



The issue of
ALS

GRAND ROUNDS



SAINT LOUIS
UNIVERSITY.

Saint Louis University School of Medicine

SPRING 2021

AT THE INTERSECTION OF TIME, HOPE AND HEART: THE SLUCARE ALS CLINIC AT SAINT LOUIS UNIVERSITY

Caring for a patient with ALS is unlike almost any other doctor-patient relationship. One of the most important considerations is time—like an unspoken ticking clock. The physicians and other providers at the SLUCare ALS Clinic at Saint Louis University all have an acute sense of urgency about them; urgency to diagnose appropriately, to anticipate problems before they happen, to help patients and families improve their quality of life—and an urgency to find a cure for ALS.

The providers at the ALS Clinic do this work with a distinct spirit of hopefulness. Each day they see patients and families who have accepted that while they may not benefit from the

clinical trials in which they participate, they are hopeful that they can contribute to advances in medicine, and provide a gift to patients who may come after them. There is a spirit of hope that a cure for ALS will be found, and new treatments will be discovered. Time and time again, providers who treat patients with ALS are buoyed by the tenacity of patients after diagnosis, and how they choose to spend their lives when faced with a terminal disease. Knowing that ALS is not the end, but rather it is part of life's journey. Patients have written books. Raised children. Worked meaningful jobs. Loved others. Been loved. And created hope.

HEART. CURIOSITY. PASSION. HOPEFULNESS.

THE ALS CLINIC TEAM DOES THIS WORK NOT JUST BECAUSE THEY HAVE THE CLINICAL TRAINING TO DO SO BUT ALSO BECAUSE THEY HAVE THE HEART. THEY BRING A CURIOSITY ABOUT THE MYSTERY OF ALS TO THEIR WORK, A PASSION FOR HELPING MAKE LIFE BETTER FOR PEOPLE ON THEIR JOURNEY, AND A HOPEFULNESS THAT A CURE IS ON THE HORIZON.



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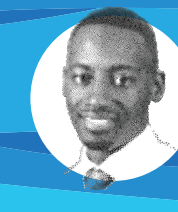
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An illustration on the left side of the page shows a small silhouette of a person standing on a light-colored path that recedes into the distance. The path is flanked by dark, shadowed areas, creating a tunnel-like effect. At the far end of the path, a bright, glowing light source is visible, casting a long, warm beam of light back towards the person. The background is a solid, vibrant red.

ON THE PRECIPICE OF A CURE;
IN THE MEANTIME—HOPE

THE SAINT LOUIS UNIVERSITY ALS CENTER OF EXCELLENCE

MANY REMEMBER THE ICE BUCKET CHALLENGE THAT WENT VIRAL IN THE SUMMER OF 2014. WHILE THE FUNDRAISER GAINED FAME FOR ITS INGENUITY AND LONGEVITY, MORE IMPORTANTLY, IT BROUGHT SIGNIFICANT ATTENTION AND CRITICAL FUNDING TO A DEVASTATING, FATAL DISEASE: AMYOTROPHIC LATERAL SCLEROSIS (ALS), OR LOU GEHRIG'S DISEASE. PEOPLE WITH ALS LOSE THEIR ABILITY TO WALK, TALK, EAT, AND—EVENTUALLY—BREATHE. AS OF NOW, THERE IS NO WAY TO HALT THE PROGRESSION OF THE DISEASE, BUT WITH SOME OF THE WORLD'S MOST BRILLIANT MINDS WORKING TO FIND A CURE, WE ARE CLOSER THAN EVER.



GHAZALA HAYAT, M.D.
Director of the SLUCare ALS Clinic

“UNFORTUNATELY, WE STILL DON’T KNOW THE EXACT MECHANISM OF ALS.
THAT’S WHY PROVING CAUSATION IS VERY HARD.

—JAFAR KAFIAIE, M.D., PH.D.

A UNIQUE DISEASE

ALS is a progressive neuromuscular disease that attacks nerve cells in the brain and the spinal cord. ALS impacts a person’s ability to use their muscles, restricting the movement of the limbs and body, including the muscles required for speech, swallowing, and breathing. The disease is progressive, and symptoms get worse over time.

According to the ALS Association, every 90 minutes someone is diagnosed with the disease, and someone passes away from it. It affects as many as 30,000 individuals in the United States, with 5,000 new cases diagnosed each year. The disease is terminal. “For the majority of people, from the onset of symptoms, survival is about 30 to 36 months,” says Dr. Ghazala Hayat, director of the SLUCare ALS Clinic at Saint Louis University.

Unlike a viral infection or a bacterial infection, which presents itself essentially the same way each time, ALS has different abnormalities. “ALS is a unique disease,” says the SLUCare ALS Clinic’s Dr. Jafar Kafaie. “In fact, it is more likely a syndrome. The mechanisms or the genes involved work in different ways, which are sometimes not closely related to each other. However, the outcome and end product of these mutations is a motor neuron disease. As we learned more, we realized that it is not only motor neuron disease; it involves a lot of parts of the brain.”

In addition to the physical degeneration that occurs, a patient with ALS will develop cognitive impairment, including memory, mood, or language problems. “Unfortunately,” says Dr. Kafaie, “we still don’t know the exact mechanism of ALS. That’s why proving causation is very hard.”

