

# Project A.L.S.

NEWS  
WINTER 2001

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## Project A.L.S. Funds Breakthrough In Stem Cell Research

BY DOUG CORDELL

On November 5, Project A.L.S. and Johns Hopkins University announced a dramatic leap forward in their investigation of the use of transplanted neural stem cells to treat ALS. In the first ever experiment of its kind, paralyzed mice with an ALS-like syndrome regained movement after

having neural stem cells injected into their cerebral spinal fluid. The results, part of an unprecedented, collaborative research effort organized and fully funded by Project A.L.S., hold exciting promise for the use of

stem cell transplants to regrow damaged cells and replace the motor neurons that are destroyed in people suffering from ALS. They also offer potential treatments and cures for millions of people afflicted with Alzheimer's, Parkinson's and

**BREAKING NEWS**



Project A.L.S. study makes national headlines

## The Stars Come Out For Project A.L.S. Benefit Nets \$1.6 Million

Today Show anchor Katie Couric joined Sarah Jessica Parker and Matthew Broderick to host an October 2, Project A.L.S. benefit at New York's Metropolitan Pavilion that netted over \$1.6 million. The event, dubbed "Tomorrow is Tonight," to underscore the imminent hope for treatments and, ultimately, a cure for ALS, also garnered television and print coverage from coast to coast, bringing the message about this devastating, but long-ignored illness to millions.



The more than 900 guests at the Pavilion were treated to dinner and cocktails, followed by an all-star lineup of performances. Among the highlights were Jon Stewart, offering his usual cutting wit, Ethan Hawke, doing a reading

of Lou Gehrig's famous farewell speech, and a moving rendition of "Lean on Me," led by Jesse L. Martin of *Law and Order*. Couric and *Spin City*'s Richard Kind served as the evening's auctioneers.

Co-chairing the event were Michael R. Bloomberg, the CEO and founder of Bloomberg LP, Michael De Luca, president of New Line Cinema, Steven Fisher, chairman and CEO of Plaza Construction, Robert S. Kaplan, managing director of Goldman,

Frederic M. Seegal, president, Wasserstein Perella Group. Mrs. Bruce C. Hackett was the honorary chair, while Nordstrom was the presenting sponsor. ■

## FROM THE FIELD

ALS patients are currently participating in the first clinical trials of buspar, an FDA-approved drug that appears to have an acute effect on respiration in SOD1 (ALS) mice. Project A.L.S. has been funding an investigation of the rescue of respiratory motor neurons in ALS. The human trials of buspar, which Project A.L.S. is also funding in full, are an extension of this work. For more information, contact Lora Clawson, R.N., at Johns Hopkins University, 410-614-5976, or Merit Cudkowitz, M.D., at Massachusetts General Hospital, 617-726-5750.

Project A.L.S. has also committed to supporting upcoming clinical trials of anti-inflammatory COX2 inhibitors. As with the buspar trials, the Project A.L.S. board of directors believes that it is crucial for the organization to take what scientists learn in the laboratory and bring the benefits of that research to patients as quickly as possible.

On another front, Project A.L.S. is working with award-winning medical inventor Dean Kamen on the development of a non-invasive ventilation device for ALS patients. ALS progressively destroys the motor neurons that make breathing possible, forcing patients to turn to invasive ventilation aids. Among Kamen's other

inventions are a portable dialysis machine, the first portable pump to dispense insulin and a 'walking wheel-chair' that can take a patient up a flight of stairs. ■

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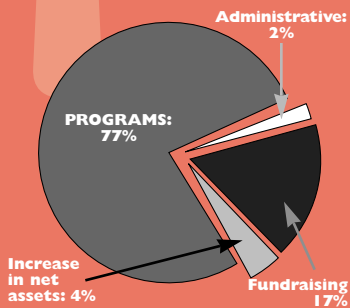
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## WHERE THE MONEY GOES

Thanks to low overhead, a very small staff and a lot of volunteer help from committed friends and supporters, Project A.L.S. is able to channel almost all the donations it receives directly into research. A report on Project A.L.S.' audited financial statements for the fiscal year ending July 31, 2000 broke down as follows:



### USES OF FUNDS AS A % OF TOTAL INCOME

Since its founding in 1998, Project A.L.S. has provided researchers with close to \$5 million in support. ■

## OF SPECIAL NOTE

A particular word of appreciation is in order for three exceedingly generous donations made recently to Project A.L.S.

