

PhysicianUpdate

NEWS FOR PHYSICIANS FROM JOHNS HOPKINS MEDICINE

WINTER 2018

Connecting Specialties for Patients with Multiple Sclerosis


The goals of any program to treat either the relapsing-remitting or the progressive forms of multiple sclerosis (MS) are largely the same: prevent progression, manage symptoms and rehabilitate patients as much as possible. Historically, Johns Hopkins patients with MS have been referred for rehabilitation in a piecemeal fashion. Now, three new Johns Hopkins providers are working to change this paradigm.

“We’re hoping to bolster a comprehensive care model and provide rehab care all in one system,” says **Abbey Hughes**, a rehabilitation psychologist who specializes in helping MS patients with sleep disorders that often accompany this condition.

The Johns Hopkins Multiple Sclerosis Center, part of the Department of Neurology and Neurosurgery, already offers a variety of services for MS patients to provide continuity of care. To strengthen these efforts, Hughes—along with psychiatrist **Alexius Sandoval** and fellow rehabilitation psychologist **Meghan Beier**—is forming a link to the Multiple Sclerosis Center from the Department of Physical Medicine and Rehabilitation. The goal is to facilitate additional access and communication between providers for the best outcomes.

“MS is one of the more complicated conditions in medicine,” Sandoval says. “As a rehabilitation physician who takes care of patients with MS, part of my job is to take a 100-foot view and look at everything about the patient’s condition.”

Besides coordinating care with patients who might be struggling with problems as diverse as pain, mobility, cognition and swallowing, he says care for patients with progressive MS changes over time. “Patients might need a cane one year and a wheelchair the year after,” he says. “It’s



“WE’RE HOPING TO BOLSTER A COMPREHENSIVE CARE MODEL AND PROVIDE REHAB CARE ALL IN ONE SYSTEM.”

—ABBEY HUGHES, REHABILITATION PSYCHOLOGIST

a lifelong process, and we can help with every stage.”

For Beier, medical concerns may come up during a neuropsychological assessment that could benefit from referral to neurologists at the Multiple Sclerosis Center or to other rehabilitation specialists. “With a multidisciplinary team, I don’t feel like I’m on an island trying to take care of symptoms outside my areas of expertise,” she says. “I can focus on the things I know well, and utilize the channels of care for the other issues that arise.”

“Being able to provide the best care for our MS patients involves coordinating efforts between all their providers,” Sandoval says. “In this model, the rehab team is already playing a very important role.” ■

Information: 410-614-1522
International inquiries: 1-410-502-7683



Watch **Alexius Sandoval** and **Abbey Hughes** discuss rehabilitation, precision medicine and more for patients with multiple sclerosis: **Multiple Sclerosis Rehabilitation: What You Need to Know | Q & A.** bit.ly/MSrehab

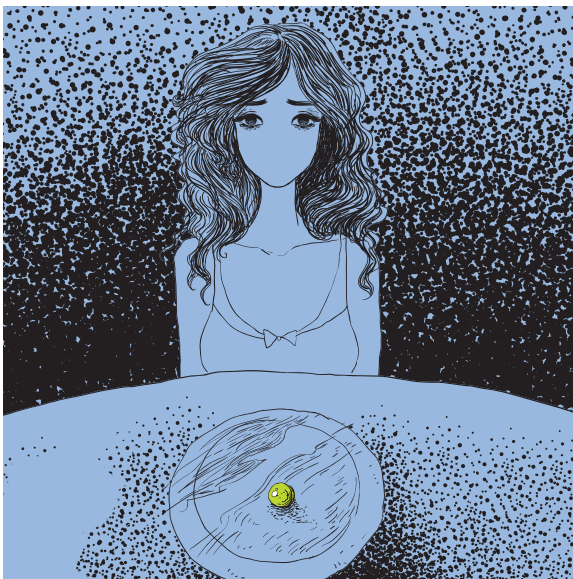
Evidence-Based Anorexia Treatment

Anorexia has a higher risk of mortality than any other psychiatric disorder, says **Angela Guarda**, director of the Johns Hopkins Eating Disorders Program. Yet, in an era of increasing accountability within health care, outcomes research on intensive treatment of anorexia nervosa has been “surprisingly absent.”

