

SPRING 2021

# New Thinking

ABOUT THINKING

A Publication by Cleveland Clinic Lou Ruvo Center for Brain Health



KEEP MEMORY ALIVE



100  
YEARS  
EST. 1921

Cleveland Clinic Founder George W. Crile, MD, center, and Lakeside Unit medical staff during World War I

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

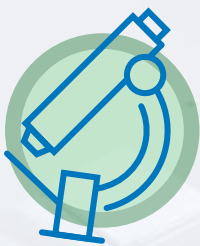
## DIRECTOR'S MESSAGE

Unwavering dedication and optimism are the driving forces behind the innovation, research and scientific discovery happening at Cleveland Clinic Lou Ruvo Center for Brain Health. Innovation has always been in Cleveland Clinic's DNA, and is a hallmark on which I reflect in 2021 as we celebrate Cleveland Clinic's Centennial (see page 5). **Our year-long Centennial celebration kicks off on February 26 with Founders Day, and I invite you to join me at this online event** (see back outside cover).

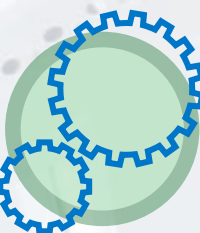
Despite the COVID-19 pandemic, 2020 was a remarkable year, and I'm exceedingly proud of what the team accomplished.



**In September, the NIH named us Nevada's first and only exploratory Alzheimer's Disease Research Center,** expanding our work to enhance care among rural populations in our state. The program includes a national network of researchers and clinicians at major medical institutions pursuing improved diagnosis and care for people with Alzheimer's disease. (See page 7.)



**With support from the NIH,** our brain imaging team is conducting a novel study of how biomarkers may be used to develop a predictive mathematical model to identify individual Parkinson's disease patients who may develop dementia. Our research into the mysteries of Parkinson's disease expands, thanks to a blend of public and private funding. (See page 35.)



Building on peer-reviewed science indicating that up to 40 percent of all Alzheimer's disease cases might be preventable through risk reduction strategies, in June we opened the **nation's first Alzheimer's prevention clinic designed just for women: The Women's Alzheimer's Movement Prevention Center at Cleveland Clinic, in collaboration with Maria Shriver.** Demand for prevention is strong; the clinic is booked through 2021.



With safety in mind, in March 2020 we decided not to rent our Keep Memory Alive Event Center. We also put a hold on the annual rodeo at Shakespeare Ranch and all the one-of-a-kind events the Keep Memory Alive team stages. I am more appreciative than ever of the community for collaborating with us on creative approaches to fundraising. (See page 39.)

I am grateful to the Keep Memory Alive Board of Directors for their support as I lead the Lou Ruvo Center for Brain Health into our second decade, and Cleveland Clinic's second century. Our Centennial tagline is "The Future of Healthcare Since 1921." With board and donor support, innovation remains my priority.

I look forward to seeing you at our 25<sup>th</sup> annual Power of Love® gala in Las Vegas on Saturday, October 16. (See back inside cover.)

Thank you for supporting innovation amidst a pandemic.

**Marwan N. Sabbagh, MD, FAAN**

*Director*

*Camille and Larry Ruvo Chair for Brain Health*

SPRING 2021

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## CONTENTS

### FEATURES

- 3 Cleveland Clinic Celebrates 100 Years
- 7 Nevada's First and Only Exploratory Alzheimer's Disease Research Center

### CLINICAL RESEARCH UPDATE

- 9 A Snapshot of Our Research You, Too, Could Be Part of the Picture
- 11 For Asymptomatic Volunteers, Research Study Is a "Win-Win"
- 13 Collaborating to Tease Out the Mystery of FTD
- 15 The Quest to Diversify Clinical Research Studies
- 17 Physical Therapy Benefits Mind and Body
- 20 A Novel Approach to Motor Fluctuations in Parkinson's Disease

### WORLD CLASS CLINICAL CARE

- 21 From Education to Exercise, Center of Excellence Serves Parkinson's Disease Patients
- 22 Novel Therapies Bring Hope to Patients With Demyelinating Disorders
- 23 New Year, New You: Line Up an eCoach in Your Corner
- 24 Fatigue Doesn't Have to Be a Way of Life
- 25 Neuropsychology: Exploring the Links Between Brain and Behavior
- 27 A Push to Bring Geriatric Care to Nevadans Everywhere
- 28 Surprise! Virtual Observation Enhances Students' Training

### CARING FOR CAREGIVERS

- 29 Reene's Song
- 31 Online Delivery Expands the Multi-State Reach of Artmaking

### PHILANTHROPY AT WORK

- 33 Bringing a Sense of Belonging Into Homes Across the Country
- 34 Thanks to Donor Support, Professional Athletes Brain Health Study Marks Its 10<sup>th</sup> Anniversary
- 35 Lynn Weidner: From Pageantry to Philanthropy

### ON THE SCENE

- 39 Community Support for Keep Memory Alive Continues, Even as Events Take on a New Look
- 43 Remembering Sheldon Adelson
- 44 Remembering Siegfried Fischbacher
- 45 Recognized for Excellence

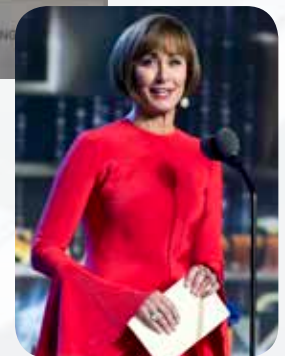


3



29

34



35



39

The centerpiece of the original Clinic building was this spacious atrium lobby



**100**  
YEARS  
EST. 1921

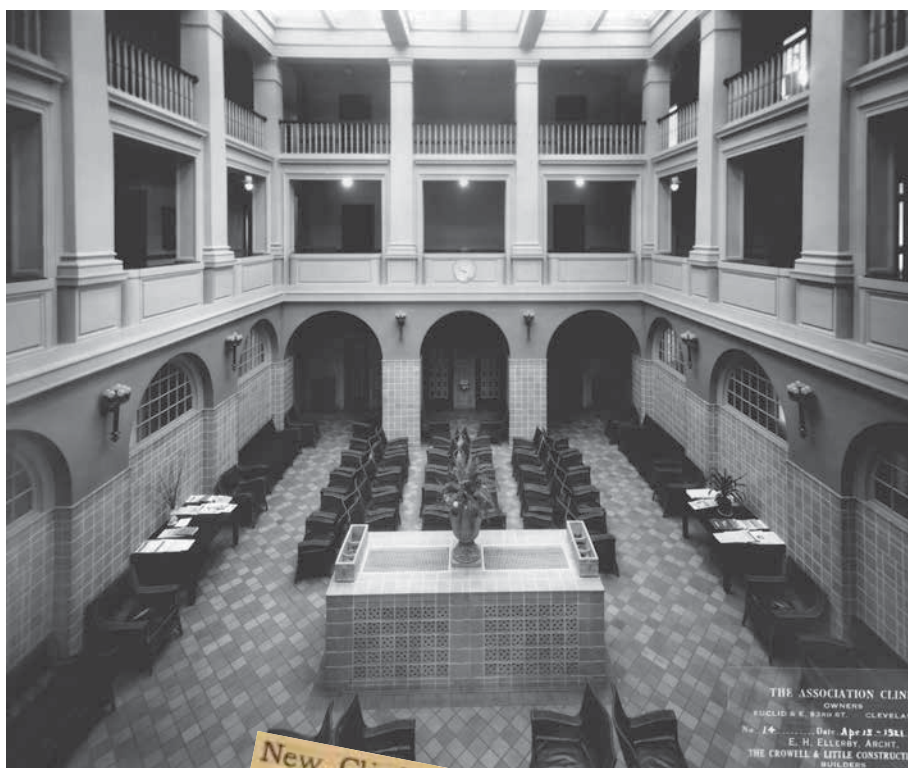
**1921: Cleveland Clinic Opens in Cleveland, Ohio**

On the evening of Saturday February 26, 1921, more than 1500 people, including 500 physicians, attended the opening of Cleveland Clinic, an event we will commemorate on February 26, 2021 as "Founders Day" (see *back outside cover*). In the beautiful reception area of the new Clinic building, the audience enjoyed the music of Johnson's Orchestra and refreshments provided by the wives of the Cleveland Clinic founders.

The founders, **Dr. Frank Bunts, Dr. George W. Crile, Dr. William Lower and Dr. John Phillips**, gave speeches, as did Dr. William Mayo, founder of Mayo Clinic and personal friend to the Cleveland Clinic founders.

The Cleveland Clinic was hailed as "unique among the medical institutions of the world" for gathering "into one unit every device and facility" to "work out the problems of the sick."

Dr. Mayo stated that the opening of Cleveland Clinic was of "great importance to American medicine" and was a "scientific response to the rapid advance" of medicine and its practice.



In his address, Dr. George W. Crile spelled out the principle reasons for the founding of the Clinic:

**COLLABORATION:** Advances in medicine made it impossible for the individual physician to undertake complex problems alone. The physician required the “aid and cooperation of colleagues of special training” and the “advantages of laboratories of the applied sciences.”

**RESEARCH:** The founding of the Cleveland Clinic was meant to ensure “the active investigation of disease” so that “we are considering not only our duty to the patient of today, but no less our duty to the patient of tomorrow.”

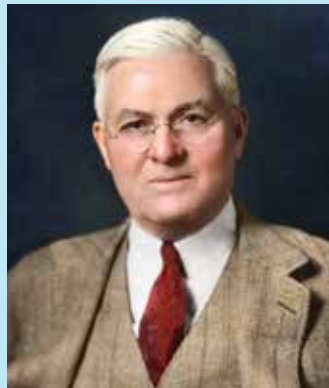
**EFFICIENCY:** Using one facility for physicians and laboratories would lower overhead costs allowing that “the patient with moderate means may have at a cost he could afford, as complete an investigation as the patient of ample means.”

**EDUCATION:** Fellowships, conferences and lectures would be established so that Cleveland Clinic could become “an additional educational and research institution”...“allied with...medical colleges.”

**LEGACY:** The establishment of Cleveland Clinic would allow its Founders “to pass on to our successors the experience, methods and special technical achievement without a break in continuity.”



Dr. Frank Bunts



Dr. George W. Crile



Dr. William Lower



Dr. John Phillips

## THE FUTURE OF HEALTHCARE SINCE 1921

Established by our founders 100 years ago, these principles remain the foundation of Cleveland Clinic’s mission. Today’s values of Quality, Innovation, Teamwork, Service, Integrity and Compassion can all be traced directly to the work started by Drs. Bunts, Crile, Lower and Phillips.

That evening Dr. Crile stated that “if the Founders may look into the future and see an institution carrying out these designs”...“their ambition will have been fulfilled.”

# 100 YEARS OF INNOVATION AT CLEVELAND CLINIC

## FEBRUARY 26, 1921

Cleveland Clinic hosts an opening ceremony.



## 1922

When four-year-old orphan **Madeleine Bebout** fell into a diabetic coma, Henry John, MD, was able to save her life using a new discovery: insulin.



## 1926

**Maria Telkes, PhD**, joins to perform cell research — the first woman employed at Cleveland Clinic as a physician or scientist.

## 1920s

Otto Glasser, MD, invented a way of **accurately measuring the radiation** doses being given to patients during what became known as radiotherapy for cancer.



## 1936

Cleveland Clinic begins providing hospitalization insurance for employees.



