

## October 2009- Connections eNewsletter

### *In this issue:*

- [Letter from the Executive Director](#)
- [Walk to Defeat ALS™](#)
- [Patient and Caregiver Services](#)
- [Research](#)
- [How You Can Help](#)
- [Local Highlights](#)

---

## Letter from the Executive Director

### *Tax time again? Well, for some of us...*



Photo by [Christina Shook](#)

I wanted to thank you for your support of the [California tax check-off](#) measure (SB 1502) that allows California taxpayers to donate some or all of their tax refund to the Lou Gehrig ALS Research Fund. So far in 2009, almost 18,000 taxpayers donated over \$200,000 to the fund. To reach these figures, many of you had to have solicited others to donate to the Fund, for which the ALS community thanks you as well.

For those who have not yet filed their tax returns this year (which are due by **October 15th**) there is still time to make a donation. Next year, we will have to meet a higher threshold (\$250,000), and we hope you will continue your support to such a worthy cause.

Time is moving quickly! Our Fall events will be concluding in October. Please join us as we **Walk to Defeat ALS™** in [Berkeley on October 11th](#) and in [Monterey on October 18th](#).

Breathing problems are some of the most severe symptoms of ALS because the muscles involved slowly weaken. The basic act of breathing becomes harder as well as the ability to cough and swallow well. Working with a respiratory therapist (RT) can assist people with ALS by teaching them breathing techniques, as well as helping to obtain equipment to aid and breathing.

ALS does not discriminate. The irony that a respiratory therapist herself would be diagnosed with ALS is not lost on [Juri Kameda](#) in our "[I am Lou](#)" profile this month. But, she has chosen to help others with her professional expertise while spreading awareness of ALS all the way to Washington DC.

Finally, I am proud to shine the light on the work of our [dedicated Support Group facilitators](#) in this month's "[We are Lou](#)" feature. Every month across Central and Northern California, our Chapter offers these opportunities for People with ALS, caregivers, family members and friends to share stories, hear about other people's experiences and ask questions about living with ALS. There are even groups who meet online!

These [support groups](#), like all of the other services provided by our Chapter, are always free of charge. It is only together that we will defeat ALS.

Sincerely,



Fred Fisher  
Executive Director  
The ALS Association Greater Bay Area Chapter



---

## Walk to Defeat ALS™

The [Walk to Defeat ALS™](#) season has opened to a phenomenal start. Chapters with spring Walks posted record breaking results both in number of participants and funds generated. Over 40 Walks occurred nationwide between the months of March and June, raising approximately \$3.9 million in the fight against ALS. Each penny raised by Walkers will help support crucial patient services programs and global ALS research endeavors.

Several economists have noted that events like the [Walk to Defeat ALS™](#) can withstand the volatility of our current economy. Walkers are successfully collecting donations from coworkers, family, and friends. As our fall Walk events begin, [The ALS Association Greater Bay Area Chapter](#) is very confident that our dedicated Walkers will raise more significant money to battle this unforgiving disease.

Thank you for your continued support of The ALS Association's [Walk to Defeat ALS™](#). By uniting against Lou Gehrig's Disease, we can let the spirit of perseverance thrive in the face of adversity.

[Find a walk near you.](#)

---

## Patient and Caregiver Services

### *Ask the Doc: Deep Vein Thrombosis*

Monthly "Question and Answer" with Dr. Kasarskis — The topic this month is "Vein Thrombosis". [Read the full story.](#)

[The ALS Association Greater Bay Area Chapter](#) has a variety of resources to help you improve your quality of life. Please learn more about our [support groups](#) and [caregiver tips](#) to enhance your ability to deal with the physical and emotional issues associated with ALS.

---

### *People with ALS Needed for a Research Study on Quality of Life*

Researchers at Penn State College of Medicine are seeking participants with ALS for a research study on why individuals access a multidisciplinary clinic versus receiving traditional practitioner care. Participants will also be asked questions about quality of life and problem solving skills. The purpose of the study is to better understand the quality of life and problem solving skills of patients with ALS who attend multidisciplinary clinics versus those who do not.

[Click here to read more about this study.](#)

---

## Research

### *FDA Approval Received for First ALS Stem Cell Trial*

The U.S. Food and Drug Administration (FDA) has approved a Phase I trial aimed at treating ALS with spinal cord stem cells. Neuralstem, Inc., based in Maryland, will launch the trial and will study the safety of Neuralstem's cells, as well as the procedures required for multiple injections of the cells directly into the gray matter of the spinal cord.

The FDA's approval represents a significant step toward delivering regenerative medicine directly to damaged neural cells in humans.

"This is an extremely important trial that will test the stem cell approach in ALS in a rigorous way," said Dr. Lucie Bruijn, senior vice president, Research and Development at The ALS Association. "This is the first stem cell trial in ALS, and it will be conducted initially to study its safety in humans."

[Click here to read more about this trial.](#)

---

### *Researchers Identify Genes Potentially Linked to Sporadic ALS*

A team of mathematicians, led by Professor Shuanglin Zhang at Michigan Technological University, employed a new statistical method that led to the identification of three genes that the investigators believe may be linked to the sporadic form of ALS, which occurs in individuals with no family history of the disease and accounts for 90 percent of cases diagnosed.



"Identification of genes linked to ALS has been extremely important in opening up new directions for ALS research and providing the tools to develop therapies for the disease," commented Dr. Lucie Bruijn, senior vice president, Research and Development at The ALS Association. "In the case of familial ALS, several genes have now been identified." Familial ALS accounts for 10 percent of all cases diagnosed.

[Click here to read more about this exciting research breakthrough.](#)

---

## How You Can Help

### *Compassion for Clunkers?*



The popular Cash for Clunkers program may be over, but you can always participate in "compassion for clunkers" by donating your used car to [The ALS Association Greater Bay Area Chapter](#). It is a great way to help those living with ALS, save yourself the hassle of selling your car, and receive a charitable tax deduction!

[Click here for more information.](#)

---

## Local Highlights

### Resources for People with ALS and their Loved Ones

- [Find your Care Manager and Support Group Leaders](#)
- Mark in your favorites this listing of [Resources and Special Events are happening each month](#)
- ["The ABC's of ALS" presented by Dallas Forshew](#)  
See this informative lecture for People with ALS and their families!  
Or you can see it yourself on The Greater Bay Area Chapter's [You Tube Channel!](#)
- [Watch a Special Research Presentation](#) given by Dr. Lucie Brujin for our Chapter!
- Many thanks to [Bruce and Eric's Message of Hope](#)
- Why do you choose to receive your care from a multidisciplinary ALS clinic?  
[Help with a Nationwide Survey for People with ALS](#)

### Spread the word to your friends and family!

- Join our Chapter's Group on [Linkedin](#)
- Subscribe to our [You Tube Channel!](#)
- Become one of our many Fans of our [Facebook](#) Page!
- See photos from our events on [Flickr!](#)
- You can play a pivotal role in improving the lives of People with ALS and their families.  
[Join our Campaign for Care and a Cure](#)

### Special Events Updates

- **Sunday, October 11th**  
East Bay *Walk to Defeat ALS™* - [Register Now!](#)
- **Sunday, October 18th**  
Monterey *Walk to Defeat ALS™* - [Register Now!](#)

### In the Community

- Watch two compelling interviews with person with ALS [Matt Chaney](#) and Board President [Brian Griggs](#) on CNN Comcast Newsmakers.
-