# NEW THINKING ABOUT THINKING







#### DIRECTOR'S MESSAGE

We began 2023 by convening leading Alzheimer's disease (AD) researchers from around the world for the Leon Thal Summit<sup>®</sup> conference, an event Keep Memory Alive hosted even before our center's doors opened in 2009.

In hosting the "AD illuminati", we sustain our tie to Leon Thal, who would have been our center's first director were it not for a fatal plane crash. His substantive contributions to the understanding, prevention and treatment of Alzheimer's and related disorders are seen to this day in AD research worldwide — including right here in Las Vegas (see page 3).

It was Dr. Thal who not only gave Lou Ruvo the diagnosis of Alzheimer's disease, explaining the changes his family had observed, but whose influence inspired the services that Cleveland Clinic Lou Ruvo Center for Brain Health offers at no cost our patients and families (see page 19).

In February, we convened another type of illuminati at our 26th annual Power of Love<sup>®</sup> gala: the donors whose passion combines with our purpose to meet the needs of patients, families and our community (see page 25). Please save the date: the next Power of Love is Saturday, May 11, 2024.

Funds raised at the gala support investments that enhance our care and research capacity, making possible nuanced diagnoses that truly change the way we help patients manage diseases they have, while removing diagnoses of conditions they don't (see page 9). We continue to innovate patient care, from the ataxia comprehensive clinic that provides convenient access to a transdisciplinary team of specialists in a single day (see page 13) to our shared medical appointment entitled "Living Well With Cognitive Changes," which groups patients and care partners to do just that through shared learning alongside a team of providers (see page 12).

The through line that connects our patients' care is our care coordinators, a team of registered nurses who serve as our patients' advocates and render quick responses to their concerns on behalf of our neurology care team. As a behavioral neuropsychiatrist, I continue to learn about my own patients through our care coordinators; I encourage you to do the same (see page 17).

Whether you're a grateful patient or community member, a long-time donor or just now contemplating an initial donation, your passion can fuel our purpose. From \$25 for a book in our library to help families navigate challenging brain diseases (see page 23) to endowing a chair to fuel a clinician-scientist's work (see page 22) or supporting our endowment campaign that sustains our center's future in southern Nevada (see page 24), your passion and our purpose can change the future of brain disease for our community.

#### **DYLAN WINT, MD**

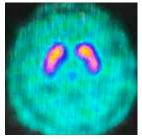
Center Director Camille and Larry Ruvo Chair for Brain Health

Director, Education

Las Vegas Legacy Chair for Neuroscience Education

Cleveland Clinic Lou Ruvo Center for Brain Health











**On the cover:** Mark Davis, Owner, Las Vegas Raiders, at the Keep Memory Alive Honor Wall at the entrance to our Frank Gehry-designed campus (see page 32).



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# NEW THINKING ABOUT THINKING

Cleveland Clinic

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Research, treatment and education for patients and families living with brain disorders

ALZHEIMER'S DISEASE FRONTOTEMPORAL DEMENTIA LEWY BODY DEMENTIA AND OTHER DEMENTIAS HUNTINGTON'S DISEASE PARKINSON'S DISEASE ATAXIA AND OTHER MOVEMENT DISORDERS MULTIPLE SCLEROSIS AND OTHER AUTOIMMUNE NEUROLOGICAL DISORDERS

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# Blood-Based Biomarkers for Alzheimer's Disease:

In January, leading Alzheimer's disease (AD) researchers from around the world convened at Cleveland Clinic Lou Ruvo Center for Brain Health for the Leon Thal Summit<sup>®</sup>, which had been on hiatus since 2010.

This group continued to drive forward the contributions of the late Leon Thal, MD, who was Chair of Neurosciences at the University of California, San Diego when he died. The commemorative think tank focused on advancing blood-based biomarkers to improve Alzheimer's disease research, diagnostics and clinical care globally.

#### BRAINSTORMING IN VEGAS JUST MIGHT AFFECT BRAINS WORLDWIDE

Discussion within the invitation-only group of clinician-scientists centered

around the application of biomarkers, or measurable signs of disease, in research and clinical care. Amyloid PET, the gold standard for diagnosing AD, is a costly imaging assessment not currently covered by insurance.

In search of a lower-cost, easier-toadminister yet accurate tool, the Alzheimer's disease research community holds high hopes for blood-based biomarkers (BBB), which could be obtained through a simple blood draw at a neighborhood lab.

#### THE STAKES FOR PATIENTS

Knowing that an individual is accumulating abnormal amyloid in the brain opens doors for participation in clinical research as well as use of novel drug treatments that target amyloid — perhaps the most notorious suspected contributor to AD. Conversely, normal biomarkers may exclude AD as the cause of a patient's cognitive impairment.

"Whether blood biomarkers can accurately detect disease processes of AD, even before characteristic symptoms are evident, is immensely relevant to patient care worldwide," says Dylan Wint, MD, Director, Lou Ruvo Center for Brain Health, who hosted the Summit with Larry Ruvo.

The hope is that, eventually, biomarker performance will be sufficiently accurate and available to be incorporated into the routine annual assessment of older individuals to track the effectiveness of therapeutic intervention.

### Leon Thal Summit<sup>®</sup>: A HISTORY OF IMPACT

► 1978

The search for a cure for Alzheimer's disease begins in the U.S.

## ► **2012**

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Department of Health and Human Services (DHHS) releases the framework for the National Plan to Address Alzheimer's Disease, shaped by recommendations from the 2007 – 2010 Leon Thal Summit<sup>®</sup> conferences

## ▶ 2009

▶ 2013

The National Institutes of Health

agenda for a national plan to

prevent and effectively treat

Alzheimer's disease by 2025

(NIH) develops a specific research

Recommendations from the 2007 and 2008 Leon Thal Summit<sup>®</sup> conferences become the core scientific framework for the Alzheimer Study Group's (ASG) Report, which is presented to the 111<sup>th</sup> Congress

### ► **2011**

President Barack Obama signs into law the National Alzheimer's Project Act (NAPA) based on the ASG Report's framework

## ▶ 2014-2023

The NIH's investment in Alzheimer's disease research grows from nearly \$600 million to \$3.7 billion



#### WHO WAS LEON THAL?

The groundbreaking for Cleveland Clinic Lou Ruvo Center for Brain Health took place on February 9, 2007, just six days after Dr. Thal's fatal plane crash. Tragically, Dr. Thal died before he could fulfill his promise to serve as the center's director, but we sustain his legacy through the Leon Thal Summit<sup>®</sup>.

"Leon Thal's three decades of substantive contributions to the understanding, prevention and treatment of Alzheimer's and related disorders have resulted in new pathways for scientists to create a new paradigm for clinical practice and diagnosis. The Alzheimer's cause mourns the loss of an essential and unforgettable leader."

— Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 2007

#### **Experts foresee a decade of progress in** Alzheimer's disease care

► Justin Miller, PhD, Director of Research Operations at the Lou Ruvo Center for Brain Health, invited panelists to predict the state of Alzheimer's disease care 10 years into the future.



Blood-based biomarkers will be available at primary care level to help eliminate disparities in healthcare.

Sid O'Bryant, PhD Institute for Translational Research, Texas College of Osteopathic Medicine



Blood-based biomarkers will be established in clinical practice across primary care and specialty clinics. There will be standardization of these tests, allowing clinician-scientists to work together as a community on the longitudinal follow-up of patients..

Alicia Algeciras-Schimnich, PhD Clinical Immunoassay Laboratory, Mayo Clinic



Research developments have led to widely available and cost-effective blood-based biomarkers. This will facilitate and streamline triaging and management of patients with cognitive symptoms and suspected Alzheimer's disease.

Kaj Blennow, MD, PhD University of Gothenburg



Thanks to extraordinary innovation following the initial acceptance of blood biomarkers, patients will be able to access amyloid-lowering therapies more easily and earlier in the course of their disease, changing the trajectory of Alzheimer's disease progression.

Joel Braunstein, MD, MBA C<sub>2</sub>N Diagnostics



Blood-based biomarkers may offer insight into which individuals are on the pathway to Alzheimer's disease even before they develop amyloid, allowing us to imagine actually preventing the disease.

#### Charles Bernick, MD, MPH

Cleveland Clinic Lou Ruvo Center for Brain Health

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### A Roadmap: **A WOMAN'S BRAIN HEALTH BY THE DECADE**

Our brains change more than any other organ in our bodies. In fact, the frontal lobes responsible for executive functions — such as planning, working memory and impulse control — may not fully develop until age 25-35. But as we get older, our brains lose volume. The cortex becomes thinner, the myelin sheath surrounding the fibers of neurons begins to degrade and receptors don't fire as quickly. Among cognitive changes associated with aging, the most noticeable is in declarative memory: recall of episodes, events and facts. These changes are considered normal and our brains can compensate, so we can still function independently.

