

A Growing Mission to Ease Neurosurgical Pain

In 2011, a \$25 million gift from an anonymous donor launched the Johns Hopkins Neurosurgery Pain Research Institute—To Control, Prevent, and Eliminate Pain. Over the past four years, this generous donation provided the impetus to launch a revolutionary effort centered around easing neurosurgery patients' pain before, during, and after operative care now and in the future. Subsequent funding from this same donor has bolstered this effort, providing support for a pain resource team that rounds on neurosurgery patients to tackle immediate pain issues; scientists doing basic pain research to better understand how pain arises and develop innovative ways to treat it; and a group working on developing clinical trials for novel pain therapies to help future patients.

Now, a recent \$40 million gift from the same anonymous donor is providing an even stronger boost for these efforts.

"We've been entrusted with an exceptional body of resources," says institute co-director **Michael Caterina**, a sensory neurobiologist whose research focuses on the molecular basis of pain. "There's a tremendous sense of responsibility to make a meaningful and transformational impact on patients' lives."

Part of the new gift is slated toward maximizing the talent working on the problem of neurosurgical pain at Johns Hopkins. Some of the funds will go to forging ambitious collaborations across the university to pool experts in various pain-related fields. The institute will also use this gift to hire experts in pain research areas not well-represented at Johns Hopkins to bring more knowledge and skills to bear on this problem as well as encourage the careers of talented young researchers whose work shows promise in the pain field.

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Working on
the problem of
neurosurgical pain



Forging ambitious
collaborations to
pool experts



Hiring experts in
pain research areas

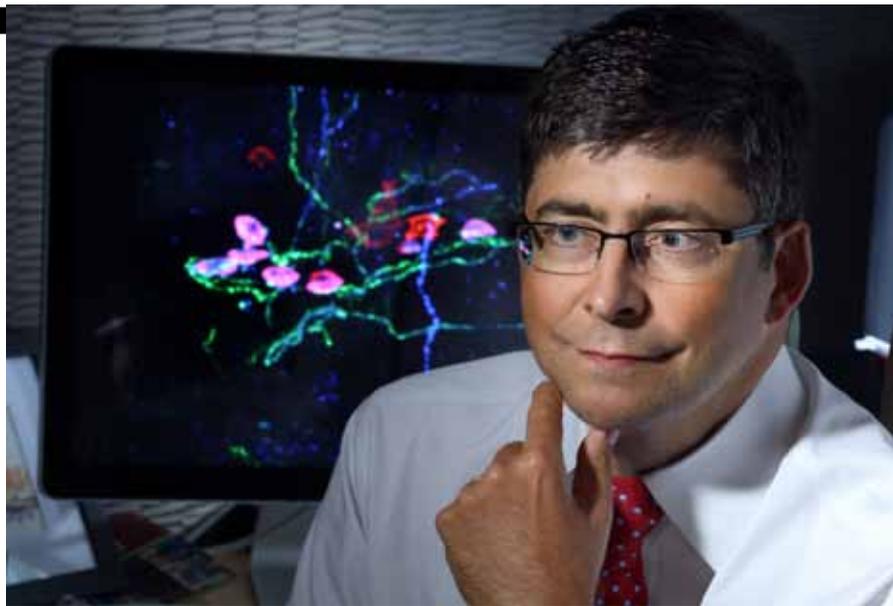


Encouraging the
careers of talented
young researchers



Delivering a One-Two Punch for Peripheral Neuropathies

During neurologist **Michael Polydefkis**' fellowship at Hopkins in the late 1990s—a natural next step after medical school and residency here—he was working in the lab one day with **Justin McArthur** and **Jack Griffin** examining punch skin biopsy samples. The two senior physician-scientists, who eventually rose to current and former chair of Hopkins' Department of Neurology, had developed the punch skin biopsy technique several years earlier as a way to spot problems in the small caliber nerves that sense touch, pain, and temperature. Absentmindedly, Griffin commented that one day neurologists would carry



THESE BIOPSIES CAN TRACK NERVE DAMAGE FROM CHEMOTHERAPIES OVER TIME, ALLOWING RESEARCHERS TO STUDY HOW THESE DRUGS AFFECT THE NERVOUS SYSTEM DURING THE COURSE OF TREATMENT.

a reflex hammer for testing reflexes, a tuning fork to test sensation, and a skin punch tool for taking the small, circular samples of skin necessary for their technique.

"That really got me thinking and set me on my course," Polydefkis remembers.

