Outlook

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THERE HAVE BEEN MANY special years since I started this Foundation, but this year in particular was truly a dream come true. I’m thrilled to announce the launch of three new Bachmann-Strauss Dystonia and Parkinson’s Disease Centers of Excellence, funded with $1.2 million raised through the efforts of our generous supporters. These centers will change patients’ lives and provide compassionate care and new research programs from coast to coast at three academic health institutions: the University of Alabama at Birmingham; the University of California, San Francisco; and the University of Florida. These new centers are in addition to our first Bachmann-Strauss Center of Excellence at New York’s Beth Israel Medical Center, which is led by Dr. Susan Bressman. You will read about the new centers and meet their dynamic directors, Drs. David Standaert, Jill Ostrem and Michael Okun, in this issue of OUTLOOK.

I’m delighted to report that the amazing progress of one of the projects we’ve supported over the years—the drug discovery program of Dr. Ellen Hess—has taken a major leap forward. This special program may bring an effective dystonia drug one step closer to patients.

Our 21st Annual Golf Invitational this past summer, which recognized two decades of growth for the Foundation and continues to raise more than $1 million annually for research, was a huge success. One of our other key fundraising events, Jake’s Ride for Dystonia Research, had a record-breaking year, raising an incredible $350,000! Both of these events allow us to support our initiatives and fund research.

As you can see, your generosity and our philanthropic efforts have directly impacted the lives of patients with dystonia and Parkinson’s disease and their families. I am so proud of what we have accomplished and what we continue to achieve. We are grateful for your commitment, and thank our board, staff and volunteers as well for all their hard work.

IT IS ESTIMATED THAT at least 500,000 Americans are living with dystonia and up to 1 million Americans have Parkinson’s disease. Although there are currently no known cures for dystonia or Parkinson’s, scientists are learning more about these disorders through research, and are developing innovative treatments as well.

As baby-boomers approach retirement age and people live longer, the incidence of Parkinson’s and other degenerative neurological conditions will continue to rise, making the quest for treatments and cures more important than ever. With increasing awareness and improved diagnostic techniques, there is every reason to believe that the number of people diagnosed with dystonia will also grow.

Unfortunately, research funding has been hard-hit by budget deficits. In a troubling trend, federal support of research has declined dramatically over the past decade, particularly in the area of biomedical science. The recent government-mandated spending cuts—referred to as sequestration—have reduced research dollars further. Additionally, support for neurological disorders has not kept pace with funding for other diseases, including cancer, cardiovascular disease and HIV/AIDS.

This bleak scenario puts the brakes on innovative science. The downturn in funding may discourage bright young people from pursuing careers in research. Established scientists may think twice before applying for grants they have little chance of receiving. That is why funding available through private foundations like The Bachmann-Strauss Dystonia & Parkinson Foundation is so critically needed.

In this issue of OUTLOOK you’ll read about our efforts in raising money to support cutting-edge research, towards a goal of finding cures for debilitating movement disorders. We will fight for more government funding and will seek support as well from industry, venture capital and biopharma. With your help, we will also continue to raise awareness about dystonia and Parkinson’s disease. Our efforts will make a difference.
Three New Centers Offer Hope & Healing

The Foundation’s New Centers of Excellence Support Patient-Centric, One-Stop Care

SEEKING RELIEF for the tremors, pain, muscle spasms, and other symptoms characterizing dystonia and Parkinson’s disease (PD) once meant days spent searching out specialists and coordinating a myriad of appointments. To make compassionate, innovative care more accessible, this fall The Bachmann-Strauss Foundation launched new Dystonia and Parkinson’s Disease Centers of Excellence in partnership with three academic health institutions: the University of Alabama at Birmingham; the University of California, San Francisco; and the University of Florida in Gainesville.

Each institution received a grant of $400,000 from the Foundation and will provide matching grants to ensure that they will be self-sustaining. They follow in the success of the first Bachmann-Strauss Dystonia Center of Excellence, which was launched at New York’s Beth Israel Medical Center in 2009.

Learn more about the new centers at www.dystonia-parkinsons.org/centersofexcellence.
“We know there are many more people with dystonia and PD out there. This center will enable us to help them.”