#### ▶ The following timeline outlines what women should expect from our brains as we age, decade by decade.

### 20s - 30s

Congratulations! Your brain has reached peak speed. By your late 20s, however, your brain begins losing neurons, the building blocks of brain networks. Occasional "slips of the brain," such as forgetting where you placed your keys or why you went into a room may occur, particularly when you are stressed or sick.

During this period, intellectual stimulation, aerobic exercise, and good diet are especially important for brain health and can have long-term protective benefits. Avoid bad habits such as smoking, excessive alcohol use and neglecting health issues.

Of course, these are also peak childbearing years. Pregnancy, childbirth and breastfeeding are associated with significant hormonal changes. Postpartum mood changes are common and should be brought to the attention of your healthcare team.

As with all life changes, there may be disruption to routine (less sleep, less healthy dietary choices). All these factors can significantly impact cognition.



#### ASK A DOCTOR:

- Which lifestyle habits will protect my brain health throughout life? Ask about diet and exercise, and discuss any vitamins, supplements and hormones including birth control you are taking.
- I'm pregnant. What cognitive changes should I expect as a result? Be aware of mood swings. Take notes about any signs of depression during pregnancy or postpartum and review them with your doctor.



#### **TAKE CHARGE:** Get moving, eat smart

Exercise improves blood flow and memory, stimulating chemical changes in your brain that enhance learning, mood and thinking. It can also change the brain in ways that protect memory and thinking skills. Exercise is an excellent stress buster, so it serves many purposes. Build physical activity into your daily life: dance, wash your car, walk with a friend, jog or play a sport.

Complement a healthy lifestyle with a healthy diet. Research shows that a Mediterranean-style diet rich in fish, whole grains, leafy green vegetables, olives and nuts helps maintain brain health and may reduce the risk of Alzheimer's disease. Cook and eat fresh food and enjoy dining with family and friends.

## 40s - 50s

Around age 40, the myelin sheaths in the white matter tracts start to deteriorate and the volume and weight of the brain begin to decline. From your mid-40s to late 50s, strategic memory functions such as recall of names and numbers, reasoning and spatial skills slow down. This process will continue in the decade ahead.

More noticeably, during this time you may see a subtle decline in episodic memory, information that is stored with "mental tags" such as who was present at a meeting last week. Events that happened long ago tend to be more firmly set in your memory than more recent events.

On the upside, other facets of cognition — such as moral judgment, wisdom and emotional regulation — improve during this period. You also gain wisdom, skills and knowledge over time.

During midlife, it becomes increasingly important to address adverse health conditions such as high blood pressure and obesity. These conditions increase the risk of cognitive decline and should be addressed as they occur, making regular preventive medical care essential to brain health.

Menopause usually occurs at this time. The hormonal changes it brings can result in significant disruption of sleep, energy levels, mood and metabolic processes, etc., which can affect thinking and memory. Discuss this issue with your healthcare team to ensure that menopause is managed most effectively for your lifestyle and needs.



#### ASK A DOCTOR:

- I am considering a hysterectomy. Is there a link to brain health? Early studies showed a correlation between a hysterectomy (removal of the uterus) and an oophorectomy (removal of the ovaries) and increased risk of cognitive decline. However, numerous factors come into play, including age, whether you've gone through menopause, and other health challenges. Ask about all your options to make an informed decision.
- I have a family history of Alzheimer's disease. Is there anything I can do to protect myself? Having Alzheimer's in the family doesn't mean you'll get it, but it's good for your doctor to know.
- I think I am entering perimenopause. What should I expect? Menopause includes hormonal transitions that may impact memory. Talk to your doctor if you are depressed, moody or have a hard time focusing. Ask about hormone therapy and any associated cognitive impact.



#### **TAKE CHARGE:** Rest well, stay sharp

Few things feel better than a good night's sleep. Sleep improves mood and sharpens your intellect. It also gives you the energy to keep up with a busy lifestyle. In the hustle and bustle of your hectic life, make sure you are getting a quality night's sleep; eight hours is typical.

Agility or "cognitive reserve" enables your brain to respond to challenges and resist functional decline. Cognitive reserve begins to develop in childhood and can be strengthened through activities such as pursuing education and learning new skills.

Having strong cognitive reserve allows you to compensate for vulnerabilities that develop as you age.

The brain is analogous to a muscle: If you exercise regularly and the muscle is strong, it should do and withstand more than if it had not been subject to a regular workout. As you age, it's important to continue to learn, embrace new activities, and develop new skills and interests, all of which helps to build and improve cognitive reserve.

### 60s – 70s

Later in life, brain shrinkage becomes visible as gyral atrophy (shrinkage of the ridges on the surface of the brain), widening of sulci (the folds in the brain surface) and an increase in ventricular volume (the normal fluid-filled spaces in the brain).

After a lifetime accumulating knowledge, your brain becomes less efficient at accessing that knowledge and adding to it. Around 70, you may start to see subtle decline in ability to learn new information and effectively utilize the information you have already. Age is the greatest risk factor for common neurodegenerative diseases such as AD, which occurs most often in individuals 65 or older.

On a positive note, semantic memory — such as knowing that Paris is the capital of France — continues to grow in normal aging. When you stop working, enjoy retirement with activities that keep you active physically, mentally and socially. Lifestyle choices and health factors that increase cognitive risk include untreated depression, sedentary lifestyle, social isolation and diabetes.

# $\sum_{\Box}$

#### ASK A DOCTOR:

What should I do if I have a concern about memory loss? If you are experiencing forgetfulness, trouble with communication or other symptoms that concern you, requesting a consultation with a geriatrician or neurologist is a good place to start. It doesn't mean you have Alzheimer's disease or another type of dementia, but a specialist can help to narrow down the cause and any potential treatments or lifestyle changes that may be helpful.

They may suggest brain scans, bloodwork or a cognitive assessment. The combination of tests advised depends on the nature of your concerns and other pieces of your medical history and background. If interested in research studies or clinical trials, discuss possible participation with your healthcare team.

- I have heard that hormone therapy may be linked to an increased risk for Alzheimer's disease. What do I do? Whether your doctor is recommending hormone therapy or you're already on it, ask about any effects on brain health. Review your symptoms, risk factors, and preferences and make a decision that is best for you.
- I am going through cancer treatment. How will this affect my brain health? Some cancer treatments and chemotherapies that suppress estrogen production may affect brain health. Many women experience brain fog and "chemo brain."



#### **TAKE CHARGE:** Stay connected, control risks

While your body may start to slow down, making it increasingly difficult to go out, strive to stay connected with friends and family. A rich social network provides support, reduces stress, combats depression and enhances intellectual stimulation. Studies have shown that those with the most social interaction within their community experience slower rates of memory decline. Enjoying happy, supportive, long-term relationships and having purpose in life have shown significant protective effects against age-related cognitive impairment.

It's important to stay on top of your medical health during this period. Many medical conditions are strongly linked to decline in brain function. Keep your blood pressure and weight at healthy levels, take medication as prescribed, cut down on salt and sugar, keep active, and stay socially connected and positive.

Hearing problems can keep you from engaging with those around you so, if your hearing is declining, make sure to address it. A healthy body can help keep you sharp and increase your vitality and quality of life throughout your golden years.

## 80s

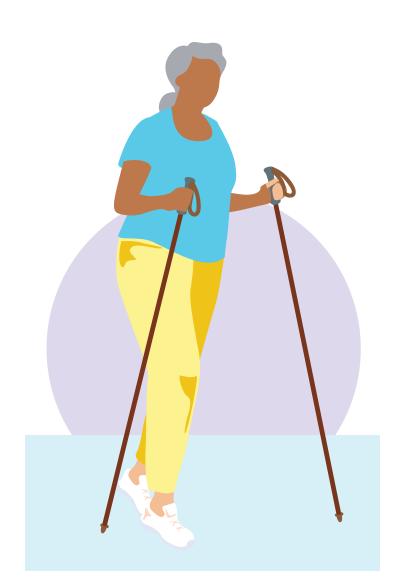
With average life expectancy in the United States at 77 years, living well into your 80s is a reasonable aspiration. If you've been focusing on your brain health, congratulations! You can continue to enjoy the fruits of your labor. Yet, you can still do more to ensure your brain span matches your lifespan.

Strength, flexibility and balance training become more important than in earlier years and can be alternated with cardio. Social activity is more critical than ever and may be part of your decision to consider a community setting where activities are easily accessible versus continuing to live in your own home. Or, perhaps you are already surrounded by a supportive network of friends and family with whom you frequently engage.



#### ASK A DOCTOR:

- What is the best way to maintain my vascular health? Vascular health is important, but blood pressure should not be over-corrected (target 120-140 systolic).
- What can I do to exercise safely? Can physical therapy or a personal trainer help?
- How is my overall health? Health issues that were minor 20 years ago can now have a big impact on brain health.