About 90% of ALS cases occur without family history; this is known as sporadic ALS. Sporadic ALS can occur in those

who have experienced infections, inflammations, or physical chronic trauma, such as football players who suffer from chronic traumatic encephalopathy (CTE) or veterans who have experienced trauma in combat. In fact, military veterans are up to twice as likely to be diagnosed with the disease as the general public. The remaining 10% of ALS cases are known as familial ALS, meaning the disease was inherited genetically.

A COMPLEX PROBLEM REQUIRING
A COMPREHENSIVE APPROACH

Due to the complexity of the disease, diagnosing and treating ALS patients requires many different medical specialists’ expertise. As a Center of Excellence for the past 15 years and the only ALS Association-certified clinic in Missouri, the SLUCare ALS Clinic at Saint Louis University brings together numerous medical experts from across disciplines to care for those fighting this insidious disease, to conduct life-changing research, and to ultimately help change the prognosis for future ALS patients.



JAFAR KAFIAIE, M.D., PH.D.

“ WHEN YOU BREAK THE NEWS TO A PATIENT THAT THEY HAVE ALS, MANY THINK IT IS THE END OF EVERYTHING FOR THEM. THAT IS WHERE OUR WORK COMES IN. OUR JOB IS TO LET THEM KNOW THAT THEY CAN STILL MAINTAIN A QUALITY OF LIFE. WE SAY TO THEM, ‘WE ARE HERE TO HELP YOU.’ ”

—GHAZALA HAYAT, M.D.

The Clinic provides a team approach to care, coordinating services to diagnose and treat patients. The team includes neurologists, a neuromuscular clinical nurse, a neuropsychologist, a gastroenterologist, a pulmonologist, an occupational therapist, a physical therapist, a speech/language pathologist, a respiratory therapist, a dietitian, a social worker, and a representative from the ALS Association who visits bimonthly. “It is a team effort, and it is amazing,” says Dr. Hayat. “The team—they do their work from the heart.”

By bringing together a team of experts in a single location and taking a scientific and evidence-based approach, the SLUCare ALS Clinic can coordinate treatment for ALS patients and address their wide-ranging needs in one visit rather than multiple appointments. The team works in conjunction with the patient’s primary care physician to develop a treatment plan that maximizes function and maintains the highest possible quality of life.

This multidisciplinary center provides a central point of care for diagnosis, treatment, and follow-up; advanced testing capabilities for accurate diagnosis; specialized services; participation in clinical trials where patients can access new drug therapies; education for patients and their families about the ALS disease process, treatment options, and research; and even access to medical device representatives. Reports and studies show that patients who visit multidisciplinary clinics have an increase in their quality of life. In fact, 30-40% of ALS patients seek treatment at a multidisciplinary clinic, and some studies suggest these patients live 10-12 months longer.

Ensuring patient nutrition is key to optimal health and quality of life. “I think about one person in particular...

He had been a park ranger at a national park his entire life. And then he had to come back and live with his parents, but he lived for two or three years. After getting his G-Tube put in, he wrote two books about the national park where he worked using his eyes. I’m not saying it was easy, but he had a meaningful life,” says Mary Burton, M.D., gastroenterologist, a member of the ALS Clinic multidisciplinary team.

“WE ARE HERE TO HELP YOU”

The SLUCare ALS Clinic is headed by Dr. Ghazala Hayat, a neurologist who specializes in neuromuscular disorders. Dr. Hayat joined Saint Louis University in 1986 after completing her residency and fellowship in neuromuscular disorders and neurophysiology at Virginia Commonwealth University Medical College. “When you break the news to a patient that they have ALS, many think it is the end of everything for them,” says Dr. Hayat. “That is where our work comes in. Our job is to let them know that they can still maintain a quality of life. We say to them, ‘We are here to help you.’”

The Clinic works with approximately 75-95 unique patients per year, seeing 12-15 patients per day. Patients come from all over the region, including Illinois, Tennessee, Kansas, and Kentucky. When the patient first comes into the Clinic, they are evaluated by the whole team. The doctors determine what their motor strength is, how they are swallowing, their speech, their respiratory qualities, and other factors. They identify what their needs are before beginning treatment. Generally, a new patient is seen within two weeks of calling for an appointment; with an ALS diagnosis, time is everything. “That is the most important thing,” says Dr. Hayat, “the patient should not be waiting.”



The Clinic provides a team approach to care, coordinating services to diagnose and treat patients.

After the initial appointment, the team of doctors discuss the diagnosis and finalize the treatment plan. Then, the patient is generally seen every 2-3 months, depending on the progression of their case. The team often collaborates with the patient’s primary care physician to develop a treatment plan—coordinated to maximize their function and help them maintain the highest possible quality of life.

According to Dr. Hayat, “The diagnosis does not mean we cannot do anything to help. There are a lot of things we can do to help patients by being preemptive and coordinating care.” Among the options available, there are two FDA-approved medications for the treatment of ALS—Rilutek (riluzole) and Radicava edaravone.

