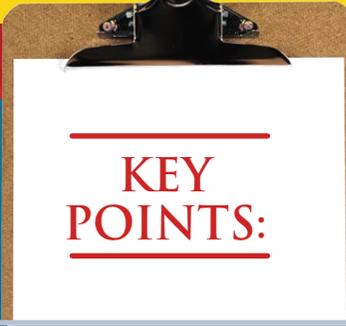




# UNIVERSITY OF MARYLAND ROUNDS

CLINICAL AND RESEARCH UPDATES FROM *THE UNIVERSITY OF MARYLAND SCHOOL OF MEDICINE*  
AND *THE UNIVERSITY OF MARYLAND MEDICAL CENTER*

## UM CANCER CENTER RANKS IN TOP TIER NATIONWIDE



### KEY POINTS:

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A slight name change signals a huge accomplishment for the University of Maryland Marlene and Stewart Greenebaum Cancer Center, which has become the 46<sup>th</sup> facility in the United States to be designated a comprehensive cancer center by the National Cancer Institute (NCI).

After a rigorous, months-long review process that included a site visit by 22 NCI cancer experts in late February, UMGCC gains another "c" in its name as its prowess at fighting the big C — cancer — is

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- The National Cancer Institute designates the University of Maryland Marlene and Stewart Greenebaum Cancer Center as a comprehensive cancer center
- Renamed the University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center (UMGCC)
- Recognized in the *U.S. News & World Report* 2016-17 Best Hospital rankings as #21 in the country for cancer care
- Having a profound impact on the fight against cancer in the U.S. and around the world
- Stellar cancer research includes the invention of the GammaPod™



# UM CANCER CENTER RANKS IN TOP TIER NATIONWIDE

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broadly recognized. Its new name, the University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center (UMGCCC), primarily reflects the institution's achievements in researching and developing new cancer-fighting drugs and technologies, according to Director Kevin J. Cullen, M.D.

"This tells everyone we are now one of the top cancer programs in the

country and making contributions in science, patient care and education that are having a real impact on the fight against cancer in the U.S. and around the world," says Dr. Cullen, who is also the Marlene and Stewart Greenebaum Distinguished Professor of Oncology at University of Maryland School of Medicine. "We can point to new treatments invented here that are now the standard of care around the world. So we're having an impact

that's being felt well beyond Baltimore and Maryland."

## RESEARCH, TRAINING PROGRAMS ESPECIALLY IMPRESSIVE

Its stellar research — the main qualifier for the NCI designation — will receive a boost as a result of the honor, with its grant increasing 50 percent to \$1.5 million. Additionally, the center will be eligible for other funding from the NCI and other public and private sources. The new designation took effect at the start of the cancer center's grant cycle on August 1.

New and improved cancer treatments and prevention strategies tackled at UMGCCC include the invention of the GammaPod™, a radiotherapy system under FDA review for treating breast cancer in a prone position to better protect the heart, and the Population Science Program, which has uncovered risk and prevention implications for human papillomavirus-related cancers, among others.

Other key aspects of UMGCCC's offerings leading to the unanimous NCI endorsement include its training and education initiatives.

"The NCI expects its comprehensive cancer centers to be strongly committed to training the next generation of cancer scientists and clinicians," Dr. Cullen explains. "We now have a total of eight NCI-funded training programs that range from giving middle school students in West Baltimore more experience in science, technology and math all the way to subspecialty training as cancer physicians for radiation oncologists, medical oncologists and surgeons.

"It's this comprehensive suite of training programs, along with our research, that helped us earn this distinction," he adds.



"WE CAN POINT TO NEW CANCER TREATMENTS INVENTED HERE THAT ARE NOW THE STANDARD OF CARE AROUND THE WORLD."

- KEVIN J. CULLEN, M.D.



DIRECTOR KEVIN J. CULLEN, M.D., the Marlene and Stewart Greenebaum Distinguished Professor of Oncology at University of Maryland School of Medicine



SHANA O. NTIRI, M.D., is an assistant professor of family community medicine and medical director of the Baltimore City Cancer Program.

## STANDOUT MINORITY PARTICIPATION

UMGCCC also stands out nationally because of its high minority participation in clinical trials, even when compared to other comprehensive cancer centers. Minorities comprise only about 2 percent of clinical trial patients across the United States, but here, minority patients represent more than 30 percent of clinical trial participants, which Dr. Cullen says makes sense in light of University of Maryland Medical Center's core patient population.

"Our community in the areas around Baltimore has a significant representation of African Americans, and that community suffers disproportionately from cancer incidence and mortality," he says. "One of the comments we received from the NCI is that we really do focus on the health issues facing people in our backyard, which is an important part of our mission."

Considering other factors even before the center earned its elevation to NCI-CCC, in August *U.S. News & World Report* ranked the center #21 among the nation's cancer programs.

"Everyone is extraordinarily proud — not just the faculty, but the staff and everyone associated with the cancer center, from the board of directors to the donors," Dr. Cullen says. "It really has been a collaborative effort over time. No one person owns credit for this — it's the accumulated excellence of the entire team that has gotten us to this point." +



Appointments at UMGCCC can be scheduled by calling **410-328-7904**.