## INNOVATION IN OUR DNA

Innovation was in Cleveland Clinic's DNA long before it was established in 1921. Co-founder George W. Crile, MD, was already a leading surgeon in the United States in 1906, when he performed a pioneering human-to-human blood transfusion. He would help create the American College of Surgeons in 1913 and was recognized as the father of physiological surgery, specializing in surgical shock.

Cleveland Clinic's four founders [see page 4] pledged to spend at least one-fourth of their net income on research to fund further medical innovations, as well as infrastructure improvements, treatment for indigent patients and other needs.

It was a staggering amount to fund research at any medical institution, and that percentage only increased in the years to come.

Since producing the first commercial dosimeter in the 1920s, Cleveland Clinic has remained in the vanguard of healthcare innovation. For nearly two decades, some of the most innovative uses of technology in healthcare have been developed and championed by Cleveland Clinic Innovations and its sister organization, Cleveland Clinic Ventures. Collectively, they manage more than 1,200 patents, 550 licensing agreements and helped create more than 80 spinoff

companies. These ventures represent an array of technologies in medical devices, pharmaceuticals and health information technologies.

Innovation at Cleveland Clinic has never been more focused on pushing boundaries in pursuit of improved public health. And Cleveland Clinic's innovative solutions are sure to continue evolving in the decades ahead.

What won't change is Cleveland Clinic's commitment to harnessing innovation to meet patients' needs, just as the founders did when they made research a cornerstone of Cleveland Clinic.



**1948**

**Irvine Page, MD,** was part of the team that isolated and named serotonin.

**1950s**

Willem Kolff, MD, PhD, invented kidney dialysis and established the first hospital-based Department of Artificial Organs at Cleveland Clinic

**1955**

George Crile Jr., MD, son of a Cleveland Clinic founder, pioneers alternatives to radical mastectomy for treating breast cancer.

**1958**

**F. Mason Sones, MD,** pioneered moving cine-coronary angiography.

**1993**

Cleveland Clinic becomes the first major medical center to publish treatment outcomes for thoracic and cardiovascular surgery, demonstrating a commitment to quality, transparency and accountability.

**1984**

Cleveland Clinic performs its 100,000th cardiac catheterization. The heart transplant program is established; today, Cleveland Clinic holds the world's record for the most hearts transplanted in a single year.

**1974**

Cleveland Clinic performs the first CAT scan in Ohio, fourth in the world.

**1967**

**René Favaloro, MD,** pioneers coronary artery bypass surgery.



**1995**

*U.S. News & World Report* names Cleveland Clinic No. 1 for heart care for the first time, a distinction earned every year since.

**1998**

Marshall Strome, MD, performed the world's first successful larynx transplant

**2004**

The first class enters Cleveland Clinic Lerner College of Medicine.

**2007**

Steven Nissen, MD, discovers that a popular diabetes drug, rosiglitazone (Avandia) raises risk of heart attack and death. This is one of three drugs that Dr. Nissen got banned by the FDA; the others were rofecoxib (Vioxx) and muraglitazar.



**2009**

In June, President Barack Obama visits Cleveland Clinic to, in his own words, "see how Cleveland Clinic delivers the best possible care at the lowest possible cost."

**On July 13, Cleveland Clinic Lou Ruvo Center for Brain Health treats its first patient in Las Vegas.**



# Nevada's First and Only Exploratory Alzheimer's Disease Research Center

In September, the National Institute on Aging at the National Institutes of Health (NIH) awarded a grant expected to total \$3.3 million to Cleveland Clinic Lou Ruvo Center for Brain Health to establish the Nevada exploratory Alzheimer's Disease Research Center (NVeADRC).

The three-year award, among the first in the "exploratory" category to be presented as part of the NIH's Alzheimer's Disease Research Centers Program, will help build the infrastructure and initiate statewide collaboration needed to establish an Alzheimer's Disease Research Center focused on reducing disparities faced by individuals with dementia in rural settings.

The Alzheimer's Disease Research Centers Program is a national network of researchers and clinicians at major medical institutions. Researchers at these centers are working to translate advances into improved diagnosis and care for people with Alzheimer's disease and

related dementias, as well as to find a way to treat and possibly prevent the diseases.

## A Commitment to Rural Residents

Marwan Sabbagh, MD, Director of the Lou Ruvo Center for Brain Health, will serve as director of the NVeADRC, which is among the first cohort of centers nationally to receive this new award. It is the first and only exploratory Alzheimer's Disease Research Center in Nevada.

"As a state with historically low federal funding, the Nevada exploratory Alzheimer's Disease Research Center marks an important milestone for Nevada, allowing us to elevate the science we contribute to the NIH and effectively expand our research footprint," Dr. Sabbagh says. "Alzheimer's disease is a looming public health crisis, and this grant will play an important role in advancing the science of this disease by contributing critical data from a massively

understudied, underserved and under-supported rural population."

Health disparities in rural areas have long been recognized; Alzheimer's disease and Alzheimer's disease-related dementias are no exception. Those living with dementia in rural communities often go undiagnosed or are misdiagnosed due to lack of access to dementia specialists. In addition, data in rural areas are scarce and usually confined to a small number of individuals with limited sets of biomedical data.

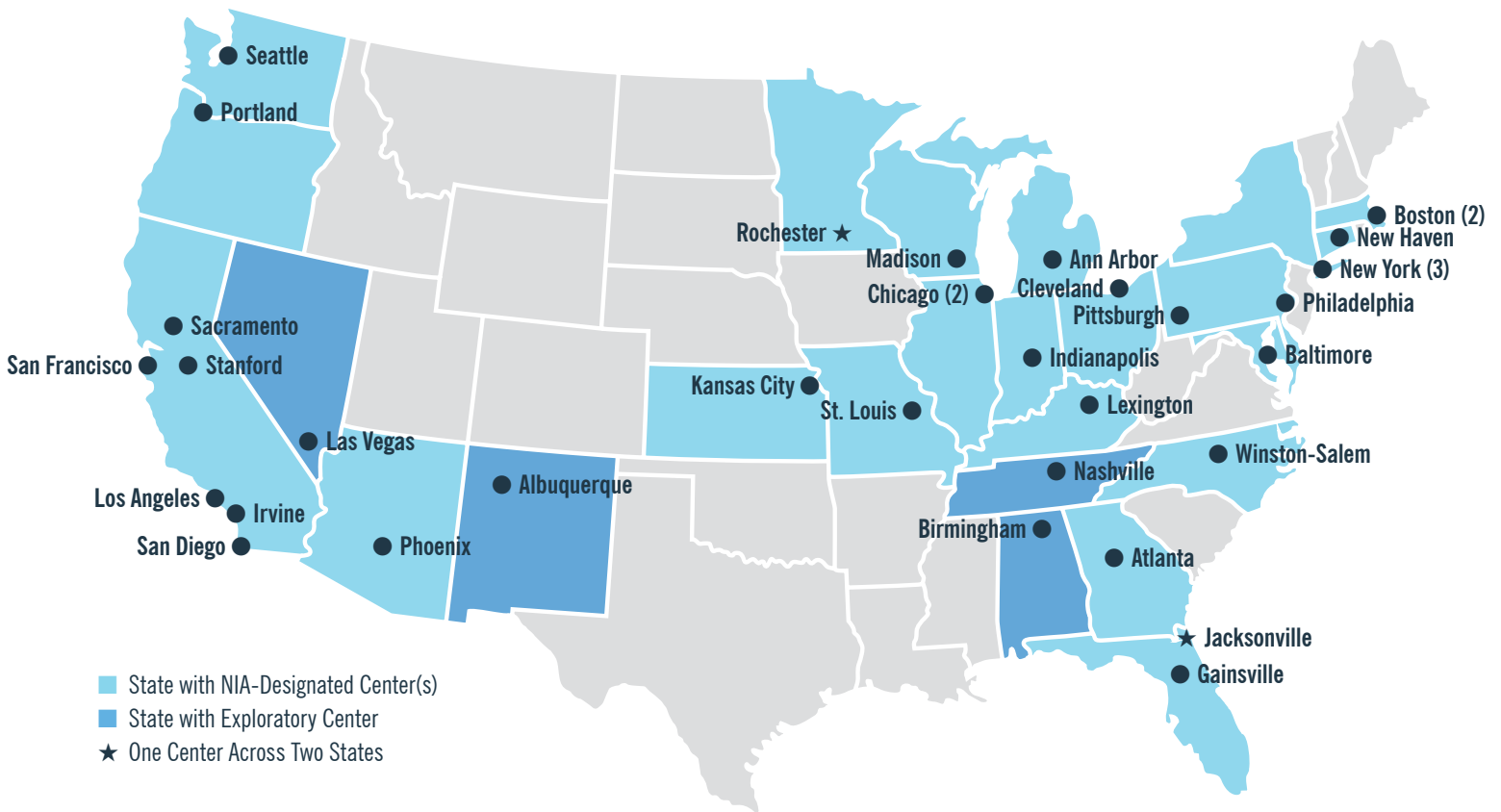
The NVeADRC will leverage our status as a frontier state (one with a significant rural population) to develop novel methodologies and technology to enroll research volunteers into a cohort of rural Nevadans. Data collected can be used by the broader scientific community and will contribute to the overall mission of the Alzheimer's Disease Research Centers network to improve diagnosis and care for people with Alzheimer's disease.

- After age 65, the **risk of Alzheimer's doubles every five years**. After age 85, the risk reaches 33%
- Nevada ranks as the **3<sup>rd</sup> fastest growing dementia population** in the country, with 15% of residents over 65
- **49,000 Nevadans have Alzheimer's disease** today. That number will grow 31% to **64,000 by 2025**

- **10% of Nevada's population** is spread across roughly **90% of its land mass**, making access to healthcare geographically challenging
- By 2025, the **impact of Alzheimer's** and other dementias **on Medicaid in Nevada will increase 49%**, from \$185 million to \$275 million







## Powered by Philanthropy

Receiving Nevada’s first and only NVeADRC is an enormous accomplishment, made possible only because the Lou Ruvo Center for Brain Health was able to demonstrate to the NIH a solid infrastructure of research and education to support the project we proposed.

This infrastructure has been built over the years thanks to robust philanthropic support, which has helped to develop the leaders of the NVeADRC’s three core projects:



### Keep Memory Alive Young Scientist Award alum:

Justin B. Miller, PhD, ABPP/CN, will serve as the co-director of the NVeADRC and its

administrative core. The administrative core is responsible for overseeing all operations of the NVeADRC and ensuring that this novel, ambitious

research endeavor delivers to fill the gap among existing ADRCs: collecting and sharing high-quality biomedical data and specimens from individuals suffering from dementia in rural areas.



### Graduate Medical Education program

alum: Aaron Ritter, MD, who started with us as a fellow prior to spending four years as a staff

neuropsychiatrist, will serve as director of the clinical core for the NVeADRC.

Clinical research, particularly for conditions like Alzheimer’s disease, benefits from the participation of a demographically and economically diverse pool of study participants.

By recruiting and studying research participants from rural areas, we will ensure that future diagnostic and treatment approaches better reflect the array of individuals in whom they might be implemented.



### Robust education program lead:

Dylan Wint, MD, Las Vegas Legacy Neuroscience Education Chair, will lead the

outreach, recruitment and engagement core. He will focus on the twofold challenge of fostering development of rural medical professionals in diagnosing and managing Alzheimer’s disease and related dementias, and increasing awareness of the disease among residents.