Before the COVID-19 pandemic, patients were seen at the Clinic by the team or in their homes by ALSA local chapter caseworkers. It is vital to meet with the patient’s family to know the patient’s support structure and see the home to gauge what services the patient might need in the future. For example, if the patient has difficulty walking, the Clinic team will determine that the patient needs a power wheelchair and will see how it fits into the home setting. “ALS is not just the disease of a person; it involves the whole family,” says Dr. Kafaie.

The ALS Clinic team has a support structure in place to think outside of the box when it comes to finding solutions to meet the needs of patients and families. “We partner closely with the ALS Association to support patients in many different ways, including help with loaner programs for medical equipment. We also screen for any barriers that may impact a patient’s ability to receive appropriate care and services. We have an ALS fund to help with any patient and family financial barrier,” says Cindy Roseman, LPN, a member of the ALS Clinic multidisciplinary team.

The support of the Clinic team extends far beyond the walls of SLU—into the community, explains SLU Clinic member Nancy Schlechte, MSW. “My primary role is helping patients with care coordination. I serve as a navigator to help patients apply for social security disability benefits... helping them arrange home healthcare and outpatient therapy services, helping them access medical equipment.”

With the support of Schlechte and ALS Clinic team neuropsychologists Lauren Schwarz, Ph.D., ABPP-CN, and Phillip D. Ruppert, Ph.D., on staff, the Clinic team also addresses the mental health needs of patients. “One particular younger patient had to stop working and was concerned about providing for his family,” says Schlechte. “He had a wife and young kids. We worked with them to get the kids

into counseling to help them cope with the challenges of the disease, and made sure everyone’s needs were addressed. His goal was to stay in his home, and we made that work by connecting the family to different resources. After he passed, his wife called and said, ‘I could have never made it through this journey without the help of your clinic.’”

WORKING TO FIND A CURE

As part of academic medical practice and as an ALS Certified Center of Excellence, the SLUCare ALS Clinic treatment team includes Saint Louis University researchers who are actively seeking a cure for ALS. The Clinic is part of the Northeast Amyotrophic Lateral Sclerosis (NEALS) Consortium, an academic research consortium for the ALS community. Over 100 research centers are members of the NEALS Consortium, each committed to performing research in ALS and motor neuron disease (MND). These research centers share data and collaborate on clinical trials.

One such clinical trial is the HEALEY ALS Platform Trial, a multi-center, multi-regimen clinical trial evaluating the safety and efficacy of investigational products for the treatment of ALS. As a platform clinical trial, the HEALEY Trial allows for the evaluation of multiple interventions using interim evaluations and the addition of new interventions during the trial. This differs from a routine clinical trial, which tests one intervention at a time. The platform format can speed up the clinical trial process by two times, and enrollment is generally higher. Additionally, platform clinical trials can decrease the budget by up to 30%. “Research is basically the pursuit of truth,” says Dr. Hayat. “When we do research, we are not inventing anything, we are just looking at what God has created and how we can use that to help people.”

More than 50 centers across the country participate in the HEALEY Trial, and patients at the SLUCare ALS Clinic have the opportunity to participate. “We are serving our patients by giving them hope,” says Dr. Roula al-Dahhak, another neurologist at the Clinic. “It is not a false hope. I tell them, ‘Look, we’re not there yet, but eventually anything you can contribute now with being here and helping us to collect data, you are helping future patients.’”

Researchers are currently testing four medications, the last of which was added in early January; a fifth one is set to be added by March 2021. All the medications on trial have passed phase one and phase two of the clinical trials.

FOR THE SERVICE OF HUMANITY

One of the biggest challenges of ALS is that scientists do not have the biomarkers for the disease. A patient can’t just walk into a clinic, take a blood or urine test, or cerebrospinal fluid test to determine if they have ALS. Diagnosing the disease takes time and requires ruling out other possible diseases. Finding the biomarkers for ALS is critical because then gene therapy can be leveraged to find the disease earlier, changing the trajectory of a patient’s life.

In the meantime, doctors like those at the SLUCare ALS Clinic are not only doing everything they can to help patients maintain their quality of life, but they are investing significant energy in research and studies like the HEALEY Trial. While at times it can feel as though the race to find a cure for ALS is slow going, Dr. Hayat feels confident in the progress being made. “When I was a fellow, there was no medication, and then a medication was approved, and then almost two decades later, a second medication was developed. Now we have the HEALEY Trial, which will hopefully yield a few more medications.” Likely ALS treatment will involve a cocktail of medications, similar to a cancer regimen, which will slow down the progression of the disease and prolong patients’ survival times.

Dr. Kafaie also believes the next decade will bring about significant progress: “I do believe we are living in a very exciting time,” he says. “We understand more and more about ALS, and with the introduction of extensive studies like the HEALEY Trial, I am hoping that in the next decade, even if we do not have a cure, we will have a very good medication that can modify the process of ALS significantly.”

Dr. Ravi Nayak, M.D., pulmonologist, part of the ALS Clinic multidisciplinary team explains, “We live the mission of SLU through our work with the ALS Clinic. We are focused on patient-centric care. We take our time; we don’t rush our patients. We provide high-quality care with empathy and compassion, going above and beyond to take care of each patient like we care for our own.”



Patients are evaluated by the entire team to determine strength, speech, respiratory qualities and mental health.



Every 90 minutes, someone is diagnosed with and someone passes away from ALS.