“Few programs publish outcomes and if they do, there’s often more marketing than evidence-based data, making it hard for families, patients or referral sources to judge a program’s effectiveness,” says Guarda. With many private, for-profit residential treatment programs marketing directly to consumers, “We feel that it’s very important for families and patients to know what questions to ask of programs, such as, What is the rate of weight gain for anorexia?; What percentage of patients reach a normal weight prior to discharge?; and How do they do six months to a year after treatment?”

In an article published in the *International Journal of Eating Disorders*, Guarda and colleagues at Columbia University, the University of Pittsburgh and Weill Cornell Medical College called for more consistent, transparent outcomes data from eating disorder treatment programs. At a minimum, Guarda says, programs should freely share basic, de-identified information about their patients’ age and illness severity, diagnosis, and body mass index at admission—as well as weight restoration outcomes for patients with anorexia nervosa, so potential patients and their families can make informed decisions. Ideally, the programs should also include results from follow-up assessments three to six months after discharge.

“In a hospital setting, the cost per day is going to be higher than many freestanding residential programs. But in the Johns Hopkins program, with our emphasis on faster weight restoration and over 70 percent of our



“ALTHOUGH THE PROCESS IS CHALLENGING, PATIENTS TELL US OUR PROGRAM IS MORE HELPFUL THAN A SLOWER MEAL PROGRESSION BECAUSE NO CHANGE FEELS SLOW ENOUGH WHEN YOU HAVE ANOREXIA.”

—ANGELA GUARDA

patients reaching a normal weight before leaving, the advantages are both clinical as well as economic.”

Guarda’s team found that among patients who argued that they did not need intensive treatment and were admitted under pressure from family or friends, more than 40 percent reported that within two weeks,

they had changed their minds and felt treatment was helpful.

The Johns Hopkins program uses peer support from patients further along in treatment to help those newly admitted to change their eating habits. While many programs negotiate individual diet plans and calorie levels with patients, Johns Hopkins has patients follow a food plan with choices but also uniform calorie increases. This approach has been shown to safely achieve weight gain of at least 4 pounds each week—about twice the national average—while helping patients diversify their food choices and learn to eat balanced meals. “A standardized meal protocol like ours helps patients change their behavior, complete meals and practice healthy eating skills,” Guarda says.

Guarda is upfront about Johns Hopkins’ treatment protocol. Treatment for anorexia nervosa is uncomfortable, she says—patients are ambivalent about changing driven and habitual eating and weight control behaviors. “Yet changing behavior and gaining weight are the essential first steps needed for recovery,” Guarda says.

The multidisciplinary team in the Johns Hopkins Eating Disorders Program also treats concurrent medical and psychiatric illnesses and severe complications of eating disorders.

Most patients transition from inpatient to the partial hospitalization program, Guarda says, where focus shifts to relapse prevention skills training. Patients practice eating meals independently across different social settings “and work with the clinical team to plan their transition home and return to a full life.” ■

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ENDOCRINOLOGY

After The Cure: What comes next for patients with post-HCV liver fibrosis?

Direct-acting antiviral treatment of patients with the hepatitis C virus is indisputably one of the most important medical advances of the 21st century. In only a few years, the therapy has saved untold lives in the U.S. and around the world.

But Johns Hopkins hepatologist **Tinsay Woreta** wonders what comes next for patients who, while cured of HCV, suffered liver damage while they still harbored the virus.

“It’s a new era,” she says. “But there are still plenty of questions.”