### WOMEN'S ALZHEIMER'S MOVEMENT PREVENTION CENTER

Curious about lifestyle modifications you or a woman in your life can make to reduce risk for Alzheimer's disease? Start your sustainable journey towards optimal brain health. WomenPreventAlz.org

### Is It Parkinson's Disease? A (NEARLY) FOOLPROOF WAY TO KNOW

Dr. Zoltan Mari 🗸

When retired radiologist Brent B. Birkin, MD, was in his early 70s, he noticed a tremor developing in his right hand. With writing becoming a struggle, he was sure he would need a work-around for the long term. Parkinson's disease ran in his family, dating back to his greatgrandfather, and most recently had taken his mother's life. As a first step, he taught himself to use the thumb of his firm left hand to stabilize his right while writing, and he called a neurologist.

Given the family history, the general neurologist near Brent's home in Las Vegas was quick to confirm Parkinson's disease (PD) and Brent, who had practiced as a pharmacist prior to graduating from medical school, agreed that levodopa, the most prescribed medicine for PD, was a reasonable treatment.

Around 12 years later, Brent's tremors hadn't spread beyond his right hand, which was highly unusual for PD, a progressive neurodegenerative disease. Brent's neurologist recommended a consultation with a movement disorders specialist.

#### A YES-OR-NO TEST

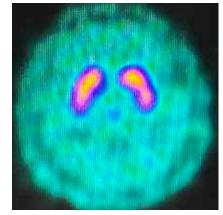
After meeting Brent, Zoltan Mari, MD, Director, Movement Disorders and Parkinson's Foundation Center of Excellence at Cleveland Clinic Lou Ruvo Center for Brain Health, was certain that the history and examination did not align with PD. Besides the long duration of non-progressive tremor restricted to the right hand, the tremor was also restricted to one activity: handwriting.

Dr. Mari also knew that the center's recently installed single photon-emission computed tomography (SPECT) scanner was exactly the tool he needed to confirm his clinical suspicion that Brent did not have PD.



#### WHAT IS DAT? By Dr. Zoltan Mari

A form of a SPECT scan, DaTscan<sup>™</sup> is named for the dopamine transporter (DaT) molecule in the brain's "striatum." The radioactive tracer ioflupane is injected into the blood and binds to the DaT molecules, providing a measure of how healthy the dopamine-producing nerve cells are.



^ A normal DaTscan<sup>™</sup> (left) indicates that the neurons that produce dopamine are at an age-appropriate number, meaning that Parkinson's disease is not present.



 The brain on the right illustrates an abnormally low amount of dopamine consistent with PD.

"A DaTscan is a yes-or-no scan," says Dr. Mari. "An abnormal scan indicates Parkinson's disease or similar disorders such as progressive supranuclear palsy, multiple system atrophy or cortical basal degeneration. However, if the DaTscan is normal, you're free of any of those movement disorders."

Dr. Mari diagnosed his patient's condition as primary writing tremor and removed the diagnosis of PD. Brent, who looked at the images alongside Dr. Mari, says it was "so clear I didn't even need to put my radiology training to use."

#### CERTAINTY INCREASES QUALITY OF LIFE

Prior to the DaTscan technology, standard of care suggested PD was a

reasonable diagnosis if the physician was at least 80% certain. Now, in cases such as Brent's, in combination with a clinical exam, the DaTscan is expected to improve diagnostic accuracy to near 100%.

Dr. Mari recalls another patient who had taken levodopa for several years for Parkinson's disease. The treatment never helped the tremor, and her general neurologist had recommended deep brain stimulation surgery (DBS). A DaTscan revealed the patient didn't have PD, sparing her from what would have been an ineffective and risky surgical procedure for a condition she didn't have.

Meanwhile, Brent, now 85, loves driving, travel with his wife of 61

years and their son, and "spur of the moment" activities. He's been treatment free since Dr. Mari weaned him off levodopa and has seen no changes in his writing tremor, for which he continues to compensate as needed with the assistance of his left hand.

To make an appointment with a movement disorders specialist to see if a DaTscan would confirm or refute a diagnosis, call 702.483.6000. Or, contact our imaging department directly at 702.701.7948.

#### DATSCANS ACCELERATE RESEARCH

Although Parkinson's disease is common, we lack precise ways of measuring and tracking disease progression and, more importantly, preventing or slowing progression.

This gap served as the catalyst for The Parkinson's Progression Markers Initiative (PPMI) — a landmark global observational study aimed at identifying progression biomarkers, or disease indicators, so that we can enhance PD therapeutics and prognosis.

The Michael J. Fox Foundation, the primary sponsor of PPMI, recently launched a major expansion of the study, adding Cleveland Clinic Lou Ruvo Center for Brain Health as one of 51 PPMI study sites worldwide.

The center's nuclear medicine capabilities make possible its participation in PPMI, for which confirming a diagnosis of PD via DaTscan is a requirement.

Now, data gathered from participants in Nevada will contribute to what will likely be the world's most robust PD longitudinal clinical and imaging data set and biosample library, aspiring to 4,000 participants globally by the end of this year.

# Behind every data point is a person

An estimated 6,700 Nevadans have been diagnosed with PD. The Lou Ruvo Center for Brain Health, the only PPMI site in Nevada, is seeking individuals who are:

- Age 30 or older
- Experiencing PD symptoms but have not been diagnosed
- Or have been diagnosed with PD but are not currently taking medication

#### **LEARN MORE:**

clevelandclinic.org/NevadaResearch or 702.701.7944.



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#### Appointments available: 702.483.6000

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HUNTINGTON'S DISEASE ATAXIA AND **OTHER MOVEMENT DISORDERS**  **MULTIPLE SCLEROSIS** AND OTHER AUTOIMMUNE **NEUROLOGICAL DISORDERS** 



Same-day imaging appointments available: 702.701.7948 Nuclear medicine, PET, CT and MRI for the entire body.

### clevelandclinic.org/Nevada

### Learning From Others **WHO LIVE WITH DEMENTIA**

For Deborah Swapp, care partner to her husband, Ron, "The key is being fearless when the unknown is fearful."

Deborah has stared into the unknown because Ron has Alzheimer's disease. So, when Jennifer Pauldurai, MD, a neurology fellow at Cleveland Clinic Lou Ruvo Center for Brain Health, suggested the couple participate in the center's shared medical appointment (SMA), "Living Well With Cognitive Changes," Deborah was intrigued. The Swapps joined five other care pairs for a session with Dr. Pauldurai; care coordinator Amy Sheets, RN; and health psychologist Lucille Carriere, PhD.

### INDIVIDUAL PLANS FOR A COMMUNAL JOURNEY

Initially, Deborah had some concerns. While she was assured that every pair in the group had experience with a cognitive disorder, she was aware that each family living with dementia manages its journey differently. *What about confidentiality? Would hearing another pair's conversation upset Ron?* 

But as she thought more about it, Deborah, a retired teacher, equated an SMA with the individualized education plans she and her colleagues had collaborated on for their students. She felt it might be a refreshingly familiar environment.

On the day of the appointment, the care pairs took their seats and conversation moved around the circle, directed by the provider team. The Swapps were the last pair to speak and, by then, she realized most of the items on the list she had prepared had already been addressed by other participants facing similar issues. "The others had trusted me with their personal information, so I automatically trusted them," says Deborah, "and Ron seemed to enjoy the community feel, being around others who had similar challenges."

#### **"STILL IN THE GAME"**

The SMA has two components: one-onone care at the outset of the appointment, followed by shared care. As the SMA's developer and facilitator, Dr. Carriere says she strives to "identify commonalities among group members' symptoms and promote discussion and problem solving for symptom management."

Deborah is quick to note that the SMA is neither a support group nor a class: "Yes, you're learning from your peers' experiences, but the professionals are there and listening to your concerns. These providers bring official knowledge and build upon what patients and family members have said."

She adds that the care team had access to Ron's medical chart, was able to review his history and "sent us home with a printed summary of our visit, just as in a traditional medical appointment." Going forward, she anticipates Ron's neurology care will be a blend of one-on-one and shared appointments.

Most importantly, Deborah says, observing the other care pairs calmed some of her own fear of the future: "They were still learning, still participating, still in the game. It made me feel more confident and hopeful that we can successfully manage dementia, too."

#### The Benefits of Sharing

A shared medical appointment (SMA) may be helpful if you:

- Are comfortable sharing health information in a group setting
- Need routine, follow-up care between your regular neurology appointments
- Need extra time to talk with a specialist about symptoms secondary to your cognitive loss
- Find group discussion sparks your memory around topics you might otherwise have neglected to ask your healthcare provider

LEARN MORE: To see if "Living Well With Cognitive Changes" can enhance your neurology care, contact your Lou Ruvo Center for Brain Health provider through MyChart or at 702.483.6000.