—Dr. David Standaert

University of California, San Francisco (UCSF)

The UCSF Movement Disorders Center has a team of neurologists and neurosurgeons specializing in the medical and surgical treatment of movement disorders. “We’re leaders in the field of DBS,” says center director Jill Ostrem, MD. “We’ve been offering DBS since 1998 with excellent outcomes. Our new Center of Excellence will help us to build on our current infrastructure and strengthen other aspects of our program.”

Currently, the UCSF team treats approximately 4,000 patients with PD and 1,500 with dystonia, and has treated approximately 650 PD patients and 130 dystonia patients with DBS. “This procedure can be life-changing,” says Ostrem. “It’s particularly gratifying when we are able to help children with generalized dystonia. The ‘before and after’ is amazing. After the surgery, they’re often walking, back in school, doing what their peers do.”

The grant will support several new initiatives at UCSF, including more integrated mental health support. A neurogenetics clinic led by Marta San Luciano, MD, will offer comprehensive medical evaluations to patients with genetic forms of movement disorders.

Building the research component is also on Ostrem’s to-do list. “The grant will further our research efforts in several areas,” she says. “One is evaluating patients treated with subthalamic nucleus DBS for primary dystonia.” Another study led by Philip Starr, MD, looks at how pediatric dystonia patients respond to DBS when electrodes are placed using interventional MRI, which allows surgeons to guide the electrodes through real-time imaging.

“Our collaboration with Bachmann-Strauss allows us to expand our work and will also provide a platform for long-term funding from other sources,” says Ostrem.

For patient information, contact Yameen Gonzalez at 415-353-2311, select option 1.

University of Florida (UF)

“A decade ago we envisioned opening a center for movement disorders,” says Michael Okun, MD, the Adelaide Lackner Professor of Neurology at UF. “I came to UF in 2002 with neurosurgeon Kelly Foote and a single staff member to make that dream a reality. Since that time, we’ve seen more than 7,000 patients, and our center has become one of the largest in the U.S.”

Okun is co-director of the UF Center for Movement Disorders & Neurorestoration, which houses The Bachmann-Strauss Center of Excellence, and also Tyler’s Hope Center for Comprehensive Dystonia Care, which matched the Bachmann-Strauss grant dollar for dollar. “One of the things that makes us unique is our commitment as a patient-centric, one-stop facility,” he says. “Patients can see multiple specialists in a single day, have physical or occupational therapy, join an exercise class and hear a presentation about our clinical trials.”

The clinical portion of the center is designed to support research into dystonia and PD. A large cohort of patients will be recruited for treatment and enrollment in studies. “Virtually every patient signs a consent form to be part of the clinical research and are entered into UF’s huge database, called INFORM,” explains Okun. “This practice links our clinical care to the latest research.”

Research will focus on studies of pathogenesis, imaging, DBS and innovative drug discovery. The team is using high-level imaging to evaluate the effects of certain drugs on the brain and will continue to focus as well on their world-renowned DBS program.

“We’ve assembled a dystonia and Parkinson’s ‘dream team’ and our goals are very aligned with those of The Bachmann-Strauss Foundation in providing the best possible care,” says Okun.

Contact Dr. Michael Okun at Okun@neurology.ufl.edu.
Best-Selling Book Gives Tips on Living Well with Parkinson’s

“PARKINSON’S TREATMENT: 10 SECRETS TO A HAPPIER LIFE,” a new book by Michael Okun, MD, director of The Bachmann-Strauss Dystonia and Parkinson’s Disease Center of Excellence at the University of Florida in Gainesville, is available on Amazon, Audible.com and iTunes. Search in iTunes for “Parkinson’s Treatment: 10 Secrets to a Happier Life.” The Audible Audiobook link is free with a 30-day trial membership.