We hope you take pride in seeing how your investment in us blossoms into innovative programs that will elevate our research footprint and our status as a leading Alzheimer’s disease center. If you’d like to support additional research programs at our center, please contact the development team at 702.263.9797.

# A Snapshot of Our Research You, Too, Could Be Part of the Picture

## Why Research?

At Cleveland Clinic Lou Ruvo Center for Brain Health, we're not happy with the status quo in the United States:

- **5.5 million** individuals with Alzheimer's disease (AD)
- **1 million** with Parkinson's disease (PD)
- **400,000** with multiple sclerosis (MS)

*These numbers only continue to grow, which presents an unacceptable outlook.*

Our goal is not only to treat patients, but also to give them, their families and our community an opportunity to participate in clinical trials and research. In doing so, these people help advance our knowledge of brain health and disease. Together, we can shape a better future.

We don't know when a cure for any of these disorders will be found, but one thing is certain: *The first person to experience it will be in a clinical trial.*

What happens in Vegas just might change the world. And you could be part of that change.

## BY THE NUMBERS

3

Nevada ranks as the third fastest-growing state in the prevalence of dementia.

66

Number of seconds before yet another individual is diagnosed with AD

99.7

Percent of potential AD drugs that fail during clinical trials

146

Between 2000 and 2018, deaths from Alzheimer's disease increased by 146%, while deaths from heart disease decreased by 7.8%.

305

In 2020, Alzheimer's disease and other dementias were anticipated to cost the nation \$305 billion. Unless a treatment to slow, stop or prevent the disease is developed, in 2050, AD is projected to cost more than \$1.1 trillion (in 2020 dollars).

## AT THE LOU RUVO CENTER FOR BRAIN HEALTH

100

Number of trials we have conducted since 2009, making the center's AD clinical trials program one of the largest in the country, with a robust research program for movement disorders and multiple sclerosis, too

700

Number of individuals just like you who joined our research in a single year



780

Number of scientific papers published by our staff since 2009 to advance the science of Alzheimer's and Parkinson's diseases, MS, neuropsychology, brain imaging, repeated brain trauma and chronic traumatic encephalopathy (CTE)

2,600

Number of visits to our research studies in a single year by the army of "citizen scientists" who participate in our research



## TAKE ACTION: YOU CAN HELP

Finding new treatments depends on having enough volunteers like you willing to participate. Here's how you can help:

- **Learn more about our research programs:** [ClevelandClinic.org/NevadaResearch](http://ClevelandClinic.org/NevadaResearch).
- **Find out which trial is a match for you or someone you know:** 702.701.7944 or [healthybrains@ccf.org](mailto:healthybrains@ccf.org)
- **Support us in advancing new treatments and discoveries:** Contact our philanthropy team at 702.263.9797 or [DonateNevada@ccf.org](mailto:DonateNevada@ccf.org).



**Did You Know?** Many research studies require healthy controls — people with no disease symptoms — to serve as a comparison against trial participants affected by the disease under study.

## Join Us to Attack Brain Disease

Consider these ongoing clinical trials, many of which are still accepting participants.

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### PREVENTION

**TRIALS:**  
Trials aiming to prevent the onset of brain disease

#### AHEAD 3/45:

Can a medication that reduces amyloid plaque buildup in the brain help individuals before the symptoms start?

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**TREATMENT TRIALS:**  
Clinical trials of potential new drug treatments for individuals with brain disease

#### BouNDless:

Can an old drug learn new tricks: When infused continuously, will levodopa help motor fluctuations in Parkinson's?" (See page 20)

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#### CLARITY:

Can an antibody rid the brain of a bad protein that causes Alzheimer's disease and help patients with mild memory loss?

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#### EMBARK:

If patients who had been receiving an anti-amyloid medication in a previous study continue to receive the same medication in this study, might the result be even more impactful?

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#### Lenalidomide:

Will the anti-inflammatory properties of an anti-cancer drug be helpful in treating individuals with mild cognitive impairment?

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### OBSERVATIONAL RESEARCH:

Studies contributing to our understanding of how the brain changes over time, comparing normal to abnormal aging to identify when, where and how things go wrong

#### Dementia With Lewy Body Consortium:

Can brain scans, blood and cerebrospinal fluid give us clues into the causes of Lewy body dementia?

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#### Nevada exploratory Alzheimer's Disease Research Center:

Do people who live in rural areas age differently and experience Alzheimer's disease at different rates compared with people in urban areas? (See page 7)

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#### TRC-PAD:

A study to identify individuals at increased risk for developing Alzheimer's disease so that they can be recruited into treatment trials

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#### ADNI-3:

A long-term study to understand how brain scans change in people with mild cognitive impairment and in elderly individuals without memory problems. (See page 15)

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#### Enroll HD:

Can a national study of people with Huntington's disease and their family members help unlock the mysteries of this hereditary disease?

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#### COBRE:

A National Institutes of Health (NIH)-funded study to enhance our understanding of aging across diverse populations

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**LIFESTYLE:**  
Research on the impact of life choices on brain health

#### HealthyBrains.org:

An online community of individuals interested in receiving a free self-assessment and learning more about their brain health, with the opportunity to join a database of potential research volunteers

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## For Asymptomatic Volunteers, Research Study Is a “Win-Win”

We enjoy meeting like-minded individuals who share our commitment to the challenge of preventing Alzheimer’s disease. One key weapon in this battle is Anti-Amyloid Treatment in Asymptomatic Alzheimer’s (A4), a study that Cleveland Clinic Lou Ruvo Center for Brain Health has participated in since 2015.

In this important study of older adults (aged 65 to 85) with normal thinking and memory function, researchers are testing whether an antibody directed against

amyloid can lower the risk of developing cognitive problems in people with high brain levels of this protein, which predisposes some people to develop Alzheimer’s disease (AD).

In a world that adds a new case of dementia every four seconds, it is imperative that we discover new and better treatments for AD as soon as possible. Therapies that could prevent Alzheimer’s disease would fundamentally alter the lives of millions of people all over the world.

### Studies With Benefits

While she underwent many assessments to determine eligibility for the A4 study, the one Paula Phelps most appreciated was the PET scan, which was administered at no cost to her as a study participant. The results confirmed her suspicion: *Yes, there is amyloid in my brain.*

While age is the single greatest risk factor for AD, many other factors contribute, including genetics. Having lost her mother, father and two half-sisters to the disease, Paula, who had just turned 65 when she inquired about research at the Lou Ruvo Center for Brain Health, was justifiably concerned about her own future. Rather than let that concern fester, “I wanted to be part of the solution,” she says.

### You’re Not Alone

Ann Ayton, 83, has a similar story, having lost her mother at age 91, seven years after a diagnosis of AD. Ann says of the study, “You have to have the test to show you already have plaque in the brain, but participants also must be asymptomatic. It’s a win-win. If I develop symptoms, at least I’m attached to Cleveland Clinic. If I don’t develop symptoms, even better!”

Upon retirement, both women relocated to Las Vegas, starting from scratch to build connections. Ann read of the Lou Ruvo Center for Brain Health in the newspaper, and thought it would be a fun place to volunteer: “I was helping in the center’s exercise class but, when I realized I no longer had the strength to assist with some of the larger men in the class, I figured, why not test out my brain in research?”

Paula Phelps believes that “things are meant to be. My husband and I moved to Vegas 20 years ago, and it was just



Research Coordinator Mia Ramos with Anna Ayton

fortuitous that Cleveland Clinic came here soon thereafter to care for our brains for the long haul.”

Nearly five years into the study, she says, “The people at Lou Ruvo have become my friends. From the very first coordinator to the psychologists to Betty the infusion nurse, I look forward to seeing them. It’s a community and I enjoy being part of it.”

In their first few years in the A4 study, neither Paula nor Ann knew if they were receiving the drug or a placebo. Both are now participating in the “open-label extension” study of the drug, which means they knowingly receive it. Although neither will ever know how it all began, both women suspect they have been receiving the anti-amyloid treatment all along, and credit it with the stability of their cognition.

### Is It Worth It?

“I had a little trepidation around the lumbar puncture,” says Paula, “but I knew it was important to the research. Turned out, coordinating a time for the procedure was actually more difficult than the procedure itself!”

Ann realizes that study participation involves an array of assessments, and health problems could be uncovered along the way, but says, “At my age, health problems could crop up anytime. If you’re open in your old age to helping society, which was my main motivation, being in a study is a great way to do so.”

She hopes that increased focus on her nutrition in recent decades has helped keep both body and brain healthy, and she admits to frequently consulting her smart watch to be sure she has achieved her daily goal for steps. Paula echoes the commitment to exercise, attending classes five days a week and doing more on her own the rest of the week.

Once a month, each woman comes to the Lou Ruvo Center for Brain Health for an infusion.



Ann, who drives 20 minutes across the Las Vegas Valley, says, “If I can contribute anything, anything at all, to the resolution of the problem of Alzheimer’s, it pleases me. That’s all I ask for.”

As Paula sees it, “You feel like you’re doing something for humanity. You’re clearly doing something for yourself. If

you sign up for research and it turns out you don’t have the disease they’re studying, good for you! Every study is worth it, even the ones that have been unsuccessful, because researchers learn something from that, too.”

*And isn’t that knowledge what we all want?*

### PUTTING YOUR BRAIN TO WORK FOR RESEARCH

To find better approaches to treating brain disease, Lou Ruvo Center for Brain Health researchers need brains of all types.

Contact us to find out if we have a study for you or someone you know: [healthybrains@ccf.org](mailto:healthybrains@ccf.org) or 702.701.7944



# Collaborating to Tease Out the Mystery of FTD

Dementia, a progressive decline in the ability to think and remember, can begin in middle age as well as in old age. While older individuals with dementia most commonly have Alzheimer's disease (AD), in cases of earlier onset (aged 40-65 years), another form of dementia — frontotemporal dementia (FTD) — is almost as common as AD. Yet, FTD has been largely unstudied.

Cleveland Clinic Lou Ruvo Center for Brain Health recently joined ALLFTD, an observational study to identify families with genetic indication of FTD and, through a consortium, to pool data with other sites to accelerate the scientific community's collective understanding of this mystery of the brain.

The ALLFTD study is the longest-running, largest study of individuals with FTD. The Lou Ruvo Center for Brain Health is the newest addition to the ALLFTD

study, which includes approximately 20 of the most prestigious research centers in the country, says Aaron Ritter, MD, principal investigator, who is leading our center's participation.

## What Is FTD?

FTD is the umbrella term to describe neurodegenerative diseases caused by tau protein without the presence of amyloid protein (the latter protein is considered a biomarker for Alzheimer's disease). The ALLFTD study aims to understand the genetics, brain changes and cognitive changes that cause these diseases and to explain why certain people may have certain symptoms.

The five most common types of tauopathies, or variants of FTD, are:

1) **Behavioral FTD:** changes in personality, compoment (how a person interacts with others and

conforms to basic societal standards) and motivation. This disease usually appears in one's late 50s or early 60s.

2) **Semantic FTD:** changes in understanding spoken words. A person might forget what common things mean, and is often misdiagnosed with a hearing disorder.

3) **Nonfluent FTD:** changes in how a person speaks. Words come out jumbled or very slowly or painfully.

4) **Progressive Supranuclear Palsy:** changes in balance or coordination and eye movements as well as rigidity of limbs. People become wheelchair bound very quickly because they fall so frequently.

5) **Corticobasal Degeneration:** loss of the ability to move one side of the body, similar to a stroke.



