



Can the Human Genome Project Give Us Answers?

The first draft of the human genome just marked its 10th anniversary. While it was initially heralded by many as the key to more effective treatments and cures for a host of diseases, answers are still elusive.

"The lay community was under the impression that when we found genes, cures would quickly follow," says Ted Dawson, MD, PhD, of The Johns Hopkins University School of Medicine and chair of the Bachmann-Strauss Scientific Advisory Board. "Scientists knew that wasn't the case." However, he points out, as a result of the Human Genome Project many new genes for Parkinson's disease and dystonia have been identified and new therapies are currently being tested.

According to Laurie Ozelius, PhD, the Project has made gene finding much easier. "What used to take scientists years, can now be done in minutes on the computer," she says, pointing out that it took 13 years for the breakthrough discovery of the gene for DYT1 dystonia. Dr. Ozelius was part of

"You can't come up with cures for diseases if you don't know the causes."

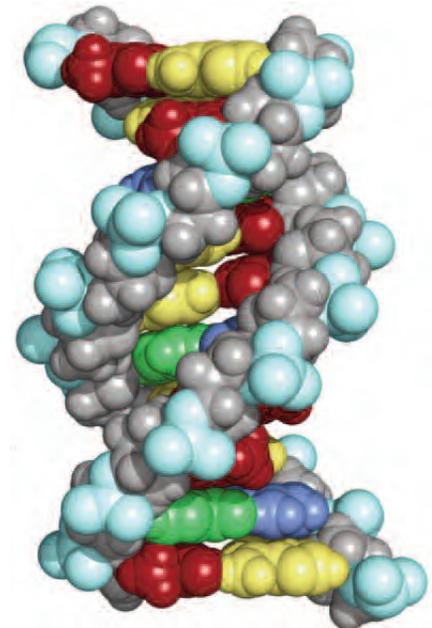
- Ted Dawson, MD, PhD

the team that discovered that gene in 1997 and, last year, her team discovered THAP1 (DYT6)*. That most recent finding, she says, enables them to screen dystonia patients to define phenotypes associated with mutations in this gene and come up with clinical testing guidelines. Phenotypes are observable clinical characteristics.

The discovery of the gene also allows us to ask what pathways are involved in dystonia and determine how or if they are related to Parkinson's disease. The Human Genome Project and all of its offshoots are creating resources that will allow us to look at diseases in different ways," she says.

"We can try to use genome-wide association studies to look for susceptibility but the only way to really use this is to collaborate world-wide. "In addition, in the near future, next generation sequencing should allow us to sequence individual genomes to directly identify disease related variations or mutations." Dr. Ozelius is Bachmann-Strauss Professor and Associate Professor of Genetics and Genomic Sciences and Neurology at Mount Sinai School of Medicine, New York City.

John Hardy, PhD, MD (Hon), FMedSci., FRS., Institute of Neurology at



A model of a DNA double helix.

University College in London, is involved in just such a collaboration as part of a genome-wide association study for cervical dystonia. "This new technology means we can test all genes at a single time for their effect on disease risk," he says.

A feasibility study has been conducted in the UK, and an international consortium of researchers are using a common diagnostic approach to collect samples from about 3,000 patients with dystonia to jointly find the risk genes.

Continued on page 2

Sandra F. Cahn
Appointed Foundation's
Executive Director

Noted for her strong portfolio in fundraising, development and business administration, Sandra F. Cahn joined our Foundation as Executive Director on March 1st, 2010.

Previously, Sandy was Northeast Regional Director for The Diabetes Research Institute Foundation responsible for major gifts and development and building the New York, New Jersey and Connecticut region from start up.

Sandy has held a wide range of senior volunteer leadership positions. She is currently a member of the Board of Trustees of the UJA-Federation of NYC, and serves on the Board of Hillel: the Foundation for Jewish Campus Life, as well as on the board of the American Jewish Joint Distribution Committee.