DYSTONIA RESULTS from a complex interaction between genetic and environmental influences. Part of this “environment” is the developing brain itself, as evidenced by the fact that several forms of dystonia begin during a relatively narrow window in childhood. The 2013 Think Tank, entitled “Dystonia Pathogenesis and Treatment: Clues from Genes and Development” assembled an impressive cast of scientists and clinicians to review exciting advances in dystonia genetics, and consider factors that may make the brain particularly susceptible to the effects of dystonia-causing mutations. Co-chairing the event were Bachmann-Strauss Impact Grant recipient William Dauer, MD, director of the Movement Disorders Group and the Elinor Levine Professor of Neurology at the University of Michigan; and 2011 Bachmann-Strauss grant recipient Christine Klein, MD, Schilling Professor of Neurology and director of the Institute of Neurogenetics at the University of Lübeck, Germany. Watch for a summary of these presentations in the Spring 2014 issue of OUTLOOK.

WHILE NEW DRUGS have improved the lives of millions, there are currently no drugs designed specifically for dystonia. However, new research from the laboratory of Ellen Hess, PhD, has the potential to transform the field of dystonia drug development.

Since 2008, The Bachmann-Strauss Foundation has funded an antidystonia drug discovery program headed by Hess, who is a professor in the Departments of Pharmacology and Neurology at Emory University School of Medicine. “We are delighted that a new anti-dystonia drug is one step closer to reaching patients,” says Hess. “This work could not have been done without the support of Bachmann-Strauss.”

Hess is studying the pathomechanisms of dystonia through the manipulation of mouse models. “This strategy allows us to induce or ameliorate motor dysfunction in the context of an intact nervous system revealing potential targets for therapeutics,” explains the researcher.

Her lab evaluated several FDA-approved drugs that have promise as treatments for dystonia. Studies of one drug, dipraglurant, made by Addex Therapeutics, indicated a striking improvement in dystonic symptoms in mice. Dipraglurant is already in Phase 2a testing in humans for the treatment of the unwanted extra movements that sometimes accompany Parkinson’s disease. The ability of dipraglurant to reduce the severity of the dystonic movements in mice now opens up new therapeutic possibilities for the use of this and similar compounds to treat dystonia in patients.

“The Bachmann-Strauss Foundation has supported this initiative from the start,” says Hess. “When we began this work there was no screening program in animals. In just four years, we’ve come from that point to a partnership with pharma to move this compound forward.”
Teeing Off for Research

“COMING OF AGE” was the theme of The Bachmann-Strauss Foundation’s 21st Annual Golf Invitational held on June 17. The event recognized two decades of growth for the Foundation and celebrated its most recent milestone: the establishment of three new Bachmann-Strauss Dystonia and Parkinson’s Disease Centers of Excellence. The event raised more than $1.3 million, which will be used to fund next year’s research grants and provide support for the new centers.

The day began with a Pro-Am golf tournament, followed by a cocktail reception, dinner and live auction. Emceeing the event was Willie Geist, co-host of the third hour of NBC’s Today, co-host of MSNBC’s Morning Joe, and the Foundation’s spokesperson. The guest of honor was his father, award-winning journalist Bill Geist, who recently revealed that he has Parkinson’s disease. Other honorees included Katie Loeb, a member of the Foundation’s Young Leadership Council, who received the Scott M. Johnson Memorial Award for her support of the Foundation and its goals.

Susan Bressman, MD, chair of the Department of Neurology at Beth Israel Medical Center in New York, spoke about the progress made in finding novel treatments for dystonia. Other speakers included Allison London, chair of the Young Leadership Council and recipient of last year’s Scott M. Johnson Memorial Award; her father and Foundation board member Ron Hersh; and Lauren Von Der Ahe, daughter of board member Chris Von Der Ahe, who spoke poignantly of her sister Kristin’s courage in living with dystonia. Jamie Niven (below) of Sotheby’s served as auctioneer for the live auction, which featured some fabulous prizes, including “A Decadent Dinner for 12” prepared by chef David Burke, a week’s vacation in St. Barth’s and other items. The event was a wonderful celebration of the Foundation’s growth.

Bachmann-Strauss Welcomes Two New Board Members

THE Bachmann-Strauss Foundation is pleased to announce the appointment of two new members of its Board of Directors:

Attorney Allison London serves the Foundation as chair of its Young Leadership Council, where she plans and organizes events targeted to young professionals. Since being diagnosed with dystonia four years ago, she has worked tirelessly to support the Foundation and promote its mission.