## Nature or Nurture?

Although FTD is usually considered a sporadic disease — meaning its causes are environmental rather than genetic — about 5 percent of cases are caused by genetic mutations. There are three well-known genetic mutations: MAPT, GRN and C9orf72. ALLFTD studies families who carry one of these genes (both people who carry the genes and those without), in addition to individuals with FTD who have no genetic indication of the disease.

“Developing a better understanding of the genetics is exciting because emerging technologies may one day make it possible to ‘turn off a certain gene’ and prevent the onset of disease,” explains Dr. Ritter. “Ultimately, being part of the ALLFTD study consortium is a unique national opportunity to contribute to an understanding of the causes of FTD and impact the future of patient care.”

To make the study successful, we need individuals with FTD as well as healthy, cognitively normal individuals. To learn more about participating in the ALLFTD study, contact [healthybrains@ccf.org](mailto:healthybrains@ccf.org) or 702.701.7944.

If you would like to support science at the Lou Ruvo Center for Brain Health, please contact our development team at 702.263.9797 or [DonateNevada@ccf.org](mailto:DonateNevada@ccf.org).



## Giving to Eradicate “the Most Wicked of All Dementias”

As David Reese sees it, “Scientists have made such strides with cancer, and there are very few diseases these days that the medical community doesn’t have pretty good answers for. But you get ALS or FTD and there are no concrete answers.”

He’s speaking from family experience, having watched his father-in-law succumb to amyotrophic lateral sclerosis (ALS). In addition, his wife, Weezie Reese, lost both her brother and her father’s sister to frontotemporal dementia (FTD). More recently, the disease claimed her sister, Janet, 68.

“Janet fell off a cliff mentally,” says Weezie. “All of a sudden, her behavior completely changed. She would lash out verbally at her husband, and she developed unfounded concerns about people ‘stealing her stuff.’”

Adds David, “FTD is the most wicked of all dementias.”

Despite witnessing the ravages of brain disease at close range, the couple feels blessed by a life that has allowed them to travel, and they are quick to remark on how lucky they are.

As they count their blessings and evaluate opportunities to share with others, they focus their giving on areas that many others ignore, such as the disabled and mental health.

“Historically, it has been hard to raise money for brain problems. Now, dementia has become a public health crisis,” David notes.

“The brain is the last organ in the body to which anyone has paid attention. Until recently, if you had any mental issue, they put you away in an asylum,” says Weezie.

Through conversation with researchers, the Reeses learned that an abnormal



Weezie and David Reese

C9 chromosome is believed to be common to both ALS and FTD. In search of answers for their loved ones and all families, the couple established the FTD Discovery Accelerator Fund at Cleveland Clinic Lou Ruvo Center for Brain Health. One of their first endeavors that the fund supported was a conference jointly convening national ALS and FTD experts to discuss synergies in research and treatment.

David, 80, contemplates his chances of developing dementia, given that his brother developed symptoms at 82, following in the footsteps of their father, who had dementia by 85. The average age of diagnosis of FTD is 60; at 75, Weezie hopes to have escaped the dread disease.

“We hope that one day, research will solve the mysteries of the brain and this public health crisis will cease,” says David. “Until then, to get the best answers available, people absolutely have to go to places like Cleveland Clinic where there is deeply specialized expertise.”

# The Quest to Diversify Clinical Research Studies



Dr. Jiong Shi, Director,  
Clinical Trials

If you're a Black/African American 65 or older, you're roughly twice as likely as a Caucasian in that age group to have Alzheimer's disease or another dementia. For older Latinos, the ratio is about 1.5 to 1, according to the Alzheimer's Association.

Yet, minorities are woefully underrepresented in clinical studies of Alzheimer's disease, which affects an estimated 5.8 million Americans. The downstream effect of this health disparity is that potential new drugs might be less effective in some individuals than in others.

Recruiting underrepresented populations is a huge challenge for Alzheimer's disease trials. College-educated Caucasians comprise 95 percent of study participants, which is a problem because we need to be able to apply findings from our studies to all Alzheimer's patients.

## It's About Precision Medicine

"The brain is not just a biological organ; it is also nurtured by education and ethnic culture. Diversity in research participants isn't just about skin color. We strive to examine individuals of different education levels, cultural backgrounds and geographies," says Jiong Shi, MD, Director, Clinical Trials, for Cleveland Clinic Lou Ruvo Center for Brain Health.

It's not just Alzheimer's disease. The same diversity goals exist across other dementias such as Lewy Body and frontotemporal; as well as Huntington's disease, Parkinson's disease and other movement disorders treated at our center; and multiple sclerosis (MS). Regrettably, the lack of diversity across brain disease research is a broad-based shortcoming, but we hope to change that.

After all, you wouldn't expect one T-shirt size to fit everyone, would you? So why

should we expect that in a treatment? This concept, referred to as precision medicine, summarizes the future of brain research across the country. But for a drug to achieve its desired goal in everyone, we need to make sure we are testing it in everyone.

## Listening and Learning

For the last three years, the Lou Ruvo Center for Brain Health has committed sustained resources to amplify our community outreach and education efforts, implemented institutional programs like implicit bias training for all staff and hired more culturally diverse members to our research team. We listened to our community advisers and integrated their views and ideas in our marketing, community outreach and even in our HealthyBrains.org education and recruitment platform, which is now available in Spanish.

"Trust is earned," says Dr. Shi, who believes our authenticity, institutional efforts and investment in our Southern Nevada neighborhoods have established a foundation of trust and relationship-building that supports our commitment to enrolling more diverse research participants.

The Alzheimer's Disease Neuroimaging Initiative (ADNI) Diversity Task Force shares this belief. In September, it awarded the Lou Ruvo Center for Brain Health a grant to support our recruitment efforts targeting Black/African American and Latino participants for ADNI. Using brain scans and other tests to track changes in individuals with Alzheimer's disease, ADNI is perhaps the largest and most influential study of the disorder ever conducted, and one in which our center has been involved for nearly a decade.



## Candid Conversations, Concrete Action

In November, Cleveland Clinic Lou Ruvo Center for Brain Health hosted “Candid Conversations About Clinical Research,” an online event aiming to demystify and diversify participation in research.

Comparing each individual's responses pre- and post-event, 17 percent of respondents who declined to answer during the pre-event survey said “yes” to research participation after attending the event. Within 48 hours of the event, 89 individuals registered at [HealthyBrains.org/clinical-trials](https://HealthyBrains.org/clinical-trials) for more information.

To what do we attribute this increased interest in lending their brain power to help our research scientists delve into the mysteries of the brain? As one attendee wrote in the post-event survey, “Having actual participants share their experiences helped me understand the importance and need for clinical research trials.”

True to the event's billing, the panel of research participants was candid about sharing their fears:

“If you feel like you need to get out, you can. It's not like you're a lab rat,” said Pam Shields, who has served as a normal control in research studies. “The fears I did have were quickly resolved by the program. You feel like part of the family at Cleveland Clinic.”

Onkelos Bradford, who has multiple sclerosis, participated in the SUNBEAM



trial that resulted in FDA approval of ozanimod for treatment of MS, said, “I almost said ‘I can't do this’ and walked away just because of the needle, but I told myself I needed to get over it. Research is so important.”

Jodi Martin acknowledged a common concern: “Being part of a double-blind study with a placebo group, our biggest fear was the unknown. Sitting in the infusion room and looking at that little black bag connected to my mom who has Alzheimer's, we were wondering, ‘What's in it?’ At the same time, you know what you're doing is good.”

The panel encouraged event attendees to consider research participation:

“Just as much as every vote counts in an election, every participant counts in research,” said Pam.

Jodi talked about how being in research can be empowering: “When you receive a diagnosis, it feels like an end. Being in a trial can feel like a beginning.”

Onkelos reflected on the history of research: “Think of things like Tylenol.

You just run to the store and buy it but, at one point, there wasn't a store for that. Hopefully, one day, this medicine for relapsing MS will be the same thing: You just run to the store.”

As the nation grapples with diversity and inclusion, we remain focused on the important role diversity — in race, ethnicity, age, gender, socioeconomic status, environment and more — plays in healthcare research. It is our mission to ensure that people from all backgrounds and cultures be inspired to contribute to the solutions we seek.



## TOGETHER, LET'S DIVERSIFY BRAIN RESEARCH

Join our ranks. Cleveland Clinic Nevada is always in search of citizen scientists — both those with brain disorders and healthy volunteers — to complete a variety of research studies to advance new treatments and diagnostic approaches for individuals with:

- Alzheimer's disease, Lewy Body and other dementias
- Parkinson's disease, Huntington's disease and other movement disorders
- Multiple sclerosis

Contact us at [healthybrains@ccf.org](mailto:healthybrains@ccf.org) or 702.701.7944.



# Physical Therapy Benefits Mind and Body

## Study shows improvements in people with cognitive impairment

Memory lapses, mental confusion... They are the type of symptoms most commonly associated with cognitive impairment disorders like Alzheimer's disease and other forms of dementia. But cognitive disorders can also affect movement, causing slower gait and unsteady balance.

Motor impairment often gets less attention than cognitive impairment, even though it can seriously impact daily activities and lead to falls, which are a major risk for disability in older adults.

"Research has shown that motor impairments appear early in the disease process and, as the disease worsens, play a big role in how people function," says Jason Longhurst, PT, DPT, a board-certified clinical specialist in neurologic physical therapy in the Department of Neurorehabilitation at Cleveland Clinic Lou Ruvo Center for Brain Health.

At the center, patients with cognitive disorders who have motor impairment are routinely referred to physical therapy, especially if they have experienced a fall.

"Most individuals with cognitive impairment can benefit from physical therapy, even those at an advanced stage," says Dr. Longhurst.

### A month of PT makes a difference

To better understand the effects of physical therapy on motor and cognitive function, Dr. Longhurst, working with researchers from the University of Nevada, Las Vegas, Department of Physical Therapy, conducted a retrospective study of 173 individuals aged 50 to 90 with cognitive impairment who received physical therapy at the



Dr. Jason Longhurst at a physical therapy session

center from 2016 to 2017. The participants were divided into groups based in their diagnosis, which included Alzheimer's disease (AD), Lewy body dementia (LBD), vascular dementia (VaD) and mild cognitive impairment (MCI), which can sometimes progress to AD.

Physical therapy was tailored to individual needs and designed to prevent or slow disease progression; participants also received a home exercise program. After a month of treatment, the researchers compared the cognitive and motor assessment tests that participants underwent before and after physical therapy.

All groups experienced improvements in balance and gait, with the MCI group experiencing the greatest improvement

from physical therapy. In addition, the AD, VaD and MCI groups showed improvement in cognitive function.

"With the current lack of effective treatments for cognitive impairment disorders, it is significant that participants showed meaningful improvement with just a month of physical therapy," says Dr. Longhurst.

