Atrium, East Side  
NIH employees and contractors – protect your patients, coworkers, family, friends and yourself by getting a flu shot. See the CC immunization schedule (right) and others at: [www.foiltheflu.nih.gov](http://www.foiltheflu.nih.gov).

### Annual Maurice B. Burg Lecture: Facts and Uncertainties: Science and the Practice of Medicine

October 17, 2017, 2:00 p.m. – 3:00 p.m.  
*Lipsett Amphitheater*  
Presented by Josephine P. Briggs, M.D., National Center for Complementary and Integrative Health.

### Karin Loya on Cello

October 19, 2017, 12:30 p.m. – 1:30 p.m.  
*Clinical Center Atrium*

### University of Maryland Jazz Concert

October 24, 2017, Noon – 1:00 p.m.  
*Clinical Center Atrium*

### NHLBI Systems Biology Symposium

October 25, 2017, 8:00 a.m. – 5:00 p.m.  
October 26, 2017, 8:00 a.m. – 4:00 p.m.  
*Lipsett Amphitheater*  
Conference will focus on single-cell systems biology, imaging-based systems biology, quantitative proteomics, systems biology of metabolism and large-scale data integration.

### Foil the Flu: 2017 Immunization Schedule

Location: Main Campus, Building 10 CRC, 7th Floor Atrium, East Side  
NIH photo ID required

Date	Day	Morning	Afternoon/Evening
10/02/17	Monday	8:00 – Noon	Noon – 3:30
10/03/17	Tuesday	8:00 – Noon	Noon – 3:30
10/04/17	Wednesday	8:00 – Noon	Noon – 3:30
10/05/17	Thursday	6:00 – Noon	Noon – 7:00
10/06/17	Friday	8:00 – Noon	Noon – 3:30
10/09/17	Monday	Closed	Closed
10/10/17	Tuesday	8:00 – 11:30	12:30 – 3:30
10/13/17	Friday	8:00 – 11:30	12:30 – 3:30
10/24/17	Tuesday	8:30 – Noon	Noon – 3:00
10/25/17	Wednesday	8:30 – Noon	Noon – 3:00
10/26/17	Thursday	8:30 – Noon	Noon – 3:00
10/27/17	Friday	8:30 – 11:30	12:30 – 3:00
10/30/17	Monday	8:00 – 11:30	12:30 – 3:30
10/31/17	Tuesday	8:00 – 11:30	12:30 – 3:30
11/01/17	Wednesday	8:00 – 11:30	12:30 – 3:30
11/02/17	Thursday	8:00 – 11:30	12:30 – 3:30
11/03/17	Friday	8:00 – 11:30	12:30 – 3:30
11/04/17	Saturday	6:30 – 8:00	6:30 – 8:00
11/06/17	Monday	8:00 – 11:30	12:30 – 3:30
11/07/17	Tuesday	8:00 – 11:30	12:30 – 3:30
11/08/17	Wednesday	6:00 – 11:30	12:30 – 7:00
11/09/17	Thursday	8:00 – 11:30	12:30 – 3:30
11/10/17	Friday	Closed	Closed

Read more online! Scan the barcode or visit [www.cc.nih.gov/about/news/newsletter.html](http://www.cc.nih.gov/about/news/newsletter.html)



- 2017 NIH Director's Award presented to 78 Clinical Center employees Sept. 1
- CEO Dr. James Gilman conducts quarterly town hall, presents length-of-service awards

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: Deborah Accame, Lester Davis, Cindy Fisher, Donovan Kuehn, Maria Maslennikov, Angela Missouri

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](mailto:Molly.Freimuth@nih.gov)



Clinical Center

## Mindfulness program reminds staff to care for themselves as well as patients

Being a healthcare professional at the NIH Clinical Center is incredibly rewarding, but at the same time it can be quite stressful for staff caring for patients with life-threatening illnesses. A new Mindfulness Self-Care Program for staff began in August, created by the Pain and Palliative Care Consultation Service. The program is designed to teach medical staff the skills to cope with this stress. All NIH staff are invited to attend.

“Medical staff can become so focused on caring for patients, they forget to take care of themselves,” said Dr. Ann Berger, chief of the Clinical Center’s Pain and Palliative Care Consultation Service. “The culture has been that doctors cannot be vulnerable by asking for help. This is not true.”

