Research, treatment and education for patients and families living with brain disorders
ALZHEIMER’S • HUNTINGTON’S • PARKINSON’S • FRONTOTEMPORAL DEMENTIA • LEWY BODY DEMENTIA • MULTIPLE SCLEROSIS • MULTIPLE SYSTEM ATROPHY
2019 was a year-long celebration at Cleveland Clinic Lou Ruvo Center for Brain Health as we commemorated our 10th anniversary via multiple touch points. We celebrated milestones, such as 165,000 patient visits with our providers and 41,000 visits to our no-cost, evidence-based education and support programs that arm family caregivers for success.

We recognized employees and volunteers who have been with us since 2009. In July, we celebrated with 300 members of our Las Vegas community via a time capsule event and in October, Tom Mihaljevic, MD, CEO and President of Cleveland Clinic, joined us as we celebrated with many of the donors who have made it all possible (see page 3).

We opened our doors in 2009 with a focus on the treatment and research of Alzheimer’s disease, but we have expanded to add other dementias (Lewy body, frontotemporal); movement disorders (Huntington’s disease, Parkinson’s disease, multiple system atrophy and more); and multiple sclerosis.

THE CHALLENGE: BEST AT BRAIN HEALTH

The Las Vegas community has long requested Cleveland Clinic add service lines that would give Cleveland Clinic Nevada a breadth of offerings similar to other locations, such as Cleveland Clinic Florida and Cleveland Clinic Abu Dhabi.

Dr. Mihaljevic sees it differently, and my vision for our future has been inspired and refined by our October conversation. He challenged me to focus on what we do best: brain health. Together, we contemplated what the best center for brain health might look like 10 years from now. What additional treatment options might we investigate? How can we better support patients and families as they navigate brain disease? I invite you to join the conversation “north of the neck,” as I like to call it.

JUST IMAGINE

In October, we received heartening news from Biogen that aducanumab has been found to remove amyloid plaque from the brain and might be approved to treat Alzheimer’s disease; we were among the first to test this drug in clinical trials. We have made tremendous progress over the last decade; imagine what we can do in the next 10 years. These possibilities are accelerated by your philanthropy and by the infrastructure provided by Cleveland Clinic under Dr. Mihaljevic’s leadership.

To make our ambitious vision of being the best center for brain health a reality well into the future, we need your support. We are fundraising for a $100 million campaign that would sustain the center in perpetuity. Funds would be used to achieve the center’s goals for the future: superior patient outcomes, excellence in education, research that advances care and, one day, a cure for degenerative brain disease.

Thank you for sharing our vision of a future without brain disease.

Marwan N. Sabbagh, MD, FAAN
Director, Cleveland Clinic
Lou Ruvo Center for Brain Health
Camille and Larry Ruvo Endowed Chair for Brain Health
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Building on a Decade of Accomplishment

In just 10 years, Cleveland Clinic Lou Ruvo Center for Brain Health has earned a global reputation for neurodegenerative disease care, research and education.

Much has changed since the Lou Ruvo Center for Brain Health opened in 2009. A decade ago, for example, only researchers could scan individuals to observe brain changes; now, MRI and PET/CT are approved for clinical use, and the center deploys these imaging technologies daily to offer greater clarity of diagnosis.

The Lou Ruvo Center for Brain Health also conducts prevention trials for people at risk of brain disease; offers risk reduction programs such as HealthyBrains.org, where visitors from around the world sign up to receive free online brain health self-assessments; and, thanks to donor support, has provided more than 41,000 visits to no-cost education and support programs for family caregivers.

**Celebrating our success**

In October, Tom Mihaljevic, MD, CEO and President of Cleveland Clinic, visited the Lou Ruvo Center for Brain Health in Las Vegas for an all-day 10th anniversary celebration. Among the activities, he hosted a candid roundtable conversation with patients and family members, learning firsthand how the center fills a need for their families and for the community.

That evening, in his remarks to a gathering of supporters, he quoted one of the caregivers, who said that music therapy stimulated his wife’s memory and “gave him his wife back, if only for 15 minutes.” Dr. Mihaljevic also shared the families’ hopes that additional funding will expand patient and family support services.

**Toward a common goal**

Philanthropy always has played an important role in supporting the work of the Lou Ruvo Center for Brain Health, which this year launched a $100 million campaign to ensure that the center will be able to meet the growing need for neurological care.

Nevada businessman Larry Ruvo founded the Lou Ruvo Center for Brain Health in honor of his late father, Lou, who had Alzheimer’s disease. Larry Ruvo also founded Keep Memory Alive, a nonprofit organization that supports the center in its treatment of Alzheimer’s disease, Lewy body and frontotemporal dementias; movement disorders such as Huntington’s and Parkinson’s diseases and multiple system atrophy; and multiple sclerosis.

“A decade of Cleveland Clinic Lou Ruvo Center for Brain Health was made possible through generous donors who..."
believed in our mission,” Larry Ruvo said, “and now we are calling on all of you again to help us set our sights on long-term sustainability.”

Noting the tremendous progress that has occurred, Marwan Sabbagh, MD, Director, Lou Ruvo Center for Brain Health, asked supporters to imagine what can be done in the next 10 years: “These possibilities are accelerated by your philanthropy and by the infrastructure provided by Cleveland Clinic.”

Added Dr. Mihaljevic: “I’m calling on your legendary generosity. Help us put an end to Alzheimer’s, Parkinson’s and dementia forever. We can make it happen. Right here, in Las Vegas.”

———

GIVE TODAY FOR A BETTER TOMORROW
You can help pave the way to a better future for patients and families affected by brain disease. Gifts of all sizes make a meaningful impact. Contact DonateNevada@ccf.org or call 702.263.9797.
We’ll host Keep Memory Alive’s annual fundraising gala, the Power of Love®, on Saturday, March 7, when we’ll honor Neil Diamond. A Grammy Award-winning artist who has sold more than 130 million records worldwide, he is a member of the Rock and Roll Hall of Fame and the Songwriters Hall of Fame, and has received the Johnny Mercer Award, the Grammy Lifetime Achievement Award and the Sammy Cahn Lifetime Achievement Award — three of the highest honors bestowed upon songwriters and artists.

Now you, too, will have a chance to honor this legend.

This same night, we will present the 2020 Community Leadership Award to Dr. Miriam and Sheldon Adelson. The Adelsons are among the world’s most generous philanthropists and are widely recognized for their vast contributions to medical research, education, and many Jewish causes and organizations.

**The finest food and festivities**

Over the past two decades, our Power of Love gala has become one of Las Vegas’ signature celebrity events, attracting guests from across the country. Chefs represent a culinary who’s who: This year, Wolfgang Puck and Masaharu Morimoto will be in the kitchen. Following a reception replete with Dom Pérignon, master sommeliers from Southern Glazer’s Wine & Spirits hand-select world-class wine pairings to accompany each chef’s preparation.

Then, entertainment kicks into high gear. Guests have been entertained by legends, A-listers and Grammy Award winners: Tony Bennett, Andrea Bocelli, Jon Bon Jovi, Bono, Michael Bublé, James Corden, Celine Dion, Gloria Estefan, Jennifer Hudson, Carole King, Lenny Kravitz, Queen Latifah, Barry Manilow, Ricky Martin, Steven Tyler, Stevie Wonder and many more. Join us and find out who will continue this legacy of excellence.

**More than a party**

This annual celebration of life exists to raise money for Cleveland Clinic Lou Ruvo Center for Brain Health’s programs, family services and support, community outreach and research. The gala underscores the critical role of generous donors, all of whom share the mission of eradicating devastating brain afflictions forever. In fact, the Power of Love is our single largest annual source of funds.

We need you. And we’re ready to entertain you.
A Time Capsule for Brain Disease: Celebrating the Past, Looking to the Future

2019 marked the 10th anniversary of Cleveland Clinic Lou Ruvo Center for Brain Health. Given that the last Alzheimer’s disease (AD) drug was approved 16 years ago, some might wonder what researchers here at the center have been doing over the last decade to combat this grim statistic.

In fact, our physician-scientists have been hard at work, providing care across a spectrum of brain diseases during 165,000 patient appointments while simultaneously growing our research footprint, in part by conducting more than 70 clinical trials.

What does the future of brain disease look like?

“A ‘one size fits all’ T-shirt never suits anyone perfectly, so wouldn’t it make sense that treatment, like clothing, needs to be tailored to individuals?” suggests Aaron Ritter, MD, Director, Clinical Trials Program. This concept, referred to as precision medicine, summarizes the future of AD research and treatment.

Currently available AD treatments target only the symptoms of the disease. What’s more, they don’t take into account the individual receiving treatment, and instead employ the “one size fits all” approach. We know that brain disease is caused by different changes in the brain, some of which are due to genetics and others to environmental factors.

Precision medicine tailors treatments to the individual based on genetics, environmental exposure and clinical history for a more refined, personalized approach. With recent advancements in research and diagnosis, we hope that AD will follow a similar course to breast cancer and HIV, where highly personalized treatment approaches have transformed these “death sentences” to manageable, chronic diseases in many patients.