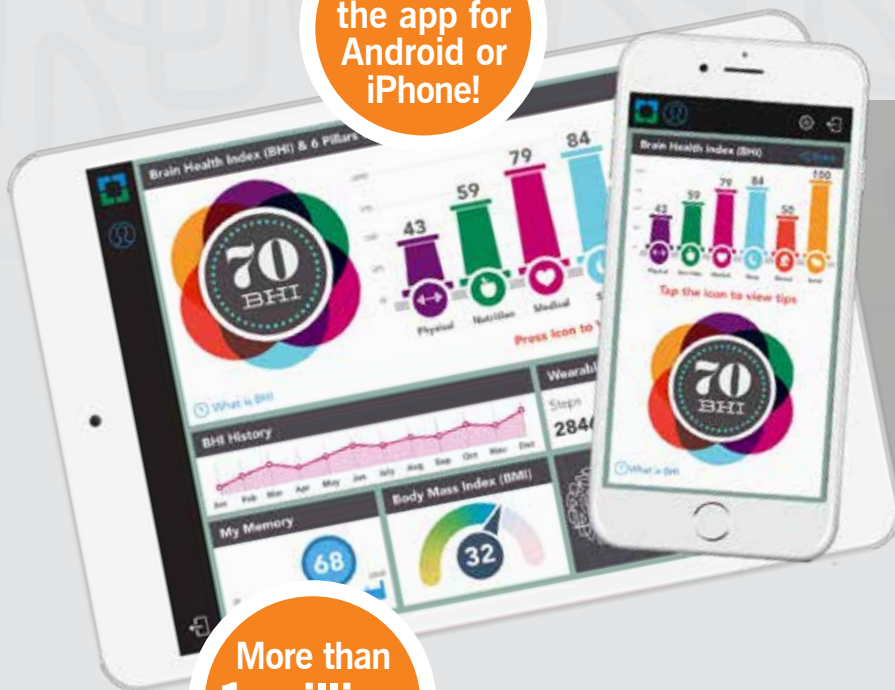
The department continues to investigate cognitive impairment using imaging studies: "Conducting research helps us to stay current with the latest developments in the field and provide the best, evidence-based care," says Dr. Longhurst.

**To schedule a physical therapy appointment, call 702.483.6032.**

# How Healthy is Your Brain?



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Available in English and Spanish



One of the major hurdles in finding treatments for Alzheimer's disease is finding enough volunteers for clinical trials. Learn more: [HealthyBrains@ccf.org](mailto:HealthyBrains@ccf.org).

# Help Solve the Mysteries of the Brain



## 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



702.701.7944



healthybrains@ccf.org

[ClevelandClinic.org/NevadaResearch](https://ClevelandClinic.org/NevadaResearch)

# A Novel Approach to Motor Fluctuations in Parkinson's Disease



Dr. Zoltan Mari

Parkinson's disease (PD) is a progressive movement disorder in which symptoms such as slowing and loss of coordination and balance gradually worsen over the years as new symptoms emerge.

While currently available treatments can be markedly effective in alleviating certain symptoms — in particular, early in the disease — individuals with PD experience decline in quality of life over time. In great part, this is because of the progressively variable and inconsistent manner in which medications help patients with advancing PD. But now, these patients may have hope.

## The Predicament of Motor Fluctuations

One of the common and troublesome problems in more advanced PD is motor fluctuations. This symptom is characterized by a pattern of intermittent improvement of motor symptoms — referred to as an ON state, when PD medications “kick in” — soon followed by an OFF state as medications wear off and motor symptoms worsen again.

This roller coaster can be very disruptive, distressing and disabling, even when predictable due to medication dose timing. Later in the disease, however,

the timing of motor fluctuations often becomes unpredictable, making it even more challenging to plan activities. Also, while movement is possible and fluid during ON states, individuals may be confounded by involuntary, chaotic movements known as dyskinesias.

## Imagine PD Without Motor Fluctuations

While there are many existing ways to alleviate motor fluctuations, each treatment option has caveats and none will help every PD patient suffering from motor fluctuations. Therefore, motor fluctuations continue to represent one of the greatest unmet treatment needs, which movement disorders specialists hope to address through a new clinical research study known as BouNDless.

Currently recruiting research participants, BouNDless is evaluating the administration of levodopa via an investigational continuous infusion method to help individuals with PD manage motor fluctuations. If confirmed safe and effective, this experimental administration of therapy could offer these patients a new treatment modality to give them more control over their motor fluctuations and, potentially, over their lives.

### PD RESEARCH

If you or someone you know is experiencing motor fluctuations caused by Parkinson's disease, contact Cleveland Clinic Lou Ruvo Center for Brain Health's research team at 702.701.7944 or [healthybrains@ccf.org](mailto:healthybrains@ccf.org) to learn more about participation in this research study.



# From Education to Exercise, Center of Excellence Serves Parkinson's Disease Patients

While a Center of Excellence (CoE) is a source of pride to all recipients, more importantly, it's an indication to prospective collaborators — be they patients, researchers or healthcare professionals — of an organization's aptitude and approach to patient care.

In addition to core neurology care, a CoE represents a holistic approach to disease management, offering patients access to integrated services that support more nuanced diagnoses and treatment, including imaging, neurorehabilitation, education, support groups, social work and other supportive services, and opportunities to participate in research to uncover potential new treatments.

## A Point of Pride

Cleveland Clinic was named a Parkinson's Foundation Center of Excellence in 2018; the designation includes its main campus in Ohio as well as locations Weston, Florida; Abu Dhabi, United Arab Emirates; and Las Vegas.

"This CoE reflects the tireless and dedicated effort of our entire team across the Cleveland Clinic health system, who share the designation," says Zoltan Mari, MD, FAAN, Director, Movement Disorders Program and Ruvo Family Chair at the Lou Ruvo Center for Brain Health. "Moreover, the designation inspires us to reach even greater heights in providing compassionate care, offering the latest in research and clinical trials, and continuing to reinvent how we treat Parkinson's disease."

The backing of the Parkinson's Foundation supports Cleveland Clinic Lou Ruvo Center for Brain Health in conducting outreach and education in Las Vegas to increase awareness, educate and update patients, families and our community about Parkinson's disease (PD). This effort

includes monthly Lunch & Learn sessions dedicated to the disease as well as bi-monthly evening symposia and twice-annual all-day sessions.

## Unique Resources at Nevada's Only CoE

These highly popular PD education initiatives, now in their third continuous year, have featured dozens of speakers, including many national and international Parkinson's disease experts. The programs have addressed every topic relevant to PD and drawn thousands in cumulative attendance. The sessions are interactive and are recorded for later viewing, with slide presentations also available online.

Our CoE education effort also includes a library with many important titles on Parkinson's disease; our CoE team picks a "Parkinson's book of the month" at each aforementioned event. In 2021, we're launching a biannual Parkinson's & Movement Disorder newsletter.

In 2020, a supplemental Parkinson's Foundation Center of Excellence CORE grant enabled the launch of Yoga for Parkinson's classes each Saturday. These classes are among the most highly anticipated activities for patients and families. (See [ClevelandClinic.org/NevadaEvents](http://ClevelandClinic.org/NevadaEvents) for a full calendar of Parkinson's and patient support programming.)

"We're so proud to hold the designation of the first and only CoE in Nevada, enabling us to offer unique resources for individuals with Parkinson's," says Dr. Mari. "We strive to provide the highest level of multidisciplinary clinical care, exceptional education for patients and families, and ability to participate in world-class research studies to expand our collective understanding of the disease."



Dr. Zoltan Mari

Since opening in July 2009, Cleveland Clinic Lou Ruvo Center for Brain Health has earned numerous designations:



Parkinson's Foundation Center of Excellence (named among Cleveland Clinic locations)



"Partners in Care" from the National Multiple Sclerosis Society (only program in Southern Nevada)



CurePSP Centers of Care (among the first five in the United States)



Research Center of Excellence from the Lewy Body Dementia Association



And in 2020, Exploratory Alzheimer's Disease Research Center from the NIH (Nevada's first and only)

# Novel Therapies Bring Hope to Patients With Demyelinating Disorders

Although 2020 was a year most say they'd rather forget, for physician-scientists specializing in two demyelinating disorders — neuromyelitis optica spectrum disorder (NMOSD) and multiple sclerosis (MS) — the year offered cause for celebration. The approval of four new drug treatments, coming on the heels of three in 2019, means more options than ever for physicians to deliver the most targeted, individualized patient care possible.

“The rapidly evolving landscape of unique neurotherapeutics for MS and NMOSD allows a variety of choices for our patients and truly sets the stage for personalized decision making,” says Carrie Hersh, DO, MSc, FAAN, Program Director of the Multiple Sclerosis Health and Wellness Initiative.

FDA approval of new treatments comes only after positive results from clinical research (see page 9). Cleveland Clinic Lou Ruvo Center for Brain Health was involved in studying the two recently approved MS treatments, both of which are now being prescribed at our center and across the country.

“Our entire MS team is excited by this array of new, diverse treatments for demyelinating disorders, which hold the promise of making a significant impact on our patients' lives,” says Dr. Hersh. “We are proud of our center's role in making these advances available to individuals who can benefit from them.”



**If you're interested in hearing more about the newest approved treatments being prescribed — or those still being studied in pursuit of FDA approval — contact us at 702.483.6000.**

## FOR PEOPLE WITH MS

### **Ozanimod (Zeposia®)**

*FDA approval date: March 2020*

Ozanimod is a once-daily pill for the treatment of active (still inflammatory) forms of MS. Considered a disease-modifying therapy, ozanimod is another oral treatment option to address the disease's hallmark relapses and brain lesions. Pivotal clinical trials showed significantly less brain shrinkage and clinically meaningful improvements in cognitive processing speed compared with pre-existing treatments, thus “modifying” the disease.

Under the direction of Le Hua, MD, FAAN, in 2015, the Lou Ruvo Center for Brain Health was part of a Phase 3 clinical trial, SUNBEAM that led to FDA approval of ozanimod.

### **Ofatumumab (Kesimpta®)**

*FDA approval date: August 2020*

Ofatumumab is the first self-injected (subcutaneous) B-cell depleting

therapy for the treatment of relapsing (still inflammatory) forms of MS. This new drug therapy, which is considered a highly effective disease-modifying therapy, represents a novel treatment option for individuals who are interested in starting a B-cell depleting therapy, but who find administering the medication in the comfort of their own home more convenient than going to an infusion facility twice a year.

Under the leadership of Dr. Hersh, from 2016 to 2019, the Lou Ruvo Center for Brain Health was a site for the Phase 3 clinical trial ASCLEPIOS that led to FDA approval of ofatumumab. The center is currently conducting ALITHIOS, a clinical trial for the open label extension phase, in which participants are knowingly taking ofatumumab versus the Phase 3 trial, which randomized some participants to another approved therapy, teriflunomide (Aubagio®).

## FOR PEOPLE WITH NMOSD

“The advent of three different FDA-approved therapies for seropositive NMOSD, with various mechanisms of action and administration, is a revolutionary opportunity to effectively treat this rare, yet complicated, condition,” says Dr. Hersh. “We did not have an approved therapy before eculizumab was approved in 2019.”

### **Eculizumab (SOLIRIS®)**

*FDA approval date: June 2019*

The first immunotherapy for seropositive (AQP4 positive in serum/blood test) adults with NMOSD, eculizumab represented a breakthrough treatment for this devastating neurological disease, which affects principally the nerves of the eye and the spinal cord. While infusions every other week can present a logistical challenge

for some, eculizumab remains a welcome option for patients.

### **Inebilizumab (UPLIZNA®)**

*FDA approval date: June 2020*

The second disease-modifying therapy to be approved for seropositive adults, the immunotherapy inebilizumab is administered via infusion every six months. Individuals may like this option if they want a therapeutic strategy that is infrequent, with administration overseen by a medical team.

### **Satralizumab (ENSPRYNG®):**

*FDA approval date: August 2020*

The third disease-modifying therapy to be approved for seropositive NMOSD, this immunotherapy is administered via subcutaneous injection once a month. Patients may prefer this option if they want a therapeutic strategy that they can self-administer at home or if there are safety issues with other treatments.