ALS is 20 percent more common in men than in women. However, with increasing age, the incidence of ALS is more equal between men and women.

Most people who develop ALS are between the ages of 40 and 70, with an average age of 55 at the time of diagnosis. However, cases of the disease do occur in people in their twenties and thirties.

About 90 percent of ALS cases occur without a family history, which is known as sporadic ALS. The remaining estimated 10 percent of ALS cases are inherited through gene disorders, known as familial ALS.

Military veterans are up to twice as likely to be diagnosed with ALS as the general public. The reasons are unknown.



ALS affects as many as **30,000 individuals in the U.S.**, with **5,000 new cases diagnosed each year**.

The incidence of ALS is **five times higher** than Huntington's disease and about equal to multiple sclerosis.

Estimates suggest that ALS is responsible for as many as **five of every 100,000 deaths in people aged 20 or older**.



ALS occurs worldwide with no racial, ethnic, or socioeconomic boundaries.

The average life expectancy of a person with ALS is about 2-5 years from the time of onset of symptoms.

ALS patients burn calories faster than non-sufferers and, as a result, are often underweight.

ALS does not affect mental ability. Although, some patients may have frontotemporal dementia affecting executive functioning.

More than half of all ALS patients live more than three years after diagnosis; 20 percent live five years or more, up to 10 percent live more than 10 years, and about five percent live 20 years or more.

Sources: <https://www.als.org/understanding-als> and <https://alsnewstoday.com>



RESEARCHING THE UNSEEN EFFECTS OF ALS

When most people think of the symptoms of ALS, they think of the loss of muscle control, inability to walk, and difficulty speaking. However, because ALS affects nerve cells in the brain and the spinal cord, there are many unseen autonomic dysfunctions that afflict patients, such as constipation, sexual dysfunction, gastrointestinal disorders, and others. In addition to the physical toll these symptoms take on a person's body, there is also an acute impact on their mental health and quality of life.

Since October 2019, third-year medical student Anika Mazumder has been working closely with the SLUCare ALS Clinic to study the effect of autonomic dysfunction, specifically constipation, on ALS patients. To conduct the study, titled Assessment of the Burden of Constipation in Patients with Amyotrophic Lateral Sclerosis, and Possible Relationship to Dysautonomia, Mazumder uses a series of questionnaires to assess how constipation has affected ALS patients' daily life. Questions focus not only on the physical discomfort around constipation and other autonomic dysfunctions, but also the psychological impact, and range from "To what extent or intensity have you felt bloated to the point of bursting?" or "To what extent or intensity have you been embarrassed to be with other people?"

"While the patients were waiting to be seen by the doctor, I would go in and introduce myself to the patient and tell them about the project," says Mazumder. "They were all very interested in participating because this is something that has affected many of them. So many patients have

said things like, 'Yes, I'm afraid,' or 'I'm embarrassed to leave my home and go visit my children because I don't want to spend the entire time in the bathroom when I'm there.'" Thus far, the sample size is 44 patients, but Mazumder is hoping to recruit additional participants to reach a sample size of at least 100.

Findings from the study have been presented at the Northeastern ALS Association and Saint Louis University's Alpha Omega Alpha Honor Medical Society's Student Research Forum. In April 2021, Mazumder presented the study to the American Academy of Neurology.

For many, the study of ALS extends beyond understanding how the disease functions or how to best diagnose it, or even how to cure it. "I want more research to be dedicated to other aspects of ALS than just the motor symptoms because it's a multi-system disorder," says Mazumder. "We need more research on ALS patients' quality of life and their mental health."

When Mazumder first tells patients about the research project, she explains that answering the assessment questions will likely not alleviate their own discomfort and pain. "I say to them, 'We won't be able to find anything that might specifically help you, but this will help somebody in the future.'" Even when presented with this realization, patients are eager to help those who may suffer from ALS in the future.



UNDERSTANDING ALS THROUGH DATA

When Dr. Neha Gandhi was a medical student in India, she—like so many others around the world—participated in the ALS Ice Bucket Challenge. Little did she know that years later, she would be a fourth-year neurology resident working in the multi-disciplinary SLUCare ALS Clinic, contributing to advancing the understanding of ALS through vital data collection.

The SLUCare ALS Clinic is a part of the ALS/MND Natural History Consortium, the mission of which is to collect real-world data about ALS, make it available for ALS research, and inform clinical trial design. Ultimately, the work of the Consortium supports gaining a better understanding of ALS and enabling improved care practices for people living with the disease. Nine academic medical centers in the U.S. and Europe are part of the Consortium: Saint Louis University School of Medicine; Henry Ford Health Systems; University of Minnesota; Providence ALS Center in Portland, Oregon; Virginia Commonwealth University Health; University of Florida Gainesville; Neuromuscular Omnicenter (NEMO) in Milan, Italy; MDA/ALS Center of Hope, Temple University; Neurological Clinical Research Institute; and Les Turner ALS Center at Northwestern Medicine.

There are currently over 1,500 people living with ALS who have enrolled in ALS/MND Natural History Study, a multi-disciplinary clinic-based registry that prospectively and longitudinally captures essential clinical information

about the disease process from people living with ALS. Dr. Gandhi supports this work by conducting data collection, curation, and analysis through NeuroBANK, a flagship clinical research platform run by the Neurological Clinical Research Institute at Massachusetts General Hospital.

