

## **CARRE Foundation Has Chosen Multiple System Atrophy as the Spotlight Charitable Cause for CSP Business Media's 2013 Outlook Leadership Conference**

- *The Charitable Alliance of Restaurant and Retail Executives (CARRE) Foundation provides leadership through charitable giving while building stronger relationships and bonds within the CSP Business Media's conference community.*
- *CSP Business Media brings the best of the convenience and petroleum retailing industry leaders together for functional networking and thought-provoking education and business-building sessions*
- *The convenience and petroleum retailing industry has two beloved members diagnosed with multiple system atrophy (MSA), a rare and fatal neurodegenerative disease.*
- *The money raised by CARRE in their 2013 fundraising event will be used to support MSA research grants being awarded this fall by The Multiple System Atrophy Coalition.*
- *Working together The MSA Coalition and CARRE have established a goal to significantly increase funding for multiple system atrophy research leading to identification of a cure.*
- *A portion of the money raised by the CARRE Foundation will be earmarked to support a multiple system atrophy genetic project now in progress at the Translational Genomics Research Institute (TGen).*

**Oakbrook Terrace, August 15, 2013:** The Charitable Alliance of Restaurant and Retail Executives (CARRE) Foundation has announced the selection of multiple system atrophy (MSA) as the spotlight charitable cause at CSP Business Media's 2013 Outlook Leadership conference. MSA is a rare and fatal neurodegenerative disorder with approximately 13,000 Americans currently diagnosed, including two members of the convenience and petroleum retailing industry. To ensure the money raised is targeted to the most promising research the CARRE Foundation is partnering with The Multiple System Atrophy Coalition, the most influential MSA patient organization in the United States. The MSA Coalition has an established MSA Research Fund and world-class scientific advisory board tasked with identifying research with the most promise for finding a cure for multiple system atrophy. The partnership also aims to increase awareness for the rare disease.

"We are very pleased the CARRE Foundation has selected multiple system atrophy as the charitable cause for their 2013 fundraising campaign" stated Judy Biedenharn, co-President of The MSA Coalition. "CARRE is an outstanding charitable organization. As such, working in partnership with the CARRE Foundation to increase awareness and research funds for this horrible and little known disorder is an incredible opportunity for The MSA Coalition and the MSA community. CARRE activities and fundraising will add momentum to our new MSA

Research Grant Program by quickly increasing the funds available. With the help of the CARRE Foundation fundraising we anticipate having \$300,000, and hopefully more in our Multiple System Atrophy Research Fund by the time we decide on this year's grant awards."

Early this year, The Multiple System Atrophy Coalition announced its new MSA Research Grant program. The primary goal of the program is to encourage and fund meaningful research leading to the discovery of a cure. Average life expectancy after diagnosis is only 5-9 years. Due to the rapid progression of MSA, there is a tremendous sense of urgency to raise sufficient money to immediately fund promising research. The first financial awards will be granted in the fall of 2013 and will include money raised by the CARRE Foundation.

"The CARRE Foundation provides leadership through charitable giving while building stronger relationships and bonds within our conference community. Primary support is to other non-profit organizations, including, but not limited to, those that assist others suffering from disability, disease, illness and other hardships, as well as organizations that promote the development of programs that extol the virtues of leadership" stated Kay Segal, Senior Vice President, CSP Business Media.

"In conjunction with our Outlook Leadership conference, November 9-12, 2013, we will focus our CARRE efforts on a disease that has affected the lives of two industry members, one just this past year" continued Ms. Segal. "Rex Griswold, of Nestle Waters North America and Tom Gillard, formerly of Tropicana, QTG and MetRx. The disease is called MSA, Multiple Systems Atrophy. We are driven to help put MSA into the spotlight and do everything in our power to push forth research that truly makes a difference. Because The MSA Coalition has a world-class scientific advisory board to review research proposals, CARRE will give a significant amount of proceeds raised over to the Coalition's MSA Research Fund."