# New Year, New You: Line Up an eCoach in Your Corner

Kick start your personal wellness journey and join more than 3,700 Cleveland Clinic patients who have been matched with their very own coach. Cleveland Clinic eCoaching pairs individuals with a dedicated Cleveland Clinic Health Coach to set and reach sustainable goals through optimal nutrition, physical activity, stress reduction, adequate sleep and other lifestyle behaviors.

It is well known that these and other wellness components are essential to good health. For people with one of the brain disorders treated at Cleveland Clinic Lou Ruvo Center for Brain Health, these practices are especially important.

For example, studies have shown that exercise can help patients manage multiple sclerosis (MS) symptoms, reduce complications of the disease, improve cognitive function and boost mood, says Carrie Hersh, DO, MSc, FAAN, Program Director of the Multiple Sclerosis Health and Wellness Initiative. Also, people with MS who exercise and maintain a healthy weight retain a higher level of physical ability over time.

While starting a new regimen can be challenging, sticking with it is even more difficult. That's when having a coach in your corner can help.

## eCoaching: Virtual Communication, Real-World Goals

Cleveland Clinic coaches connect with participants through email, text and virtual visits, encouraging small changes designed to create long-lasting behaviors to keep you well over time. As a participant, you can expect:









- Regular communication and support from your health coach

- Specific advice to guide you toward your wellness goals

## Get Started

eCoaching is available at no cost to Cleveland Clinic patients, and for a fee to the community. Learn more at [ecoaching.clevelandclinicwellness.com](http://ecoaching.clevelandclinicwellness.com) or call 216.448.8880.

Coaches, who include registered dietitians, exercise physiologists and health education specialists, among other licensed counselors, offer programs in:

 <b>WEIGHT LOSS</b>	 <b>DIABETES MANAGEMENT</b>	 <b>HYPERTENSION CONTROL</b>	 <b>HEALTHY LIFESTYLE</b>
 <b>STRESS MANAGEMENT</b>	 <b>HEALTHY PREGNANCY</b>	 <b>MENOPAUSE</b>	 <b>TOBACCO CESSATION</b>

## WELLNESS CONSULTATIONS FOR MULTIPLE SCLEROSIS

At the Lou Ruvo Center for Brain Health, wellness is an integral part of MS treatment. Dr. Hersh offers one-on-one wellness consultations that address nutrition, exercise, the importance of vitamin D supplementation, tobacco cessation, sleep and stress reduction. A variety of complementary approaches, such as yoga, meditation and stress management, is encouraged.



“People with MS who follow a healthier lifestyle have more energy and manage their daily routine with greater ease. Healthy lifestyle practices allow them to feel more empowered, despite living with a complex and unpredictable disease,” says Dr. Hersh.

Wellness consultations complement core neurology care and are billable medical appointments. To schedule an in-person or virtual wellness consultation, call 702.483.6000.



# Fatigue Doesn't Have to Be a Way of Life

Feeling fatigued? While the primary reason may be something serious like depression, anxiety, untreated pain, sleep apnea or a chronic illness, a secondary cause may be modifiable lifestyle factors, from staying up too late, to feeling bored, to consuming too much caffeine, alcohol or junk food. Too much — or too little — exercise can be a culprit, too.

Shaina Meyer, OTR/L, Neurorehabilitation Manager, says across the various cognitive disorders, movement disorders and multiple sclerosis cases that Cleveland Clinic Lou Ruvo Center for Brain Health treats, patients routinely report fatigue.

“Fatigue can be one of the most debilitating symptoms, reducing a person’s ability or interest in any activity that might otherwise be important to them,” she says.

While one-third to one-half of all older adults struggle with significant fatigue, the good news is that among individuals spanning all ages and abilities, better energy management can often reduce fatigue. And occupational therapy (OT) can help.

“What OT can offer is really empowering because it allows people to manage their disease, instead of letting the disease manage them,” says Ms. Meyer.

“It’s unreasonable to go from no exercise to 30 minutes a day, but starting small can take you far,” says Ms. Meyer. For example, get on an exercise bike, try it out for a few minutes and see how your legs feel. Or, if you’ve been sedentary for a long time, the movement involved in meal preparation may constitute exercise, though you may have to start this activity in five-minute increments.

Most of us just don’t know how to take a break, even when the opportunity presents itself.

“Rest can simply be using the 15-minute break you’re allowed at work to take a walk or meditate instead of checking social media on your cellphone,” Ms. Meyer says.

## One Size Doesn't Fit All

While the OT team has worksheets that offer general guidance (see **Conduct Your Own Energy Audit**), by working one-on-one with patients, OTs can identify barriers specific to the individual and develop modifications to meet personal goals.

Ms. Meyer frequently finds herself asking a patient, “Thinking about what we talked about today, what are you going to try this week that you weren’t doing last week?”

As she says, “It starts with making a commitment to change.”

Shaina Meyer, OTR/L



## CONDUCT YOUR OWN ENERGY AUDIT

Wondering what your energy expenditure looks like on a daily basis? Try this simple exercise.

1. List all meaningful activities you need and want to do in a given day.
2. Put a star by your most important activities.
3. Sort the list of starred activities into anticipated energy levels (low, medium, high).
4. Look at how much you are doing in a day and ask yourself where you may be able to save physical, mental or psychosocial energy.

If you think you could benefit from assistance interpreting your findings or maximizing your approach to energy conservation, call 702.483.6000 and ask your neurologist for a referral to occupational therapy.



## Common Challenges

TYPES OF FATIGUE	WHAT YOU CAN DO ABOUT IT
<p><b>Primary fatigue</b> Fatigue that is a common symptom of a specific disease</p>	<p><b>Energy conservation strategy</b> Save energy for times and activities that are important to you</p>
<p><b>Secondary fatigue</b> The modifiable lifestyle causes of fatigue</p>	<p><b>Energy management strategy</b> Modify your health and wellness routines</p>

# Neuropsychology: Exploring the Links Between Brain and Behavior

Christina Wong, PhD



When it comes to dementia — a loss of memory or thinking that affects daily functioning — it can be immensely reassuring for the affected individual, as well as family and care partners, to gain a more nuanced understanding of how well the brain is working. That's where neuropsychology can help.

While many think of psychology as a “therapy appointment,” neuropsychology is a specialty within psychology that emphasizes understanding the relationship between the brain and behavior. It can shed light on where an individual might be on the spectrum, from normal cognition to mild cognitive impairment (MCI) to dementia, and even on the specific type of dementia, such as Alzheimer's, Lewy body or frontotemporal.

“Individuals with MCI may have some difficulties on our neuropsychological assessments, but those difficulties don't affect daily functioning. When function is affected, the individual has progressed to dementia,” says Christina Wong, PhD, Staff Neuropsychologist at Cleveland Clinic Lou Ruvo Center for Brain Health.

## Are These Changes Normal?

The beauty of neuropsychological assessments is that they are standardized, which “allows us to fairly and objectively compare an individual's scores to similarly aged, healthy adults,” Dr. Wong explains. “For example, is this specific 85-year-old woman doing as expected, worse or better for her age?”

Neuropsychological testing, which takes a few hours to administer, examines verbal and visual memory (learning, recall and recognition); language comprehension and fluency; executive function (planning, organizing and reasoning) and visuospatial abilities (perceiving and processing visual information). The goal is to determine if there has been a significant decline from a prior level of functioning or if changes are normal and age related.

Dr. Wong emphasizes that performance on assessments can be affected by education level, cultural background or sensory impairments common among older individuals, such as hearing loss. Sometimes, the cause is modifiable, as with stress, vitamin imbalance, depression or a sleep disturbance: “The challenge is separating secondary factors from the key cause of cognitive change.”

## The Value of Knowing

Knowing the cause helps providers establish a diagnosis and manage symptoms, arms families to better support a loved one with a progressive condition, and gives individuals the ability to plan for the future and participate in research to access potential new approaches to treatment.

Dr. Wong offers examples of neuropsychologists collaborating with neurologists and families to optimize diagnosis and disease management:

A very active older patient was doing well in his everyday life, but started

noticing some memory difficulties. He performed in the normal range on a brief cognitive screening, but comprehensive neuropsychological testing detected impairments in cognition. This information, along with his MRI showing brain changes greater than expected for his age, supported a diagnosis of mild cognitive impairment because his memory problems were not consistent with normal aging.

For another older adult patient, it was unclear if her memory problems were due to stress and grief, as she was coping with a traumatic event. Her

neuropsychological evaluation indicated that her cognitive impairments could not be entirely explained by mood, and there might be an underlying degenerative disease. Based on this information, her neurologist started her on a medication to support memory and her family was connected with staff social workers for caregiver resources.

**If you think a neuropsychological assessment could help someone you know, ask your neurologist for a referral and contact us at 702.483.6000.**

## A GATEWAY TO BETTER PATIENT CARE

After a diagnosis, neurologists may utilize the neuropsychological evaluation to determine if any of the following might help the patient:

- **Additional diagnostic tests** (MRI or PET imaging)
- **Medical follow-up**, such as treatment for sleep apnea or review of medications that can affect cognition
- **Cognitive support**, such as guidance on using memory aids — for example, setting alarms to complete tasks of daily living. — or referral to occupational therapy to learn compensatory skills
- **Support services/social work**, such as evaluating the need for assisted living or offering community resource connections
- **Psychotherapy or counseling**
- **Health psychology** to navigate the impact of a diagnosis
- **General health practices**, such as reducing blood pressure or managing diabetes
- **Re-evaluation**

# A Push to Bring Geriatric Care to Nevadans Everywhere

Ten percent of Nevada's population is spread across roughly 90 percent of its land mass, making access to healthcare challenging for those outside the urban cores of Reno and Las Vegas. An unfavorably low ratio of providers to population throughout the state further compounds access barriers. So, providers are collaborating to do the most with the resources they have.

Such is the aim of the Nevada Interprofessional Healthy Aging Network (NIHAN), a collaboration between the University of Nevada, Las Vegas School of Medicine and Cleveland Clinic Lou Ruvo Center for Brain Health. In 2019, NIHAN received support from the federal government to launch a statewide Geriatric Workforce Enhancement Program (GWEP). The GWEP aims to build stronger understanding and competency in geriatric medicine among the state's healthcare providers in rural and underserved regions so that primary

care generalists can better handle specialty concerns, such as dementia.

## Reaching More Patients Through Teaching

NIHAN multiplies our intellectual resources, says Dylan Wint, MD, a neurologist/psychiatrist, Las Vegas Legacy Neuroscience Education Chair at the Lou Ruvo Center for Brain Health and program director for the center's work with the GWEP.

"We don't have enough capacity to treat every person with a memory disorder — more than 50,000 in Nevada," Dr. Wint points out. "But if we teach more providers how to manage these conditions, together, we can reach more patients. By leveraging technology, we can expand even further."

The Lou Ruvo Center for Brain Health presents a monthly Continuing Medical Education (CME) Grand Rounds program for community practitioners, providing no-cost education credits live online or recorded on demand. We have also collaborated with UNLV; the University of Nevada, Reno; Nevada Area Health Education Centers; and the Veterans Administration to deliver education to students, residents, fellows and interns. The curriculum is tailored to the specific audience, and is delivered through distance learning.

Another goal of the GWEP is to engage individuals with dementia and their care partners via Powerful Tools for Caregivers (see page 33) and the Mind in Design art class (see page 31), both of which are delivered exclusively online.