After getting consent from a patient at the SLUCare ALS Clinic, Dr. Gandhi creates a global unique identifier (GUID) to allow for the de-identification of data. Standard clinical information is gathered on each patient, including gender, age of symptom onset, genetic testing results, examination data, and many other data points. "We can put all the data into the NeuroBANK system," says Dr. Gandhi. "It is a very good dataset because it's prospective and retrospective data entry." Having large data sets allows Dr. Gandhi and her colleagues to study variables across ALS patients, including the rate of G-tube in different patient populations or the efficacy of Radicava, one of the FDA-approved medications used to treat ALS.

The NeuroBANK platform allows all participating ALS centers to share data and information, available for researchers in the Consortium and worldwide to study ALS to help us improve treatment and clinical care. "ALS is a rare, awful disease," says Dr. Gandhi. "Any positive research that comes from the study will truly help ALS patients around the world."



“THE HEALEY TRIAL IS PROBABLY THE BEST TRIAL I’VE EVER COME ACROSS. EVERYONE IS COLLABORATING WITH EACH OTHER, HAVING BI-MONTHLY MEETINGS TO DISCUSS PROGRESS, CHALLENGES, AND HOW TO INCREASE PATIENT ENROLLMENT.

—GHAZALA HAYAT, M.D.

WHEN EVERY MINUTE COUNTS, 54 HEADS ARE BETTER THAN ONE

When it comes to a degenerative, rapidly progressing disease like ALS, time is of the essence. Reducing the cost of research by 30%, decreasing trial time by 50%, and increasing patient participation by 67%, the HEALEY ALS Platform Trial is a vital step toward finding new ALS therapies.

The first-ever ALS platform trial, the HEALEY Trial, tests multiple investigational products for ALS simultaneously or sequentially, evaluating the safety and efficacy of medical interventions for the treatment of ALS. The study, sponsored by Massachusetts General Hospital, comprises 54 study locations across the United States, including Saint Louis University.

Each investigational product is tested in a regimen, which consists of a placebo-controlled trial. Once randomized to a regimen, participants are randomized in a 3:1 ratio to either study drug or placebo. The medications tested in the trial include:

- > Zilucoplan — an oral myeloperoxidase inhibitor
- > Verdiperstat — an oral myeloperoxidase inhibitor
- > CNM-Au8 — a new class of medicine that provides an energetic assist to impaired motor neurons, helping them improve their ability to function more normally (motor neurons consume significant energy in order to function normally, but in ALS, corrupted energy metabolism together with increased cellular stress lead to motor neuron degeneration).

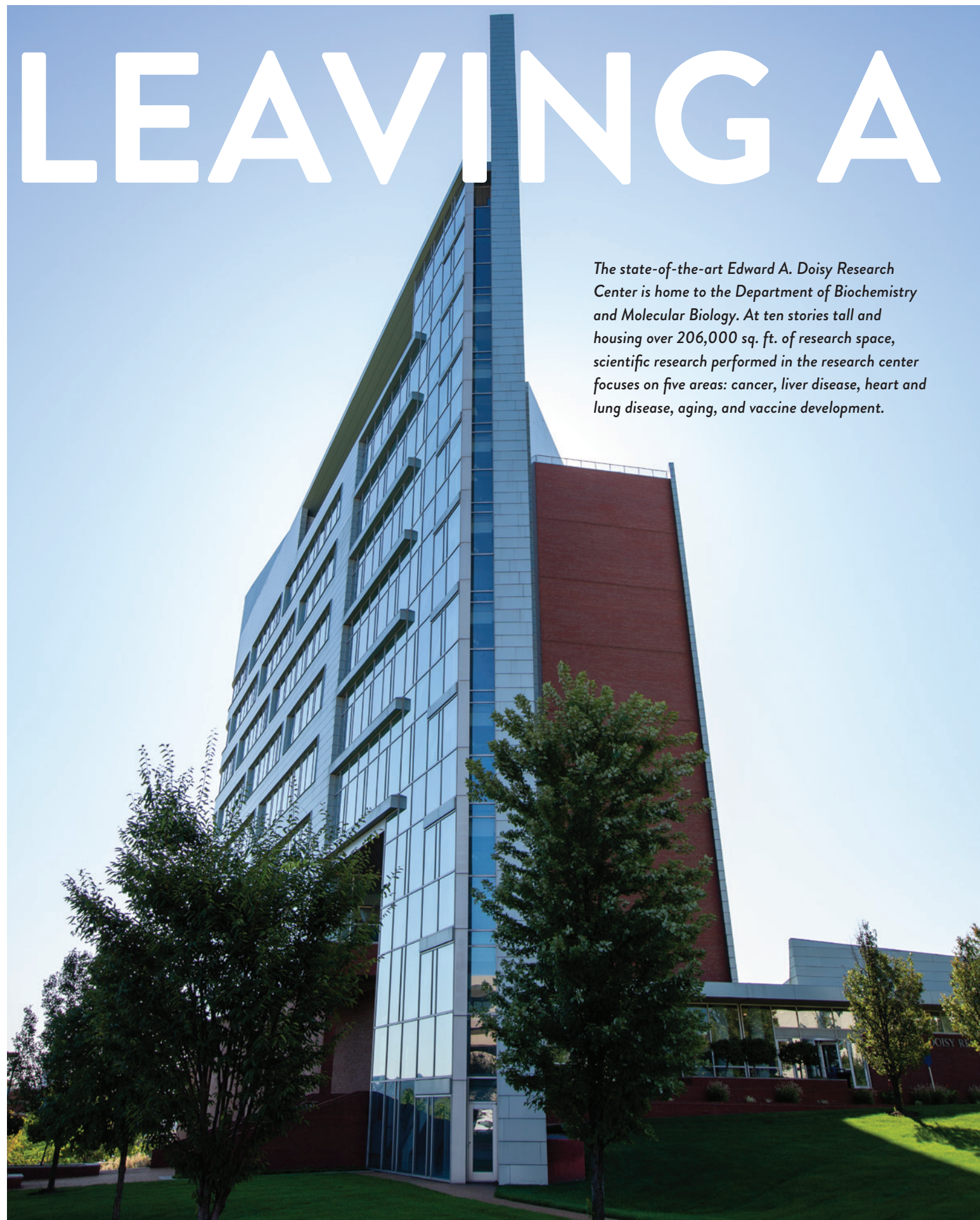
- > Pridopidine — a highly selective Sigma-1 receptor (S1R), which regulates key cellular pathways, commonly impaired in neurodegeneration