Their biopsy technique offered the first definitive and minimally invasive diagnosis for peripheral neuropathies, damage to nerve cells outside the brain and spinal cord caused by diseases, such as diabetes or human immunodeficiency virus (HIV), or as a side effect from treatments including

cancer chemotherapies. Rather than removing a large nerve from the leg to look for this damage as doctors had done in the past, which involved significant surgery and often left patients with pain or numbness, punch skin biopsies remove just a tiny piece of skin just millimeters in diameter. Looking under the microscope, any damage to the skin's small caliber nerves is easily visible, sparing patients the need for larger surgery.

"These nerve fibers in the skin are among the first markers of peripheral neuropathies, the canaries in the coal mines that we use to diagnose patients early," Polydefkis explains.

But what began as just a diagnostic technique has morphed into much more. After taking on more and more responsibility at Johns Hopkins' Cutaneous Nerve Laboratory over the years and becoming its director in 2004, Polydefkis, has led a team of physician-scientists, laboratory coordinators, technicians and students that have expanded the uses for punch skin biopsies and published numerous research papers involving this technique. Now, these biopsies can track nerve damage from chemotherapies over time, allowing researchers to study how these

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Partners in MS Advocacy

The vast majority of people with multiple sclerosis (MS) have symptoms that appear then disappear, only to return somewhere else. The ups and downs of this aptly named relapsing-remitting MS—on top of the disability it can cause—are frustrating and stressful.

But Karen Jackson's type of MS, known as primary progressive multiple sclerosis (PPMS), is dishearteningly predictable. Accounting for only 10 to 15 percent of MS cases, this disease offers no breaks. Arms and legs get heavier, stiffer, and harder to move over time, without letup. It isn't the type of MS researchers like to focus on when they're developing new therapies.

"Drug companies want studies that show bigger, faster results, so they work with the chronic relapsing and remitting types of MS," the 54-year-old southern Marylander says. There's no therapy available for PPMS, and Karen and thousands of others, along with their loved ones, are waiting for one.

It's a major reason why the support and advocacy of her physician, **Peter Calabresi**, has been so important. Calabresi, who directs the Johns Hopkins Division of Neuroimmunology as well as its Multiple Sclerosis Center, met Karen Jackson in December 2003 when she came to Johns Hopkins. Her positive attitude in the face of her tough diagnosis moved him.

"Karen is the kind of patient who inspires all of us to work harder for a cure," says Calabresi. "We are now starting to make real progress in understanding PPMS, in part due to people like her."

Over the years, Calabresi has encouraged her to participate in studies in which her data could make a significant contribution to the field. She has endured six lumbar punctures (spinal taps) and stayed motionless in MRI tunnels for an hour or more at a time, all in the name of advancing PPMS research.

Jackson admits that participating in trials is not for everyone and that the choice is intensely personal. It's important to her to stay connected with the community of researchers who are looking for answers, considering it her duty to be part of the discovery process.

"I assist by donating my time and participating in research, and advocacy," she says. "None of the experimental treatments has helped me, but I'm no worse off than if I hadn't done it. And maybe some of my data can help someone else."

In September 2013, Jackson and Calabresi spoke at a congressional briefing on National Institutes of Health funding for PPMS. Jackson said she was glad to put her face on the illness. "People can approach me and ask me anything," she says. "It's natural that they have questions about my illness. My symptoms are not invisible. I figure that's why I'm here: to raise awareness."

Regardless of what the future brings Jackson's way, she still says she's blessed, in large part because of Calabresi's advocacy. "Some doctors forget they're human," Jackson says, "but Peter never has." ■

"SOME DOCTORS FORGET THEY'RE HUMAN, BUT PETER NEVER HAS."

—KAREN JACKSON

To support the MS Center, contact 443-287-7877.



After Jon Weingart, left, removed a baseball-sized tumor from beneath Pat Bernstein's skull, she feels she has a fresh start in life.



To see a video about Pat Bernstein's journey, please visit bit.ly/Pats_Story.

A Fresh Start After Tumor Surgery

The changes that Baltimore resident Pat Bernstein had noticed in her mind and body over the last few years were nearly imperceptible. She didn't feel quite as sharp, felt a lot more impatient and irritable, and eventually had a hard time walking straight—she'd even had a few falls. These annoying differences came with age, she reasoned. But an MRI revealed a shocking reason for these symptoms: a mass just larger than a baseball growing beneath her skull, pressing on her brain.

After receiving the news, Bernstein packed her bags immediately. Her surgeon, **Jon Weingart**, had booked her for an urgent operation to remove the tumor, known as a benign meningioma—which, he told her, was the largest of its kind he'd ever seen.

"It wasn't as though I had information to ponder over for weeks and start to worry," Bernstein remembers. "Everything was put in motion."