## Together, Caring for the Community

"We can measure success with aggregated metrics," says Dr. Wint, "but also through individual anecdotes." He recalls a patient referred by a community physician who had attended one of the Lou Ruvo Center for Brain Health's CME seminars. The patient arrived demonstrating symptoms of dementia but, with surgical intervention, was able to recapture quality of life and enjoy better cognition.

"We neither conducted the surgery nor provided long-term disease management for this patient, but this example demonstrates how, by providing education and collaborative assistance to our colleagues in the community, we are together able to improve the wellbeing of Nevadans," Dr. Wint notes.

49,000 Nevadans have Alzheimer's disease today; that number is anticipated to grow 31 percent to 64,000 by 2025. It's going to take a village to care for our community, and we're proud to be part of it.



Dr. Dylan Wint

# Surprise! Virtual Observation Enhances Students' Training

As an academic medical center, Cleveland Clinic Lou Ruvo Center for Brain Health focuses not only on patient care, but also on training the next generation of healthcare providers, helping them prepare to transition from the classroom to the exam room.

Our collaboration with Touro University's physician assistant program began in 2014, with groups of 15 students at a time traveling to our center to observe a single neurological exam and debrief with our neurology team. With 60 students to a class, it took four such sessions to accommodate everyone. As much as we would have liked to increase the students' interaction with our patients and providers, we were constrained by the limits on their time and ours.

## Then Came COVID

Due to safety concerns related to COVID-19, we ceased all group gatherings, classes and programs in March 2020 (see page 33). At first, it seemed the pandemic might limit our training initiatives, but we soon realized that when we migrated to a virtual format, space and time limitations disappeared into cyberspace.

Today, we're able to invite Touro's even larger class of 70 physician assistant students to join a single patient exam. In the time we would have spent replicating that presentation for other groups of



Gwen Vaughn

students, we are instead expanding the entire class' exposure to all three of our specialty neurology practices: cognitive disorders, movement disorders and multiple sclerosis.

The class still enjoys the new patient evaluation experience, which includes physician interviews with both patient and caregiver, a physical exam and necessary test orders. After the patient-caregiver pair leaves the exam room, the neurologist conducts a question-and-answer session with the students, offering insight into caregiver stress, which can be difficult to comprehend until observed.

## An Education for the Patient, Too

The online observation marks a departure from the patient perspective, too. For nearly three decades, Gwen Vaughn has visited academic health centers for management of an array of chronic diseases. While she remembers a particularly awkward moment as a teenager "sitting shirtless for a procedure in front of seemingly 20 male students," over the years, she has grown reluctantly accustomed to students being in the exam room, observing her appointments.

In advance of her appointment at Cleveland Clinic, the neurology team asked if she would be willing to have students observe via videoconference.

"I quickly realized that, while I couldn't see the students whom I had granted permission to virtually observe my appointment, the doctor was acutely



Dr. Odinachi Oguh

aware of them. She explained everything in great detail for their benefit, which was also to my benefit," says Gwen. "While I thought I knew a lot about Parkinson's, given that for years I've been caring for my mom who has the same disease, I myself received an education that day."

The result? "This was the most comfortable way of conducting an education appointment I've ever encountered," says Gwen, who laughingly adds, "And the guy in the room? He was there to oversee the videoconference technology, not observe me."

From the perspective of Gwen's doctor, Odinachi Oguh, MD, "The very presence of students keeps me on my toes, reminding me to translate science to a more digestible level, choose my words carefully and try to anticipate a family's questions by offering information about the patient's condition before it is requested. In short, that's what every patient deserves in every encounter with me and from the next generation of providers."

## YOU CAN HELP A STUDENT

Study opportunities at our center, from summer experiences to fellowships, are funded by philanthropy. If you'd like to make a difference in a student's future, please contact our development team at 702.263.9797 or [DonateNevada@ccf.org](mailto:DonateNevada@ccf.org).



AFTERNOON, CLEVELAND CLINIC LOU RUVO CENTER FOR BRAIN HEALTH IN LAS VEGAS.

THE MUSIC THERAPIST LEADS A GROUP OF PEOPLE WITH DEMENTIA IN SONG.

♪ In the town... where I was born

♪ Lived a man... who sailed to sea

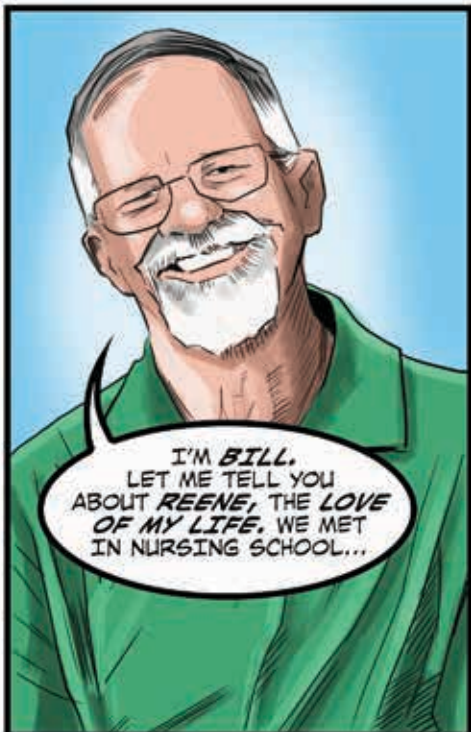
WE'D LIKE TO INTRODUCE YOU TO ONE OF THEM. SHE LOVES TO SING SONGS BY JIMMY BUFFETT...AND JOHN DENVER... AND ESPECIALLY THE BEATLES.

HER NAME IS MAUREEN.

EVERYONE CALLS HER REENE.

# REENE'S SONG

STORY BY JOHN SOEDER | ART BY LEN PERALTA



"A FEW YEARS AGO, REENE GOT LOST. THEY FOUND HER WALKING OUR DOG ALONG A BUSY HIGHWAY. AFTER A STRANGER BROUGHT THEM HOME, REENE COULDN'T REMEMBER WHAT HAPPENED."



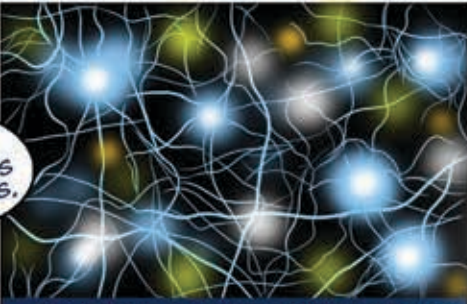
AT THE LOU RUVO CENTER FOR BRAIN HEALTH, REENE WAS DIAGNOSED WITH YOUNG-ONSET ALZHEIMER'S DISEASE.



SHE BECAME A REGULAR THERE AT TWICE-WEEKLY MUSIC THERAPY SESSIONS LED BY DR. BECKY WELLMAN.



MUSIC TRIGGERS MEMORIES.

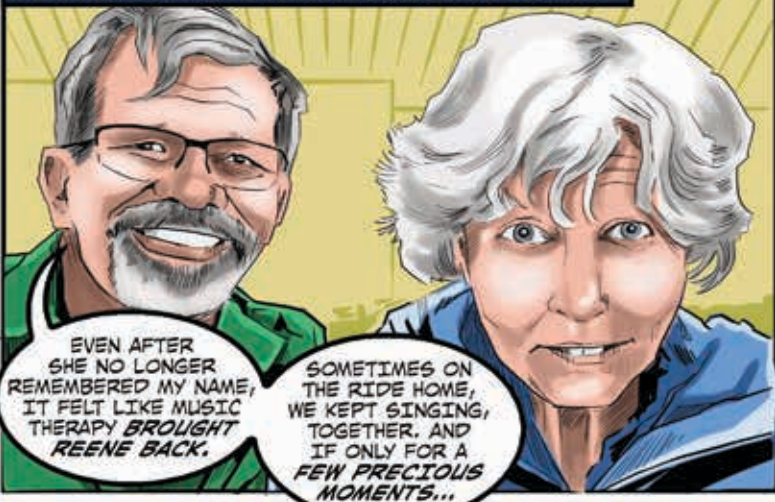


"IT'S NOT CENTERED IN ONE PART OF THE BRAIN. MUSIC CAN INVOLVE THE AUDITORY CORTEX, VISUAL CORTEX, MOTOR CENTER, LANGUAGE CENTER, MEMORY CENTER. MUSIC THERAPY WORKS BECAUSE IT PULLS FROM EVERYWHERE."

"IT WORKED FOR REENE. SHE WAS A WALKING JUKEBOX. OLD SONGS, NEW SONGS - SHE KNEW THEM ALL AND SANG ALONG. REENE KNEW EVERY WORD, EVEN WHEN I DIDN'T."



WHEN REENE SINGS, SOMETHING DEEP INSIDE STIRS...



EVEN AFTER SHE NO LONGER REMEMBERED MY NAME, IT FELT LIKE MUSIC THERAPY BROUGHT REENE BACK.

SOMETIMES ON THE RIDE HOME, WE KEPT SINGING TOGETHER. AND IF ONLY FOR A FEW PRECIOUS MOMENTS...



**CODA:** REENE KRAMER CONTINUED TO PARTICIPATE IN MUSIC THERAPY UNTIL TWO WEEKS BEFORE SHE DIED IN 2019. BILL KRAMER SERVES AS A SOUNDING BOARD FOR OTHER CAREGIVERS WHOSE LOVED ONES HAVE DEMENTIA. AT NO COST TO PATIENTS, CLEVELAND CLINIC LOU RUVO CENTER PROVIDED 3,000 ENCOUNTERS WITH MUSIC THERAPY IN 2020, SUPPORTED ENTIRELY BY THE GENEROSITY OF DONORS. [clevelandclinic.org/NVgroupMT](http://clevelandclinic.org/NVgroupMT)

# Online Delivery Expands the Multi-State Reach of Artmaking

Billed as an “artmaking class for everyone,” Mind in Design brings together friends and families across the community and the country to enjoy a new online spin on a program to promote patient-caregiver interaction, increase socialization and provide space for individuals to change their routine, de-stress and unwind.

Wondering what artmaking together might look like online in as many locations as there are participants?

So were we. Beginning in October 2019, Mind in Design was offered on campus at Cleveland Clinic Lou Ruvo Center for Brain Health. For some, it provided a highly anticipated monthly excuse to leave the house; for others, driving more than an hour round trip was the only thing they didn't like about the 90-minute class. Then came COVID-19.

In March, the Lou Ruvo Center for Brain Health paused all in-person programming and migrated all educational, therapeutic

and support programs online, effectively eliminating transportation and geographic limitations. Since that time, Mind in Design has expanded to two sessions in a single day to accommodate the increased demand. The class is routinely garnering more than three times its pre-COVID attendance, reaching up to 60 households each month in places as far away as Cleveland; Glendale, Washington; Kenosha, Wisconsin; Chico, California; and rural northern Nevada and Arizona.

## “Your Programs Are a Lifeline”

Through quarterly surveys, Verla Niebuhr, Caregiver and Community Education Program Manager, gets a pulse on participant satisfaction with the social engagement, intellectual/artistic stimulation (“Do you enjoy engaging in this activity with your partner?”) and mood impact (“Do you feel better/happier at the completion of this activity?”) that Mind in Design is creating. Here's a sample of the feedback:



*This makes me feel less lonely. I live alone and don't go out. Your programs are a lifeline.*

*It's fun to see my friend in this class since she lives in Las Vegas and I am here in Wisconsin.*

*I was amazed that someone out there had gifted enough money for the program to send art supplies out to people the donors don't even know.*

*The art supplies are such a special gift. It is so important and such a treat to get mail that is not a bill. It makes me feel connected to Lou Ruvo in a unique way. I know it takes extra expense and effort, but REALLY makes a difference in morale.*

*It's virtual, so it saves me three and a half hours' drive one way to join in person.*

*My friend just loves it when the moderator speaks to her and calls her by name.*

*The instructor is very kind, talks to each member of the class and is most knowledgeable about how to communicate with students who have various memory issues.*

*Please, please continue the class, as it has been something I look forward to each month.*







Participants ready to begin virtual artmaking class in their respective homes.