## ROUNDING OUT CARE AND RESEARCH

### STUDY EVALUATES EFFECTIVE ESSENTIAL TREMOR TREATMENT

Treatment with MRI-guided focused ultrasound significantly improves tremors and quality of life in patients with essential tremor (ET), the most common movement disorder, according to a study published in the August 25 issue of the *New England Journal of Medicine*. Researchers at the University of Maryland School of Medicine were among an international group of investigators studying this new noninvasive treatment, which was recently approved by the U.S. Food and Drug Administration (FDA), based on this research.

The randomized, double-blinded study showed that 56 patients who received the treatment experienced a nearly 50% improvement in their tremors and motor function after three months and retained a 40% improvement after a year. In contrast, 20 patients who received a sham treatment saw no improvement and were able to cross over into the treatment group three months later. Twenty-two of the patients were treated at the University of Maryland, with many who received the new therapy achieving up to a 99% improvement in their tremors.

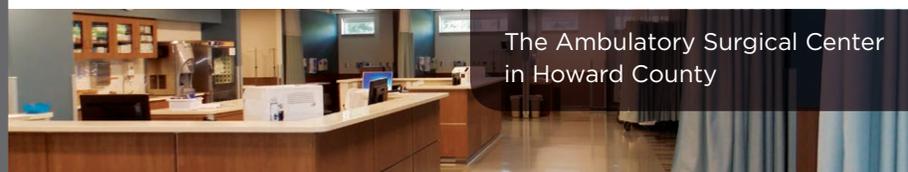
For more information, please call **410-328-5332**.

### OPERATING IN COLUMBIA, HOWARD COUNTY

The University of Maryland Faculty Physicians, Inc., in Columbia recently opened a state-licensed, Medicare-certified, and Joint Commission accredited ambulatory surgery center. With one operating room, two procedure rooms and 11 recovery bays, patients can undergo same-day surgery, medical procedures and pre- and post-op care at this convenient location. Open Monday through Friday, surgical services are provided by University of Maryland School of Medicine faculty physicians for general surgery, ophthalmology, orthopaedic surgery, pediatric surgery and more. +



For more information, visit [umm.edu/Columbia](http://umm.edu/Columbia) or call **667-214-2100**.



The Ambulatory Surgical Center in Howard County



# NEW NEUROLOGY CHAIRMAN

**R**elishing his dual roles as physician and scientist in developmental brain disorders, Peter B. Crino, M.D., Ph.D., the newest Chairman of Neurology at the University of Maryland School of Medicine, plans to reinforce the nationally regarded program's focus on brain science and translational research with an eye toward expanding its innovative treatments for devastating neurological conditions.

Before arriving at the University of Maryland in July, Dr. Crino served as professor of neurology and vice chair for research at Temple University's Lewis Katz School of Medicine and Shriners Hospitals Pediatric Research Center in Philadelphia. Internationally acclaimed for his research, Dr. Crino says he carries deep respect for all that has already been accomplished here and hopes to continue building the 50-strong group of interdisciplinary brain scientists and neurological experts.

## KEY POINTS:

- Peter Crino, M.D., arrived at UMMC in July as Neurology Chair
- Dr. Crino came from Temple University, serving as vice chair for research
- Internationally acclaimed physician-scientist hailed for research on brain's mTOR signaling pathway
- Dr. Crino's four current NIH grants total more than \$4 million
- New goals at UMMC include establishing dedicated center for neurodegenerative disorders

PETER B. CRINO, M.D., Ph.D., the newest Chairman of Neurology at the University of Maryland School of Medicine

Dr. Crino has taken the helm of a department boasting \$10 million in research funding and renowned for developing innovative therapeutic services based on basic science research and scientific advances. Only a handful of comparable programs in the United States offer advanced management, treatment and rehabilitation to patients with such a variety of neurological conditions, ranging from Parkinson's disease and movement disorders to multiple sclerosis, stroke, epilepsy, Alzheimer's disease, and spasticity and neuromuscular diseases.

"It's been my goal for a long time to help shape and be part of a great neurology program. I wanted the chance to build a department in my vision," says Dr. Crino, who succeeded Interim Chair and Professor of Neurology Barney J. Stern, M.D., who replaced William Weiner, M.D., after his passing in 2012.

"What I liked about the University of Maryland was the great emphasis on translational medicine here, and that's been a hallmark of my career," he adds. "I've always been a physician-scientist, and there's an emphasis here on combining clinical medicine and translational research that I really found attractive."

## LEGACY-BUILDING BRAIN PATHWAY RESEARCH

Earning his medical degree from Yale University and his Ph.D. in neuroscience from Boston University, and later becoming a Howard Hughes Medical Institute physician post-doctoral fellow, Dr. Crino says he has always viewed taking care of patients as a privilege. It's a philosophy he now tries to impart to medical students and residents in the course of his teaching duties, which he especially enjoys in addition to traveling for lectures.

"At the end of the day what matters is being able to help people when they need help," he notes. "Over the course of my career, that's been one of my greatest experiences. I've learned a tremendous amount about fortitude and courage from patients experiencing great challenges every day."

Dr. Crino has earned continuous funding for the past 20 years from the National Institutes of Health (NIH) for his translational research studying mechanisms of altered brain development associated with autism, intellectual disability and epilepsy. He feels his main contribution to the field of neurology thus far has been his work in defining the mTOR (mammalian target of Rapamycin) pathway, in which abnormal signaling may be critical in the development of epilepsy, congenital brain malformations, and related lesions in the brain's cerebral cortex.

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## UMMC'S EPILEPSY PROGRAM STRENGTHS PLEASE NEW CHIEF



Epilepsy appointments can be made at **410-328-4323**.