Compassion fatigue can happen when a healthcare professional becomes so consumed with the suffering and condition of the patients that it creates traumatic stress for the staff member.

“This kind of stress and fatigue can have significant impact on the healthcare provider’s own health and the care of a patient. It is imperative that Clinical Center doctors, nurses and other staff recognize the importance of self-care and methods for relieving stress,” said Dr. Rezvan Ameli, with the National Institute of Mental



NIH staff and trainees gather Aug. 24 during a Mindfulness Self-Care class in the NIH Clinical Center.

Health. “We need to teach our staff the skills to strengthen their emotional resilience. That is what the Mindfulness Self-Care program is designed to do.”

According to Ameli, mindfulness can engage a person’s natural healing abilities to increase wellbeing on all levels – physical, psychological and spiritual. Mindfulness is paying focused attention to what is happening right now; at the core of mindfulness is the ability to accept all experience and suspend judgments and expectations.

It sounds really simple, but it requires discipline and regular practice to benefit from what mindfulness can offer.

In stressful situations, people often have thoughts of what ifs, regrets and past

wrongs or fears and worries about the future that create additional stress and impede focus. Mindfulness helps spot this kind of thinking and allows a person to refocus on the present moment. This has been proven to have a healing affect. Mindfulness is a growing area of evidence-based research and practice, Ameli added.

“It is a very healing process for people to center themselves, because if you are centered for yourself, you can be centered for others,” Berger added.

The program at the Clinical Center consists of five sessions, each one and a half hours long, to teach participants how to practice and incorporate mindful attention in to day-to-day activities. Guided instructions in mindfulness meditation are part of the sessions. The program is offered in collaboration with the Clinical Center’s Spiritual Ministry Department – Chaplain Mike Zoosman is assisting with the course. While very interactive, the sessions are educational in nature and not intended as a form of group therapy or exploration of concerns outside of the workplace.

The first session, which began in August, is underway and the second session will begin Oct. 6. For more information, email rezvan.ameli@nih.gov or call 301-402-7360.

## Special events, visitors, bring smiles to pediatric patients and their siblings



Eight children, including 7-year-old Zevaeh Daugherty, above, participated in Sibling Day at the NIH Clinical Center and The Children’s Inn at NIH July 19. The event focused on the brothers and sisters of pediatric patients and the important role they play as a part of the medical care team. Dr. Muhammad Yousef, with the Department of Perioperative Medicine, demonstrates a video-assisted intubation of a practice mannequin during a hands-on session in the operating room.



Proving that the experience at the NIH Clinical Center is “out of this world,” members of the Star Wars costume organization, the 501st Legion’s “Old Line Garrison” came to the hospital to visit with pediatric patients. Staff members and pediatric patient Farrah, seen above, enjoyed the July 27 visit at the NIH Clinical Center and The Children’s Inn at NIH.

## Healthy volunteers endure mosquito bites to advance research



Research volunteer Melissa Meerdt holds her arm over the canister during the controlled exposure to biting mosquitoes in the Special Clinical Studies Unit on Aug. 25.

Mosquitoes beware! Researchers within the Clinical Center began a Phase 1 clinical trial this year to protect humans against mosquito-transmitted diseases. The trial, led by the National Institute of Allergy and Infectious Diseases (NIAID), is testing an investigational vaccine intended to provide broad protection against a number of diseases, such as Zika, malaria, West Nile fever and dengue fever by hindering the ability of mosquitoes to transmit such infections.

The investigational vaccine is designed to trigger an immune response to mosquito saliva rather than to a specific virus or parasite carried by mosquitoes.

As of late August, the clinical trial has enrolled 43 participants. Investigators are expected to enroll up to 60 healthy adults ages 18 to 50 years. Participants come to the CC and receive either an investigational vaccine or a placebo. Approximately 21 days after completing the vaccination schedule, participants return to undergo a controlled exposure to biting mosquitoes. Participants are not at risk of becoming infected with a mosquito-borne disease because the mosquitoes are not carrying viruses or parasites. Up to 10 mosquitoes from the insectary in NIAID's Laboratory of Malaria and Vector Research are put in a feeding device that is then placed on each participant's arm for 20 minutes. The mosquitoes will bite the participants' arms through the netting on the feeding devices.

Afterward, investigators take blood samples from each participant at various time points to see if participants experience a modified response to the mosquito bites as a result of the vaccination.

