Searching for Better Options for ALS Treatment

OSF HealthCare Newsroom
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The OSF HealthCare Foundation recently received a $1 million gift which will be used to support neuroscience innovation focused on assistive technologies, improving access to care, and aiding in earlier diagnosis to benefit patients with ALS (Lou Gehrig's disease) and other complex neurological conditions.

The gift was made by Ed Rapp and his wife, Ann. Ed retired as Caterpillar Group President in 2016 after being diagnosed with ALS. Since then he has made it a personal challenge to support efforts to find more effective treatment options and, ultimately, a cure.

The Ed and Ann Rapp Family Endowment, created at OSF HealthCare in 2017, will attract and inspire teams of clinicians and engineers to work together to rethink what is possible and revolutionize neurological care.

The collaboration is expected to drive innovative solutions ranging from tools leading to early diagnosis to allowing remote patient monitoring, lessening the burden on both patients and caregivers

"Patients who are newly diagnosed being able to participate in research trials at a distance is very important to them, and to have access to some programs that they otherwise wouldn't be able to, and so developing those tools to get care into the home and allow for research from home is very important," said Dr. Chris Zallek, neuromuscular disorders specialist with OSF HealthCare Illinois Neurological Institute.

Through his ongoing work, Dr. Zallek knows early diagnosis of ALS will be increasingly important as new medications and treatments are developed to slow disease progression.

"Communication is one of the major frustrations that patients have - weakness in and of itself is a huge barrier being able to move your arms and legs – but being able to ask for assistance when you like or just communicate emotions is incredibly important. These are things that are gradually slowed down as communication is impaired and so speeding that up will help these patients," explained Dr. Zallek.

It is projected that within the next 30 years more than 12 million Americans – nearly one in 25 – will suffer from a neuro-degenerative disorder or autoimmune condition, including ALS, dementia, Parkinson's disease, Multiple Sclerosis and others.

The work of the Rapp Endowment is a collaboration between OSF HealthCare Illinois Neurological Institute, Jump Trading Simulation & Education Center, and engineers from the University of Illinois.

Technology developed is being introduced to medical students at the University of Illinois College of Medicine Peoria this fall, with plans to expand to medical students and other health care providers at institutions across the country.