^ Ron and Deborah Swapp

### All About Ataxia, **A LITTLE-KNOWN DISORDER WITH MANY FORMS**

When walking became difficult and she started falling frequently, Kristy Taylor, then 33, had a sinking feeling she knew the culprit: ataxia. With a mother, uncle and grandfather stricken with the condition, she says, "I wasn't surprised to receive the diagnosis myself, but I was crushed."

Now, 10 years later, Kristy runs support groups and chairs the Las Vegas chapter of the National Ataxia Foundation. The organization estimates that 15,000 –20,000 Americans have the dominant inherited form, spinocerebellar ataxia (SCA). Tens of thousands more are affected by recessive, sporadic and yet-unknown forms of ataxia.

#### **HELP IS AT HAND**

Ataxia is a neurological condition that causes people to move in an uncertain, awkward or clumsy way. Everything takes longer, so Kristy has learned to pre-plan her day, prioritizing necessary activities before fatigue sets in.

That's where Cleveland Clinic Lou Ruvo Center for Brain Health's ataxia comprehensive clinic can help, facilitating convenient, same-day visits with an array of multidisciplinary specialists who attend to physical, emotional, cognitive and behavioral needs.

While drug treatments occasionally reduce symptoms related to ataxia, physical, occupational and speech therapy are typically the most successful approaches to ongoing management. The weighted vest prescribed by Kristy's Lou Ruvo Center for Brain Health physical therapy team can help with body position awareness and movement. She also appreciates the social work team's referrals to vendors who can make her home safer through modifications, such as shower bars.



#### "I'M A REGULAR PERSON"

In 2019, Kristy, whose motto is "No surrender," was having terrible seizures that she says almost killed her, but they also inspired her to prioritize her health. She is grateful to neurologist Odinachi Oguh, MD, Director of the ataxia comprehensive clinic: "Dr. Oguh has saved my life. Every time I see her, I learn something new."

Often, individuals don't know they have a gene for ataxia. At Cleveland Clinic, Dr. Oguh says, "we can provide genetic information and guide you through the benefits, limitations and risks of testing including genetic

# discrimination, workplace issues, and health insurance limitations."

Kristy's goal is to reduce societal stigma.

"I would echo the words of anyone with a disability. It's hard, but I'm a regular person," she says. "It would be helpful if parents would talk with their children about people with disabilities and why we use wheelchairs or walkers. I don't want kids to be afraid of our mobility aids."

For an appointment for genetic testing or in our ataxia comprehensive clinic, call 702.483.6000 or learn more at clevelandclinic.org/NevadaMovement.

#### **Seeking support?**

The National Ataxia Foundation offers an array of online support, including a Facebook group that Kristy launched in summer 2023: Age 30-55 with Ataxia Support Group.



# Imaging Services

Twisted a knee? Wrenched your shoulder or back? We image nearly every part of the body.

Taken in Las Vegas and interpreted by sub-specialized Cleveland Clinic radiologists, we offer high-resolution images in MRI, nuclear medicine, CT and PET.

We can typically offer same-day access and results are usually available within 24 hours.

> clevelandclinic.org/Nevada or 702.701.7948 to schedule your imaging appointment



### SPEAKING OF Swallowing...

You've been swallowing nourishment without a thought since the day you were born, so why might you now be struggling to accomplish this simple, seemingly mindless activity?

Because the brain controls everything that happens in the body, including swallowing. So, when it comes to degenerative brain disease, the common symptoms of each disorder — ranging from numbness to slowness to forgetting how to do something also show up in swallowing.

#### WHEN SWALLOWING ISN'T A FLUID MOVEMENT

Kristen West, SLP, a speech therapist at Cleveland Clinic Lou Ruvo Center for Brain Health, notes that patients themselves will be the first to identify a swallowing problem, and "they're always spot on when they say something doesn't work."

She encourages family care partners and fellow healthcare professionals to question the individual directly: "A person with dementia who may otherwise have difficulty expressing themselves will say, 'It doesn't go down right' or 'I can't get the food out of there.""

#### WHO CAN HELP?

Because of the profession's very name, a speech language pathologist — commonly referred to as a speech therapist — might be the last person you'd think to ask for help. However, Ms. West says, "We have a master's degree in mouth, breath support, voice, swallowing, all of which are functions or connecting functions of the larynx and, yes, speech."

She adds that SLPs understand not only aphasia, or loss of the ability to speak, but the anatomy of the brain, such as the motor cortex and brainstem that control the muscle movements of speech and swallow. Diagnostic assessments can include swallow function studies and speech/cognitive assessments.

Wondering if you could benefit from a consultation with an SLP? Send your neurology team a message via MyChart or call 702.483.6000.

BRAIN DISORDER	SWALLOWING CHALLENGE	HOW TO SPOT IT	WHAT TO DO
Multiple sclerosis (MS)	Oral numbness	Something that has no weight in the mouth, such as water, doesn't trigger a swallow. Watch for coughing while drinking or even choking on one's own saliva.	Take smaller sips.
	Lack of coordination	Chewing, but food isn't going anywhere, or it seems to take longer to eat.	Alternate liquids and solids.
	Xerostomia (lack of saliva or "dry mouth"), a side effect of some medications	A person may describe "feeling as if something is stuck" or suddenly requiring more than one swallow to get food down.	Avoid dry or crumbly foods, such as crackers.
Parkinson's disease	Lip incoordination	Slow eating. Drooling, caused by less frequent swallows or weak lip and cheek muscles.	Work on keeping chin up, not speaking when eating.
	Freezing of swallowing	Similar to freezing of gait, throat muscles become rigid and movement is slow to respond. Coughing with liquids and difficulty with dry textures are usually apparent.	Eat softer, more cohesive textures such as casseroles or meats with gravy.
	Fatigue in eating	Mealtime starts off well, but then the pace slows because each step of swallowing takes longer.	Consider more frequent, smaller snacks instead of big meals.
Dementia	Lack of awareness, losing track of activity of eating	While the person may retain the capacity to swallow, they may say, "I've eaten too much" or get distracted by environment.	Eliminate distractions such as TV; make eating the sole focus.
	Diminished sense of taste; resistance to textures	Forgetting they've already eaten; losing interest in food. Failure to recognize textures; foods they've previously enjoyed seem like foreign objects.	Alternate textures or temperature: soft vs. chewable or cold vs. hot items.
	Pocketing	Holding food in mouth: forgetting how to manipulate food, chew, swallow. Not using tongue to check for food remaining in mouth.	Brush teeth after eating to avoid aspirating on food hidden in cheek pockets or gums.
	Forgetting how to feed self	Not picking up food from plate; residue in mouth. Watch for food visible in mouth as person is talking.	When assisting persons with dementia, go slowly and make sure they've swallowed the preceding bite.

#### ▶ Here's a quick guide to some of the most common brain diseases and how they can affect swallowing.

### **GETTING A GRIP** on Your Overall Health

As you age, your muscles tend to weaken. Wear and tear impact your whole body, including your knees, hips, back and more. But another part of your body matters more than you may think.

Researchers call grip strength the amount of force you can exert when you clench your hand around an object — an indispensable biomarker for older adults. It's also an indicator of your risk for injury, mental health conditions and more.

Grip strength begins to decline around age 50. People who maintain their grip strength age more slowly. They stay healthier longer and are stronger throughout their bodies.

#### UNDERSTANDING THE RISK

Grip strength is tested using a device called a hand dynamometer, which measures the force generated when you squeeze as hard as you can. It's part of the evaluation process in your first appointment with an occupational therapist (OT) at Cleveland Clinic Lou Ruvo Center for Brain Health.

OTs focus on maximizing the ability to perform daily routine tasks, as well as the enjoyable and enriching activities with which you choose to keep yourself occupied.

"If you can't get out and do things that make you happy, such as spending time with friends and family, you become more isolated. And isolation has a negative effect on your cognitive health," says Priscilla Flores, OTD, MSOTR/L, an occupational therapist at the center.

Researchers have connected weak grip strength to conditions like:

- Cognitive impairment (such as confusion, poor memory and slower processing)
- Depression
- Trouble sleeping

"Lowered grip strength is a sign of frailty and associated with a high risk for dangerous complications. As those conditions and hospitalizations rack up, it takes its toll," says Ms. Flores.

#### WHAT CAN YOU DO?

Although your grip strength is an indication of your overall strength and strengthening your hands and forearms is important, you shouldn't ignore the rest of your body

Depending on your health conditions, you may enjoy building whole-body strength through activities such as:

- Walking
- Biking (traditional or stationary)
- · Swimming and water aerobics
- Yoga (and chair yoga)
- Weightlifting
- Stretching •
- Dancing
- Gardening

When you add it all up, your grip strength is essentially a signal of your overall health and longevity. Your grip strength can almost predict your future health.