We can’t get there without you

The biggest impediment to AD drug development is clinical trial participation. While Dr. Ritter is encouraged by the number of drugs in the pipeline, the bottom line is that as the pipeline fills, so does the number of people needed to test these medications.

Participation in the Lou Ruvo Center for Brain Health’s research and clinical trials program is free and open to the public. Even those with normal cognitive function are needed to participate as healthy controls. To learn more about how you can get involved, visit clevelandclinic.org/clinicaltrials or contact us at healthybrains@ccf.org or 855.LOU.RUVO.
We are making progress. We are filled with hope for what lies on the horizon, partly because of these clinical milestones:

**ADVANCED IMAGING**

Installation of Positron Emission Tomography (PET) imaging has allowed us to look at the brain like never before, visualizing its structure to observe changes on a cellular level and enabling us to participate in clinical studies of new compounds with potential for early diagnosis.

In 2013, the Amyvid scan was FDA-approved to image amyloid plaque, a hallmark of AD. Amyvid ranks among the major milestones in research and treatment of the disease in the last decade. Confirming and imaging amyloid plaque in the brain is one of three “puzzle pieces” we use to diagnose AD before death.

**PREVENTION**

Ten years ago, the idea that we could prevent brain disease didn’t exist. Today, we see this concept as a trend in AD drug development. We know that modifiable lifestyle factors such as nutrition, sleep and exercise can potentially ward off brain disease so, in 2015, we launched our HealthyBrains.org platform. In its first four years, the site received more than 1 million visitors.

Based on six pillars of brain health, HealthyBrains.org arms individuals with the tools they need to take a proactive approach to brain health, including a free online brain health self-assessment and personalized reports with customized recommendations.

**ANNUAL AD PIPELINE PAPER**

The Lou Ruvo Center for Brain Health has become a leading voice on the AD drug development landscape with the publication of our annual “Alzheimer’s Disease: Drug Development Pipeline” paper, which draws attention to a 99.7 percent failure rate, while making recommendations for improvement.

The 2019 edition of the paper revealed a surprising outcome: We’ve never seen more agents, more diversity of drugs targeting the disease or more funding in the pipeline, signaling an exciting and unprecedented era in drug development.
Cleveland Clinic Lou Ruvo Center for Brain Health caregivers join the leadership team to commemorate the center’s 10th anniversary
A New Approach to an Old Dilemma: Recruiting Clinical Trial Participants

One of the biggest challenges researchers face in their efforts to learn about and discover new treatments for Alzheimer’s disease is finding qualified volunteers for research studies. Without enough qualified participants for clinical trials, research can be delayed and efforts to find new and better treatments for Alzheimer’s disease, which affects an estimated 5.8 million Americans, can fail.

Cleveland Clinic Lou Ruvo Center for Brain Health is among multiple sites in the United States working to improve the process of finding and enrolling qualified volunteers in clinical trials for Alzheimer’s disease. The goal is to build a database of people who are at risk and who want to be involved in preventive trials.

To achieve this aim, the Lou Ruvo Center for Brain Health is participating in the Trial Ready Cohort for the Prevention of Alzheimer’s Dementia (TRC-PAD) study, which is funded by the National Institute on Aging/National Institutes of Health.

How It Works

Lou Ruvo Center for Brain Health physicians and caregivers provide one round of screenings such as electrocardiograms, blood and urine tests, genetic tests and lumbar punctures to participants in TRC-PAD, who come in through an online assessment — the Alzheimer Prevention Trials (APT) Webstudy — because they have been identified as being at risk for developing Alzheimer’s disease. In addition to the screenings, participants are monitored with cognitive assessments, neurological and physical exams every six months. There is no cost to participate.

Participants in TRC-PAD may have the opportunity to enroll in a clinical trial if they qualify and choose to do so. Once they are enrolled in a clinical trial of their choice, their participation in TRC-PAD is put on hold until their participation in the trial is over. It may then be restarted. Participants are not obligated to enroll in any clinical trials in order to stay in TRC-PAD, and they can opt out anytime.

“We are proud to be a part of this important and novel study,” says Marwan Sabbagh, MD, Director of the Lou Ruvo Center for Brain Health and Principal Investigator for the study. “The knowledge we stand to gain through the gracious participants in TRC-PAD, as well as the APT Webstudy, will be a tremendous resource as we work toward a more nuanced understanding and find treatments for Alzheimer’s disease.”
Repurposing: A Faster Way to Effective Treatments

A blood pressure drug that treats baldness. A sedative that combats multiple myeloma, a type of cancer. These are examples of repurposing: using an approved drug to treat another disease or medical condition.

Repurposing is a common practice in medicine that saves the time and costs of developing drugs from scratch. Sometimes it happens by a fortunate accident, as when a drug shows an unexpected benefit. But mostly, scientists and drug developers are constantly searching libraries of thousands of existing drugs, looking for potential candidates for repurposing.

Leading the search

Cleveland Clinic Lou Ruvo Center for Brain Health has long been a leader in the quest to identify and study drugs that could be repurposed to treat neurodegenerative diseases. In 2019, Jeffrey Cummings, MD, ScD, Director Emeritus of the Lou Ruvo Center for Brain Health, was awarded the prestigious Melvin R. Goodes Prize for Excellence in Alzheimer’s Drug Discovery for his work on repurposing rasagiline (see below).

All drug candidates must be tested in clinical trials to determine their effectiveness for a new purpose. Like all drug development, it can be a trial-and-error process, with some drugs proving effective and others not. The Lou Ruvo Center for Brain Health has led a number of clinical trials of existing drugs to determine their effectiveness in treating neurodegenerative diseases.

“We know the medications we consider for repurposing are safe. Since they are already approved for clinical use, we can bring them for testing much more quickly than new drugs,” says Aaron Ritter, MD, Director, Clinical Trials Program.

Following are examples of trials of repurposed drugs at the Lou Ruvo Center for Brain Health.

**Rasagiline**

Commonly used to treat Parkinson’s disease, rasagiline was studied for use in Alzheimer’s disease. The recently completed trial was groundbreaking in evaluating the drug based both on biological markers of the disease and clinical features (tests of memory and other brain functions).

The results, which were presented at the annual Clinical Trials on Alzheimer’s Disease Congress in December, were promising. Participants who were treated with the drug showed some notable improvements compared with participants who received a placebo:

- Improved brain metabolism in several key regions
- Better performance on cognitive and functional tests
- Reduced accumulation of the tau protein (the other protein that builds up in the brains of individuals with Alzheimer’s disease)

“Overall, the results of this small study seemed to indicate that treatment with this medication could have an effect on both the biology and the symptoms of Alzheimer’s disease,” says Dr. Ritter.

The next step is a second, larger trial, which will be funded in part by the Goodes Prize that Dr. Cummings received.

“Traditionally, studies have involved thousands of individuals across hundreds of clinical trial sites, which is very costly and logistically challenging. This study offers a new approach: early trials using more...”
sophisticated technology in small numbers of people and then validating the results in larger trials,” says Dr. Ritter.

**Lenalidomide**

Trials of this cancer drug are underway at the Lou Ruvo Center for Brain Health, led by Director Marwan Sabbagh, MD, who secured funding for the studies from two organizations.

Funded by the National Institute on Aging, one study will focus on the drug’s effects on amyloid deposits in the brain. The other study, funded by the Alzheimer’s Drug Discovery Foundation, will focus on the drug’s effects on neuroinflammation, which occurs in response to the presence of amyloid proteins. The two studies will test lenalidomide in participants with amnestic mild cognitive impairment, the first time the drug is being used to treat Alzheimer’s disease at an early stage.

“This drug is exciting because it works on two different fronts: It is very strong in reducing inflammation and can also reduce amyloid. In the future, Alzheimer’s patients may take a drug ‘cocktail’ that treats a variety of different disease processes such as inflammation or amyloid. Repurposed agents could be important as part of a multifaceted approach to treating neurodegeneration,” says Dr. Ritter.

Dr. Jeffrey Cummings, left, receives the prestigious Melvin R. Goodes Prize for Excellence in Alzheimer’s Drug Discovery from Mrs. Goodes and Howard Fillit, MD.
Become a Citizen Scientist: Sign up for Research

Whether you have been diagnosed with a brain disease or are a healthy volunteer with normal memory and thinking ability, you can help us meet our goal of finding more effective treatments for brain disease.

We conduct different types of research studies for:

- Alzheimer’s and other dementias
- Huntington’s, Parkinson’s and other movement disorders
- Multiple sclerosis

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One of the major hurdles in finding treatments for Alzheimer’s disease is finding enough volunteers for clinical trials. Learn more: HealthyBrains@ccf.org.
Explosion in MS Drugs Heralds New Era, Treatment Challenges

In the decade since Cleveland Clinic Lou Ruvo Center for Brain Health was founded, one of the center’s greatest achievements has been the expansion of service lines beyond Alzheimer’s disease to study all aspects of brain disease, including multiple sclerosis (MS). And while Alzheimer’s researchers haven’t seen a new drug approved since 2003, MS researchers are experiencing the opposite issue: an abundance of new drug approvals posing challenges in MS care.