With a long history of spearheading pivotal epilepsy research, including two current NIH grants bolstering his attempts to identify genes associated with seizures, new Neurology Chair Peter Crino, M.D., Ph.D., likes what he sees in the University of Maryland Medical Center's Epilepsy Center.

Ticking off only a short list of the program's accomplishments is difficult. In 2014, it earned a renewed designation from the National Association of Epilepsy Centers (NAEC) as a Level 4 center, a distinction achieved only by those offering the most complex forms of intensive neurodiagnostic monitoring, along with extensive surgical, medical, neuropsychological and psychosocial treatment.

On top of that, UMMC neurologists led the creation of a new guideline last year that was the first to address treatment of a first seizure in adults. Sponsored by the American Academy of Neurology and the American Epilepsy Society, the guideline impacts care for the 150,000 American adults who experience a first seizure each year. UMMC faculty members were also awarded \$1.1 million in 2013 to investigate whether brand-name and generic versions of epilepsy medications are bioequivalent.

Dr. Crino, whose prior role at Temple University in Philadelphia included directing its Comprehensive Epilepsy Center, plans to increase UMMC's presence in neurogenetics and neurogenomics, which are attempting

to identify genes instrumental in triggering epilepsy. He'd also like UMMC to increase its use of newer approaches tackling medically uncontrolled epilepsy, including responsive neurostimulation — which monitors brain signals and delivers neurostimulation when a seizure is imminent — and infrared laser epilepsy surgery, which inserts laser fibers into small holes in the skull to heat and ablate defined areas of abnormal brain tissue.

"The epilepsy program here is very solid, really delivering cutting-edge care to patients," Dr. Crino says. "I think there's great potential for growth in not only clinical research, but translational research and working collaboratively on drug trials."

# UNIVERSITY OF MARYLAND CENTER FOR HAND AND UPPER EXTREMITY CARE TACKLES FULL SPECTRUM OF CONDITIONS

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When an 18-year-old from southern Maryland was struck by a car, severing his arm and sustaining a devastating leg injury, Raymond Pensy, M.D., an assistant professor of orthopaedics at the University of Maryland School of Medicine, knew it would be harder for the young man to rehabilitate from the leg injury if he had no arm to help him.

Over several days, the University of Maryland Medical Center (UMMC) orthopaedic hand surgeon performed a series of operations that successfully reattached the teen's arm, using nerves from his leg to eventually restore some grip strength in his hand. While the patient unfortunately ended up losing his leg, the case spotlights UMMC's orthopaedics hand and upper extremity program, which increasingly has become a magnet for patients in the region seeking comprehensive, multidisciplinary care for routine or traumatic conditions affecting their arms and hands.

"That's one of the more spectacular cases," explains Dr. Pensy, who previously performed complex reconstructive hand surgeries in Iraq while serving with the U.S. Air Force. "But this young man, who was nearly on death's door, left the hospital with his left arm and his life saved. As a hand surgeon, I had just a small part to do with saving his life, but I had a lot to do with saving his hand."

It is the routine cases as well where this orthopaedic team is making a difference. "Carpal tunnel syndrome is probably the number

RAYMOND PENSY, M.D.,  
an assistant professor of  
orthopaedics at the University  
of Maryland School of Medicine



one diagnosis we see," explains Ngozi M. Akabudike, M.D., assistant professor of orthopaedics at the UM School of Medicine, who specializes in adult upper extremity. "We start with conservative measures to treat, but if surgery is needed, we use both minimally invasive and open techniques in outpatient operations to release the ligament covering the carpal tunnel," she adds.

## A GROWING NEED FOR HAND SPECIALIZATION

A steady increase in patients and a heightened awareness of the hand specialization available here are among the factors fueling the

program's next step: the recent opening of the new University of Maryland Center for Hand and Upper Extremity Care at the new School of Medicine faculty practice office location at Camden Yards.

"I think people recognize the importance of hand specialization in the 21<sup>st</sup> century," says Dr. Pensy, who was fellowship-trained in hand surgery after obtaining his medical degree and completing his residency in orthopaedics at the University of Maryland.

## A FIX FOR ANY HAND OR ARM PROBLEM

The recent addition of a fifth surgeon to the program provided



## KEY POINTS:

- New University of Maryland Center for Hand and Upper Extremity Care at Camden Yards opens
- Fifth orthopaedic hand/upper extremity surgeon added to program to help fill demand
- More than 7,200 patients underwent surgery for hand and arm conditions at UMMC between 2011-2015
- Arm and hand replantation procedures rare but notable
- Program treats full spectrum of hand and arm problems, both routine and traumatic, in adults and children

the impetus to formally define the Center. The program forged its reputation over many years, with the last five providing a numerical benchmark highlighting its demand in the community. Between 2011 and 2015, UMMC arm and hand surgeons operated on more than 7,200 patients, including children, who underwent some combination of nerve, tendon, bone and/or vascular surgery. Another 8,200 patients were treated for fractured arms in that time period, and five major hand/upper extremity replants were performed (not including fingers).

In addition to Dr. Pensy and Dr. Akabudike, the other core surgeons in the program include Joshua Abzug, M.D., in pediatric upper extremity; Andrew Eglseder, M.D., in trauma; and Ebrahim Paryavi, M.D., in trauma/adult hand who will be joining the team in October. They collaborate with occupational and hand therapists and other support staff to tackle a wide range of problems related to the hands and arms, including trauma and injuries; carpal tunnel syndrome; wrist pain; hand pain; Dupuytren's contracture, which is a gradual thickening and tightening of tissue under the skin in the hand; fractures; tendon and ligament injuries; trigger finger; and arthritis.