She is Co-Founder of UJA-Federation's Women's Executive Circle, a group of female CEO's, CFO's, and Presidents of major corporations that mentors the young Jewish business community. In addition, she is Co-Founder and Financial Resource Development Chair of "Limmud-FSU," an innovative program connecting the Russian Jewish population to pluralistic informal Jewish learning. She has helped the program for Russian-speaking young people expand to Russia, Ukraine, Belarus, Israel and America.

Sandy holds a Bachelor's and Master's degree in Education from Queens College of the City of New York.

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The process is expected to take approximately two years, but Dr. Hardy says it "should also have spin out benefits such as common approaches to diagnosis." The technology, although expensive, has already been successfully used in Type 2 Diabetes and Crohn's disease and to find risk genes for Parkinson's disease.

Along with progress, there have been obstacles. "Part of the problem is we now generate so much data and we really don't know the best way to analyze it," Dr. Ozelius says, "so we are sequencing the genome in small chunks. It is a bioinformatic nightmare."

Despite the hurdles, the future still seems to hold great promise of bringing us closer to better understanding. As Dr. Dawson says, "You can't come up with cures for diseases if you don't know the causes."

** Research that resulted in these breakthrough discoveries was funded in part by the Bachmann-Strauss Foundation.*

A Legacy of Hope

Through the years your support has brought us closer to finding answers to the mysteries of dystonia and Parkinson's disease and the suspected link between the two.

The accomplishments are significant. Just to name a few, they include the discovery of new genes, gaining better insight into the proteins and interactions in the brain that can cause these terrible movement disorders, and funding of pioneering research that is, right now, leading to new drug treatments.

The solutions to the puzzles that researchers must solve will come with time. In the meantime, our goal must be to proactively escalate the extraordinary work that is underway and to continue to fund the most promising studies that might otherwise not see the light of day. To do so, our challenge is to exponentially grow the number of people who are involved in our organization.

While it is difficult to continually ask people who have done so much to do more, we can't afford not to – there is too much at stake. Please continue to involve your friends, family, business and social contacts in our events, volunteer positions and other opportunities to directly impact progress.

The breakthroughs that have been achieved result from your support and provide an unprecedented legacy of hope to so many. Please help grow that legacy.

Thank you so much.



BONNIE STRAUSS
FOUNDER AND PRESIDENT



SANDY CAHN
EXECUTIVE DIRECTOR

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Think Tank to Discuss Link between Parkinson's Disease and Involuntary Movements

A gathering of some of the world's noted experts in the field of movement disorders will come to New York in early November to take part in the Bachmann-Strauss Foundation's ninth annual Think Tank.



Antonio Pisani, MD

Co-chaired by Antonio Pisani, MD, professor of Neurology at the University of Rome Tor Vergata, Italy and Thomas

Wichmann, MD,

professor of Neurology, Emory University, Atlanta, GA, this two day summit titled "Interface between Parkinson's Disease and Involuntary Movements" will include discussions about Parkinson's disease, dyskinesias and dystonia to explore the latest

knowledge in these fields. The term dyskinesia refers to involuntary movements that may constitute a separate disorder, or may appear as a side effect of the treatment of Parkinson's disease, different from the typical parkinsonian tremor.

"While Parkinson's disease and disorders that produce involuntary movements are clinically distinct, there is a growing realization among researchers that these conditions may affect the same brain regions, and biological systems," says Dr. Wichmann. "Exploring the interface between these diseases may

help us to better understand how they develop, how specific clinical features can be explained, and how we can treat patients more effectively."

The Think Tank comes under the auspices of the Bachmann-Strauss Scientific Advisory Board. A portion of the funding for this year's Think Tank is being provided by The Michael J. Fox Foundation for Parkinson's Research. Our Foundation continues to be the lead funding partner with the Michael J. Fox Foundation in the area of dyskinesia.

"...there is a growing realization among researchers that these conditions may affect the same brain regions and biological systems."