Jason Spacek is managing director of the Alternative Assets Group at RBC Capital Markets, where he is responsible for sales and structuring of hedge fund-linked products and lending. His longtime support of the Foundation includes serving as co-chair of the 2011 Golf Invitational and being part of our marathon team over the past few years.

Shopping Event Raises More Than $6,000 for Dystonia and Parkinson’s Research

SOME 200 SHOPPERS came out for shopping, champagne and hors d’oeuvres at a special event held at fashion designer Rebecca Taylor’s Los Angeles store on September 26, raising more than $6,000 for much-needed dystonia and Parkinson’s research. The event was organized by the Foundation’s Young Leadership Council, which is chaired by new board member Allison London. The event featured raffles and prizes, and twenty percent of the proceeds were donated to the Foundation. An earlier event held this past spring at the Rebecca Taylor store in New York’s Meatpacking District was equally successful. The Foundation thanks Rebecca Taylor and all the attendees for their generosity.
MORE THAN 1,000 PEOPLE took to the road on bikes and on foot to support the 6th Annual Jake’s Ride for Dystonia Research held September 29 in Short Hills, NJ. This day of fun and exercise raised approximately $350,000—the largest amount ever for a Jake’s Ride event—to support research to help find more effective treatments and a cure for this debilitating neurological disorder.

The bikers and walkers had plenty of company—the more than 170 people who volunteered at the event and assisted with registering participants, guiding them through the race. The festivities were emceed by Willie Geist, co-anchor of the third hour of NBC’s Today, co-host of MSNBC’s Morning Joe, and the Foundation’s spokesperson. Jeffrey Waugh, MD, PhD, whose research fellowship is being funded by the Foundation, spoke about the critical need for dystonia research in patients. Corporate sponsors included BlackRock, Equinox, investorsBank, Macy’s, Overlook Medical Center, Paul Miller Automotive and Wells Fargo, to name a few.

Since its launch in 2008, Jake’s Ride has raised more than $1.6 million for dystonia research. The Foundation offers heartfelt thanks to the Silverman family, as well as all the participants, volunteers, and sponsors who made this event a success.

Dancing for Dystonia

HIGH SCHOOL student Lily Sabol, a talented dancer, knows too well the devastating effects of dystonia: Her cousin Allison London, chair of The Bachmann-Strauss Foundation’s Young Leadership Council, lives with the disorder. Lily found the perfect way to show solidarity with her cousin and support dystonia research. Each year her high school’s dance company holds a recital to benefit a charity. This year, Lily proposed donating the proceeds to the Foundation, with great success. It just goes to show that the sky’s the limit when it comes to fundraising. Every event, large or small, can make a difference!

Team Dystonia Launches in September

TEAM DYSTONIA officially launched in September to raise awareness about dystonia and provide support for the approximately 500,000 Americans who are affected by this disorder. Its debut in September is timely—it’s also the start of the school year and the beginning of a new season for many athletic teams.

New York City Mayor Michael Bloomberg and Suffolk County (NY) Executive Steven Bellone issued proclamations declaring the month of September Dystonia Awareness Month. The founding members of Team Dystonia—the American Dystonia Society, The Bachmann-Strauss Dystonia and Parkinson Foundation, and Tyler’s Hope for a Dystonia Cure—in-vite other organizations, foundations and nonprofits to join their efforts.
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<td><strong>Dinner with Dr. Ruth:</strong> Carmine’s</td>
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<td><strong>To purchase tickets contact:</strong></td>
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<td><a href="mailto:events@bsdpf.org">events@bsdpf.org</a> or 212-682-9900.</td>
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<td><strong>Spring 2014 (Date TBD)</strong></td>
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<td>Dystonia and Parkinson’s Disease</td>
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<td>For information call 212-682-9900.</td>
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Your support is gratefully appreciated. To learn more or make a donation visit [www.dystonia-parkinson.org](http://www.dystonia-parkinson.org) or call 212.682.9900.

The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc. was established in 1995 to find better treatments and cures for the movement disorders dystonia and Parkinson’s disease, and to provide medical and patient information. An independent, nonprofit, 501(c)3 organization, its funding is made possible through the generosity of individual and corporate contributors.