More information from NIAID: <https://go.usa.gov/xRAak> and details of the trial: <https://go.usa.gov/xRAa9>

## Patient with rare spinal cord cancer bounces back

After being diagnosed with a rare cancer in her spinal cord, 38-year-old Sarah Rosenfeld looked to the NIH for help. At the Clinical Center, researchers are studying more than 500 rare diseases in partnership with nearly 15,300 unique patients like Rosenfeld.

In January 2016, Rosenfeld began to experience intense pain in her lower back and leg. After numerous doctors' visits, her medical team in Northern Virginia finally found the cause. Her MRI results showed a myxopapillary ependymoma, or slow-growing tumor, in the lower portion of her spine. The tumor, which was 5 centimeters (about the size of a lime) arises from the supportive tissue of the brain and spinal cord.

This type of cancer can often be cured by surgically removing the tumor. But for Rosenfeld, that was not the case. In April, her medical team was unable to remove all of the tumor.

"Hearing a diagnosis of cancer is frightening, but you have to let go of the fear and get started asking lots of questions," Rosenfeld said. "The doctors advised me to wait and have the remaining tumor monitored, but I wanted to take a more proactive approach."

That's when she heard of the NIH. One of Rosenfeld's neurosurgeons explained to her that the CC may be able to provide treatment opportunities for the tumor in her spinal cord.

"Myxopapillary ependymoma is a rare tumor so it was essential that I found somewhere that had experience treating it. Learning about the clinical trials at NIH was fortuitous," Rosenfeld said. "All the brilliant minds for this are here. I feel very fortunate and lucky to be a patient."

Three months after her first surgery, she came to the CC and met with Dr. John Heiss, with the Surgical Neurology Branch of the National Institute of Neurological Disorders (NINDS).

Heiss is part of a NIH multi-institute neuro-oncology team that includes physicians and scientists with a shared mission of providing cutting-edge treatments and research studies to patients with brain and spinal tumors. The multispecialty team includes neurosurgeons, neuro-oncologists, neuroradiologists, neuropathologists, radiotherapists, nurse practitioners, research nurses and scientists.

Together, Heiss and Rosenfeld reviewed a new MRI of her spinal cord which revealed residual tumor tissue.

Heiss and his team recommended a second surgery followed by radiation. In October 2016, Heiss and many others colleagues conducted a nine-hour procedure in the operating room to try to remove the tumor tissue. Doctors were able to remove nearly all of the remaining tumor tissue except for a small amount that, due to its placement, was deemed too risky to remove surgically.



Sarah Rosenfeld, right, hugs her care provider, Dr. John Heiss, from the Surgical Neurology Branch of the National Institute of Neurological Disorders.

The possibility of causing permanent nerve damage was too great.

The NIH team decided the next step was to irradiate the remaining tumor cells. This involved 30 treatments over six weeks – once a day every day except for weekends and holidays.

The nurses and support staff at the hospital were instrumental in getting her through the process, she said. The radiation itself was not painful but the aftermath for Rosenfeld was fatigue, among other side effects.

"[Our] team includes some of the world's experts in ependymoma therapy, outcomes and research," Heiss said. "Brain and spinal tumor specimens removed at surgery by NINDS neurosurgeons undergo histopathological analysis and molecular profiling to identify tumor characteristics that make them susceptible to specific treatments. NIH clinical and laboratory research on ependymoma and other malignancies has the ultimate goal of improving the care and long-term outcomes of patients."

"They were so supportive and understanding," Rosenfeld said. "The level of patient care here is like nowhere else. On my last day of treatment, (the staff) gave me flowers, an NIH sweatshirt and a card. I was thrilled to be finished with radiation, but quite sad to say goodbye to everyone."

"It is a very patient-centric environment here," said Lois Goodstein, her mother. "You draw comfort and hope knowing that you are at the absolute best place for this."

Rosenfeld will continue to be monitored and scanned at the NIH for at least the next year. She is participating in three clinical trials at the CC: Evaluation and treatment of neurosurgical disorders (<https://go.usa.gov/xRACN>); Care of the adult oncology patient (<https://go.usa.gov/xRAC5>); Evaluation of the natural history of and specimen banking for patients with tumors of the central nervous system (<https://go.usa.gov/xRACX>).