- Anonymous, \$600,000
- Ten Dots, \$125,000
- The Horace W. Goldsmith Foundation, \$100,000

Our special thanks to Rory Boyes-Varley, Mark Thomas, and Thomas Slaughter for this unprecedented show of support. Their contributions, and others we have received since our founding in 1998, are speeding the way toward the development of treatments and the discovery of a cure for ALS and other neurodegenerative diseases. ■

## A LETTER FROM PROJECT A.L.S. PRESIDENT, JENIFER ESTESS

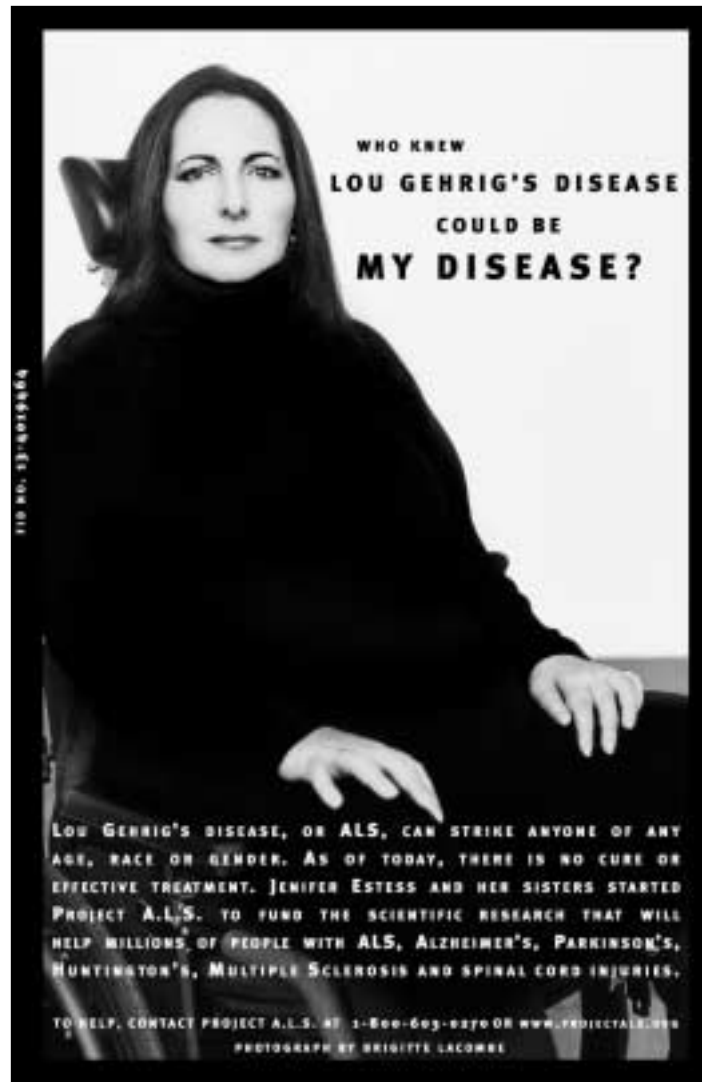
**Hello, and thank you** for helping Project A.L.S. do its best work. I am proud of our accomplishments this past year. With you, we have managed to leverage the best minds in science. We have brought *Cell Replacement in ALS* into focus as a real possibility for people living with ALS. We have raised important funds, kept our operating overhead to a minimum, and are now applying 80% of funds directly to research.

Of course, we will need to intensify our efforts in the coming months. We must continue to drive science in the best laboratories so that we offer effective treatments to ALS patients as soon as possible. In January, Project A.L.S. will go full throttle with *Cell Replacement in ALS*, introducing several promising cell lines into every available laboratory model of ALS.

Heart transplants, liver transplants, bone marrow transplants — though considered science fiction just a few decades ago, all have become standard, life-saving therapies. Now, initial data are telling us that cell transplants may be the first viable treatment for ALS. Cells may also help the millions of people suffering from Parkinson's, Alzheimer's, stroke and spinal cord injury. Yes, we are on the verge of great things — solutions for millions of people and those who love them. But we must continue to earn our way — with grace, generosity and hard work.

On behalf of the board of directors, founders and staff of Project A.L.S., I wish you and yours a happy and healthy holiday season.

**JENIFER ESTESS**



One of the Project A.L.S. public service announcements, this one featuring co-founder and president Jenifer Estess, that are running in a number of national magazines, raising the profile of ALS and letting people know how they can help.

