

511 Avenue of the Americas, PMB 341, New York, New York 10011 email: [projectals@aol.com](mailto:projectals@aol.com) website: [www.projectals.org](http://www.projectals.org)

## Project A.L.S. Leads the Way on Stem Cell Research

BY DOUG CORDELL

**O**n July 25, readers of The Wall Street Journal learned of a historic scientific breakthrough — mice paralyzed by a crippling disease regained use of their legs after being injected with human embryonic stem cells. Readers also learned that the dramatic breakthrough by a team of Johns Hopkins University researchers was made possible by funding from one source — Project A.L.S.

The historic findings by the team of Drs. Douglas Kerr, John Gearhart and Jeffrey Rothstein offer tremendous hope not only for people suffering from ALS, but for those afflicted with a wide range of neurodegenerative diseases, including Parkinson's and Alzheimer's.

They are also the latest evidence of the enormous impact



**“The work received no federal research funding. Instead, financial support came from Project A.L.S....”**

Project A.L.S. has had on stem cell research in the little more than three years since it was founded.

Late last year, Drs. Kerr and Gearhart, working with funds from

Project A.L.S., announced similar results with mice that had been treated with mouse stem cells.

Noting Project A.L.S.' crucial role in this rapidly evolving science, co-founder Valerie Estess said,

“Lots of folks talked about matching stem cell biology with ALS research. We did it.”

Now, with stem cell research in the public spotlight as never before, thanks to a nationally televised speech by President Bush, Estess and her Project A.L.S. colleagues believe this is a critical moment to push that research to the next level. As Estess put it, “We welcome the national platform the speech provided

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## GERALD FISCHBACH JOINS RESEARCH ADVISORY

**P**roject A.L.S. is honored to welcome Gerald D. Fischbach, M.D., to its research advisory board. Along with Thomas M. Jessell, Ph.D. (Howard Hughes Investigator/ Columbia University), Lewis P. Rowland, M.D. (Columbia University), Robert H. Brown, Jr., M.D., D.Phil (Massachusetts General Hospital/ Harvard Medical School), and Jeffrey D. Rothstein, M.D., Ph.D. (Johns Hopkins University), Dr. Fischbach will review research proposals to Project A.L.S. and will advise the organization in shaping and prioritizing its research interests.



Gerald D. Fischbach, M.D.

Dr. Fischbach is Executive Vice President for Health and Biomedical Sciences; Dean of the Faculties of Health Sciences and Dean of the Faculty of Medicine at the College of Physicians and Surgeons of Columbia University. From 1988-2001, he served as Director of the National Institute of Neurological Disorders and Stroke, National Institutes of Health (NIH). He began his research career at NIH in 1966, and subsequently served on the faculty of Harvard Medical School and the Washington University School of

*continued on page 3*

## WHO WANTS TO BE A HERO?

### Stars Win Big for Project A.L.S. on ‘Millionaire’

**E**die Falco, star of the Sopranos, and actor and director Ben Stiller together won \$280,000 playing for Project A.L.S. on a celebrity version of ABC's “Who Wants to be a Millionaire?”

In appearances over two nights on the highly rated game show, Falco and Stiller also helped bring the Project A.L.S. message to an audience of millions.



Edie Falco and Ben Stiller appearing on “Who Wants to be a Millionaire?”

During her appearance on the show, Falco talked movingly with host Regis Philbin about her involvement with Project A.L.S. During Stiller's turn in the hot seat, Philbin took a moment to chat with Project A.L.S. co-founder Valerie Estess, who was on hand to cheer on the stars. Relaying a

message from her sister, Jenifer, president and co-founder of Project A.L.S., who has the disease, Valerie thanked Stiller for his tireless work on behalf of the foundation, adding, simply, “You're awesome.”

After the shows aired, Project A.L.S. was inundated with calls from people wanting to know more about ALS, and what they could do to help. Meanwhile, the producers of “Millionaire” have expressed their desire to work with Project A.L.S. on future shows.