The CARRE Foundation is also using a portion of the money raised to support a multiple system atrophy genetic project now in progress at the Translational Genomics Research Institute (TGen), a non-profit 501(c)(3) organization. The project is evaluating the genes of several families, each with one MSA patient. The aim is to compare the genes of the MSA family member with the genes of their non-MSA diagnosed family members, including parents, siblings and children. The hope is to identify a gene that might be the cause of MSA and to identify potential disease-modifying therapies.

### **About Multiple System Atrophy**

Multiple system atrophy (previously known as Shy-Drager Syndrome) is a rare and fatal disorder with less than 15,000 Americans diagnosed and 35,000 undiagnosed

at any given time. According to the National Institutes of Health, "Multiple system atrophy is a progressive neurodegenerative disorder characterized by symptoms of autonomic nervous system failure such as fainting spells and bladder control problems (neurogenic orthostatic hypotension), combined with motor control symptoms such as tremor, rigidity, and loss of muscle coordination. MSA affects both men and women primarily in their 50s. MSA tends to advance rapidly over the course of nine to 10 years, with progressive loss of motor skills, eventual confinement to bed, and death. There is no remission from the disease. There is currently no cure is available."

### **About the CARRE Foundation**

At CSP's Leadership Conferences & Events, our CARRE Foundation (Charitable Alliance of Restaurant and Retail Executives) plays a critical role in the attendee experience. CARRE Foundation's purpose is to provide leadership through charitable giving while building stronger relationships and bonds within our conference community. Primary Support will be to other non-profit organizations, including, but not limited to, those that assist others suffering from disability, disease, illness and other hardships, as well as organizations that promote the development of programs that extol the virtues of leadership.

### **About CSP Business Media**

Oak Brook, Ill.-based CSP Business Media, publisher of *CSP*, *Convenience Store Products*, *FoodService Director* and *Restaurant Business* magazines, is a market-dominant, business-to-business, multi-media communication company specializing in the convenience retailing, restaurant and on-the-go food industries. In addition to its print products, CSP Business Media has an extensive portfolio of online products including e-newsletters, websites, web conferences, CSPTV and other video products, mobile applications and custom solutions. And CSP Leadership Conferences & Events produces more than 20 major EduNetworking live conferences and focused meetings.

### **About The Multiple System Atrophy Coalition<sup>SM</sup>**

The Multiple System Atrophy Coalition is a positive beacon of hope standing up to a little known, rare, insidious disorder. Made up of dedicated volunteers, The MSA Coalition has a primary purpose of encouraging and funding research to find a cure. The Coalition also provides much needed patient and caregiver support, educational resources, and advocacy to create awareness and to fight for issues important to the MSA community. At present, 75% of all donations go directly into a dedicated Multiple System Atrophy Research Fund which now supports a research grant program. The MSA Coalition also has a world-class scientific advisory board (SAB) to review and award research grants to the most promising MSA research proposals.

For more information or to donate to The Multiple System Atrophy Coalition, please visit: [www.MultipleSystemAtrophy.org](http://www.MultipleSystemAtrophy.org)

### **About TGen**

The Translational Genomics Research Institute (TGen) is a non-profit 501(c)(3) organization focused on developing earlier diagnostics and smarter treatments. Translational genomics research is a relatively new field employing innovative advances arising from the Human Genome Project and applying them to the development of diagnostics, prognostics and therapies for cancer, neurological disorders, diabetes and other complex diseases. TGen is on the cutting edge of translational research where investigators are able to unravel the genetic components of common and complex diseases. Working with collaborators in the scientific and medical communities, TGen believes it can make a substantial contribution to the efficiency and effectiveness of the translational process. TGen's vision is of a world where an understanding of genomic variation can be rapidly translated to the diagnosis and treatment of disease in a manner tailored to individual patients. TGen is dedicated to the next revolution in health care. With the patient at its helm, TGen is guided by three core principles: integrate, translate and accelerate.