"We have the capability now to treat any hand and upper extremity condition," Dr. Pensy says. "Unlike some surrounding hospitals, we have specialists from pediatric to adult and microsurgery ability, so we can do replantation. With a full staff, we can really handle everything."

### WARTIME SERVICE BROADENS UNDERSTANDING, GOALS

Dr. Pensy's wartime experiences in Baghdad "laid the foundation" for him to understand both the complexity of traumatic injuries to the hand and how patients overcome such severe injuries. His stint also helped him realize he wanted to develop ways to not just fix decimated bones, but to "fill those holes" created by trauma with intricate microvascular techniques.

The foundations of modern hand surgery actually began around World War II, when physicians started recognizing that patients returned from a battleground environment with injuries requiring surgery on their tendons, nerves, bones and blood vessels, he explains. But general surgeons weren't competent in all

of those aspects, and so the field of hand surgery was born.

While meticulous microvascular surgery or the replantation of a hand or arm can take 8 hours or more, elective surgeries done in a "more relaxed environment" can be performed multiple times per day by the same surgeon. Dr. Pensy is now fostering an appreciation for all these techniques among medical residents and fellows in hand and arm surgery, but especially the need for surgeons skilled in microvascular approaches.

"It's kind of like building a house — how are you going to put a roof on top of it?" Dr. Pensy says. "I teach them not just about what plate they're using or what hot new implant, but ask them what they're doing to cover that beautiful interior they've just created. We're working on the best skin flaps or microsurgical transfers to allow that to happen. And as we save more limbs, we can elucidate what the factors are for a great outcome and what the risk factors are for a not-so-great outcome."

### CENTER SETS UMMC APART

The new center should not only raise University of Maryland's profile in orthopaedic hand and arm treatment, but also optimize patient care by streamlining occupational therapy and other hand services, Dr. Pensy says.

"As we add another fellowship-trained hand surgeon, more research will be done and care will improve," he says. "There will be solidarity behind that vision, and surgeons will not just work toward making a name for the department or themselves, but for the vision that we do great hand surgery here." +



Appointments can be made at **410-448-6400**.



ANUJ GUPTA, M.D., assistant professor of medicine, and BARTLEY P. GRIFFITH, M.D., professor of surgery

## UM PART OF ELITE GROUP TESTING TRANSCATHETER AORTIC VALVE REPLACEMENTS IN LOW-RISK STENOSIS PATIENTS



### KEY POINTS:

- UMMC selected by FDA for new clinical trial testing transcatheter aortic valve replacement (TAVR) in low-risk patients
- Artificial valve replaces diseased aortic valve in patients with severe aortic stenosis
- Fewer than one-quarter of U.S. centers that perform TAVR procedures are participating in rigorous new trial
- Durability of valve in question in minimally invasive procedure
- FDA stipulates five-year follow-up



With an impressive history of partnering with industry to evaluate innovative, less invasive aortic valve replacements, the University of Maryland Medical Center (UMMC) is continuing this trend as part of an elite group participating in a new trial evaluating transcatheter aortic valve use in low-risk patients, for whom surgical aortic valve replacement is the standard of care.

Patients with severe aortic stenosis whose predicted risk of death with surgery is less than 3% will be randomized to undergo either transcatheter aortic valve replacement (TAVR) with the CoreValve® Evolut® R valve or open-heart surgery in a clinical trial in which UMMC is participating. Compared to conventional aortic valve replacement, which requires open surgery and the use of a heart-lung machine, transcatheter valves can be implanted using less-invasive techniques that can offer less pain and blood loss and a quicker recovery.

Fewer than one-quarter of the approximately 450 medical centers in the United States that perform TAVR — popularized over the last decade in aortic stenosis patients too sick to undergo the rigors of open surgery — are participating in this new trial, according to Anuj Gupta, M.D., assistant professor of medicine and director of UMMC's Cardiac Catheterization Lab.

“Participating in clinical research trials is important for us as an academic medical center because much of what we do is try to discover new things,” Dr. Gupta says. “It’s part and parcel of what we do.”

Principal investigator, Bartley Griffith, M.D., the Thomas E. and Alice-Marie Hales Distinguished Professor of Transplant Surgery at the University of Maryland School of Medicine, believes this trial is significant because, “here cardiac surgeons and cardiologists are combining strengths in the office as well as in the operating room where they stand shoulder-to-shoulder doing the intervention. It also means that this type of therapy might not just be surgical, but surgical and surgical/interventional.”

Both physicians describe the low-risk TAVR trial as “exciting” because it represents an opportunity to extend this type of procedure to another subset of patients with aortic stenosis, a dangerous narrowing of the aortic valve that often proves fatal and affects up to 1.5 million Americans. The research will also help determine if artificial aortic valves used in TAVR are as durable long-term as those used in open surgery, which has been a pervasive concern among cardiologists.

“If I’m a 60-year-old man with severe breathlessness and a stenotic valve, I would get open-heart surgery, because that valve should last until I’m 75,” explains Dr. Gupta. “For these patients in a low-risk patient population, the durability of the valve becomes an incredibly important consideration.

“We don’t want a bunch of 60 year olds whose valves fail in four to five years,” he adds. “So the benefit of this trial is that it potentially expands the indication for catheter-based valves to the entire risk spectrum for severe aortic stenosis, but the threshold a low-risk trial needs to reach is durability of the valve for an extended period of time.”