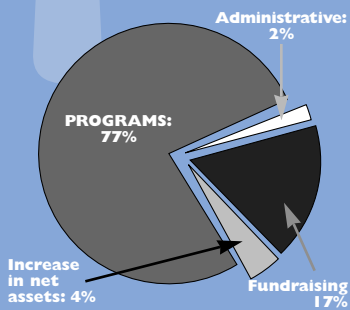
For their part, the Project A.L.S. family wishes to thank Regis Philbin, along with Michael Davies, Executive Producer, and Wendy Roth, Supervising Producer, for their partnership and generosity. ■

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## WHERE THE MONEY GOES

Thanks to low overhead, a small staff and volunteer help from committed friends and supporters, Project A.L.S. is able to channel almost all of 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. (Pending audit indicates rise in program allocation to approximately 80%):



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

Since its founding in November 1998, Project A.L.S. has provided researchers with close to \$6.5 million in support. ■

## OF SPECIAL NOTE

Project A.L.S. would like to express particular thanks to the following for their exceptional support:

- The Brad and Jill Grey Family Foundation, which provided \$250,000 to create the Sam and Dorothy Levin Memorial Fund at Project A.L.S.
- An anonymous contribution of \$600,000
- Katie Couric, who donated \$50,000
- The Kibel Company, which has made a \$100,000 commitment to Project A.L.S.
- An anonymous contribution of \$500,000
- Marcel and Belda Lindenbaum who donated \$50,000
- Carol and Gerald Kaufman, who donated \$25,000

## IN HER DAD'S NAME

For her 10th birthday, Katherine Moore, of Rocky Hill, Tennessee, held a fundraiser for Project A.L.S. Katherine's father, Kenneth, was 45 when he died last May 16, after a two and a half year struggle with ALS. In memory of her father, Katherine asked the friends that joined her birthday party at a local roller skating rink not to bring presents. Instead, she asked them to donate money to Project A.L.S. Katherine and her mother, Jennifer, say they wanted to raise awareness about ALS and do what they can to help find a cure. For the party, which raised \$700, Katherine made a poster explaining the mission of Project A.L.S., featuring photos of prominent Project A.L.S. supporters. The poster also shows



10-year-old Katherine Moore, with the Project A.L.S. poster she made in honor of her father.

a photo of Katherine with her dad in the cab of his delivery truck, on a day when she joined him for his rounds as a driver for UPS. "I know he would be really glad I am doing this," Katherine said of the fundraiser. ■

### DONOR SPOTLIGHT

### Benefit Premiere

On Tuesday, October 16th, Project A.L.S. held its fourth Annual New York City benefit, featuring the world premiere of *Jenifer*, the CBS TV movie about Jenifer Estess, the president of Project A.L.S. The evening, beginning with the film screening at the Loews Astor Plaza and followed by a gala dinner at Roseland, was hosted by Katie Couric and cleared over \$1 million for research. (See article on page 4.)

### Baseball Announces Project A.L.S. Day

Major League Baseball has announced its first ever league-wide commitment to support Project A.L.S. After meeting with Project A.L.S., Baseball Commissioner Bud Selig announced that, beginning next season, June 2, the anniversary of Yankee great Lou Gehrig's death from ALS, will be designated Project

A.L.S./Lou Gehrig Day. At all 15 league contests around the country that day, games will begin with a celebrity reading Gehrig's famous farewell speech. Fox-Television will run national, on-air promotions, and Diamond Vision will also do spots.

### Celebrities Tee Up for Project A.L.S.

On July 30, Project A.L.S. held its 2nd annual Celebrity Golf Classic at the Hudson National Golf Club at Croton-on-Hudson, New York. The star-studded event, sponsored by Departures Magazine, featured, among others, William Baldwin, Rob Morrow, and Dweezil Zappa. Corporate sponsors included Goldman, Sachs & Co., JP Morgan, Morgan Stanley Dean Witter, Plaza Construction and Neuberger & Berman. Contributors donated \$10,000 a foursome, each of which was joined by a celebrity player. All told, the event cleared close to \$200,000 for ALS research.