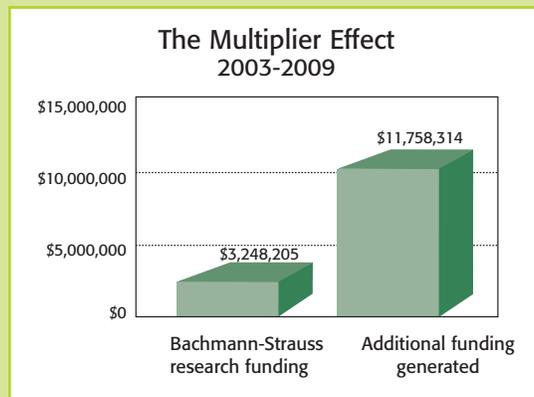
Thomas Wichmann, MD

Research Investments Realize Great Returns

A recent analysis of Bachmann-Strauss Foundation funding over a six-year period demonstrated how our strategy of providing "seed money" to scientists enabled them to leverage our grants into additional, major support, so they could continue their work.

The \$3.2 million awarded by our Foundation from 2003-2009 had a multiplier effect, generating more than \$11.7 million in funding from the National Institutes of Health (NIH).

"The Foundation identifies new, groundbreaking research and is often the catalyst that moves research to the next level," says Ted Dawson, MD, PhD, Director of Parkinson's Disease and Movement Disease Center, The Institute for Cell Engineering, The Johns Hopkins University School of Medicine and chair of the Bachmann-Strauss Scientific Advisory Board. "Seeing our research investments result in NIH funding is validation of our research investment strategy."



Collabo

Countdown Begins to Third Annual Jake's Ride

While many of us sweltered in record-breaking summer heat, an intrepid group of men biked 300 miles in the Rocky Mountains of central Colorado and promoted the upcoming 2010 Jake's Ride for Dystonia Research.

Now in its third year, Jake's Ride will be held on Sunday, September 26 beginning at Hartshorn Elementary School in Short Hills, NJ.

More than 1,000 participants and 100 volunteers are expected at this popular event, which features options of riding one, five, ten or 20 miles or doing a one mile walk on a separate course. The goal is to raise \$250,000 to help find better treatments and a cure for this devastating movement disorder.

Since its inception Jake's Ride has raised almost \$500,000 for dystonia research, and has funded seven research grants. It was created in honor of Jake Silverman, now age 14, and other children with dystonia.

To register, participate, volunteer or to donate go to www.jakesride.org.



From left: Jake's Ride committee member Fred Orlan, David Gardner, who was instrumental in creating this event two years ago, Committee Member Jon Levison, MD, and Gary DeBode, a Jake's Ride participant.



CBS Sports Anchor Otis Livingston, shown here with Jake Silverman, will again emcee Jake's Ride for Dystonia Research.

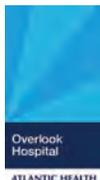


Jake at the finish line.

Featured Sponsors

Jake's Ride thanks

Stew Leonard's Wines



for supporting the 2010 event

orations

Bachmann-Strauss Funds DNA Biorepository Program

Our Foundation has recently supported the Dystonia Coalition to help fund a Biorepository for DNA. The goal is to build a large collection of DNA samples from patients with primary focal dystonia for genetic studies. Once established, the biorepository will be kept at Washington University in St. Louis although the data and materials will be accessible by any member of the Dystonia Coalition.

The Dystonia Coalition, of which we are a member, is a collaboration of scientists, institutions, patient advocacy organizations and the National Institutes of Health – all united to advance clinical research for dystonia. It includes more than 30 participating centers throughout North America and Europe.

Marathon Team to Fund Research

A champion team of men and women will be off and running to help benefit our organization in the world-famous ING New York City Marathon on Sunday, November 7.

Selected as a partner in the ING New York City Marathon's charity program for the fifth year, we were granted 45 slots in this year's Marathon. Our TEAM Bachmann-Strauss goal is to raise over \$200,000 for research into dystonia and Parkinson's disease.

Add your support to the team's efforts at www.teambachmannstrauss.kintera.org



Sagar Mehta is 2010 Team Captain.



RBC Capital Markets®

We are grateful to RBC Capital Markets for underwriting TEAM Bachmann-Strauss this year.

Signature Golf Event Raises Over \$1.3 Million



WNBC News Anchor and Reporter DeMarco Morgan, who emceed our dinner program, with Bonnie and Tom Straus.