FOR MORE INFORMATION OR TO MAKE A DONATION, PLEASE WRITE TO:

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# A RUN FOR THE MONEY NYC Marathon Team Raises ALS Funds

A team of 29 runners, led by Margaret Angell, a former track and field captain at Harvard, raced in the Nov. 5 New York City Marathon to raise money for ALS research. Project A.L.S. Marathon 2000 Team members, ranging in age from 25 to 59 and hailing from New York, Massachusetts, New Jersey, Florida, Pennsylvania, California and Washington, DC,



raised nearly \$200,000.

Angell's leadership of the marathon team arose out of a very personal connection to ALS. Her mother, Jean Angell, was diagnosed with the illness in 1998 and now serves on the board of Project A.L.S. Margaret says that, "After my

## Margaret Angell of the Project A.L.S. Marathon 2000 Team

mother was diagnosed with ALS, it was very difficult for me to talk about the disease or what was happening to us. When my parents became involved with Project A.L.S., I decided that if I could mobilize a group of people to train for the marathon and raise money, we could raise a considerable amount for Project A.L.S., and reach a broader group of supporters. Running the marathon is a way of using a very positive experience to fight back against ALS."

Margaret and the rest of her squad are now gearing up for another fundraising run, this time in the April, 2001 Boston Marathon, and they plan a return engagement in next year's NYC race. ■

## Project A.L.S. Funds Breakthrough

(continued from page 1)

Huntington's diseases, multiple sclerosis, epilepsy and spinal cord injuries.

Project A.L.S. president Jennifer Estess, who is also living with ALS, says of the news, "This is the kind of breakthrough we've been working toward. Our scientists are our partners in this fight — we knew they were applying best efforts to stem cell replacement in ALS. Project A.L.S. is thrilled that the mice are moving again. Now it's time to give people the same option. I am confident we'll get there."

Johns Hopkins neuroscientist Douglas Kerr, M.D., Ph.D., the principal investigator on the experiments, said, "This work was driven by the people at Project A.L.S. with their diligence and support. It is rare for a private organization to dramatically reshape the way research is pursued. But that has happened here."

Johns Hopkins researchers injected neural stem cells into mice that had been paralyzed by Sindbis, an animal virus. The Sindbis virus works much like ALS in its selective

destruction of motor neurons, the cells responsible for movement and breathing. Normally, the Sindbis virus, like ALS, destroys motor function permanently. But more than half the mice injected with stem cells regained motor function within eight weeks of the transplant.

Project A.L.S. researchers are currently negotiating with the Food and Drug Administration on guidelines for the first human trials of neural stem cell replacement in ALS. ■

**PARALYZED MICE WITH AN ALS-LIKE SYNDROME REGAINED MOVEMENT AFTER HAVING NEURAL STEM CELLS INJECTED INTO THEIR CEREBRAL SPINAL FLUID.**

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# Project A.L.S.

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## NEWS PROJECT ALS NEWS PROJECT ALS NEWS PROJECT FINDING AND FUNDING TREATMENTS AND A CURE FOR ALS WINTER 2001



Michael J. Fox, Mary Tyler Moore, Project A.L.S. president Jenifer Estess and Project A.L.S. advocate Gina Gershon at Senate hearing on stem cell research

Research Foundation, Moore, international chair of the Juvenile Diabetes Foundation, and Gershon, an advocate for Project A.L.S.

ible potential of stem cells to replace what is destroyed in ALS, but we need the federal government to mentor research along in the most responsible, humane way." Pointing out that, "non-profits

The hearing came on the heels of new NIH guidelines governing embryonic stem cell research, an area of some contention in Congress. Scientists believe that embryonic stem cells, with their ability to migrate and differentiate into

like Project A.L.S. and private industry have started stem cell replacement on the right track," she urged Congress to,

**Estess urged Congress to, "do the right thing and take us to the next level with this life-saving science."**

multiple cell types, hold particular promise for the treatment and cure of the entire range of neurodegenerative diseases.

Senator Specter

"do the right thing and take us to the next level with this life-saving science."

Those sentiments were echoed by Fox, president of the Michael J. Fox Parkinson's

and Senator Tom Harkin have introduced legislation that would ensure government support, oversight and controls for embryonic stem cell research. ■

### PROJECT A.L.S. ON CAPITOL HILL

**J**oining Michael J. Fox, Mary Tyler Moore and Gina Gershon in testimony before the Senate in September,

Project A.L.S. president Jenifer Estess pushed for government funding and oversight of stem cell research and called for a major, national initiative on neurodegenerative diseases.

Testifying at a hearing of Senator Arlen Specter's subcommittee on Labor, Health, Human Services and Education, Estess said, "My life and millions of others are in the hands of Congress. We are already seeing the incred-