The Lou Ruvo Center for Brain Health has been in the forefront of new drug research. Two MS drugs approved since 2017 (Ocrevus® and Mayzent®) were tested at our center, and we were involved with another MS treatment that should be approved in 2020, according to Le Hua, MD, Director, Cleveland Clinic Mellen Program for MS at the Lou Ruvo Center for Brain Health, Las Vegas.

A burning question

While the rapidly expanding MS treatment landscape is exciting, Dr. Hua notes a new challenge: The variability of these new medications, coupled with the unpredictability of the disease, is making it difficult for doctors to determine the best course of treatment for individual patients.

That’s why the Lou Ruvo Center for Brain Health is engaged in innovative research aimed at answering the burning question: What is the best way to treat MS? We are focusing on three areas:

1. MS treatment approach: Currently, there are two treatment approaches to MS: The first uses a highly effective treatment early in the disease state and the second uses lower-efficacy yet safer medications first, reserving escalation to higher-efficacy medications if the disease is not adequately controlled.

Each approach carries its own risk of side effects, and science has yet to determine which is better. Carrie Hersh, DO, MSc, and Dr. Hua are conducting research to help answer this question through trials like DELIVER-MS, marking the first time the risks and benefits of the two approaches have been compared in a head-to-head trial.

2. Reparative trials: Drugs approved for MS only stabilize the disease and prevent further relapses; no treatments are available to repair the damage already done. We are exploring ways to repair the damage through remyelination and axonal regeneration.

ANYONE CAN HELP DISCOVER NEW TREATMENTS; NO MS REQUIRED!

Participation in the Lou Ruvo Center for Brain Health’s clinical trials program is free and open to the public. Even those with normal cognitive function are needed to participate as normal, healthy controls.

To learn how you can get involved, visit clevelandclinic.org/clinicaltrials or call 855.LOU.RUVO.
Remyelination is aimed at altering the course of MS by rebuilding myelin, the sheath covering nerve fibers in the brain and spinal cord. When myelin becomes damaged, it slows or blocks electrical signals from reaching the eyes, muscles and other parts of the body. Another approach is to repair myelin and regenerate axons, the nerve fibers that carry the electrical signal.

Our patients were among the first to test these treatments through the AFFINITY trial and the RADIUS trial. In addition to controlling disease and preventing disability, the future of MS will include reparative agents.

3. Real-world evidence: While randomized, controlled clinical trials provide the highest level of evidence for MS drug safety and efficacy, comparing individual therapies in robust clinical trials is cost- and time-prohibitive and has more limited application in the clinical setting. Here at our center, Dr. Hersh and Dr. Hua are interested in real-world evidence to compare existing treatment options and treatment effectiveness in the aging population, using both observational studies and comparative effectiveness research to inform decision-making based on clinical imaging markers, precision medicine and quality of care.

**Rolling Back the Clock to Move Forward**

This is an exciting time for MS research and treatment. Drs. Hua and Hersh’s hope for the future of MS care is to have tangible biomarkers to predict treatment response immediately.

“We’re observing the power of repairing neural cells, effectively rolling back the clock to improve patient health,” she says. “I envision these disease-modifying therapies revolutionizing the way we look at MS, and I encourage those interested in our programs to reach out to the center to help us move toward a new era of treatment,” says Dr. Hua.
Since being diagnosed with multiple sclerosis, Eve Cross has changed her lifestyle, from eating differently to attending barre classes: “Some days my body shakes, but other days I wow myself that I can hold a plank with the very little strength I have left. Exercise has given me a more positive outlook, knowing I’m doing something great for myself when everything else around me feels as if it’s falling apart.”
We have classic visions of the ever-faithful Boy Scout helping the proverbial elderly lady across the street, but what happens to the visibly healthy, 38-year-old woman whose multiple sclerosis (MS) is raging with symptoms invisible to passersby, such as numbness, blurred vision, motor fatigue or anxiety?

“When I use the handicap parking on a day when getting out of the car is a struggle mentally and physically, I’m certain onlookers are thinking, ‘She’s not sick, old or in a wheelchair. She’s probably just lazy and using someone else’s handicap tag to get a convenient parking spot,’ ” says Eve Cross, who was diagnosed with relapsing-remitting MS in 2017. “The guilt is always there.”

She adds, “It’s difficult to explain to friends, family and coworkers. Most say, ‘But you look fine’ or ‘You’re doing a great job,’ not realizing that staying awake throughout the day, focusing at work and taking care of my kids takes double the energy, strength and time with my MS. I wish people would ask, ‘Can you help me understand what you’re going through?’ ”

Managing “on the job”

Cleveland Clinic Lou Ruvo Center for Brain Health Social Worker Sandy Chapman, LSW, frequently hears from families who don’t understand why a loved one is sleeping so much, “being lazy” or needing more help with housework: “Fatigue, cognitive impairment and depression are among the most common invisible symptoms, and managing anxiety around these issues can be challenging for patients and family members alike.”

Carrie Hersh, DO, MSc, says the varied and largely invisible symptoms of MS are precisely the reason that the center offers an integrated approach to care.

“MS typically strikes individuals in their 20s to 40s, when most are working full time and often have young families, so learning to manage the disease ‘on the job’ is challenging,” she says.

**Looks can be deceiving**

Meanwhile, back in that parking lot…

Occupational therapy at the Lou Ruvo Center for Brain Health helped with strategies for energy conservation. Eve says the delivery-to-car apps that many retailers offer “are huge for me. Before, I would sit in my car and strategize how to get into the store and back. Now, the store comes to me.

“Believe me, I just want to be normal,” she adds. “And I know I look normal. I just don’t feel normal.”

Ms. Chapman advises, “It’s important for families to talk about these symptoms, which may be invisible to strangers but need to be made visible to family.” She recommends bringing family to see the MRI brain scan for themselves and hear the doctor’s explanation of the disease.

As for the workplace, it’s the individual’s decision regarding how much information to reveal to an employer, she says: “Accommodations can be helpful, but there can also be downsides. On the other hand, patients can think of themselves as ambassadors of this disease. These symptoms are invisible, but you can be visible.”

**Seeing Is Believing? Not Always With MS**

Dr. Carrie Hersh

works with people with MS

keepmemoryalive.org • clevelandclinic.org/Nevada
For Parkinson’s disease, Alzheimer’s disease, Huntington’s disease and many other neurodegenerative disorders treated at Cleveland Clinic Lou Ruvo Center for Brain Health, no new medications have been introduced in years.

“When I was in fellowship seven years ago, we only had one drug treatment for Huntington’s disease, and not much has happened since,” says Odinachi Oguh, MD, a movement disorders neurologist who moved her family from Florida to Las Vegas because of Cleveland Clinic’s reputation for innovative research.

Pursuing a Genetic Game Changer

Fortunately, the drug landscape is improving for Huntington’s disease (HD). In November, Dr. Oguh attended the Huntington’s Disease Study Group’s annual meeting, where she was heartened to learn that more than five companies are developing potential genetic and neuromodulating therapies to manage symptoms and reduce the progression of disease.

“It’s exciting to think that with a hereditary disease such as Huntington’s, we might one day be able to reduce the mutant gene in young, newly diagnosed patients,” she says.

“The challenge has been that by the time individuals show motor changes, the disease has already progressed beyond symptom treatment, so a genetic modifying agent would be a real game changer for families.” Dr. Oguh predicts such a therapy could be available within the next five years.

Until then, she’s working on ENROLL-HD, a global longitudinal, observational study of HD aimed at collecting a common set of data from all participants across all sites around the world to learn more about the disease, improve clinical care and find new treatments.

A Coveted Designation

In addition to treating Huntington’s disease, Dr. Oguh treats a broad spectrum of movement disorders spanning ataxia, dystonia, essential tremor, multiple system atrophy, Parkinson’s disease, progressive supranuclear palsy (PSP) and more.

In 2018, Cleveland Clinic earned a CurePSP Center of Care designation, which signals excellence in care and research to patients and prospective research collaborators alike. Dr. Oguh’s goal is to earn a Center of Excellence designation from the Huntington’s Disease Society of America (HDSA), which would recognize the impact the Lou Ruvo Center for Brain Health’s Huntington Disease Comprehensive Clinic has been making on its patients and their families. That impact extends to the community through collaboration with the HDSA Las Vegas affiliate’s awareness-building and education efforts and annual fundraising walk.

Most importantly, Centers of Excellence are among the first selected to test new drug therapies, thus bringing potential treatments to patients more quickly.

To make an appointment with Dr. Oguh or another member of the movement disorders team, call 702.483.6000.