Once in the operating room, Weingart and his team set to work removing the tumor. All went well until, suddenly, the surgeons hit a snag: Bernstein began to bleed uncontrollably, a situation with the potential to become life threatening.

The doctors decided to halt the surgery and cauterize the area to stem Bernstein's blood loss. Keeping her in a semiconscious state for the next two days, they developed on a new plan of attack, then began the surgery anew. Hours later, the procedure was finished, with the mass entirely gone.

Bernstein noticed a difference immediately upon waking from anesthesia, changes that continued to evolve during her recovery over the next few weeks and months. She became more sensitive and responsive to others; she demonstrated new meticulousness; and she grew more emotional, letting her feelings show. Each of these changes she attributes to the tumor's absence. With a large portion of her head shaved for the surgery, she decided to shave the rest and continues to maintain this look—a symbol, she says, of her fresh start in life.

After the procedure, she needed physical therapy and continued treatment for some problems that developed in her left eye. There was no question of where she'd go for her procedure and all her care afterwards, she says.

"It's always been Hopkins," Bernstein says. "It goes beyond words that you feel as if you're getting the best care here that you'll get."

Weingart says that despite the size of the tumor, Bernstein's long-term prognosis is excellent. She'll continue to get frequent MRIs for assurance that the tumor isn't returning, with less frequent checks over time.

"The fact that she comes in smiling and laughing and talking about what she's working on and interested in," he says, "there's not much better reward than that." ■

To support the brain tumor center, contact 443-287-7942.

A Growing Mission to Ease Neurosurgical Pain

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Ongoing research at the institute aims to better manage perioperative pain and develop better ways to identify the origin of pain, an often challenging prospect that limits how effectively physicians can treat individual patients. Researchers are also working on novel ways to control pain, including electrical or magnetic stimulation to interrupt pain signals in the central nervous

system, and to develop a better understanding of the physical and molecular changes that lead to the abnormal and long-term sensations of chronic pain.

Much of the research that will be funded by this recent gift is what scientists refer to as "risky," says Department of Neurosurgery Director **Henry Brem**—it's in scientific areas that haven't been well studied but could offer tremendous boosts to the field once more is known. Brem's own research on tumor-related pain falls into this category, he says. Being

able to work with private donations instead of funds from government agencies, which typically commit researchers to study the same topic for five years or longer, will allow him and other researchers to adapt the direction of their work more readily as new discoveries are made.

"The institute is small enough and nimble enough that funding can be quickly and efficiently applied to targeted research programs that are promising in terms of potential transformative impact on pain," says co-director and neurosurgeon **Allan Belzberg**. "The enormous generosity of the donor will have a transformative impact on how we understand and manage and ultimately prevent painful suffering in our patients." ■



"THERE'S A TREMENDOUS SENSE OF RESPONSIBILITY TO MAKE A MEANINGFUL AND TRANSFORMATIONAL IMPACT ON PATIENTS' LIVES."

—MICHAEL CATERINA

To support the work of the Neurosurgery Pain Research Institute, contact 443-287-7942..

Delivering a One-Two Punch for Peripheral Neuropathies *(continued from page 2)*

drugs affect the nervous system during the course of treatment. They can also be used to track nerve regrowth after damage in both humans and animal models such as mice, allowing researchers to determine which factors might slow healing and test whether drugs or other interventions might help speed it up.

“Taking a small piece of skin is pretty innocuous and has helped fill a tremendous void for diagnosis and research,” says Polydefkis, who also sees patients with peripheral neuropathies and other nerve damage in the clinic.

His energies into helping those with disabilities extend beyond the clinic and lab. After sustaining a serious spinal cord injury when he was 12 years old, he has become a role model for students and trainees with disabilities. Polydefkis has an important role as a member of the Johns Hopkins University Diversity Leadership Council, aiding others with disabilities

to be as productive as possible during their time at the university.

“He’s been an incredible role model,” says current Department of Neurology director McArthur, “for others in our field and beyond.” ■

To support the work of the Cutaneous Nerve Laboratory, contact 443-287-7877.

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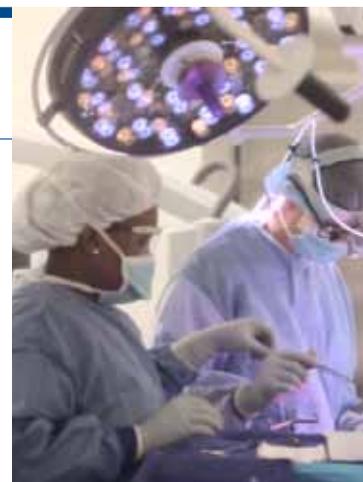
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