Mark Standish, Edward McBride and Stuart Davies.



Golf carts at the ready.



Brian Dugan, the creator of our Marathon program.

“Inspirational” was the word our guests used to sum up our 18th annual golf invitational, which was held Monday, June 21. All told, over \$1.3 million was raised at this Hedi Kravis Ruger Memorial Golf Tournament. Thanks go to our very generous supporters, to Auctioneer Jamie Niven, who generated more than \$200,000 – the most ever raised at our auction – and to the tremendous work of our Co-Chairs, Stuart Davies and Edward McBride.



Auctioneer Jamie Niven in action.



Allison London, who was recently diagnosed with dystonia, pictured with her parents, Ron and June Hersh.

This full day of golf, followed by a cocktail reception, dinner and live auction was also celebration of our organization’s 15th anniversary.



Gregg Von Der Ahe, Bachmann-Strauss Board Member Chris Von Der Ahe and Peter Von Der Ahe.



Fran Ehrlich, Fran Klingenstein, David Freedberg, Karen Freedberg and Bachmann-Strauss Board Member Felice Axelrod.



Bonnie Strauss with Susan Bressman, MD, who was one of our dinner speakers and is the head of the Bachmann-Strauss Dystonia Center of Excellence at Beth Israel Medical Center.

Sagar Mehta Receives Scott Johnson Award

Applause rang out at our golf invitational dinner as the 2010 Scott M. Johnson Memorial Award for Dystonia and Parkinson's Disease Research was presented to Sagar Mehta.

This award was established in memory of Scott Johnson, a former member of our Young Professionals group who lost his life on September 11, 2001 in the World Trade Center. It is given each year to a Young Professional who has made an outstanding contribution to our Foundation and who is recognized as embodying Scott Johnson's generous spirit.

The strong, loving memory of his grandfather was the driving force behind Sagar's involvement in our organization. A first time runner in our marathon team last year, he raised more than \$35,000 on his own for research to help people like his grandfather, whom he watched struggle with Parkinson's disease for 10 years.



Sagar Mehta with Bachmann-Strauss Executive Director Sandy Cahn



DeMarco Morgan and Layla Love

Dystonia Puts Photographer's Future Plans on Hold

Layla Love is an accomplished photographer with an uncertain future. For her, dystonia began in childhood and she was wheelchair-bound. A series of treatments helped her to walk and move more normally. Her doctors later helped stop dystonia from advancing through her neck and hands.

Now 30 years old, she is steadily losing her eyesight to this devastating disease, and doctors are trying to find treatments that can help her continue her career. She remains hopeful and is watching with interest the research that is funded through our Foundation.

You can view Layla's creative photography at www.lovephotography.org

Meet DeMarco Morgan

When DeMarco Morgan heard Layla Love speak to our dinner audience about her devastating struggle with dystonia, he wanted to let more people learn of this little-known disease. Anchor and reporter for WNBC Channel 4 and the emcee of our Golf Invitational dinner program, Morgan followed up with a news story about her, "Rare Disease, Dystonia, Stealing Career from Young Photographer", that aired in New York in early August. You can see this story at www.NBCNewYork.com and type in "dystonia" in the Search box.

We are grateful to him for his involvement in our organization and for putting a much-needed spotlight on dystonia.

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Louis Bachmann (1916-2000)
Bonnie Strauss

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SAVE THE DATE

Sunday
September 26, 2010

Jake's Ride for Dystonia Research
*Hartshorn Elementary School
in Short Hills, NJ.*

Bike ride with routes ranging from one to 20 miles in honor of Jake Silverman and other children with dystonia.

To register go to www.jakesride.org

Sunday
November 7

ING New York City Marathon

Come cheer on TEAM Bachmann-Strauss running to benefit our Foundation. Add your support at www.teambachmannstrauss.kintera.org

Monday
June 20, 2011

**The Hedi Kravis Ruger
Memorial Tournament**

19th Annual Dystonia & Parkinson's
Pro-Am Golf Invitational

For more information call 212.682.9900 or go to www.dystonia-parkinson.org

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.