New medications are continuously added as they become available.

“The HEALEY Trial is probably the best trial I’ve ever come across,” says Dr. Ghazala Hayat, director of the SLUCare ALS Clinic at Saint Louis University. “Everyone is collaborating with each other, having bi-monthly meetings to discuss progress, challenges, and how to increase patient enrollment.”

The primary outcome measure for the trial is change in disease severity over time as measured by the ALS Functional Rating Scale-Revised (ALSFRRS-R). Secondary outcome measures include change in respiratory function over time as measured by Slow Vital Capacity (SVC), change in muscle strength over time as measured isometrically using hand-held dynamometry (HHD) and survival as measured by the comparison of rate of occurrence between groups. The platform will remain open until successful cures are found.

“There are 500,000 people suffering at this moment from ALS, and we have only two medications to help them,” says the ALS Clinic’s Dr. Jafar Kafaie. “We have a big hope that by speeding the clinical trials through this HEALEY platform, we will find some new, effective interventions.”



LEAVING A

The state-of-the-art Edward A. Doisy Research Center is home to the Department of Biochemistry and Molecular Biology. At ten stories tall and housing over 206,000 sq. ft. of research space, scientific research performed in the research center focuses on five areas: cancer, liver disease, heart and lung disease, aging, and vaccine development.

LEGACY

SUPPORT THE SCHOOL OF MEDICINE THROUGH A PLANNED GIFT

Saint Louis University School of Medicine received a generous planned gift from Abdul Waheed, Ph.D., in honor of William Sly, M.D. Dr. Waheed's gift will support the endowed Centennial Chair in the Department of Molecular Microbiology and Immunology. Gifts to the Centennial Chair will also celebrate the upcoming 100th anniversary of the Department of Biochemistry & Molecular Biology, founded by Edward A. Doisy in 1924.

The future depends on the generosity of alumni and friends of Saint Louis University. Bequests help the University plan for the future and strengthen our programs. The legacy you leave through a bequest to Saint Louis University will endow and perpetuate the standards of excellence expected from the School of Medicine.

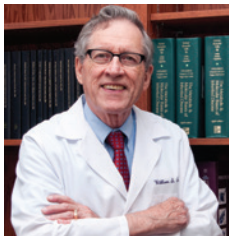
"I love Saint Louis University, and I support the research of this institution, notably in the Department of Biochemistry and Molecular Biology.," said Dr. Waheed. "When I came to SLU, Dr. Sly became a trusted mentor; and I am proud to honor his legacy through a bequest."

Dr. Waheed continued, "supporting the Centennial Chair campaign in the Department of Biochemistry and Molecular Biology, celebrating the 100th year of the department, and simultaneously recognizing Dr. Sly is a rewarding experience and essential for the future of research."

You can leave a legacy by including a bequest to Saint Louis University School of Medicine in your will or living trust. It is easier than you might think. By naming Saint Louis University School of Medicine as a beneficiary, you will ensure that our research and educational mission continue beyond your lifetime.

FOR MORE INFORMATION, CONTACT

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WILLIAM SLY, M.D.

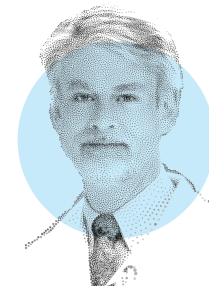
“ WHEN I CAME TO SLU, DR. SLY BECAME A TRUSTED MENTOR; AND I AM PROUD TO HONOR HIS LEGACY THROUGH A BEQUEST. ”

—ABDUL WAHEED, Ph.D.

The 1818 Society honors alumni and friends who have invested in Saint Louis University's future through planned gifts. These gifts include bequest provisions in a will or trust, life income arrangements, gifts of life insurance, and beneficiary designations made with retirement assets or insurance policies.