### AORTIC STENOSIS TREATMENT REQUIRES VALVE REPLACEMENT

Most commonly associated with aging, aortic stenosis initiates via a buildup of calcium deposits on the leaflets of the aortic valve, making normal blood flow to the rest of the body impossible. By the time the symptom of limiting breathlessness appears, half of patients die within two years. Other cardinal symptoms include dizziness resulting in passing out, or chest pain associated with exertion.

Medications aren’t effective at improving aortic stenosis, Dr. Gupta notes, saying, “It’s a mechanical problem that requires a mechanical solution.”

UMMC has been a site for several FDA studies of various TAVR models, in which an artificial valve supported in a stainless-steel mesh frame is threaded, via catheter, through a small incision in the femoral artery to the heart. The device remains compressed until it reaches



“WE’VE BEEN DOING VALVE REPLACEMENTS SINCE THE 1970S, AND THE SURGICAL VALVES HAVE IMPROVED. WE HAVE EVERY REASON TO BELIEVE SURGICAL VALVES WILL CONTINUE TO GET BETTER.”

- BARTLEY GRIFFITH, M.D.

its destination and is then expanded, taking the place of the diseased aortic valve.

Prior trials have evaluated the Sapien valve (made of porcine pericardium on a nitinol frame), manufactured by Edwards, in intermediate-risk, high-risk and inoperable patients. Intermediate-risk patients have between a 4% and 8% risk of death in open-heart surgery, while high-risk patients have an 8% mortality risk. Inoperable/extreme risk patients — who also face other serious health challenges — may exceed a 20% risk of death in open surgery, Dr. Gupta explains.

About four years ago, UMMC enrolled 33 patients considered at intermediate risk for open surgery in the PARTNER randomized trial that included 2,000 patients at multiple sites nationwide. That trial showed equivalent results for transcatheter valve replacement compared to open surgery, but the follow-up was only two years — which is probably too short to properly evaluate the longevity of the TAVR valve, Dr. Gupta says.

Intermediate-risk patients continue to be in the evaluation phase with FDA considering labeling indications for this patient population. The FDA has already approved the Sapien 3 and Evolut valves in high-risk and inoperable aortic stenosis patients.

### LONG FOLLOW-UP TO ASSESS TAVR DRAWBACKS

In the low-risk TAVR trial, the FDA has stipulated a five-year follow-up to determine not only how patients fare, but also indicate the durability of the transcatheter valve compared to open-heart surgery. Surgical aortic valves should last at least 10 years, but TAVR valve durability beyond five years is unknown.

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# GROWTH AND NUTRITION PRACTICE ENCOURAGES CHILDREN'S APPETITE AND AUTONOMY



Many parents contend their child is a picky eater, but when problematic eating habits are combined with poor growth and possibly contributing medical conditions, it's a recipe for intervention by the University of Maryland

Children's Hospital's Growth and Nutrition Practice (GNP).

The only program of its type in the state, the GNP draws patients from Baltimore, and throughout Maryland. Mostly toddlers and preschoolers are treated — just when their growth troublingly starts faltering. Up to 100 children are followed at any given time, including about 50 new referrals each year.

About 30% of children referred for evaluation at the GNP cope with medical problems that may complicate their relationship with food, including gastrointestinal issues, allergies or the effects of prematurity. But for most, there are “a host of behavioral and environmental issues determining why they haven't grown,” explains founding director Maureen Black, Ph.D., the John A. Scholl M.D. and Mary Louise Scholl M.D. Endowed Professor in the Departments of Pediatrics and Epidemiology and Public Health at the University of Maryland School of Medicine.

Teaming with pediatrician Susan Feigelman, M.D., a professor of pediatrics at University of Maryland School of Medicine, and pediatric dietitian Pamela Cureton, RDN, LDN, the Growth and Nutrition Practice takes an interdisciplinary, family-centered approach to put children with failure to thrive or other feeding difficulties back on track.

“We look at the entire picture,” says Cureton, who has worked at the GNP almost since inception. “We're not just focused on getting calories into a child or just looking at a growth chart. We look at medical issues, if any, nutrient intake and family structure. “Our philosophy is based on a division of responsibility — the parent or caregiver has a responsibility to provide healthy meals on a regular schedule in a setting appropriate for children, and the child has a responsibility to decide how much to eat.”

## MANY CONTRIBUTORS TO FAILURE TO THRIVE

The GNP was established in 1989 by Dr. Black, using grant money to analyze children diagnosed with failure to thrive, which has been estimated to affect 5% to 10% of all youngsters. Children who fail to grow according to age and

## KEY POINTS:

- Growth and Nutrition Practice for Children at UMMC provides interdisciplinary services for children with growth and/or feeding problems
- GNP staff analyzes children and families holistically to determine medical, psychological and environmental issues affecting eating behavior
- GNP pioneered therapeutic use of video to mine clues to parent-child interactions surrounding mealtimes
- Typical interventions comprised of four components
- Patients tracked for months until growth rebounds and improvements noted in diet and behavior

gender expectations, or who experience a slowdown in expected weight gain, are classified as having the disorder, which can put them at risk of decreased immune response, poor academic performance, and depressed cognitive, motor and language development, among other problems.