#### Six Pillars of Brain Health

At Cleveland Clinic Lou Ruvo Center for Brain Health, we've identified six areas of focus to reduce your risk of brain disease. Grip strength can contribute to your success in making positive changes in each pillar.



#### **FOOD & NUTRITION**

Eating well, with a focus on getting enough protein, can help build muscle mass in your hands and throughout your body.



### M PHYSICAL EXERCISE

A strong body means you're able to get out of the house more, build more exercise into your life and generally keep up with the world around you. Retaining muscle strength throughout your body is important for your mobility, balance, endurance and more.



#### **SOCIAL INTERACTION**

Greater grip strength denotes increased muscle strength overall, which leads to increased mobility and opportunity to get out and socialize.



#### **MENTAL FITNESS**

"Use it or lose it": as with your muscles, the more you use your brain, the stronger it becomes. Mental exercises may improve your brain's functioning and promote brain cell growth, decreasing your likelihood of cognitive decline.

#### **SLEEP & RELAXATION**

Poor sleep can leave you more vulnerable to stress, infections and cognitive decline.



#### **MEDICAL HEALTH**

Weak grip strength and lowered muscle mass make it harder to exercise, leading to a sedentary lifestyle and a higher risk of frailty, which raise your risk of chronic conditions like:

- Chronic Obstructive Pulmonary Disease (COPD)
- Diabetes
- Heart disease and heart failure
- Obesity or underweight
- Poor mental health

# Our Care Coordinators Share Advice

At Cleveland Clinic Lou Ruvo Center for Brain Health, the bridge between you and the members of your care team is a care coordinator: a registered nurse (RN) who facilitates communication and serves as your advocate to implement your personalized plan of care.

Between regular visits with your neurology provider, should you have questions or notice any change in your condition that you'd like to discuss, your care coordinator is your key clinical contact.

#### ▶ Let's listen to their advice for maximizing your family's health outcomes and use of our center's resources.

#### **MOVEMENT DISORDERS TEAM**



**Stephanie Giuffre, RN** Sudden physical or cognitive decline is not a normal symptom of neurodegenerative diseases. Use MyChart to communicate these changes to your neurology team and start a dialogue with us.

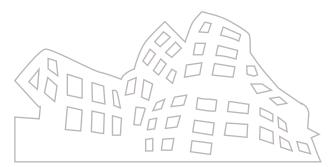


Emily Llorada, BSN, RN

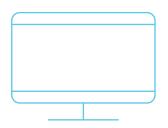
We know co-pays for some of the drug treatments can be expensive. Let's talk about it so we can help you find a solution. Some of the pharmacy companies even offer a subsidy.



Janet Nacua-Peck, BSN, RN It's important to keep moving, so our chair yoga class is great, while our Parkinson's Foundation Center of Excellence education series presents new ways to manage your condition. Check out our calendar of free programs at clevelandclinic.org/NevadaEvents.



#### Get to know MyChart, your electronic medical record



If you're not already using MyChart, you're missing out on a secure online portal that you and care partners you authorize can use to access your health records 24/7, message your care team for medication refills, check in for appointments and other matters. Your nurse care coordinator will ensure a prompt reply from your neurology team.

Users tell us MyChart is an "all-inclusive toolbox for managing my health" and a "timely, accurate way to communicate directly with the care team in our own words."

Start using this patient portal at clevelandclinic.org/MyChart.

#### **COGNITIVE DISORDERS TEAM**



#### Andrew Barstow, RN

We have medications that can help manage some symptoms of the diseases we treat, but much of the care can come from empowering yourself and your family through our free educational and support programs.



#### Stacy James, RN

As a care partner, try to create a routine for the person with dementia and stick to it every day. This can help them feel more at ease and assist with retrieving information that's stored in the brain.



#### Amy Sheets, MSN, RN

We strive to empower caregivers with tools so you have something at your disposal at the most difficult moments. Nonetheless, when you're living with cognitive disorders, you need two care teams.

We are here for the patient and their care partner but remember, the caregiver can benefit from a care team, too. Whether it's friends or family, you will need just as much help as what you're giving your loved one.



#### Jessica Valle, RN, ONC

In between appointments, keep a running list of questions and observations about your condition. Bring it with you so you can take full advantage of your time with your care team.

#### MULTIPLE SCLEROSIS TEAM



#### Nurah Ali, BSN, RN, MSCN

It's common advice to take care of yourself in your 30s and 40s so you don't have problems later, and it's no different with MS. Take your medications as prescribed. We want to help you prevent disability down the road. And don't belittle any of your symptoms or gloss over "private" concerns such as urinary or sexual dysfunction.





#### Sarah Garrett, RN

Keep an eye out for test results to show up in your MyChart online patient portal but try not to be anxious. We will review your results and let you know if there's anything to be concerned about. And you can always send us a message via MyChart with questions.

Betty Romero, BSN, RN MS and infusions

Comply with your health regimen and get your treatments on time. I also pray for you when you are not well.



Jordana Janjua, BSN, RN Getting a diagnosis of MS — particularly at a young age — is difficult news. Establishing a community of peers who understand what you're going through will decrease stress, which in turn may help limit the inflammation associated with MS.

### Our Team is Here FOR YOUR CARE NETWORK

Managing degenerative brain disease is a team sport that requires professional coaching. Our vision is driven by evidence-based approaches to programming that our Angie Ruvo Endowed Caregiver Chair, Lucille Carriere, PhD, and her fellow clinicians feel will best support families like yours.

#### EACH CAREGIVER HAS A FIRST DAY ON "THE JOB" (AND THE JOB IS 24/7).

You can't be with us 24/7, so we provide you the no-cost educational, therapeutic and support programming to arm you with the skills, wellness offerings, and enrichment to support your team whether you're navigating cognitive disorders, movement disorders or multiple sclerosis.

You support your loved one. We support you.

"Disease doesn't have to be a countdown during which you watch yourself disintegrate. You can thrive with your condition. Cleveland Clinic can help your caregiver and you be at your best through enriching programs that build on things you already like to do.

 Patty Halabuk, caregiver to her mom, Joanne, who had dementia



# SKILL-BUILDING & EDUCATION

(GROUP-BASED PROGRAMS) For Care Partners:

- **Powerful Tools for Caregivers**<sup>®</sup>: techniques for facilitating the elusive self-care
- **Dealing with Dementia**<sup>®</sup>: skills for making time for self-care while caregiving

#### For Patients:

• Adjustment to Memory Loss: a therapy group providing strategies for reducing worry specific to memory changes

#### For Patients & Care Partners:

- **HABIT**<sup>®</sup>: tools for achieving the highest possible level of function and independence while living with mild cognitive impairment
- **SHARE**<sup>®</sup>: an approach to getting the most out of today despite early-stage dementia, while planning for tomorrow
- **Parkinson's Foundation Center of Excellence Education Series:** quarterly virtual evening and bi-annual in-person weekend interactive education programs from an interdisciplinary team of experts.
- Lunch & Learn lectures: lectures on topics of interest to aging adults and those living with brain disease. Archived programs: clevelandcliniceducationnv.org/education/lunchlearn
- Lynn Ruffin-Smith Library & Information Desk On campus: Monday through Friday, 9 a.m. – 4:30 p.m. Online 24/7: Browse our e-Library Iruffin-smith.overdrive.com

#### ✓ Dr. Lucille Carriere



#### **ENRICHMENT ACTIVITIES FOR THE COGNITIVELY IMPAIRED**

(GROUP-BASED PROGRAMS) **Remembrance Activities:** 

- Conversations to Remember: telling stories through art can stimulate distant memories in individuals experiencing memory loss
- The Learning Arts: eclectic excursions via videoconferencing with museums across North America
- Dementia Conversations: a friendly space in which to share experiences living with dementia

#### Art Making:

• Mind in Design: an art making class for everyone

#### **MUSIC THERAPY**

(GROUP-BASED PROGRAMS)

- Rhythmic Reminiscence®: a music-physical therapy collaboration
- · Group music therapy sessions with a board-certified music therapist
- Limited one-on-one sessions also available with a board-certified music therapist

#### **WELLNESS** (GROUP-BASED PROGRAMS) **Physical Health:**

- Healthier Living: a workshop for living better while managing chronic conditions
- Chair Yoga: for persons living with a neurological condition and/or their care partners

#### **Emotional Health for Patients** & Care Partners:

Support Groups

#### **CASE MANAGEMENT**

#### (ONF-ON-ONF)

These appointments require a referral from a Cleveland Clinic Nevada provider.

#### For patients and care partners:

· Guidance to resources at Cleveland Clinic and in the community

#### COUNSELING

#### (ONE-ON-ONE)

These appointments require a referral from a Cleveland Clinic Nevada provider.