For Huntington’s Disease, Hope Is on The Horizon

MEET ODINACHI OGUH, MD, STAFF NEUROLOGIST

Dr. Odinachi Oguh is a board-certified movement disorders neurologist. She graduated summa cum laude from medical school at the University of Szeged, finishing her neurology residency at the University of Illinois and a post-graduate movement disorders fellowship at Northwestern University. Prior to joining Cleveland Clinic in 2019, she spearheaded the Movement Disorders Program at the University of Florida, focusing on clinical research programs, deep brain stimulation pre-surgical evaluation, botulinum toxin management and community outreach.
For nearly 300,000 people in the United States alone, dystonia, while less common than Parkinson’s disease, nonetheless can be a devastating neurological disorder that impacts daily life. Individuals with dystonia experience involuntary muscle contractions that cause twisting and repetitive movements or abnormal postures. These often-painful postures may involve a single muscle, a group of muscles (such as in the arms, legs or neck) or the entire body, and cause varying degrees of deformity, disability, and pain. The types of dystonia that affect the entire body are more common in children, whereas focal types usually present in adults.

How can we help?
At Cleveland Clinic Lou Ruvo Center for Brain Health, a multidisciplinary team spanning neurologists, neurorehabilitation therapists, social workers and psychiatrists works in a coordinated fashion, assessing and addressing the physical, emotional, mental and behavioral needs of patients and families living with dystonia. Our team members have specialized training and experience in treating movement disorders such as dystonias.

While there is no cure for dystonia, multiple treatment options are available to reduce the severity of symptoms:
- **Oral medications** can be used, but their benefits are often limited
- **Deep brain stimulation (DBS) surgery** is available, but only a small portion of dystonia patients are good candidates
- **Botulinum toxin** injections are the primary and most effective form of treatment for most types of dystonia

What is botulinum toxin?
Botulinum toxin is a neurotoxin, but it provides significant relief for many types of dystonia and is safe when injected into affected muscles in very small doses. After an injection, it blocks the signal between nerve and muscle, allowing the muscle to relax temporarily. The effect of botulinum toxin on the muscle begins approximately two to three days after injection, peaks between two and six weeks, and usually provides relief for approximately three months, at which point the injection can be repeated.

“For botulinum toxin injections to be successful, it is critical that the injecting physician be specifically trained in the techniques of injecting, fellowship trained in movement disorders such as dystonia, and well-versed in the functional anatomy of the involved muscles and the type and doses of botulinum toxin to use,” explains Zoltan Mari, MD, Director, Parkinson’s Disease and Movement Disorders Program. “Injections administered without such highly specialized training and expertise can lead to suboptimal injection outcomes, causing patients to incorrectly conclude that botulinum toxin injections ‘don’t work’, which is far from the truth.”

The Lou Ruvo Center for Brain Health’s movement disorders neurologists offers a weekly botulinum toxin for dystonia clinic. To make an appointment, please call 702.483.6000.
Exploring a Link Between Hearing Loss and Cognitive Decline

As a neuropsychologist focused on older adults with neurodegenerative disease, Christina Wong, PhD, specializes in assessing memory and determining what has gone wrong — information that assists neurologists in rendering a nuanced diagnosis.

Dr. Wong was drawn to Cleveland Clinic Lou Ruvo Center for Brain Health by what she says is a “rare hybrid of clinical care and research opportunities” in her area of focus. Among the older adults to whom she administers memory tests requiring the listening, learning and recall of auditory information, she is often trying to determine whether poor performance is due to cognitive decline or, perhaps, to hearing loss.

“Studies have found a link between hearing loss and reduced memory performance, but the cause of this relationship is unclear,” Dr. Wong says. “Difficulty hearing could result in an individual appearing impaired on testing, or there may be brain changes that are associated with both hearing loss and cognitive decline.

“Another possibility is when older adults experience hearing loss, they tend to isolate themselves socially, yet we know that staying socially active is important for brain health,” she adds.

Research Opportunities Beckon

That’s why Dr. Wong has conducted research in cognitively healthy older adults with and without hearing loss, comparing performance levels on verbal memory tests as well as on non-verbal cognitive measures. At the Lou Ruvo Center for Brain Health, she hopes to continue her research to study the effects of hearing loss in a real-world clinical setting among patients who are cognitively impaired.

Dr. Wong, who joined the center in 2019, also plans to build upon her experience in longitudinal aging studies to examine brain inflammation. She notes that the Lou Ruvo Center for Brain Health has a strong track record in “securing philanthropic funding to help junior investigators” and provides a supportive environment for research such as hers.

On the educational side, having recently completed her own fellowship, Dr. Wong is already looking forward to the opportunities an academic medical center presents to train the next generation of graduate students and fellows. She anticipates her first trainees arriving in late summer 2020.
Understanding Dementia: It Goes Beyond Alzheimer’s Disease

When many people hear the term “dementia,” they think of Alzheimer’s disease (AD), the most common cause of cognitive impairment in older adults. But there are other types of dementia and, while they have some common symptoms, each affects the brain differently.

- **Alzheimer’s disease**: AD usually first strikes the hippocampus, the area of the brain that controls short-term memory but, as it progresses, it can affect thinking and organizing skills.

- **Lewy body dementia (LBD)**: The second most common form of dementia in people older than 65, Lewy body dementia resembles both AD and Parkinson’s disease, with symptoms spanning fluctuations in alertness, thinking, movement and sleep; a tendency to act out dreams; and, sometimes, visual hallucinations.

- **Frontotemporal dementia (FTD)**: Known for loosening inhibition and causing impulsive behavior or progressive loss of language, frontotemporal dementia is the second most common dementia (after AD) in people under 65.

- **Vascular dementia**: Unlike other types of dementia that are caused by a build-up of abnormal proteins in the brain, vascular dementia is caused by impaired blood flow to the brain and/or strokes, and can affect memory, judgment and reasoning, among other cognitive processes.

**Why does type matter?**

Understanding the unique characteristics of each form of dementia is critical for accurate diagnosis. Just finding the cause of a loved one’s impairment can be deeply reassuring to family members and caregivers. It also enables the affected individual to receive the latest treatments and to participate in research, including clinical trials that are evaluating therapies for these difficult-to-treat conditions.

“As we develop new treatments, it’s increasingly important to have an accurate diagnosis so that we test medications on the right patients,” says Aaron Ritter, MD, Director, Clinical Trials Program, Lou Ruvo Center for Brain Health.

**Uniting to change the trajectory of dementia**

The bulk of research has focused on AD, but that is changing. The Lou Ruvo Center for Brain Health is a member of two initiatives that are advancing research on FTD and LBD:

- Funded by a $63 million grant from the National Institutes of Health, the Frontotemporal Lobar Degeneration (ALLFTD) research consortium aims to speed clinical trials by more accurately identifying people with the disease and finding biomarkers to track disease progression.

- The Dementia With Lewy Body Consortium (DLBC) is a national research initiative dedicated to improving the diagnosis and treatment of LBD, established by Cleveland Clinic with a grant from the National Institutes of Health. The Lou Ruvo Center for Brain Health is embarking on its first LBD clinical trial.

“These initiatives are a major step forward: They are increasing awareness of these diseases and enabling researchers to share data and collaborate on clinical trials,” says Dr. Ritter.

To make an appointment with a neurologist specializing in dementia, call 702.483.6000.

To find out if a clinical trial of a potential new dementia treatment is right for you, contact us at 855.LOU.RUVO or healthybrains@ccf.org. A full list of open trials is online at clevelandclinic.org/clinicaltrials.
Warning Signs of Alzheimer’s Disease: When Should You Visit a Doctor?

One in 10 Americans over the age of 65 is living with Alzheimer’s disease (AD), and that number is expected to rise exponentially over the next few decades, especially here in Nevada. Recent statistics show that the “gray tsunami” is making waves in the Silver State, with an estimated 64,000 residents living with the disease by 2025 — a 48.8 percent increase over the 45,000 residents affected today.

Given these alarming statistics, it’s likely that at some point, someone you know will be impacted, which is why it’s important to be observant of the early warning signs. While the brain changes that cause AD start years and even decades before symptoms emerge, it can be difficult to differentiate between normal aging and signs of the early stages of the disease.

However, the earlier AD is detected, the better, as an early diagnosis can help patients and their families plan for the future, initiate treatment (both lifestyle modifications and medications), and consider participation in a clinical trial. Clinical trials in AD — where new and promising treatments are being tested — are increasingly focused on testing new medications at the earliest stages of the disease.

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**BE ON THE LOOKOUT FOR THESE FIVE SYMPTOMS**

1. **MEMORY LOSS AND COGNITIVE CHANGES**
   
   AD is a brain disease that causes a slow decline in memory, thinking and reasoning skills. Most notably during the early stages, you may find that your loved one has started to forget recently learned information, repeat him or herself, and become unable to complete tasks that used to be easy (paying bills, scheduling and attending appointments or taking medications). While mild memory loss is a normal part of aging, it shouldn’t be persistent or get worse over time.

2. **BEHAVIORAL CHANGES**
   
   Aside from cognitive changes (thinking or memory), AD and other dementias can cause behavioral changes. In some people, poor judgment, faulty logic when solving problems or difficulty concentrating may be the initial symptoms. Apathy (lack of interest in activities) and social withdrawal may also be signs of brain disease.