Woreta is studying the progression of liver fibrosis in patients who have been cleared of the hepatitis C infection. In the short history of combating the infection with direct-acting antiviral (DAA) therapy, studies have described changes in liver fibrosis in the context of

interferon-based therapies or have examined the effects only during DAA therapy and through three months of post-treatment.

By the end of this one-year study, which ends in March, 2018, Woreta says she expects to understand more about the treatment of the condition and how long to monitor patients after successful DAA therapy.

“There is real concern that patients who achieve cure are still at risk for cirrhosis and liver cancer,” Woreta says, “particularly those with advanced fibrosis.”

The study looks at cases where physicians have used transient elastography (TE) to evaluate liver stiffness at various follow-up points after DAA therapy.

“TE is a noninvasive way to determine the degree of fibrosis,” says Woreta, noting that liver biopsy, long the gold standard, is imperfect,

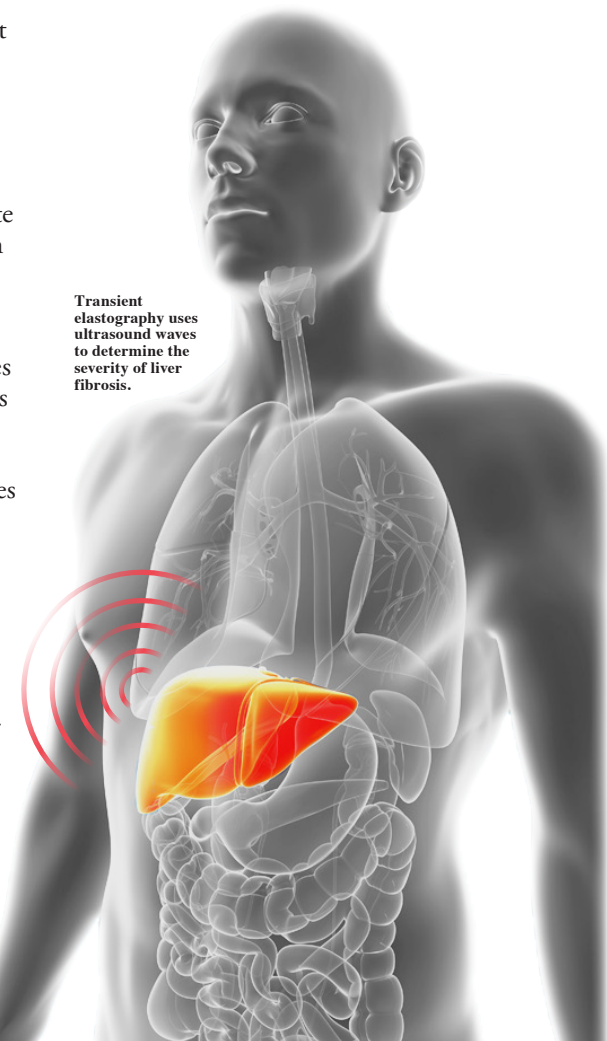
expensive and comes with significant patient risk. “This is a much better, more efficient way to learn what we need to know.”

Woreta and her co-principal investigator Carla Rodriguez of the Kaiser Permanente Research Institute are using data from electronic health records of hepatitis B and C patients who had TE at Johns Hopkins or Kaiser’s Mid-Atlantic facilities. They’re measuring long-term changes in a diverse cohort, looking at factors such as fibrosis stage, sex, race, age, BMI and therapy status.