#### For patients by themselves or together with care partner(s):

• Short-term counseling

#### JOIN US FOR DAILY PROGRAMMING

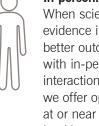
Thanks to generous philanthropic support, most of these free programs are available to the entire community, regardless of where you receive neurological care.



#### Online: Most

programs are online, so you can join us from the comfort of home — or perhaps from the office during a lunch break.

#### In-person:



When scientific evidence indicates better outcomes with in-person interactions, we offer options at or near our Las Vegas campus.

#### TAKE THE NEXT STEP IN YOUR JOURNEY TOWARDS BETTER **BRAIN HEALTH.**

- Sign up for our newsletter to receive a monthly calendar of free programs in your inbox: clevelandclinic.org/NVnews
- Learn more: clevelandclinic.org/NVprograms
- Questions? 702.483.6000 or louruvoswgroup@ccf.org

### Learn to Manage Stress: YOUR BRAIN WILL THANK YOU

Stressful events can happen any time in life, from difficulties in childhood to work deadlines to medical problems to the challenges of aging, "but it's how we manage stress that determines our long-term brain health," says Jessica Caldwell, PhD, Director, Women's Alzheimer's Movement Prevention Center at Cleveland Clinic.

She advises thinking about three aspects of each stressful event (or stressor). Consider the COVID-19 pandemic:

<b>3</b> components of stress	COVID-19 pandemic
1. Can you control the stressor?	Not controllable
2. How bad is it?	Moderate for some; very severe for others
3. How long will it last?	Didn't know when the pandemic might end

"It turns out that the most impactful stress for our brains, our emotions and our bodies occurs when the stressor is not controllable and we're uncertain how much worse it will get or when it will end," says Dr. Caldwell, which explains a lot about the pandemic's role as a significant stressor.

"Hard-wired" reactions to stressors are flight, fight or freeze as we prepare for action to avoid or neutralize the threat. Stress can be motivating when we need the extra push; it can be negative if we overshoot peak performance and develop anxiety or into a burnout.

Life presents myriad challenges. Among kids, work, aging parents, caregiving and society's expectation of us to be "fine," everyone is stressed. As Dr. Caldwell says, "We can't always control the source of stress, but we generally can control our response."

#### MEDITATION AND EXERCISE: TOOLS YOU MAY NEED

In spring 2020, researchers at the University of Wisconsin, Dr. Caldwell's alma mater, studied meditation practice in a group of stressed teachers. Over four weeks of meditation training and just five minutes of meditation practice per day, teachers who had reported feeling stressed at the onset of the study ultimately reported reduced feelings of stress and loneliness and enhanced feelings of well-being.

Likewise, exercise can improve mood, reduce stress levels and even change stress chemistry. It's important to follow a varied routine that includes resistance as well as balance and flexibility. The Centers for Disease Control recommends 150 minutes of moderate-intensity exercise each week.

#### WHAT ELSE YOU CAN DO

Long-term, chronic stress will burden the body and brain. Over time, this burden could lead to poor memory or decreased ability to learn.

Chronic stress can also reduce brain plasticity or cognitive flexibility and even cause brain cell death in the hippocampus, which is important for organizing memory. Yes, the same hippocampus that shrinks in Alzheimer disease.

If you have concerns about the outsized role that stress plays in your life, complete a free, online brain health self-assessment at healthybrains.org and receive recommendations for managing stress, exercising and maximizing your brain health.

#### ✓ Dr. Jessica Caldwell



# The body and brain's responses to stress

Type of response	GOOD	BAD
	Energized	Sweaty
Physiologic	Alert	Nauseated
		Shaky
	Excitement	Irritability
Emotional	Motivation	Blankness
		Anxiety
	l can do this	I have to get out of here
Cognitive	Let's go	This is
	I'm ready	impossible
		l might as well give up

Interested in discussing customized Alzheimer's disease prevention strategies with a doctor? Visit womenpreventalz.org.

### A Touchdown for MS **NEWLY ENDOWED CHAIR IS "THE GIFT THAT KEEPS ON GIVING"**

Wanting to ensure that world-class specialty neurology care in their new hometown is as sustainable and accessible to Nevadans as professional football now is, the Las Vegas Raiders jumped on a novel way to support healthcare by endowing a chair at Cleveland Clinic Lou Ruvo Center for Brain Health.

#### A FRONT-ROW SEAT FOR SCIENCE

Made possible by generous donors like The Raiders Foundation and Camille and Larry Ruvo, an endowed chair is the gift that keeps on giving, its principal managed in perpetuity by Cleveland Clinic's investment office. Its investment income is made available annually to the chair holder to pursue novel approaches





 (Top) Mark Davis onstage at the 2023 Power of Love gala, joining Larry Ruvo to surprise the audience by announcing the endowed chair.
(Below - L) Camille Ruvo speaks at the gala, and inaugural chair holder Le Hua, MD (R).

to research and care for degenerative brain disorders. Moreover, it ties a donor's legacy to that of Cleveland Clinic.

"Your name is associated with an endowed chair and your family can continue to see results from the chair after you're gone," says Camille Ruvo, Co-Founder, Keep Memory Alive.

Each year, the chair holder produces a report for donors on activities made possible by income from the chair.

- "There's accountability. When you're investing with your heart to support an area of passion, you want to know your donation is working smartly on your behalf," says Camille.
- "Knowing what I've learned recently about the impact that disease-modifying treatments have on preventing disability in individuals with multiple sclerosis, I only wish our friend and former quarterback, David Humm, had gone to seek treatment at a world-class MS center like Cleveland Clinic. Perhaps he would still be with us today," says Mark Davis, Owner, Las Vegas Raiders.

"By endowing The Raiders Foundation and Ruvo Family Chair for MS in Memory of David Humm, we know we're supporting innovation and care in perpetuity for our community and keeping David's memory alive forever," he adds.



#### Our Center's Endowed Chairs

#### The Raiders Foundation and Ruvo Family Chair for MS in Memory of David Humm

Established in 2023; currently held by Le Hua, MD

To support novel approaches to research and treatment for multiple sclerosis

#### The Lee Pascal Endowed Chair for Clinical Trials Research

Established in 2020; currently managed by Dylan Wint, MD To support clinical trials and research of neurological diseases

### The Las Vegas Legacy Neuroscience Education Chair

Established in 2019; currently held by Dylan Wint, MD

To provide a stable platform to initiate and sustain transdisciplinary educational initiatives to promote knowledge about brain health and disease

#### The Angie Ruvo Caregiving Chair

Established in 2018; currently held by Lucille Carriere, PhD

To provide programmatic leadership through care and research centered on the caregiver

### The Stacie and Chuck Mathewson Chair for Brain Imaging

Established in 2018; currently held by Dietmar Cordes, PhD

To provide financial support to current and future brain imaging research and other endeavors

#### The Ruvo Family Chair

Established in 2017; currently held by Zoltan Mari, MD

To provide financial support for current and future endeavors within the center

### The Camille and Larry Ruvo Chair for Brain Health

Established in 2012; currently held by Dylan Wint, MD

To advance the center's research agenda, initiate novel and innovative programs, and support community outreach initiatives



# Your Gift, Your Impact

**Thanks to gifts from people like you,** Cleveland Clinic Lou Ruvo Center for Brain Health offers a variety of brain health-related programs online daily at no cost to participants. Our community can explore topics like healthy brain aging, caregiving tools and support, and the latest research and information about the degenerative brain conditions treated at our center.

#### Your gift could support:



> Buying a book or DVD for the Lynne Ruffin-Smith Library for borrowing by our community



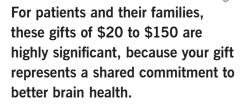
- > One session of Lunch & Learn, a weekly education program for caregivers and the community
- > A one-on-one case management session with a social worker to address workplace leave, disability paperwork and other legal or social support concerns
- > A one-on-one session with a music therapist



- > One session of The Learning Arts, dynamic conversations about art, history and more from cultural institutions worldwide
- > One session of Dealing with Dementia, a skills course about making time for self-care while caregiving
- > A one-on-one counseling session with a mental health provider

### Making an impact: It's personal

# Gifts of every size make a difference.



"Donations epitomize hope for me, and commitment from our community." — Patty Halabuk

"I was lost, but now I'm found. When I walked through the door as a patient, I found my community. These are my people." — Kathi Badreddine

"We're all in this together. It's not just my fight, it's a community battle." — Alison Lopez

# Make a difference in our community. For your neighbors, your friends, your family.

Give now: clevelandclinic.org/NVgive

Contact us: 702.263.9797 or DonateNevada@ccf.org

### Sustaining Long-term Brain Health FOR OUR COMMUNITY

No single grant or one-time donation is sufficient to solve complex issues such as the brain. That's why The Caesars Foundation strategically establishes multi-year relationships with its key philanthropic partners, including Cleveland Clinic Lou Ruvo Center for Brain Health.