At regular pediatric visits, children's height and weight are traditionally plotted using age- and gender-specific growth charts based on data from the National Center for Health Statistics. According to Dr. Feigelman, it is children between 9 months and 36 months who fall below the 5<sup>th</sup> percentile or experience a drop in growth that are typically referred by their pediatricians to this Growth and Nutrition Practice.

“We explain to parents that we expect a child to find their place on the growth chart,” explains Cureton. “All kids are not at the 50<sup>th</sup> percentile for height and weight, and their specific percentile isn't as important as their growth over time. If they're on the 10<sup>th</sup> percentile and they stay there, that's fine, rather than if they start at the 25<sup>th</sup> and they're now at the 3<sup>rd</sup>.”

All three providers agree that it is often a combination of factors that contribute to a child's faltering growth or feeding problems.

THE GROWTH AND NUTRITION TEAM is made up of (L to R) Maureen Black, Ph.D.; Susan Feigelman, M.D.; Grace Paik; and Pam Cureton, RDN, LDN.



“They could have an underlying medical issue that has driven some feeding behavior issues,” Cureton says. “For example, a child has GERD (gastroesophageal reflux disease) and may be self-medicating by not eating because it hurts. The parents become concerned about this behavior and do things to trick the child to eat, bribing the child or making 10 different foods to find one that works. They’re just trying to find any foods the child will eat and now the child is in complete control. Mealtimes become very stressful and parents are often highly anxious. We hear it all.”

### VIDEO OFFERS ACTIONABLE CLUES

At their initial visit, parents and children come in at breakfast time for about three hours, making sure the child has not eaten beforehand. The child’s weight and height are measured, and the family is videotaped — a therapeutic tool pioneered at the GNP — as the child is offered breakfast to record the youngster’s food responses.

Parents also fill out questionnaires to gather background on the child’s history, and a psychologist reviews the video with family to point out the dynamics between parent and child that may influence the child’s eating behavior.

Afterward, the clinic’s three core staff members “put our heads together and work out an action plan,” Dr. Black says. “The family gets a list of things they can work on at home, a notebook tailored to the child to log their behavior, and other handouts, depending on the child’s issues.” Additional medical investigation may be recommended. A summary of the visit is sent to the referring doctor.

Typical interventions at the GNP consist of four components:

- **Access to healthy food:** Families are counseled to provide a healthy and diverse diet and increase calories in their children’s food by adding butter, oil, cheese or peanut butter. Any nutritional supplements should be given after meals, not as meal replacements.
- **Healthy eating habits:** Consistent routines (in both times and places) are encouraged for family meals and snacks, eliminating grazing, minimizing distractions and engaging in pleasant conversation.
- **Appetite and autonomy:** Children should be actively involved in meal preparation, if possible, and encouraged to touch and pick up food to increase appetite.

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# KNOWLEDGE CAN BE POWER WITH GENETIC COUNSELING PROGRAMS

**G**enetic counseling services are expanding and diversifying now more than ever on the campus of the University of Maryland Medical Center. Specially trained in genetics and the issues surrounding inherited conditions, genetic counselors are indispensable as they contribute to the care teams in a host of specialties including but not limited to cancer, prenatal, pediatric and adult care.

## CLUES THAT SUGGEST INHERITED CANCERS

About 10% of adult cancers stem from genetic causes, with the most common inherited cancer syndromes involving breast, ovarian and colon malignancies. Genetic counselors within the UM Marlene and Stewart Greenebaum Comprehensive Cancer Center ideally would see about 20% of the center's 3,000 new patients each year in order to "catch" the 1 in 10 who could benefit from their counseling, explains Jessica Scott, M.G.C., C.G.C., a certified genetic counselor in the Greenebaum Comprehensive Cancer Center.

About two-thirds of the patients Scott and her colleagues counsel have been referred by their physician because of a concerning diagnosis or family history of cancer. Several general characteristics suggest someone's family history might be due to an inherited predisposition, she says.

"The first is intuitive: When you have multiple family members in multiple generations who all have the same cancer, it raises concern of a genetic cause," she explains. "Another example is when you see specific patterns of cancer types we know can be due to specific genes. Also, multiple cancer types in a family can show predisposition; and most

importantly, age at diagnosis. Cancers with a genetic component are more common at young ages." In fact, Ms. Scott helped to develop a special multidisciplinary clinic focusing on Genetics and Pediatric Oncology.

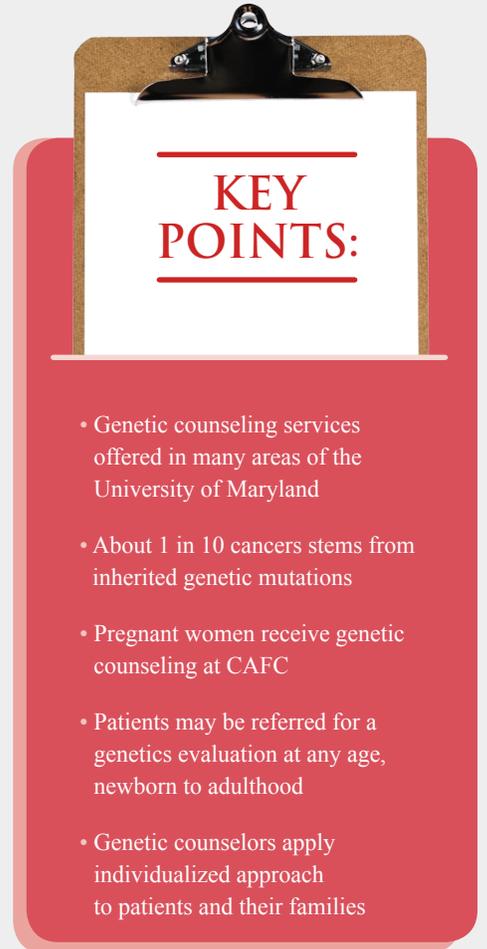
Most of a patient's genetic counseling occurs during the initial visit, typically with a 1.5-hour meeting that includes gathering a patient's medical history related to cancer and what screening techniques they may already be undergoing. Testing options are then discussed as well as the likelihood that an inherited gene mutation might be found.