ALUMNI IMPACT

GRAND ROUNDS TALKS TO FOUR ALUMNI WHO ARE
MAKING GREAT WAVES IN EACH OF THEIR FIELDS



FLORIAN THOMAS, M.D., M.S.

(M.S., '15)

Center for Health Outcomes Research (SLUCOR)

TELL US ABOUT YOUR CURRENT ROLE.

After 21 years on faculty at SLU, I left in 2016 to take a position as Founding Chair and Professor of Neurology at Hackensack Meridian School of Medicine and Hackensack University Medical Center. With a team of neurologists, medical specialists, therapists, nurses, and others, I developed the Neuroscience Institute. We treat ALS, concussions, epilepsy and seizure disorders, headaches, hereditary neuropathies, memory loss and brain health, MS, and much more.

I am the Interim Associate Dean of Faculty, tasked with recruiting additional faculty to meet the learning needs of our growing student body. I am also active with our diversity and equity efforts and serve as a faculty advisor to our Student Interest Group in Neurology and our Medical Student Pride Alliance.

WHAT IS YOUR BEST MEMORY OF SAINT LOUIS UNIVERSITY SCHOOL OF MEDICINE?

In October 2014, during my 19th year as a professor of neurology at SLU School of Medicine, I was changed, for the better, by the occupation of the campus clock tower that occurred in response to the police shooting of VonDerrit Myers, Jr. My family participated in protests and dialogue, striving to build consensus that lasting change is needed. In our separate ways and together, we found work that we could do to support racial equity.

HOW HAS THE SLU MISSION INFORMED YOUR WORK?

I strongly feel that the work I do is in the service of humanity. I prize the opportunities I had at SLU to improve patients' lives, teach future doctors how to build empathetic practices, and use my administrative role to build a just, equitable care environment.

WHAT HAS BEEN THE MOST SURPRISING THING ABOUT YOUR CAREER JOURNEY?

I came to medicine in part from a liberal arts interest in human hardship, obtained graduate degrees in psychology, microbiology, molecular biology, and spent eight years in post-doctoral research before my first faculty position. I have wondered if those pursuits made a difference. Today, I spend more time on program development and performance improvement and less on direct patient care and clinical trials. But now I realize that this circuitous path was how I broadened my horizons.

IF YOU COULD GO BACK IN TIME, WHAT ADVICE WOULD YOU GIVE YOURSELF AS A MEDICAL STUDENT?

I would advise myself and students to focus on life-long learning, stay abreast of scientific developments, recognize and counteract our implicit biases, and make it our mission to overcome disparities in access to health care.

FROM YOUR PERSPECTIVE, WHAT CHALLENGES AND OPPORTUNITIES ARE ON THE HORIZON FOR THE FUTURE OF ALS CLINICAL PRACTICE?

Motor neuron diseases from a 30,000-foot view share many features with other conditions that I am interested in — including MS, Alzheimer's disease, and Parkinson's disease — including a subclinical prodrome of variable duration during which intervention may be more incisive than after symptom onset, the combination of genetic, degenerative & inflammatory aspects of pathogenesis, but also the degree to which entire families suffer with the patient and the real risk of care partner burn-out.

(CONTINUED ON NEXT PAGE)

FLORIAN THOMAS, M.D., M.S.

(CONTINUED)

HOW ARE YOU PREPARED TO MEET THOSE CHALLENGES AND OPPORTUNITIES?

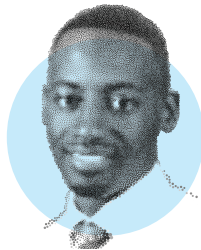
The first challenge is to provide comprehensive care. ALS progresses so much faster than other motor neuron diseases—and the demands on the team, patient, and caregivers are dramatically enhanced. I am thrilled to work with people who are enthusiastic about patient care and that we were able to integrate palliative care into our center.

From the perspective of enhancing our understanding of ALS, we are partnering with ALS Centers across North

America to derive generalizable new clinical and genetic information in collaboration with our patients.

WHAT IS THE BEST BOOK YOU HAVE READ IN THE LAST YEAR?

Lifting the Veil by Ismat Chughtai, a collection of short stories written from the vantage point of a Muslim Indian woman beginning in the 1940s.



KEVIN AFARI YEBOAH, M.D.

(RESIDENCY '16)

Vascular Neurology fellow at Washington University in St. Louis. As a fellow, I am involved in the neurovascular care of patients. I perform emergency evaluations of patients with stroke for acute thrombolytic and endovascular therapies. I also provide care in both inpatient and outpatient settings to determine the etiology of stroke.

WHAT IS YOUR BEST MEMORY OF SAINT LOUIS UNIVERSITY SCHOOL OF MEDICINE?

My best memory stems from my diverse clinical experiences—specifically, rotating in the neurointerventional suite is where my passion for vascular neurology was derived.

HOW HAS THE SLU MISSION INFORMED YOUR WORK?

SLU equipped me with the experience and tools to contribute to the medical community in a meaningful way. I value the mission of providing service to humanity and I hope to continue to be an agent of positive change.

WHAT HAS BEEN THE MOST SURPRISING THING ABOUT YOUR CAREER JOURNEY?