3. **LANGUAGE**
   
   Word-finding difficulty is a common symptom of normal aging, sometimes because we are distracted with other things on our mind, had a bad night’s sleep or are “having a bad day.” Language changes in dementia are more than just word finding, and can span challenges in making oneself understood or communicating thoughts.

4. **VISUOSPATIAL DIFFICULTIES**
   
   The visual system has two components: the capture, focus and transfer of light (completed by the lens, retina and optic nerve) and the interpretation of this light into meaningful information (completed by the back part of the brain, or occipital cortex). In some dementias, the first symptom may be due to faulty ways the brain is interpreting visual information. Symptoms of these dementias may include difficulty judging distances (driving a car) or manipulating items (such as hanging a picture or using utensils or other household objects).

5. **PERSONALITY CHANGES**
   
   As people age, they typically become set in their routines and may be upset by deviation from these patterns. However, people with dementia may experience more drastic personality changes, becoming anxious, fearful, suspicious, confused or depressed.
stages of the disease, when symptoms first emerge.

If you’re still on the fence about whether to bring in your loved one for a checkup, ask yourself these questions:

• Are you more worried about leaving the person at home alone for a week than you used to be?
• Do you think he or she would be able to get by with food, reliably take prescribed medications and handle any problems that could arise without assistance?

The course of AD varies from person to person and for some, it can be difficult to identify the early stages. But if you answered yes to either of these questions, are noticing any of the five symptoms or, most importantly, are observing a noticeable change from the person’s prior level of functioning that affects the ability to perform daily tasks, it’s likely time to consult a specialist.

To schedule an appointment with a neurologist fellowship-trained in the early detection and treatment of brain disease, call 702.483.6000.
At Cleveland Clinic Lou Ruvo Center for Brain Health, we address brain disease through two important steps: accurate diagnosis and expert disease management. Each component requires unique neurological specialization.

As our experts in ongoing disease management, the team's advanced practice providers (APPs) — nurse practitioners and physician assistants — are trained to detect subtle changes in condition and adjust treatment plans accordingly.

Nurse practitioners (NPs) have advanced degrees and are board certified; all NPs at our center have published research in peer-reviewed journals, have earned or are completing doctorate degrees and are licensed as family nurse practitioners who specialize in neurology. They can prescribe drugs and order and interpret diagnostic tests.

Prior to obtaining their advanced degrees and associated licensing privileges, physician assistants have a well-defined skill set in another practice or field of medicine, such as emergency medical technicians.

Our advanced practice providers are astute overseers and strong communicators of the relationship between overall health and neurological conditions. Let’s meet some members of this talented team.

**Kelly Papesh, DNP**
*Nurse Practitioner, Movement Disorders Team Manager, Advanced Practice Providers*

Dr. Kelly Papesh chose to become a nurse practitioner to work at the most advanced level of nursing as a generalist. However, her father developed a brain tumor and her father-in-law has Parkinson’s disease, so she became interested in neurology.

“My approach to patient care is shaped by my mother, who reminds me that they wait months for that one appointment with a neurologist back home in Minnesota,” says Dr. Papesh. “My family is looking for that ounce of hope, as is each family that comes to my clinic.”

She is inspired by her patients, notably a 96-year-old woman who Dr. Papesh says is “sharp as a tack and enjoys dancing. I have a picture of her at my desk, and I feel joy and inspiration when I see her.”

**Jenny Nguyen, MSN, APRN, FNP-C**
*Nurse Practitioner, Movement Disorders Team*

From age 10, Jenny Nguyen served as a caregiver to her parents, translating from their native Vietnamese during encounters with the healthcare system, a role she says “helped me gain perspective on how patients should be treated: with respect, dignity and empathy.”

Today, she reflects on how much easier it is being a provider — seeing an individual periodically and making changes to the care plan — versus being on the front line daily as a family caregiver.

“The neurodegenerative syndromes we manage are diseases of loss and grief,” she notes. “As our patients decline, the caregiver takes on an outstanding burden to provide love and support. It is vital that we acknowledge the caregiver’s observations and requests.”

**David Oliphant, PA-C**
*Physician Assistant, Multiple Sclerosis Team*

“I had a patient who had been diagnosed with multiple sclerosis five years ago, and had always refused MS-specific therapy,” David Oliphant remembers. “I met her for the first time, spoke with her, and explained the disease and its prognosis with and without therapy, and the risk and benefits of most common MS-specific medicines. She listened patiently to me and, to my surprise, agreed immediately to one of the treatments! At the end of the visit she told me, ‘I wish you were the first person I met when I had been diagnosed because I would have started treatment then.’

PA Oliphant explains that “the 45 minutes that Cleveland Clinic dedicates to APPs for visits is much more than most practices allow, and it gave me the time to have that conversation and change the course of that patient’s disease management.”
Simrit Kaur Saraon, DNP, APRN, FNP-BC  
*Nurse Practitioner, Cognitive Disorders Team*

Ask Dr. Simrit Saraon what she most enjoys about her work at the Lou Ruvo Center for Brain Health and there's no hesitation: “The patient interaction,” she says, beaming. “My patient population is very diverse in terms of ethnicities and backgrounds. They’re older, and so have lived a full life. I love talking with patients and listening to their histories.”

Dr. Saraon finds it rewarding to be able to help families in this time of need: “Even though I can’t offer much hope, given the diseases we treat and the lack of disease-modifying therapies, if I can manage their symptoms, it makes a difference for them and for me.”

Maileen Ulep-Reed, MSN, APRN, FNP-BC  
*Nurse Practitioner, Cognitive Disorders Team*

Maileen Ulep-Reed says of her role, “You can really make an impact in people’s lives, and I enjoy getting to know patients as we follow them long-term through their disease course. There aren’t any cures for the diseases treated at the Lou Ruvo Center for Brain Health, but we can help improve quality of life.”

She starts with the least invasive intervention, the non-pharmacological: diet, exercise and sleep. As she says, “Lifestyle choices can make more of a difference than most families realize.”

As cognitive disorders progress, she notes, the most challenging symptoms can be behavioral, which often triggers long-term placement in a facility.

“It’s rewarding to be able to postpone that placement through expert disease management,” she says.
When Death Is a Dinner Guest

If you were invited to dinner to talk about death, would you go? Last November, 175 people answered “Yes!” and attended the worldwide debut of Death Over Dinner — Alzheimer’s Edition.

A collaboration between Death Over Dinner Founder Michael Hebb, who lost his father to Alzheimer’s disease, and Cleveland Clinic Lou Ruvo Center for Brain Health, the dinner was held in the Keep Memory Alive Event Center (see page 39).

To spark guided, intimate conversation at each of the 21 tables, guests received carefully developed conversational prompts, from the icebreaker variety “What song would you like playing at your memorial?” — to the intense: “Imagine you have been diagnosed with early onset Alzheimer’s; how would it feel to receive this news? What plans would you set in motion to ensure as much happiness as possible for yourself and your loved ones?”

Too often, a subject off limits

For three months leading up to the event, Death Over Dinner and the Lou Ruvo Center for Brain Health convened local community collaborators for input on the content for the evening, including members of the center’s Voice of the Patient and Family Advisory Council and leaders at the Alzheimer’s Association, Compassion Care Hospice and Nevada Senior Services.

Silvia Perez Protto, MD, head of Cleveland Clinic’s End of Life Center, leveraged experience in her “day job” as well as learnings from the Healthcare Edition that she and Michael Hebb co-hosted in Cleveland in May. She explains, “All too often, we meet a family in the ICU who find themselves in the horrific position of having to make their best good faith decision because they never had the conversation while their loved one still had capacity.”

From the stage at the Las Vegas dinner, Michael Hebb explained that 75 percent of Americans would like to die at home, yet only 25 percent do because they have been too afraid, uncomfortable or intimidated to share their wishes for life and death, even with loved ones. Startled yet inspired by this statistic, he created Death Over Dinner, a nonprofit focused on revolutionizing the way people talk about life and death through curated tabletop conversation. More than 200,000 dinners have been hosted in homes and restaurants worldwide.

As Mr. Hebb likes to say, “You want a mission statement for life? Consider your own mortality.”

Host Your Own Dinner

The curated elements of the dinner have been placed on DeathOverDinner.org, available as a free toolkit for others wishing to host an Alzheimer’s-themed Death Over Dinner with friends and loved ones.
Intergenerational Interludes is a no-cost, multi-generational music therapy program in collaboration with Discovery Children’s Museum, our neighbors in downtown Las Vegas. Started as two six-week pilots in 2019, the program is based on music therapy research and lifespan developmental theory.

“Anthropologist Margaret Mead sums it up nicely: ‘In the presence of grandparents and grandchildren, past and future merge into the present,’” says Becky Wellman, PhD, a music therapist at Cleveland Clinic Lou Ruvo Center for Brain Health and the visionary behind Intergenerational Interludes.