"We've learned a lot more about hereditary genetic syndromes that cause cancer in the last 10 to 15 years, so there's a lot more to test for now, which increases the need for more involved genetic counseling and testing," Scott notes. "I think for a lot of patients, by the time they get to me, it's not entirely a shock that something hereditary may be going on in their family."

## IDENTIFYING GENETIC DISEASES IN-UTERO

At the Center for Advanced Fetal Care (CAFC), genetic counselors are so integral they're always on-site when pregnant patients are undergoing ultrasounds that may indicate fetal abnormalities. Between 1,700 and 2,000 patients undergo genetic counseling each year in this program, which provides information about risks surrounding conception and pregnancy for both present and future offspring.

Most patients are already pregnant when they receive such counseling, says Amanda Higgs, M.G.C., C.G.C., a certified genetic counselor who works with patients prenatally, and she and



**KEY POINTS:**

- Genetic counseling services offered in many areas of the University of Maryland
- About 1 in 10 cancers stems from inherited genetic mutations
- Pregnant women receive genetic counseling at CAFC
- Patients may be referred for a genetics evaluation at any age, newborn to adulthood
- Genetic counselors apply individualized approach to patients and their families

colleagues discuss various red flags. Common red flags include advanced maternal age, abnormal ultrasound findings, medication use in pregnancy, family history concerns and abnormal prenatal screening results.

With more women choosing to have babies after age 35, genetic counseling efforts are often focused on chromosomal abnormalities occurring more frequently in older mothers, such as trisomies 21 (Down syndrome), 13 (Patau syndrome), and 18 (Edwards syndrome), Higgs says.

"It's a little bit like trying to solve a mystery sometimes," she explains. "Some things might be obvious and some might be more subtle ... we try to figure out what genetic syndrome it looks like a baby may have. Also, women are typically screened for a

couple of conditions when they're first pregnant, such as sickle cell disease or cystic fibrosis, so it's very common to see patients because they found out during routine screening they're a carrier for one of these genetic diseases."

## DETERMINING THE GENETIC PROBLEM

While the work within the Cancer Center and the CAFC look often toward future generations, there are genetic counselors who work closely with physician colleagues to treat patients from newborns to adults, trying to decipher what genetic condition is present and how best to cope with it.

"We see the whole spectrum. There are metabolic conditions in children that need monitoring and management. There are the mitochondrial and neurodegenerative disorders in adults which are becoming more common referrals as other specialists become more aware of the possible genetic etiologies of these conditions. Then we have the unknown diagnosis too," explains Alena Egense, M.G.C., C.G.C., a genetic counselor who works with pediatric and adult patients, and their families. "We recently had a patient where we found a gene mutation so rare that when we looked at the literature, there was only one other case reported," says Egense.

While some of the conditions may be uncommon, the need for this care is becoming increasingly common. "Our adult genetics clinic is now once a week because the demand is increasing," adds Egense.

The genetics team and genetic counselors at UMMC also work closely with other specialties, including cardiology, to help identify genetic diseases, in hopes of preventing sudden death in family members.



JESSICA SCOTT, M.G.C., C.G.C., a certified genetic counselor who's also a clinical instructor in pediatrics at University of Maryland School of Medicine.



"IT'S A LITTLE BIT LIKE TRYING TO SOLVE A MYSTERY SOMETIMES. SOME THINGS MIGHT BE OBVIOUS AND SOME MIGHT BE MORE SUBTLE. WE TRY TO FIGURE OUT WHAT GENETIC SYNDROME MAY BE PRESENT."

- AMANDA HIGGS, M.G.C., C.G.C.

## SUPPORTING PATIENTS AND FAMILIES

Helping patients cope psychologically with difficult news stemming from a genetic evaluation requires an individualized approach.

"It isn't a one-size-fits-all approach," Higgs explains. "If they're by themselves and it's unexpected news, I'll ask if they want me to call someone for support. Others want all of the information right away — that's how they cope. And some say, 'I can't handle this right now.' The definition of a crisis is you're in a situation where the coping strategies you possess can't handle the information you've just been given. I call them the next day to talk more."

Scott says she "always makes a point" of connecting patients who've had disturbing genetic findings related to cancer with oncology specialists who can be their point of contact moving forward.

For Egense, she spends a lot of time interacting with patients and families, helping them understand the results. She is often translating medical information and providing the psychosocial support needed. +



To reach the division of genetics, please call **410-328-3335**. The prenatal genetic counseling office number is **410-328-3339**. Patients who need a cancer genetics appointment may call **410-328-7904**.

## NEW NEUROLOGY CHAIRMAN | CONT'D FROM P5

"I think bringing forth a public awareness of the role of the mTOR signaling cascade in neurological disorders will be the legacy of my research career," says Dr. Crino, who has co-authored more than 150 peer-reviewed manuscripts, chapters and reviews, and whose four current grants from the NIH total \$4.1 million.