One of the most surprising aspects of my career in medicine has been the journey of knowledge translation from reading textbooks and studying for exams as a medical student to applying this knowledge in clinical practice and impacting lives.

IF YOU COULD GO BACK IN TIME, WHAT ADVICE WOULD YOU GIVE YOURSELF AS A MEDICAL STUDENT?

Seek mentorship early; this can assist with developing strategies for personal and professional growth.



JAN BITTAR, M.D.

(RESIDENCY '16)

A first-year Neurocritical care fellow at The Ohio State University Hospital Wexner Medical Center in Columbus, Ohio, my current interaction with ALS patients is when they get admitted to the ICU after getting Trach/PEG placement.

WHAT IS YOUR BEST MEMORY OF SAINT LOUIS UNIVERSITY SCHOOL OF MEDICINE?

The first day of residency. I started in the pediatric neurology clinic. I still remember when I put on my white lab coat and knocked on the door to see my first patient.

HOW HAS THE SLU MISSION INFORMED YOUR WORK?

As an international medical graduate from a different background who started to work in the United States, SLU was a good starting point for me. I was welcomed, and everyone was treated equally.

WHAT HAS BEEN THE MOST SURPRISING THING ABOUT YOUR CAREER JOURNEY?

Working during the COVID-19 pandemic was unexpected. I did not expect to have such a challenge in my career.

IF YOU COULD GO BACK IN TIME, WHAT ADVICE WOULD YOU GIVE YOURSELF AS A MEDICAL STUDENT?

Enjoy every single clinical rotation. Work closely with the residents from different specialties.

WHAT IS THE BEST BOOK YOU HAVE READ IN THE LAST YEAR?

The 21 Indispensable Qualities of a Leader by John C. Maxwell

ANYTHING ELSE YOU WOULD LIKE TO SHARE?

Knowing how to lead is only half the battle. Understanding leadership and actually leading are two different activities.



JOHN SELHORST, M.D.

(M.D., '67)

TELL US ABOUT YOUR CURRENT ROLE.

Currently, I am retired in Mount Pleasant, South Carolina.

WHAT IS YOUR BEST MEMORY OF SAINT LOUIS UNIVERSITY SCHOOL OF MEDICINE?

My best memory is that of the spirit of innovation exemplified by the advances in cardiovascular surgery in the 50s, 60s, and 70s, the quest to develop vaccines and advance treatments of Hepatitis C in the 90s and 00s, and the effort to revolutionize stroke care in the 90s and 00s.

HOW HAS THE SLU MISSION INFORMED YOUR WORK?

My work centered on fulfilling the need for and developing clinical research and services in neurology.

WHAT HAS BEEN THE MOST SURPRISING THING ABOUT YOUR CAREER JOURNEY?

The most surprising aspect of my career was being asked to serve as an acting or interim chairman on three occasions, once for neurology at the Medical College of Virginia and twice for ophthalmology at Saint Louis University.

IF YOU COULD GO BACK IN TIME, WHAT ADVICE WOULD YOU GIVE YOURSELF AS A MEDICAL STUDENT?

My advice to medical students is to pursue your curiosities and try as you may to know and understand as much as you can.

WHAT IS THE BEST BOOK YOU HAVE READ IN THE LAST YEAR?

My book of the year is *Say Nothing* by Patrick Keefe that details the troubles in northern Ireland in the late 60s and early 70s.

ANYTHING ELSE YOU'D LIKE TO SHARE WITH READERS?

Dr. Ghazala Hayat is largely, if not entirely, responsible for establishing and maintaining the ALS Clinic, at least in its first decade.

GET ENGAGED WITH THE SLU SCHOOL OF MEDICINE

JOIN US

We hope to see you soon at an upcoming or virtual event—please visit slu.edu/medicine for the latest SLU School of Medicine event calendar.

GIVE

To support the researchers and clinicians at SLU who share a common interest in ALS research and clinical practice, please consider donating to the ALS Center Fund (#11056) or the ALS Research Fund (#11236).

Supporting students through scholarship is an effective way to ensure our student population is on the forefront of treating patients with ALS, ALS research, and discovery of new treatments. SLU offers scholarships for students in need; contact Pat.Dolan@slu.edu to learn more about the scholarships available to support our students.

Your gift helps define the future of ALS research and discovery at SLU. For more information on making a gift, please contact giving.slu.edu, Pat.Dolan@slu.edu, or 314-977-8316.

STAY IN TOUCH

We are always interested in our graduates' news and accomplishments, both personal and professional. If you have news to share or wish to update your address, please notify us through the proper form at www.slu.edu/universitas/. We encourage you to send your contact information so we may keep you informed about reunions, events in your area, and news from the School of Medicine, as well as invite you to submit class notes for publication online.

VISIT THE SLU SCHOOL OF MEDICINE ONLINE

There's a lot more to learn about your School of Medicine online at www.slu.edu/medicine/ and www.slu.edu/medicine/grand-rounds, including:

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How can we better serve you? Let us know with your comments and recommendations at elizabeth.e.brennan@health.slu.edu.



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For more information or to become a member of the White Coat Society, contact Jane Baum at 314-977-7538 or email jane.baum@slu.edu.