**Sharing with “grandparents”**

Maximizing quality of life for individuals navigating brain disease is a goal of all of the center’s music therapy interventions. That’s why each week, Intergenerational Interludes brings together community children under age 5, their parents or caregivers, and Cleveland Clinic patients with memory loss for music, movement and fun. Sessions focus on:

- Developing trust between the generations
- Supporting self-initiative
- Creating positive experiences
- Providing opportunities to share wisdom and enjoy positive engagement

Parents say their children look forward to seeing the “grandparents” every week and are eager to share music and stories with them.

**Children and music bring patients to life**

As the sessions progress, Dr. Wellman observes that patients participate more willingly, smile and appear happier, and engage more actively with the children.

“We love your music program,” says Stephanie Graham, referring to her mother, Irene. Irene’s dementia “takes away her speech and desire to open her eyes on a daily basis, yet she comes to life when she is surrounded by the children and the sounds of the various instruments you incorporate. I can see Dr. Wellman and the children really reach her because she opens her eyes, sings and participates. It has been such a joy that my husband and I make a point of adjusting our work schedules so we can be there to witness Mom at her best.”

In 2020, Intergenerational Interludes will be an ongoing series of six-week sessions held at Discovery Children’s Museum. Please contact Dr. Wellman at 702.701.7895 or wellmar@ccf.org to inquire about registering your family for an upcoming session. Classes are available at no cost, thanks to philanthropy.

To support arts programming at the Lou Ruvo Center for Brain Health, contact 702.263.9797 or DonateNevada@ccf.org.

“Our love of music extended to our children, and on to our grandchildren. We’re honored to support music therapy at Cleveland Clinic Lou Ruvo Center for Brain Health so that other families can find joy and create memories over music.”

— Robert and Kikie Priddy
Meet Our Center’s First Health Psychologist

Lucille (Lucy) Carriere, PhD, joined Cleveland Clinic Lou Ruvo Center for Brain Health as our first health psychologist in August 2019.

“l’m excited to return to the Cleveland Clinic family,” she says. “Having completed my fellowship in health psychology at the Mellen Center for Multiple Sclerosis on the main campus in Cleveland, I appreciate Cleveland Clinic’s commitment to delivering the best clinical care and developing evidence-based therapeutic interventions.”

Encouraging Healthy Behavior

Health psychology is a specialty that focuses on the intersection of health and behavior, taking into consideration the various factors in a person’s life to understand what’s driving certain behaviors. Health psychologists help patients reflect on how daily habits, career and family challenges — layered atop the diagnosis of a memory problem — can contribute to poor physical and psychological health.

“In our center’s specialized cognitive disorders clinic, I am focusing on how we can promote healthy behaviors, such as sleep, in the context of chronic illness, and helping patients digest how they think about their illness and how they can manage its effect on relationships,” explains Dr. Carriere. “Unlike a general psychologist, I’m not just focusing on mood. What I’m able to provide is a fuller picture of the patient’s functioning.”

A Collaborative Setting

Cleveland Clinic’s Las Vegas location, with only 160 employees and a small campus, offers “increased collaboration with cognitive neurology providers and integration with other services, such as rehabilitation therapy and social work. Here, I’m a visible part of the medical team and can truly offer whole-person care,” adds Dr. Carriere, who also holds the Angie Ruvo Endowed Caregiving Chair (see page 30).

In her practice, Dr. Carriere collaborates with patients to establish a plan for achieving goals. She describes a patient she saw for just a single session: “He wanted to age in a healthy way with his diagnosis of mild cognitive impairment. We talked about increased social interaction, good sleep, meaningful activities and how to expand what he’s already doing to keep him functioning as well as he is today.”

Want to learn more?

If you’ve recently been diagnosed with a cognitive disorder and are trying to make sense of its implications, ask your neurology provider if a referral to health psychology might help. Call us at 702.483.6000.

MEET LUCILLE CARRIERE, PHD, STAFF HEALTH PSYCHOLOGIST
ANGIE RUVO ENDOWED CAREGIVING CHAIR

Dr. Lucille Carriere is a clinical psychologist specializing in health psychology. She completed her graduate training at Auburn University; an internship through Vanderbilt University and the Veterans Affairs Medical Center in Nashville, Tennessee; and a fellowship at Cleveland Clinic’s Mellen Center for Multiple Sclerosis Treatment and Research.

Prior to joining the Lou Ruvo Center for Brain Health, she worked in geriatric primary care and provided psychotherapy for individuals and caregivers living with neurodegenerative disorders and complex medical conditions. She is interested in outcomes research related to caregivers.
After visiting numerous doctors in search of an explanation for the changes friends and family had noticed in her husband, Lou, Angie Ruvo met Leon Thal, MD, in San Diego. The renowned researcher put his hand on her shoulder and said, “Mrs. Ruvo, you have a 24-hour-a-day job here. Lou has Alzheimer’s.”

Fewer than three years later, in February 1994, she awoke in the night to find that, despite one of the tricks of caregiving she had learned “on the job” — tucking the bedcovers tightly around him and then under the mattress — Lou had gotten out of bed. She found him dead on the bedroom floor from a heart attack.

“Just go along”

Those three years had been just as challenging as Dr. Thal had predicted.

“I’d say Lou, you need professional caregiving help. He said, ‘You’ve been my wife for 50 years. You’re taking care of me,’” remembers Mrs. Ruvo.

Along the way, she developed a homegrown caregiver toolkit.

When her husband refused to eat, Mrs. Ruvo remembers, she would say, “Lou, here comes a choo-choo train. Open your mouth.” And I’d shove the food in.

“He thought I was his mother and I’d say, ‘I’m your wife. You married me,’ but I soon realized it was easier to just go along with whatever he said.”

At Cleveland Clinic Lou Ruvo Center for Brain Health, “that’s exactly what we tell our caregivers today: ‘Don’t argue, just go with it,’ ” says Lucille Carriere, PhD, the inaugural Angie Ruvo Endowed Caregiving Chair (see page 29).

Funded by Camille and Larry Ruvo and presented to Angie on her 94th birthday, the Chair provides financial support for its holder to conduct research into caregiving and expand the center’s evidence-based education and support programming.

“The Chair, I couldn’t believe it. Only Camille and Larry would think of that. They always spoil me,” Mrs. Ruvo says.

Make time for yourself

In Las Vegas prior to the 2009 opening of the center that Larry Ruvo established in his father’s memory, there were few board-certified neurologists specializing in Alzheimer’s disease. There were even fewer support group options, and Mrs. Ruvo says the one she found didn’t help.

Says Dr. Carriere, “Groups have come a long way in the last couple of decades.” One thing that hasn’t changed is the challenge of making time for self-care. She frequently reminds caregivers to try to practice a relaxation strategy. Even something as brief as a 20-minute call with a friend or a quick walk can be restorative.

While Mrs. Ruvo endured back surgery due to frequently lifting her husband following falls, today she enjoys bingo, shopping and baking her family’s favorite desserts. Her wish for her 96th birthday in 2020? She wants to see George Strait in concert and receive a birthday kiss.
Enjoy the guidance of our librarian as you peruse more than 2,000 books, DVDs and pamphlets.

**Monday – Friday**
8:30 a.m. – 4:30 p.m.

LouRuvoLibrary@ccf.org
702.483.6033

Or browse at your convenience from home, 24/7, via our e-Library: keepmemoryalive.org/library

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**JOIN US EACH WEEKDAY:**

**Education, Exercise and Support**

Every day, there is at least one organized activity on campus, from group exercise led by our board-certified physical therapists, to group music therapy, to Memory Café Respite, to support groups and more. Most are available at no cost.

Join us and grow your toolkit for managing brain disease.

Visit clevelandclinic.org/NevadaEvents or notify LouRuvoSocialServ@ccf.org to receive a monthly events update via email.
Foundation Supports Post-Doctoral Education to Benefit Patients and Community

A “living lab” for learning

An internship at the Veterans Administration in Lincoln, Nebraska, rounded out her experience in addressing health disparities across diverse groups, from ethnic minorities to rural and urban populations to individuals of varying gender identity and sexual orientations.

Moreover, when evaluating fellowship positions in her desired specialty, neuropsychology, Dr. Jeffers realized that the Lou Ruvo Center for Brain Health offered “a rare blend of clinical and research opportunities, as well as a ‘living lab’ in which to gain a more nuanced understanding of the different types of dementia.”

An academic health center, the Lou Ruvo Center for Brain Health uses its proprietary Knowledge Program™, administered via tablet, to gather and aggregate data from patients during each neurology visit. Since starting her fellowship in September, Dr. Jeffers has found the center provides “data already gathered from patients over the years, which speeds research beyond the data-gathering stage to analysis and application.”

Growing the ranks of Nevada neuropsychologists

The Engelstad Foundation, with its deep history of supporting healthcare and education, takes an analytical approach to its giving, “evaluating maximum impact on the community of each gift,” says Trustee Kris Engelstad McGarry. “As Las Vegas expands its healthcare education programs, postgraduate education is the key to expanding the number of healthcare providers in our region, given that 70 percent of individuals practice in the locale in which they complete their graduate medical education.”