"Our ongoing giving illustrates our intention to see our commitments through as we support the communities in which we live and work," says Sean McBurney, Regional President of Caesars Entertainment Las Vegas Operations. "We believe this farsighted approach is working for our partners and their constituents. too."

#### FUNDING THE FUTURE

2021

Annually since 2021, Caesars has supported our endowment that will sustain the Lou Ruvo Center for Brain Health in perpetuity and provide the funds needed to lead the discovery of neurological treatments and cures.

Endowed funds ensure the continuation of programs and projects to produce superior patient outcomes, excellence in training, research that advances care, and — soon - cures for neurodegenerative diseases.

We can only do this with the help of fearless, visionary individual and corporate philanthropists who understand that nobody ever changed the world by thinking small. Philanthropy seeded the innovations of yesterday, it speeds the discoveries of today and it will scale the progress made tomorrow.

#### YOU, TOO, CAN BE PART OF BETTER **BRAIN HEALTH IN OUR COMMUNITY**

Gifts of all sizes make an impact in Nevada and 100% of your generous contribution to the endowment will sustain our future. Together, we will disrupt neurological diseases, saving and changing lives for generations to come.

#### Contact us to discuss your gift: DonateNevada@ccf.org or 702.263.9797.

"What began as a promise to my father has turned into a commitment to our community to provide the world-class research, diagnosis, treatment, education and support that patients and families deserve, right here in Nevada."

- Larry Ruvo, Chairman and Co-Founder, Keep Memory Alive

#### **Strategic planning** for our future

Funds raised will support our center's continued growth to meet the ever-changing landscape of neurological care, including:

- Flexibility to advance clinical programs for those impacted by brain disease
- Capacity to pursue **cutting-edge** research and clinical trials
- Resources to attract the world's top clinicians and scientists
- Ability to offer free, ongoing educational, therapeutic and support programming to our community
- Infrastructure to train neurological leaders of the future



24

### Star-Studded Lineup Supports the Need for GREATER NEUROLOGICAL CARE IN NEVADA

Keep Memory Alive hosted a prestigious lineup of entertainers at the 26<sup>th</sup> annual Power of Love<sup>®</sup> gala on Saturday, February 18, 2023 at MGM Grand Garden Arena, including Sammy Hagar, Paula Abdul, Alice Cooper, Kevin Cronin, Nikki Glaser, Chad Kroeger, John Mayer, Michael McDonald, Sam Moore and Rick Springfield.

Keep Memory Alive Co-founders and Vice Chairs Camille and Larry Ruyo welcomed the nearly 1,500 guests, remarking on the nostalgic evening, which fell on the anniversary of the death of Larry's father, Lou Ruvo, the namesake of the Lou Ruvo Center for Brain Health, whose battle with Alzheimer's disease served as the catalyst for the gala.

"Many of you started on this Alzheimer's journey with us. Then we expanded to address Parkinson's disease and multiple sclerosis. It was shocking that a city of 2.5 million people didn't have a board-certified MS neurologist and Nevadans were going out of state for



^ John Mayer

care," Larry Ruvo said. "So tonight, we are honoring the legacy of **David Humm**. He not only was a great Las Vegan, but as I have been often told, he was the 'original Las Vegas Raider.'"

Raiders owner Mark Davis announced a \$1 million donation on behalf of the Raiders Foundation to create The Raiders Foundation and Ruvo Family Chair for MS in Memory of David Humm, who passed from the disease in 2018. The gift matched a donation from the Ruvo family to total \$2 million to further MS research and care at the Lou Ruvo Center for Brain Health. (See page 22)



(L-R) Sammy Hagar, Rick Springfield and Kevin Cronin



∧ Michael McDonald

Chefs Wolfgang Puck and Tal Ronnen prepared the dinner, paired with wines from Southern Glazer's Wine and Spirits, followed by a dazzling dessert display from the MGM Grand pastry team.

The night culminated in the full cast performing a rousing rendition of "Takin' It To The Streets."

#### SAVE THE DATE

2024 Power of Love gala: Saturday, May 11 keepmemoryalive.org/POL



"I'm so grateful to our wonderful friend, Sammy Hagar, who helped us produce this spectacular concert." — Larry Ruvo

#### THANK YOU TO **OUR SPONSORS:**





SOUTHERN GLAZER'S WINE, SPIRITS & BEER **OF NÉVADA** 

#### Moët Hennessy USA





#### 

MGI

"I am beyond grateful for Larry Ruvo's brain health center. How they took care of my father and prepared our family for what to expect, giving my dad the dignity he deserved all the way up to his passing." — Paula Abdul



Kevin Cronin dedicated his performance of "Keep On Loving You" to his mother, Millie Cronin, who battled Lewy Body dementia.



The Ruvos presented the Community Leadership Award to entrepreneur and philanthropist John Paul DeJoria, who wrote the first check that inspired Keep Memory Alive and the annual Power of Love gala.

DeJoria shared, "Through the decades, what l've found is when you do something for someone else and ask absolutely nothing in return, especially someone you know nothing about, you get the greatest high you will ever get in your life."

 Camille Ruvo then surprised the audience by presenting a second Community Leadership Award to Eloise DeJoria for the depth of her philanthropic endeavors.



∧ Paula Abdul

m Péri

EMO

### The Restorative Power of Art: A FAMILY AFFAIR

In 1972, Las Vegas — then a small desert outpost of around 180,000 people — seemed to Joel Lubritz, MD, a veritable blank canvas on which to establish his practice as only the town's fifth otolaryngologist, or ENT specialist.

In time, Dr. Lubritz and his wife, Carol, met another pioneering family: Angie and Lou Ruvo and their son, Larry. Soon enough, the Ruvos became patients of Dr. Lubritz, the Lubritzes dined frequently at the Ruvos' Venetian Ristorante, and the families became dear friends and next-door neighbors.

In a frontier state referred to as "Battle Born," fighting to bring a vision to life seemed often necessary. So, some years later, when Larry decided to establish an outpatient Alzheimer's clinic in memory of his father, Dr. Lubritz supported Larry's plan to increase the number of neurology providers in Nevada. Cleveland Clinic Lou Ruvo Center for Brain Health opened in 2009.

#### **ART AND ARCHITECTURE** FOSTER HEALING

With a mission to enrich, inspire and enliven patients, visitors, employees and the community, the Cleveland Clinic Art Program was incorporated into the Frank Gehry-designed Lou Ruvo Center for Brain Health from its inception. An emphasis on contemporary art promotes an environment of creative excellence, encourages dialogue and challenges viewers to experience diverse points of view. Art is also a way to both calm and expand the mind. Enter Michael Dodson.

#### **BRUSH STROKES AND STRIDES**

The grandson of Carol and Joel Lubritz, Michael Dodson, 35, was born and raised in Las Vegas. After receiving his Master in Contemporary and Modern Art History in New York, in 2016 Michael returned to his hometown, where he has

been teaching the next generation of artists and painting what he describes as "subconscious expressions of the desert Southwest."

An ultra-marathoner, Michael encourages locals and visitors alike to look beyond the lights of the Strip to the healing power of world-renowned parks only a few miles away. He says his commitment to fitness not only helps him manage his own mental health, but also inspires his art: "I refer to the process of creating my

- > Michael Dodson signing "Singularity," a painting purchased by the Ruvo family and installed in the Lou Ruvo Center for Brain Health. The artist says his paintings reflect our natural world; specifically, the cacti found throughout Southern Nevada. The idea for "Singularity" came to him while he was running in Red Rock Canyon National Conservation Area.
- ∨ L-R: Larry Ruvo, Michael Dodson, Carol and Joel Lubritz, MD, with "Singularity"

work as extra-dimensional travel through the mediums of trail running and yoga."

Larry Ruvo, Chairman and Co-Founder of Keep Memory Alive, the fundraising team that supports the Lou Ruvo Center for Brain Health, understands. Art, he says, is "a key part of preserving brain health in the next generation."

#### If you're interested in supporting art and healing, contact us at 702.263.9797 or DonateNevada@ccf.org.



IN SUPPORT OF:

Cleveland Clinic Lou Ruvo Center for Brain Health

We need WHAT IS businesses like yours to help bring awareness to **Alzheimer's** disease

# **MONTH OF MEMORIES?**

Month of Memories is a communityfocused fundraiser that gives Las Vegans the opportunity to shop, dine and support local businesses during the month of November. Together, we can shine an important light on National Alzheimer's Disease and Family Caregiver Awareness Month while raising funds to provide

no-cost educational, therapeutic and support programming for Nevadans.

#### Here's How Your Business Can Participate



**KEEP MEMORY ALIVE** 

#### **Donate a Dollar**

Ask customers to make a \$1 donation or round up their change during the month of November at the point of sale.



**Cocktail or Menu Item** Create a special cocktail

or menu item that is available during the month of November.



