Planting Seeds of Hope:

Through the generosity of local businessman Steve Blume and his fiancée Jennifer Leavengood, the ALS Clinic at USF became reality.
GENEROUS DONATION BRINGS WORLD-CLASS CARE TO HUNDREDS ON FLORIDA’S GULF COAST

PLANTING SEEDS OF HOPE

Multidisciplinary ALS clinics offer the most up-to-date clinical therapies and services to people diagnosed with the disease. They are typically staffed with ALS experts in physical and occupational therapy, respiratory therapy, speech therapy, nursing and social services who work closely with physicians to address and manage the issues that stem from ALS. The ALS Association Florida Chapter has longstanding affiliations with the Mayo Clinic ALS Center in Jacksonville, the Lee Memorial ALS Clinic in Ft. Myers, the Shands Neuromuscular Clinic in Jacksonville, and the Suncoast ALS Clinic in St. Petersburg.

There was a recognized need for a multidisciplinary university clinic on Florida’s gulf coast. The USF ALS Clinic was a project years in the making, which needed funding to become reality, and this dream finally came to fruition with the help of generous benefactor and longtime supporter of the ALS Association Florida Chapter, Steve Blume and his fiancée Jennifer Leavengood.

Blume, a USF alum and local businessman, donated $100,000 to provide the seed money needed to launch the clinic, which opened in October of 2010. Blume made his considerable donation in memory of his father, Frank Blume, who died from ALS.

"My dad was diagnosed after showing symptoms for six to eight months in 1983. At that time it was really hard to get any information about the disease. There was no local association and certainly no clinics," Steve said. "He was an avid golfer and ALS deprived him of his quality of life. He was only 56 and felt robbed by the disease. Over the years we have made many donations and supported research."

Tampa’s central location made it a logical choice for a clinic and fortunately, The Association’s plans coincided with USF Health’s hire of a new Chair of Neurology, Dr. Clifton Gooch from Columbia University, who was recruited to dramatically expand neurology at USF. Dr. Gooch came with nearly twenty years of experience in ALS care and research, and made the establishment of the USF ALS Clinic and Research Center a priority, partnering with the Chapter shortly after his arrival to help bring this vision to reality. But to move forward, a significant donation was needed to provide funds to hire an ALS nurse and help fund the start-up of the multidisciplinary team. Steve remembers being approached by Chapter leaders.

"I met with the executive director and lead scientist, Lucy Brujin, and they told me about their plans for an ALS clinic. They said it would cost $100,000 to get it off the ground and I said ‘I can do that,’” Steve said. “My donation would be the seed money and hopefully other donors would join me. I wanted to be a part of opening this clinic. The convenience for people with ALS is great. I couldn’t do anything for my dad – we didn’t know there were people that could help us when he was diagnosed. The clinic shows people with ALS that someone cares. It gives them hope and a better quality of life. I am a graduate of the USF College of Business so I was happy to support both the ALS Association and USF.”

Chapter President Kim Hanna believes that the USF ALS Clinic will one day become the preeminent multidisciplinary ALS clinic in the nation. “In three years, I would love the USF Clinic to be the clinic that people reach out to for clinical trials,” she said. “When we have the growth that we are hoping for, we would have to have a clinic every week instead of every month.”

Steve Blume agrees. “The future of the clinic is very promising.” He said, “The most important thing we have to do is get the word out and continue the momentum so we can serve more people.”
"The clinic would not be operating today without the gift from Steve and Jennifer," said Kim said, President of The ALS Association Florida Chapter. "Their remarkable generosity has improved the lives of ALS patients in West Central Florida."

Among the significant accomplishments during the clinic’s year and a half tenure is the number of patients it reaches. "Reaching so many people so soon is a clear sign we are serving ALS patients throughout the entire region and not just in Tampa, and also reinforces the tremendous need for the clinic here," said the ALS Center Director Tuan Vu, MD, Professor of Neurology and Director of the Neuromuscular Division in the USF Department of Neurology.

Dr. Gooch explained the importance of multidisciplinary care in the treatment of ALS.

"Multidisciplinary ALS clinics increase a patient’s quality of life and can extend their lives," he said. "In studies of ALS patients using multidisciplinary clinics, life spans were significantly increased."

Patients who attend multidisciplinary ALS clinics may live an average of one or more years longer than patients who don’t. Dr. Gooch explained this is largely due to the fact that ALS patients attending clinic receive comprehensive and specialized care that addresses all of their needs early and at once, including:

- Monitoring and maintenance of nutrition
  (The most effective way to slow the progression of ALS)
- Respiratory monitoring, support and care
- Pharmacologic treatment of the disease and its complications
- Strategies for maintaining speech and communication
- Advance planning for different disease stages
- Supportive and medical care for emotional health
- Social worker assistance with financial and caregiver challenges and identification of resources for assistance

Despite the great value multidisciplinary care offers a person with ALS, most insurance companies do not offer sufficient payment to cover the cost. Multidisciplinary ALS clinics are incredibly important to patients and their families, but currently, our health care system has not evolved financially to support this approach.

Centers like the USF ALS Clinic rely on support from The ALS Association Florida Chapter and others to provide the funding necessary to continue serving patients.

Most ALS clinics face a financial challenge every day to keep the doors open. The reality is that ALS clinics don’t break even – they rely upon partnerships with The ALS Association and the generosity of people like Steve and Jennifer to fill the funding gap that is always there.

And just as important as patient care are the clinical trials that take place at multidisciplinary ALS clinics. The USF ALS Clinic has started five clinical trials since it opened in the fall of 2010. These include USF’s selection as a center for the largest current clinical therapeutic trial in the world using a mitochondrial membrane stabilizer which has already shown promise in ALS patients (the EMPOWER study) and also becoming one of that study’s fastest enrollees, as well as the launch of a new pilot trial of high dose GCSF exclusive to USF, using a drug which mobilizes the body’s own bone marrow stem cells to move into the brain, potentially helping to repair injured neurons.

"We are moving along at warp speed," Dr. Gooch said. "With the Association’s help and the hard work of our faculty and team, we’ve accomplished more in a year than most new ALS clinics accomplish in five or ten years. We are determined to find better and better treatments for this disease. However, despite our best efforts, we can do nothing without the dedication and financial support of patients with ALS and those who care about them. Ultimately, the Association and its donors provide the fuel for this engine, and without their support, we would not be able to provide the kind of care they deserve and need, or to do the kind of research we hope will one day lead us to a cure."

Philanthropic support is critical to keeping clinics like the one at USF open and to provide ongoing patient care and research. Donations help to elicit the greatest potential and fuel the research that will result in better treatments and ultimately a cure for ALS.

Please consider a gift to support ALS research and clinical care today.