The Engelstad Foundation and Sharlene Jeffers, PhD, share a passion for expanding health education opportunities for marginalized populations.

While completing her doctorate in clinical psychology at the historically black university, Howard, Dr. Jeffers gained experience in multicultural competence: “I’m passionate about providing disadvantaged populations with the education to ask the right questions that open doors to the healthcare access everyone deserves.”

Dr. Jeffers pays no tuition for her post-doctoral fellowship; in fact, thanks to philanthropic funding from The Engelstad Foundation, she earns a salary at the Lou Ruvo Center for Brain Health. At present, the center employs two of Nevada’s five board-certified neuropsychologists. We hope that when Dr. Jeffers completes her training in 2021, she will become the sixth in our state.

In mid-2020, thanks to The Engelstad Foundation gift, two additional fellows are slated to join the Lou Ruvo Center for Brain Health: the center’s inaugural fellow in multiple sclerosis and one additional post-doctoral neuropsychologist.

If you are interested in funding the training of the next generation of Nevada’s healthcare providers, please contact us at 702.263.9797 or DonateNevada@ccf.org.
Building on a 10-Year Foundation in the Nevada Community

ARCHITECTING THE FUTURE OF CLINICAL CARE, RESEARCH, AND NO-COST FAMILY EDUCATION AND SUPPORT SERVICES

clevelandclinic.org/Nevada  |  702.483.6000
Same-week appointments available
The Power of a Simple Flower

Since opening in July 2009, Cleveland Clinic Lou Ruvo Center for Brain Health has been offering a complimentary flower to each patient. Initially a nod to the level of hospitality the Ruvo family extended to guests at its legendary Venetian Ristorante, the flowers have become a hallmark of the center's hospitality experience. However, the flower program wouldn't be sustainable without the generous philanthropy of R.T. Smith (see sidebar).

HEARD IN THE LOBBY BY OUR VOLUNTEERS

“Patients are so appreciative to receive flowers. I love to tell them, ‘We want you to be happy and comfortable.’ They look forward to receiving the flowers, and tell me they’re amazed how long they last.”
Murlin Hampton

“When I present the flower, I say, ‘You deserve it for visiting today’ and guests beam and it just makes my day.”
Pat Lindsey

“Patients may not remember me from week to week, but they remember the flower. I love when they ask for it.”
Fran Funtleyder

“One guest shared, ‘The flower sitting on my kitchen counter is a nice reminder of how special it felt to receive it. Thank you.’”
Karen Mariano

“If I don’t offer a flower quickly enough, patients ask, ‘Do I get one today?’ They say one of the perks of coming here is to get a flower when they leave. First-time guests are surprised the flowers are a gift. They assume they have to make a donation, but we explain, ‘No, the flowers are free, thanks to philanthropy.’”
Margaret Griffin

“The flowers create a little bit of joy and happiness on the way out the door. You don’t see this at other doctors’ offices.”
Lisa Naves

“The flowers create a little bit of joy and happiness on the way out the door. You don’t see this at other doctors’ offices.”
Lisa Naves

“A GIFT OF HOSPITALITY

In considering where to donate in honor of his late wife, Lynne Ruffin-Smith, R.T. Smith had been looking for an organization that matched her personality, style and interests. Upon touring the Lou Ruvo Center for Brain Health in 2014, Mr. Smith made his philanthropic decision. He explained, “Everyone at the center is courteous, friendly, passionate about their work and happy to answer every question. The experience is at once hospitable yet understated.” Just like Lynne Ruffin-Smith.

We regret to announce that R.T. Smith died on December 31 at the age of 77, shortly before the publication of this issue of New Thinking. We honor and thank him posthumously for his generosity.
Keep Memory Alive’s Month of Memories is a community-wide initiative in support of National Alzheimer’s Disease Awareness & Family Caregiver Month. Each November, Keep Memory Alive engages to raise awareness of and funds for this devastating disease that affects so many patients who come through our doors at Cleveland Clinic Lou Ruvo Center for Brain Health. We also honor their friends and family who serve as dedicated caregivers.

A thank you to supporters

Again this year, DelFrisco’s Double Eagle Steakhouse generously opened its doors to Keep Memory Alive, hosting a reception November 22 for community partners and Month of Memories supporters and beneficiaries. Guests enjoyed delectable beverages and tidbits from this world-class steakhouse.

Melody Dagash, General Manager of DelFrisco’s, noted that it, too, is in the business of creating memories for
families who gather over a meal. To cap off Month of Memories, the restaurant presented Agnes Liguori and her husband and caregiver, Sammy, with a dining certificate to return to Del Frisco’s.

“Nearly 50 years ago, she grabbed my hand and asked me to dance,” says Mr. Liguori, “and before I could explain that I didn’t know how, Agnes had me doing the samba.” The couple celebrated his 90th and her 83rd birthdays in December at Del Frisco’s.

PARTNERS IN GENEROSITY
Throughout the month, Las Vegans participated in opportunities to support Keep Memory Alive, from specialty cocktails to “round up” promotions at cash registers, with the following community collaborators:

Ada's
Americana Las Vegas
Anna Marie's
Atomic Liquors
Big Dog Brewery
Bin 702
Blume Restaurant
Buddy V's Ristorante
Carson Kitchen
Del Frisco's
  Double Eagle Steakhouse
Echo & Rig
El Dorado Cantina
Ellis Island Casino & Brewery
Empress 1908 Gin
Evel Pie
Flippin Good Chicken, Burgers, Beer
Honey Salt
La Strega
Lee’s Discount Liquor
Marche Bacchus
Mt. Charleston Lodge
Nacho Daddy
Numb Bar and Frozen Cocktails
Piero's Italian Cuisine
Pinkbox Doughnuts
ProteinHouse
Santos Guisados
  Tacos & Beer
Sparrow + Wolf
The Golden Tiki
The Kitchen at Atomic
The Martini
The Pasta Shop Ristorante & Art Gallery
The Pint
Therapy
Topgolf
Village Pubs
[yellow tail]
Throughout 2019, the Keep Memory Alive special events team was busy collaborating with enthusiastic event hosts who selected Keep Memory Alive as their charity of choice. Here are but a few examples.

**PBR CHARITY GOLF CLASSIC**

The Professional Bull Riders designated Keep Memory Alive the sole beneficiary of their annual golf tournament, the PBR Charity Golf Classic. It was an exciting day at Bali Hai Golf Course in Las Vegas with a great tournament, fun contests and delicious food — all in the name of brain health.

**VEGAS GIVES**

Keep Memory Alive was delighted to celebrate Nicole Taffer, a member of our Fundraising Advisory Board (see page 44), at Vegas Magazine’s 11th annual Vegas Gives reception at Wynn Las Vegas.

Ms. Taffer, of Taffer Media, Inc., told Vegas Magazine, “My uncle has Parkinson’s disease, so when I learned about Cleveland Clinic Lou Ruvo Center for Brain Health, I knew I wanted to be involved with and spread awareness of this facility and all that it does for patients and caregivers living with these diseases.”

Asked to share her recipe for success, she said, “The recipe for success in marriage, as well as our professional lives, is to choose a great partner, trust your instincts, treat those around you with dignity and respect, and have fun.”

Each Vegas Gives honoree identifies a charity partner, which becomes the beneficiary of 100 percent of event tickets sold by the honoree. We’re grateful that Nicole Taffer has chosen to support Keep Memory Alive and the Lou Ruvo Center for Brain Health.
Students at six Las Vegas middle schools participated in Keep Memory Alive’s “A Penny for Your Thoughts” small change fundraiser, which aims to engage local students in philanthropy and raise funds for the Lou Ruvo Center for Brain Health. Together, students from Canarelli, Faiss, Leavitt, Fertitta, Webb and Sig Rogich middle schools collected more than $24,000 in a single day.

Every penny raised benefits the expansive education and support programs offered at no cost to patients battling neurocognitive disorders, their families and the community. Thank you to the students, faculty and staff who embraced the change that makes a difference.
Meet Us at the Keep Memory Alive Event Center

From an intimate dinner for 20 guests to a massive concert for more than 1,500 people, the team at Keep Memory Alive Event Center has the experience and resources to create impactful events of all sizes.

At 9,200 square feet, the Frank Gehry-designed center can accommodate 450 guests seated and up to 700 standing. Extension into the breezeway and courtyard expands the complex’s footprint to 60,000 square feet, providing the ability to produce events other venues can’t.

And, with all proceeds supporting the research, treatment and prevention of brain disorders at Cleveland Clinic Lou Ruvo Center for Brain Health, every unforgettable event, regardless of size, helps others remember.

For information or to schedule a site visit, contact 702.263.9797 or email eventcenter@keepmemoryalive.org.

On the smaller end of the spectrum, hosts of smaller events don’t need to worry about getting lost in the space.