#### **Percentage of Sales** Donate a designated percentage of sales

during the month of

November.



**Another Idea** 

Do you have a creative promotional idea? We'd love to hear it.

PAST PARTICIPANTS: Honey Salt | Albertson's | Terrible Herbst | Yellow Tail Wines | Treasure Island Las Vegas Stoney's Rockin' Country | The Kitchen at Atomic | Lee's Discount Liquor | Trattoria Reggiano Italian Restaurant Ellis Island Hotel, Casino, & Brewery | Del Frisco's Double Eagle Steakhouse

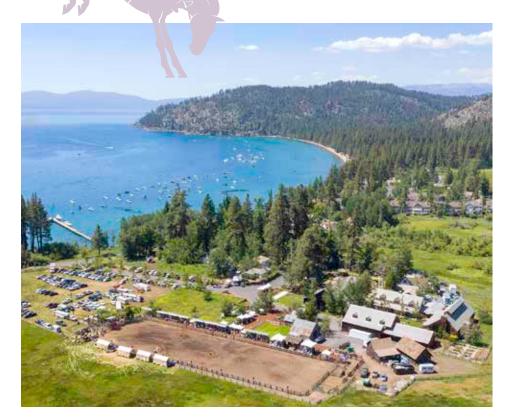
**JOIN US NOVEMBER 1 - 30** (m) keepmemoryalive.com/MoM HAVE A BUSINESS OR GREAT IDEA? CALL US FOR MORE INFO Contemporary 102.263.9797

### Back in The Saddle TO SUPPORT BRAIN HEALTH

On July 8-9 at Shakespeare Ranch, the private Lake Tahoe estate, Keep Memory Alive hosted its annual Summer Social and Rodeo to raise funds in support of Cleveland Clinic Lou Ruvo Center for Brain Health.

On Saturday afternoon, following an iconic American rodeo complete with bull and bronco riding, barrel racing, and entertainment from rodeo clowns, winning cowboys were presented with customdesigned Glenbrook Rodeo belt buckles. Guests enjoyed a barbecue accompanied by specialty drinks from Southern Glazer's Wine & Spirits and artisanal gelato from Chef Luciano Pellegrini.

The next evening, guests returned to the picturesque venue to enjoy delectable cuisine by Nevada-based chefs Colin Smith, Shawn Giordano, Alex Stoppa, and Luciano Pellegrini, and to dance to the legendary REO Speedwagon.





∧ Larry and Camille Ruvo with Kevin Cronin



#### ∨ Reno McGill



Larry Ruvo, Chairman and Co-Founder of Keep Memory Alive, left, presented an award to Bob Davidson, founder of the Davidson Academy. A former student, Sriya W., far right, touched the audience with her eloquent words about the impact of Mr. Davidson and the school.











## Dining for Brain Health



^ (L-R) - Larry Ruvo, Chef Tal Ronnen and Camille Ruvo

Billed as an "Elevated Dine-Around Experience," the June 1 event at Resorts World Las Vegas did not disappoint.

Long-time Keep Memory Alive supporters, restaurateurs Chef Tal Ronnen, Sean Christie, Ernie Moody and Bernie Schiappa hosted this first-ever culinary journey to raise funds for better brain health in our community.

The tour included:

- Crossroads Kitchen with Chef Tal Ronnen
- Brezza with Chef Nicole Brisson
- Carversteak with Chef Daniel Ontiveros
- Dessert and an exclusive Louis XIII tasting and presentation

Scott Sibella, President and CEO of Resorts World, got in on the action, presenting guests with a VIP Resorts World card for VIP Valet services year-round, as well as a private concierge to assist with future restaurant reservations at Resorts World Las Vegas.

#### Join Us

To get "on the list" to receive updates in your inbox about Keep Memory Alives's upcoming events, sign up for our enews at clevelandclinic.org/NVnews or call 702.263.9797.

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## Visitor Photo Gallery



L-R- John Paul DeJoria, Romero Britto and Eloise DeJoria



Charles Bernick, MD, with DJ Steve Aoki



L-R- Larry Ruvo, Patrick Dumont and Scott Goldstein



L-R- Sam Gehry, Opal, Daisy, Joyce Shin Gehry, Berta Gehry, Frank Gehry, Alejandro Gehry, Carrie Jenkins Gehry



Gina and Waco McGill



Carolyn Solomon, second from right, and guests



**Carl and Hillary Stoney** 

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L-R- Michael Milken, Dr. Dylan Wint, Jo Ann Jenkins and guest



Jackson Family Wine Visit with (L-R) -Bill O'Connor, Larry Ruvo, Barbara Banke, Don Hartford, John Landry and Chef Michael Mina



Mark Davis

### Remembering Tony Bennett, American Icon and Keep Memory Alive Champion 1926 - 2023

For more than seven decades, legend Tony Bennett has helped millions of fans around the world make memories that mark special moments — a favorite tune played over and over at home, a night out with a special someone, or an unforgettable celebration, such as Tony's 90<sup>th</sup> birthday in 2016, which he shared with Keep Memory Alive supporters at our 20<sup>th</sup> annual Power of Love<sup>®</sup> gala.

Tony died in his native New York July 21, almost two weeks short of his 97<sup>th</sup> birthday.

As a young busboy at the Sahara Hotel, Larry Ruvo remembers being in awe when Tony Bennett headlined the Congo Room. "He was a superstar, and we were in the same room!"

"When we became friendly later in life, Tony shared great memories about playing the Sahara. I learned a lot of inside stories about my own former workplace," adds Larry, now Chairman and Co-Founder of Keep Memory Alive.

Tony, a prolific artist known offstage for his critically acclaimed paintings, took great interest in Keep Memory Alive, donating artwork to be auctioned off at fundraising events and touring Cleveland Clinic Lou Ruvo Center for Brain Health.

"To know Tony Bennett was to love him, and I'm proud to have known Tony as a friend and a Keep Memory Alive supporter," says Larry Ruvo.

Thank you for making memories with us, Tony.



# Recognized for Excellence

In recent months, Cleveland Clinic Lou Ruvo Center for Brain Health staff have been honored by the community, peers and professional associations for clinical excellence and leadership in the field.

#### We celebrate these accomplishments.

#### SB-286 (May 2023)

Cleveland Clinic Lou Ruvo Center for Brain Health proudly supports SB-286, the "David Humm Bill." Signed into law by Governor Lombardo, SB-286 recognizes the third week of March as Multiple Sclerosis Awareness Week in Nevada and requires the Department of Health and Human Services to include important multiple sclerosis (MS)-related information and resources on their website.

In this way, David Humm — the original Las Vegas Raider who died of MS in 2018 and was honored posthumously at our 2023 Power of Love<sup>®</sup> gala — continues to make a lasting impact in our community.



## Elected Vice-Chair, Task Force on Alzheimer's Disease

(State of Nevada, July 2023)

LeeAnn Mandarino, MA

Named to Nevada Women in STEM (Senator Jacky Rosen, May 2023) Jessica Z.K. Caldwell, PhD

#### Best Conference Center, 2023 Smart Stars Awards

(Smart Meetings, May 2023)

Keep Memory Alive Event Center

#### Selected as an abstract reviewer, World Conference on Parkinson's Disease and Related Disorders

(International Association of Parkinsonism and Related Disorders, May 2023)

Zoltan Mari, MD, FAAN

**Elected to the Executive Committee, Sex and Gender Professional Interest Area** (Alzheimer's Association International Conference, 2023)

Jessica Z.K. Caldwell, PhD

#### Elected to the Board of Trustees

(Nevada, Idaho and Utah Chapter, National Multiple Sclerosis Society, 2023-2025)

Lucille Carriere, PhD

#### Appointed Team Training Faculty Member, National Planning Committee

(Parkinson's Foundation Centers of Excellence, 2023)

✓ David Humm

Lucille Carriere, PhD

#### Top Doctors

(Castle Connolly, 2023)

Le Hua, MD, FAAN

Zoltan Mari, MD, FAAN

**Dylan Wint, MD**; also recognized among the first-ever 2023 Castle Connolly Top Black Doctors



#### CLEVELAND CLINIC HAS BEEN RECOGNIZED AMONG:

America's Best Large Employers 2023 (Forbes, 2023)

World's Most Ethical Companies 2023 (Ethisphere, 2023)

**2023 America's Most Innovative companies** (*Fortune*, 2023)



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clevelandclinic.org/Nevada



# SAVE THE DATE

### Saturday, May 11, 2024 MGM Grand Garden Arena

Join us for an evening of superstar entertainment, celebrity chefs, fine wine and tantalizing cocktails as we celebrate the Power of Love<sup>®</sup> and raise funds for Cleveland Clinic Lou Ruvo Center for Brain Health.

702.263.9797 or keepmemoryalive.org/POL