### SETTING SIGHTS ON NEW GOALS

As he sets goals for his tenure here, Dr. Crino is particularly keen on collaborating with the University of Maryland's Institute for Genome Sciences and the Neurosciences program to further investigate the mTOR pathway's role in brain function. He also wants to establish a dedicated center

for neurodegenerative disorders such as Parkinson's, Alzheimer's and amyotrophic lateral sclerosis (ALS) "because I think there is great potential for growth in our department," he says.

Other priorities include brain cancer; assessing and boosting UMMC's growth in pediatric neurology; and approaching and brokering issues such as healthcare disparities and care delivery to underserved populations in neurology.

Dr. Crino feels fortunate that the Department of Neurology is already such a standout, noting that "there are a lot of programs already running smoothly." He intends to continue fostering his department's national

reputation across three broad thematic missions: state-of-the-art clinical care, cutting-edge research and top-quality education for future neurologists and neuroscientists.

"I'm especially interested in working with faculty to come up with initiatives that will be funded by the NIH in various disciplines," he says. "I also think there is a huge opportunity for other areas of growth and outreach in the city of Baltimore, to become the defining name of neurology in the city." +



To be in touch with Dr. Crino, please call **410-328-2172**.

## UM PART OF ELITE GROUP TESTING TRANSCATHETER AORTIC VALVE REPLACEMENTS IN LOW-RISK STENOSIS PATIENTS | CONT'D FROM P9

Possible complications of TAVR valves include back leak (paravalvular regurgitation), because no sutures are involved. Also, some patients require a pacemaker to be implanted because the pressure the metal part of the valve places on the heart disrupts its rhythm, says Dr. Griffith.

"There's no free pass getting one of these devices," explains Dr. Griffith, an internationally known heart surgeon. But, "It doesn't have to have the same durability, it has to have reasonable durability. If the TAVR valve is 30% less durable than the surgical valve, that's OK if you're 82 years old. It's less OK if you're 55.

"We've been doing valve replacements since the 1970s, and the surgical valves have improved," he adds. "We have every reason to believe surgical valves will continue to get better."

### PATIENTS PREFER MINIMALLY INVASIVE TECHNIQUES

Patients who choose to enroll in the low-risk TAVR trial, which recently launched at UMMC, must accept they have a 50-50 chance of undergoing TAVR or open surgery.

"One of the things we try to explain clearly is that patients don't enter randomized trials with the idea that it will benefit them — it will benefit those who come after them," Dr. Gupta says. "We know that cardiac surgery works; we don't know if transcatheter valve replacement works as well in this population. We do randomized clinical trials when there is equipoise—that is, when we don't know which treatment option is better."

# GROWTH AND NUTRITION PRACTICE ENCOURAGES CHILDREN'S APPETITE AND AUTONOMY | CONT'D FROM P11

- **Responsive feeding:** Using the video, caregivers are shown through a process of “motivational interviewing” how to model positive behaviors and respond to their child’s cues.

“The principle is the parent ‘owns’ the solution and we work hard to lead them there,” Dr. Black says. “Through these strategies, I think families feel supported without us telling them what to do. We have the luxury of time with families, and our team has worked together for a long time, so we make sure our messages are complementary.”

## OPTIMAL OUTCOMES ACHIEVED

Four to six weeks after their initial visit, families are brought back into the GNP to follow up with additional growth measurements and to determine how effectively they’ve established better eating habits and routines.

But as minimally invasive surgical techniques have become increasingly popular over the last two decades, not just for cardiac procedures, patients have embraced the ideal of avoiding major surgery when possible, Dr. Griffith says.

“Patients have this thing about having their ‘chest cracked’ — they use those words time and again — and I tell them it’s not like I’m using a nutcracker ... but they have an image of having their breastbone ripped open. It’s pretty scary to people,” Dr. Griffith explains. “If we can just approximate the durability (of the TAVR valve compared to open surgery), I see this as a winning technology to reduce the healthcare costs and improve patient outcomes.

“Even though we’re surgeons, we’re physicians first,” he adds. “So the bottom line for us is a smiling patient.” +

Kids may be tracked for several months or longer, depending on how quickly their growth rebounds, but “if we discharge them too soon, the family may forget some of the things we talked about, and the child’s growth falters,” Dr. Black says.

What does success look like when it comes to these children? The providers describe a scenario that includes reaching a benchmark of the 10<sup>th</sup> percentile on growth charts that is sustained long-term with no dietary supplements. Research done since the clinic’s inception shows that the vast majority of children treated grew better than children followed in general pediatric clinics. A recent publication by the team in the *Journal of Pediatrics* found that weight recovery was greatest among children younger than 24 months and among children with multiple child and household risk factors.

“The optimal result is there’s both an improvement in growth and an improvement in their diet and behavior,” Dr. Black says. “Not only is their growth back on target, but mealtimes are pleasant and not stressful, and the family has adopted a routine, with the child eating three meals and two snacks.” +



“THE PRINCIPLE IS THE PARENT ‘OWNS’ THE SOLUTION AND WE WORK HARD TO LEAD THEM THERE. THROUGH THESE STRATEGIES, I THINK FAMILIES FEEL SUPPORTED WITHOUT US TELLING THEM WHAT TO DO.”

- MAUREEN BLACK, PH.D.



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<http://medschool.umaryland.edu/growth/clinic.asp>

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