When chef and TV personality Eric Ripert hosted a 20-person dinner, the event center team suspended floor-to-ceiling crystal chandeliers and oversized sculptures to help visually enclose the 75-foot ceiling and create a warm, inviting atmosphere.
For Toyota's 50th anniversary, nearly every square foot of campus was used. The team designed food and beverage stations and VIP areas inside the event center along with car installations and a red carpet in the garden and breezeway. Then, the team erected a domed tent in the parking lot to present a multi-course dinner from celebrity chef Cat Cora and a concert from legendary country star George Strait.
ON THE SCENE

Visitor Photo Gallery

L–R: Michael Severino, Dr. Marwan Sabbagh and Kelsey Grammer

Camille Ruvo, left, with Carol Foley

L–R: Dr. Ram Dandillaya and Terry Wright

Jody Ghanem with visitors from Korea’s Samsung Medical Hospital

Jody Ghanem and Dr. Charles Bernick with Kevin Camper of the Las Vegas Motor Speedway

Maria Christina Annaloro, Andy Abboud, Larry Ruvo, JT Foley, Dr. Marwan Sabbagh, JR Bloom and Dr. Dylan Wint
Janet Caine surprises Marwan Sabbagh, MD, by dedicating a plaque on our Honor Wall.


(below) L–R: Jim Gentleman, Michael Severino, Jimmy Kimmel, Camille Ruvo, Dr. Dylan Wint, Dr. Dietmar Cordes.

Cheryl Azar and Joe Clark.

Doni Taube joins Michael Severino, KT Lim and Scott Sibella of Resorts World.
HOST YOUR EVENT
IN AN ARCHITECTURAL AND CULTURAL LANDMARK

From the mind of world-renowned architect Frank Gehry, the iconic Keep Memory Alive Event Center is a sculptural masterpiece, designed for guests who have an uncompromising eye for the exquisite and extraordinary.

Nestled in the cultural campus of Symphony Park and the Downtown Las Vegas Arts District, the ambitious steel structure brings together sumptuous cuisine from the likes of Wolfgang Puck, Four Seasons, Emeril Lagasse and Cut & Taste, paired with incomparable attention to detail, and advanced technology, to create a truly elevated and exclusive guest experience.

For corporate, incentive, and social events, receptions, meetings or galas, the stunning complex accommodates 450 guests seated and up to 700 standing. Consider extending into the breezeway and Gehry-designed courtyard for a reception for up to 1,500+ guests.

By choosing to host your event at Keep Memory Alive Event Center, you help support the research, treatment and prevention of brain disorders at Cleveland Clinic Lou Ruvo Center for Brain Health.

Thank you for your consideration in hosting an unforgettable event, and in return, helping others to remember.

KEEP MEMORY ALIVE
EVENT CENTER
702.263.9797 • kmaeventcenterlasvegas.com
888 W. Bonneville Avenue • Las Vegas, NV 89106

For information about date availability or to schedule a site visit, please contact:
Special Events at 702.331.7043 or email eventcenter@keepmemoryalive.org
Back row, left to right: Dawn Russi, Michael Shulman, Camille Ruvo, Victoria Otter, Kimberly Laub, Kathy Antonino and Anna Robins
Front row, left to right: Kelly Pettit, Kimberly Thesman, Ellen Schaner, Sandy Hardie and Angela Doherty
Not pictured: Sheryl Goldstein, Debbie Ledbetter, Nicole Taffer, Stephanie Wilson and Andrea Wynn

The members of Keep Memory Alive’s Fundraising Advisory Board (FAB) serve as ambassadors for brain health, leveraging their expertise and reach in the Las Vegas community and beyond.

These ladies — and gentleman — embrace Keep Memory Alive’s mission to find, fund and facilitate the most effective, innovative research and caregiver programming for patients and their families affected by brain disorders.

You’ll see their impact at Keep Memory Alive’s annual Power of Love® gala (see page 5) and throughout the year.
Diagnosis Was a Relief: “It Had a Name!”

At a memory screening event at Christ Church Episcopal organized by Dementia Friendly Southern Nevada (DFSN), people lined up to have their cognitive health tested — many for the first time. Kathy Kesner was one of those people.

After reading literature listing the warning signs of Alzheimer’s disease, she had noted that she had eight of the 12 symptoms described. She was forgetful, had trouble remembering names and had gotten lost several times. So Kathy took the assessment at the church and followed up with her personal physician, as recommended. A diagnosis followed more extensive testing.

“It had a name!” recalls Kathy. She was diagnosed with vascular dementia based on a CT scan indicating multiple mini-strokes.

Knowledge is Power

“Having a diagnosis was a relief,” Kathy says. “I’m not just a forgetful old lady. If you don’t know what you’ve got, it’s frustrating. Now that I know, I can deal with it. I can explain to people why I am forgetting and they won’t fault me for it.”

Her husband, Master Sgt. Dennis Kesner, who is also an ordained minister and parishioner at Christ Church Episcopal, is Kathy’s primary caregiver and biggest supporter, just as she was his during his 20 years in the U.S. Air Force.

All these years later, the tables have turned and Dennis is the one following his wife to provide the support she now needs.

“He makes me leave the house and engage with other people, and I’m busy at church,” she says. “I’ve also lost weight because of diet and exercise.”

Caring for the Community

Both are dedicated members of the DFSN advocacy group championed by Cleveland Clinic Lou Ruvo Center for Brain Health. They have never missed a meeting and actively participate in community activities the group organizes. For example, they helped implement a second memory screening at Christ Church Episcopal and encouraged fellow parishioners to obtain cognitive tests.

Dennis has undergone training to become a Community Awareness Trainer; in this volunteer role, he visits community organizations throughout Las Vegas to discuss the signs of dementia, dementia-friendly communication and physical environment, and the importance of support for caregivers.

“IT’s all about service,” he says. “Finding out who needs the help, and determining how to help them.”

Kathy enjoys being a part of DFSN, she says, “because I like to tell my story. It’s a blessing because if I see someone who is having a problem, I tell them I have dementia. I can’t get a shot or take a pill. I have to go on and if I can do it, so can they.”

To schedule a Community Awareness Training at your faith-based or community organization, contact Susan Hirsch: hirschs@ccf.org or 702.701.7940.
In recent months, Cleveland Clinic Lou Ruvo Center for Brain Health employees have been honored by their community, peers and professional associations for clinical excellence and leadership in their fields. We celebrate their accomplishments.

Elected Legislative Chair
(Nevada Occupational Therapy Association, November 2019)

Shaina Meyer, OTR/L

Inspired Excellence in Healthcare
(Las Vegas HEALS, October 2019)

Aaron Ritter, MD

The Melvin R. Goodes Prize for Excellence in Alzheimer’s Drug Discovery
(Alzheimer’s Drug Discovery Foundation, September 2019)

Jeffrey Cummings, MD, ScD

Angel Awards:
Nonprofit of the Year
(VegasINC, September 2019)

Keep Memory Alive

Chair, Healthcare Advisory Council
(Multiple Sclerosis Association of America, September 2019)

Carrie Hersh, DO, MSc

Top Score Poster
(ECRIMS, September 2019)

Carrie Hersh, DO, MSc

Le Hua, MD

Distinguished Service Award:
Service to the Field of Psychogeriatrics
(International Psychogeriatric Association, August 2019)

Jeffrey Cummings, MD, ScD

Top Doctors
(KNPR’s Desert Companion, August 2019)

Jeffrey Cummings, MD, ScD

Dylan Wint, MD

Chairperson, Healthcare Advisory Council
(Multiple Sclerosis Association of America, Dec. 2019)

Carrie Hersh, DO, MSc

Neurologic Clinical Specialist Certification
(American Board of Physical Therapy Specialists, June 2019)

Sondi Facer, PT, DPT, NCS

Member, MS and CNS Inflammatory Disease Topic Work Group, and Vice Chair, Aging, Dementia, Cognitive and Behavioral Neurology Work Group
(American Academy of Neurology Conference Subcommittee, 2019)

Dylan Wint, MD

Men of the Moment
(Vegas Magazine, 2019)

Marwan Sabbagh, MD, FAAN

Fellow
(American Academy of Neurology, 2019)

Zoltan Mari, MD, FAAN

Stella Award for Best Conference Center Far West
(Northstar Meetings Group, October 2019)

Finalist, Best Event Venue
(Special Events Magazine, 2019)

Industry Leader
(Smart Women in Meetings Awards, 2019)

Maggie Tuitele
Cleveland Clinic Nevada

888 W. Bonneville Ave.
Las Vegas, NV 89106
Office 702.263.9797
Toll free 888.268.9797

keepmemoryalive.org
clevelandclinic.org/Nevada

HONORING NEIL DIAMOND

Photo by: Denise Truscello

THE 2020 POWER OF LOVE® GALA
SATURDAY, MARCH 7, 2020
LAS VEGAS, NV

Power of Love® is a one-of-a-kind food, wine and spirits, and entertainment experience that raises funds and awareness for Cleveland Clinic Lou Ruvo Center for Brain Health.
Alzheimer’s ♥ Huntington’s ♥ Parkinson’s
Multiple System Atrophy ♥ Multiple Sclerosis

For more information, go to keepmemoryalive.org/pol or call 702.263.9797