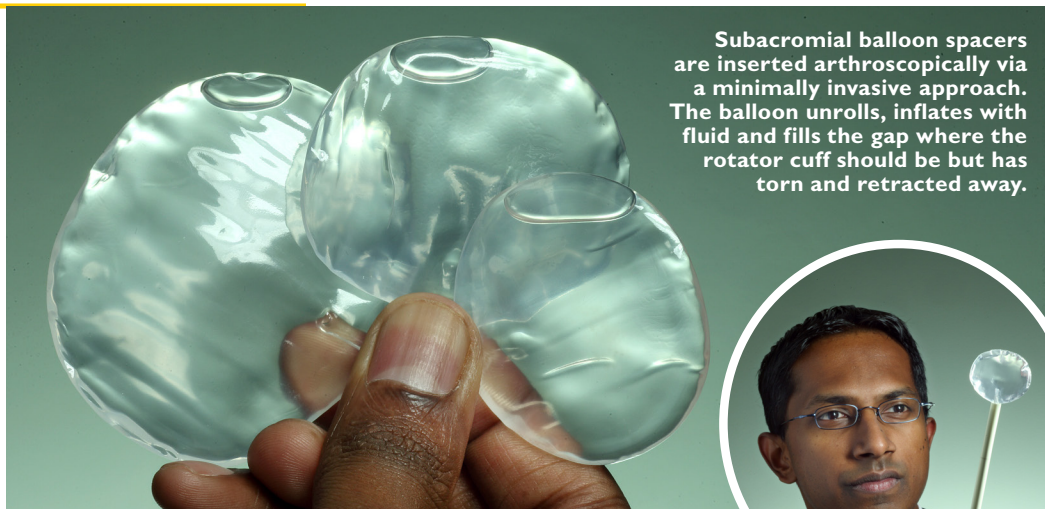
“We hope this research contributes to the way clinicians assess risk for liver cancer and other serious diseases,” says Woreta. “Looking at the rate of progression—or even regression—after therapy should teach us more about how and when to treat patients and should tell us about the need and the frequency of follow-up TE.” ■

Information: 410-955-9270

Transient elastography uses ultrasound waves to determine the severity of liver fibrosis.



New Technologies for Repairing Shoulder Damage



Subacromial balloon spacers are inserted arthroscopically via a minimally invasive approach. The balloon unrolls, inflates with fluid and fills the gap where the rotator cuff should be but has torn and retracted away.

Uma Srikumaran,
orthopaedic surgeon

Uma Srikumaran, Johns Hopkins orthopaedic surgeon, is excited to be able to offer patients new shoulder treatments through his participation in several ongoing FDA clinical trials. He is particularly enthusiastic about helping younger patients avoid joint replacements.

One new treatment under trial is a subacromial balloon spacer for patients with massive rotator cuff tears. The balloon is inserted arthroscopically via a minimally invasive approach. The balloon unrolls, inflates with fluid and fills the gap where the rotator cuff should be but has torn and retracted away.

“It has been found to be very safe in European trials. It is simple, easy to do and will be lower cost than a joint replacement,” Srikumaran says.

The subacromial balloon spacer is also an option for a subset of patients who are not strong candidates for reverse total shoulder replacement or who don’t want to have a joint replacement. Srikumaran says the subacromial balloon spacer fills a gap in terms of available treatments, but he is currently able to offer

it only through participation in the clinical trial.

As the value of care becomes increasingly important, Srikumaran says the balloon spacer fits the bill. “A lot of the research we are working on focuses on value-centered treatments,” he says. “These options are faster, cheaper, easier and achieve the same or better outcomes for patients.”

Another new technology Srikumaran and his colleagues are studying is the Conventus CAGE PH for the treatment of complex proximal humerus fractures. The implant is a scaffold structure that is inserted into the bone and expands like a balloon cage, allowing the surgeon to place screws from different angles and support the fractured bone. The cage is intended to overcome some of the limitations of locking plates. Srikumaran expects it will be “a significant step forward in fracture care,” especially for younger patients for whom arthroplasty is not a reasonable option.

Pyrocarbon hemiarthroplasty, a new alternative surface to metal for shoulder arthroplasty devices, may be an answer for young patients with arthritis

or avascular necrosis of the humeral head.

Srikumaran is part of another trial that is currently evaluating this new material, believed to have advantages for the joint socket in terms of better cartilage protection.