### Running for Research

The second annual Billy Mead ALS 5K Run for Research raised over \$100,000 for Project A.L.S. On August 5th, over 850 runners and walkers convened at Point Gratiot Park on Lake Erie in Dunkirk, NY for the race and a barbecue. Margaret Mead, Race Director, and her brother Billy started the event last year to raise funds for ALS research, increase awareness in their community and celebrate life. ■

### BENEFIT BRIEFS

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DOUG CORDELL

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

Dear Friends,

These have been days of profound sadness and pain. The terrible and tragic events of September 11th have left us shocked and saddened. Our sympathy for the families of the victims of this unspeakable tragedy could not be deeper. Our admiration for the heroic rescue workers could not be stronger.

Though still in the shadow of this devastation, Project A.L.S. feels it is essential to resume our work searching for treatments and a cure for people with ALS and related diseases. The promise we've made to them and their loved ones is one we must pursue.

In that spirit we have decided to deepen our commitment to supporting the promising research that will ultimately benefit millions of sick Americans.

Thank you for helping us to achieve this goal.

With warmest regards in this difficult time,  
JENIFER ESTESS

## Stem Cell Research (CONTINUED FROM PAGE 1)

for this issue, but, as yet, no one knows the full implications of the administration's policy. Meanwhile, we can't waste time. We need to continue to support the kind of independent research that has led the way on stem cell science."

Currently, Project A.L.S. is funding a range of collaborative efforts by its Stem Cell Core Group of researchers and the team of Jonas Friesen, PhD and Johan Erikson, PhD, of Sweden's Karolinska Institute, to transform stem cells into new, functioning motor neurons.

Looking ahead, Project A.L.S. and its researchers hope to answer some fundamental questions about stem cell treatment. Which stem cell lines, for example, will be most

helpful to patients? How many cells constitute an effective dosage? What are the most effective and safest methods of transplanting the cells? To get some answers, they are continuing their ground-breaking investigations. And if the short history of Project A.L.S. is any indication, they may get those answers very soon. ■

## Dr. Fischbach (CONTINUED FROM PAGE 1)

Medicine. He is a past president of the Society of Neuroscience.

Throughout his career, Dr. Fischbach has studied the neuromuscular junction, where nerve cells meet their muscle targets. Project A.L.S. is currently funding scientists to understand the role of the neuromuscular junction in ALS. (See "From the Field.") ■

# FROM THE FIELD

With funding from Project A.L.S., Yang Teng, MD, PhD, of

Children's Hospital, Boston and the Harvard Medical School, is testing the ability of innovative drug therapies to help save respiratory motor neurons. The deterioration of respiratory motor neurons, and the resulting loss of breathing function, is the most pressing health threat for ALS patients.

■ Washington University's Joshua Sanes, PhD, a leading expert in what is known as the neuromuscular junction (NMJ), will look for the first time at the role of the NMJ in ALS. For decades, scientists have focused primarily on nerve cells and their

immediate surroundings for clues to the destructive pathways of the disease. Project A.L.S. has fully funded Dr. Sanes and colleague Jeffrey Lichtman to examine the area where nerves meet muscle tissue. The investigation promises to yield important new information about causes and treatments.

■ Thanks to the rapid screening of FDA approved drugs, patients from around the country

...patients from around the country will soon participate in the largest ever ALS clinical trial.

will soon participate in the largest ever ALS clinical trial. Project A.L.S.-sponsored research at Johns Hopkins University showed that COX2 inhibitors, a class of drugs most commonly used to treat symptoms of arthritis, appear to have an effect on inflam-

mation and lifespan in SOD1 (ALS) mice. The results were so promising that Pfizer, Inc., the manufacturer of Celebrex, a popular commercial brand of COX2 inhibitor, has agreed to underwrite the 350-patient, multi-center trial in its entirety. ■

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

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