Having worked on an array of complex cases, including revision rotator cuff reconstructions and failed arthroplasties, Srikumaran is collaborating with his fellow clinician-scientists to build the clinical research program. He hopes to offer patients more treatment options before complicated end-stage procedures are necessary. “We believe in the careful adoption of new technologies, and participating in multicenter clinical trials allows us to do just that.” ■

Information: 443-546-1550
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Getting to the Heart of Inherited Cardiac Disease

Some patients come to Johns Hopkins’ Center for Inherited Heart Disease after experiencing puzzling and frightening episodes, such as fainting from an abnormal cardiac rhythm or being resuscitated after a sudden cardiac arrest. Others come after a family member dies unexpectedly from a previously unknown cardiac condition. Either way, says **Gordon Tomaselli**, chief of Johns Hopkins’ Division of Cardiology and co-director of the Heart and Vascular

Institute, they come for answers and to set up a long-term plan to help themselves and anyone in their family who might also be affected.

The center, Tomaselli explains, follows Johns Hopkins’ long history of research and treatment for heritable conditions, starting with Johns Hopkins geneticist Victor McKusick’s groundbreaking work in the late 1950s. Here, a multidisciplinary team of specialists cares for patients of all ages, streamlining care for members of the same family affected by the same conditions, including hypertrophic, restrictive, arrhythmic and dilated cardiomyopathies; rhythm disorders, such as Long QT and Brugada syndromes;

The Johns Hopkins Center for Inherited Heart Disease brings together a host of experts to streamline care for members of the same family affected by a heart ailment, says Gordon Tomaselli, chief of the Division of Cardiology and co-director of the Heart and Vascular Institute.

familial cardiac amyloid; and connective tissue disorders that cause heart or heart valve malformations, such as Marfan and Loeys-Dietz syndromes.

Many of these conditions predispose patients to sudden cardiac death, making it particularly crucial for patients to be cared for by a team of experts in these diseases. “These are obviously profoundly important problems, and ones that practitioners in the community can be a little leery of because the stakes are very high,” Tomaselli says.

At a patient’s first visit, he explains, physicians and other providers at the center carefully examine medical records and take a detailed family history to determine whether the patient’s heart problems are heritable or acquired. They also perform a battery of tests that can include electrocardiogram, stress testing, cardiac CT, cardiac MRI or heart biopsy.

For some patients and family members, genetic testing is also an important step to consider. With its

own group of genetic counselors and a strong relationship with Johns Hopkins’ McKusick-Nathans Institute of Genetic Medicine, the center helps these patients and their families to decide whether to pursue genetic testing to identify the likelihood of their developing cardiac disease.

However, although genetic testing can be extraordinarily helpful in some circumstances, results aren’t always definitive because researchers haven’t yet identified the thousands of possible variants associated with genetic heart diseases, says Tomaselli.

“Our genetic counselors often explain that if we do genetic testing, it doesn’t always mean that we identify the problem. It may, in fact, cloud the picture,” he adds.

Even when genetic testing does not yield definitive findings, doctors at the center can advise patients on treatment options. For some patients, treatment

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Getting to the Heart of Inherited Cardiac Disease, *continued from page 3*

may be as conservative as lifestyle changes or medications. For others, more aggressive interventional measures may be needed, such as implanted defibrillators or pacemakers, surgery to replace blood vessels, select denervation of the heart or heart transplantation.

"The fact that someone carries a genetic variant that causes heart disease isn't a death sentence," says Tomaselli. "We help patients manage their disease in ways that can give them a normal life expectancy and quality of life." ■

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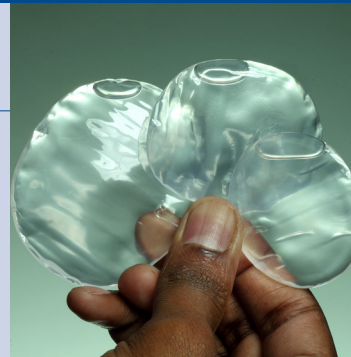
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