### Why They Give

It's this type of impact that inspired the E. L. Wiegand Foundation to fund the audiovisual technology and production services to power the online delivery of Mind in Design, in addition to the broader array of educational and therapeutic programs. President and Executive Director Kristen Avansino says measurable results are an important criterion in funding decisions.

The Mark and Carolyn Guidry Foundation, which also has provided funding for Mind in Design, says, "Our mission is supporting education and the arts. The Lou Ruvo Center for Brain Health allows us to pursue this mission for a special age group."

Leah and Andrew Gore's gift was inspired by the opportunity the new online platform presented to expand the program's reach, effectively giving more families the chance to stimulate the mind through art, despite the pandemic.

### JOIN US!

Notify us if you would like to receive our monthly eblast to stay informed about free online programs: [LouRuvoSocialServ@ccf.org](mailto:LouRuvoSocialServ@ccf.org). View our online events calendar: [ClevelandClinic.org/NevadaEvents](http://ClevelandClinic.org/NevadaEvents).

To fund educational, therapeutic or support programs, contact our development team at 702.263.9797 or [DonateNevada@ccf.org](mailto:DonateNevada@ccf.org).



# Bringing a Sense of Belonging Into Homes Across the Country

“Sad but safe” is how Lynda Israel’s family describes being at home due to COVID-19. Yet, for this volunteer facilitator of Conversations to Remember, getting online with eager students “gives life purpose” and is a break from the mundane: “After all, unless I’m at the grocery store or the doctor’s office, who else am I speaking with these days?”

While the twice monthly interactive class migrated online in March 2020, Cleveland Clinic Lou Ruvo Center for Brain Health has offered it since 2014. The class uses art to drive conversation.



Lynda Israel enjoys art at home during the COVID pandemic

“It is one way to keep individuals with cognitive decline engaged and feeling part of society and part of a group,” says Lynda, who has facilitated more than 70 sessions. A fan of Norman Rockwell since she acted alongside the artist in summer stock theater in the Berkshires decades ago, Lynda adds, “Norman Rockwell, Mary Cassatt, baseball, or anything with kids or dogs are guaranteed conversation-starters.”

While participants used to chat informally over snacks before and after class, the online equivalent has been a growing interest in each other’s lives and a desire for normalcy, reflected in a conversation that arose around the plight of a class member awaiting the arrival of an electrician to fix the refrigerator.

“Everyone was asking ‘normal’ questions and wanted a ‘normal’ conversation around ‘Was the food spoiling?’ and so on,” says Lynda.

## Caring for Caregivers

Another outreach program now offered online is Powerful Tools for Caregivers, which is designed to counteract negative feelings and positively impact the health of a diverse caregiving population. This class meets once a week for six consecutive weeks, helping participants learn self-care behaviors, manage emotions and find community resources. The evidence-based program is led by trained volunteers who either are caring or have cared for a family member.

“Their close connection to caregiving inspires hope and a path forward for participants on a similar journey,” says Verla Niebuhr, Caregiver and Community Education Program Manager.

“I’m glad we’re able to offer online classes since it’s better than having no class at all. However, even as an instructor, I’m not unaffected by the limitations of technology, which doesn’t allow the same level of interaction for all participants as being together in the same physical room,” says volunteer Jane Karadbil.



Njeri Buncamper at the 2019 volunteer appreciation luncheon



Jane Karadbil gears up to teach online

Co-facilitator Njeri Buncamper, who has a professional background in technology, says, “I love to teach and I love to learn, and seeing how much the class helps others is fulfilling for me as a volunteer.”

## An Opportunity to Join In

While she, too, misses human contact and interaction, Njeri has observed excitement and interest among caregiver participants, who reported that the class improved their lives and that they would miss it when it ended.

Moreover, the online classroom has created an opportunity for caregivers who had never been able to attend in-person classes at the Lou Ruvo Center for Brain Health due to transportation difficulties or distance. Now, participants log on from rural communities of northern Nevada and Arizona and from cities as far away as Tampa, Chicago and San Diego, says Verla.

Jane is teaching an additional online session of Powerful Tools for Caregivers in early 2021, but is nonetheless looking forward to post-pandemic times when the class will be offered both online and in-person. “One of the things we talk about in class is that caregiving can be isolating. So, being able to get out of the house once again and build camaraderie with peers face-to-face will be a welcome respite for all!”

For a full list of free education, therapeutic and support programs at the Lou Ruvo Center for Brain Health, visit [ClevelandClinic.org/NevadaEvents](http://ClevelandClinic.org/NevadaEvents).

Interested in volunteering at our center? Contact [reinkm@ccf.org](mailto:reinkm@ccf.org)



# Thanks to Donor Support, Professional Athletes Brain Health Study Marks Its 10<sup>th</sup> Anniversary

The Professional Athletes Brain Health Study (PABHS) is a landmark longitudinal study of athletes exposed to repeated head impacts (RHI). Since the first participant was enrolled in 2011, the PABHS has become an international effort led by Cleveland Clinic that brings together a multidisciplinary team of scientists to study the neurological effects of RHI over the lifespan of professional athletes.

## Role of Philanthropy

Given that the PABHS is focused on the long-term effects of RHI, the longer an athlete is followed, the more longitudinal — and therefore more valuable — the information collected during that individual’s annual study visits.

A study of this magnitude requires significant resources that the Cleveland Clinic cannot bear on its own. Thus, since its inception in 2011, the PABHS has largely relied on philanthropic donations, many of which have come from the combat sports industry.

UFC has been a valued supporter of the study from the beginning, providing strategic guidance on the sport of mixed martial arts (MMA), referring its athletes for participation, as well as providing funding. In February 2016, following a five-year, \$1 million donation, UFC became the study’s largest financial contributor in combat sports. In 2021, UFC is reinvesting in its commitment to brain health with another five-year, \$1 million donation.

On behalf of athletes everywhere from the pros to the weekend warriors, we thank UFC for its commitment to brain health.



“UFC is proud to continue its support of both Cleveland Clinic and the Professional Athletes Brain Health Study. We have supported this study since its inception, and we take pride in standing at the forefront of helping set new standards for athlete health and safety in all sports,” says UFC Chief Operating Officer Lawrence Epstein, left, accompanied by Forrest Griffin, UFC Hall of Famer and Professional Athletes Brain Health Study participant.

### 2011-2021: 10 Milestones in the Professional Athletes Brain Health Study

A LANDMARK LONGITUDINAL STUDY OF ATHLETES EXPOSED TO REPEATED HEAD IMPACTS (RHI)

- 1. Recruitment of the largest group of athletes studied longitudinally:** More than 800 athletes actively exposed — or retired from exposure — to RHI
- 2. Retention:** More than half the group has been followed over multiple annual visits
- 3. Identification of potential indicators of brain injury:** Spanning imaging and blood measures
- 4. Identification of Risk Factors:** Including genetics, sex and age
- 5. Natural History:** Potential improvement in brain function following abstinence from exposure to RHI
- 6. Expansion:** In 2019, the study enrolled its first professional bull rider and rebranded to Professional Athletes Brain Health Study
- 7. 31 Publications advancing our understanding of RHI**
- 8. More than 1,500 MRIs conducted**
- 9. Repetitive Head Impact Composite Score:** A tool that can be used to monitor response to treatments in trials of CTE
- 10. Professional Sports Brain Health Coalition:** A group of like-minded professional sports organizations dedicated to advancing brain health safety in sports

# Lynn Weidner: From Pageantry to Philanthropy

Sometimes, a single phone call can change your life. That's what happened when Sherry Hackerman received a call from a local Miss America Pageant official and agreed to enter her daughter, Lynn, then a Douglas College freshman, in the Burlington County, New Jersey, pageant.

The scholarship she received when crowned Miss New Jersey made it possible for Lynn to graduate debt free, and also helped her establish connections that launched her career as well as friendships that remain strong some 40 years later.

## At Home in Las Vegas

Lynn worked in television and then for the New Jersey Division of Travel and Tourism, serving as the governor's spokesperson for the legislation that legalized gambling in Atlantic City, the first location outside of Las Vegas to sanction gaming. Her professional and personal interests dovetailed in 1979 when she met Bill Weidner in his first weeks as Vice President of Hotel Operations at Caesars Atlantic City.

Two years and several promotions later, they married and, in 1996, they relocated to Las Vegas.

Serendipitously, the Miss America Pageant relocated to Las Vegas soon thereafter, and the former Miss New Jersey accepted an invitation to join the board, subsequently becoming chairperson of the judging committee and being named Chair of the Board for three years. She left the organization in 2017.

Las Vegas provided additional connections for the Weidners. In Bill's first months as a hospitality executive, he met Larry Ruvo, an executive at what is now Southern Glazer's Wine & Spirits, a leading supplier to the Las Vegas resort corridor. Conversation turned to Larry's passion, which was raising funds to establish a brain center in honor of his father, Lou, who had passed from Alzheimer's disease just two years earlier.

"We've been involved with fundraising for the Lou Ruvo Center for Brain Health

since before a shovel had been put in the ground," says Bill.

And who was behind that shovel? Lynn Weidner's cousin, the late Willard Hackerman, who was Chairman and CEO of Whiting-Turner when the construction firm was executing Frank Gehry's vision for Cleveland Clinic Lou Ruvo Center for Brain Health.

## Access to Great Care

"Despite so many ties to the center, we never imagined I would benefit from its expertise. Yet, in 2012, it was a doctor at the center who delivered a diagnosis of Parkinson's, and I have been privileged to be cared for by the center's world-class neurology team ever since, including Dr. Zoltan Mari and Dr. Dylan Wint," says Lynn.

While Lynn says she can't dance as well today as she did onstage as Miss New Jersey, she credits a lifelong commitment to fitness to keeping her moving despite Parkinson's disease.



Lynn Weidner, Chair of the Board of Miss America, making scholarship presentations during a preliminary competition night



Bill and Lynn with Muhammad Ali at his training camp in 1980, prior to a championship fight.



“I can’t say thank you enough,” Dr. Cordes says. “We simply can’t do science without philanthropy.”

As donors to the Lou Ruvo Center for Brain Health, the Weidners enjoy an inside look at research by following and supporting the work of Dietmar Cordes, PhD, the medical physicist leading the brain imaging research team.

“Were the science settled,” Bill notes, “we wouldn’t need those masterful mathematicians. Until then, we enjoy following their progress, and are confident that spectacular discoveries will come out of this research team.”

Lynn, whose mother also has Parkinson’s disease, says, “If I’d known as much about the disease at the time of her diagnosis as I do now, I might have picked up on the clues earlier on.”

Bill sums up the couple’s sentiments: “It’s wonderful to have access to Cleveland Clinic, which has great patient treatment, support and education, but is also an important research institution. At the end of the day, what we and all families want is prevention or a cure.”



Lynn Weidner with Dr. Zoltan Mari at the Lou Ruvo Center for Brain Health

### Probing Parkinson’s Disease Via Brain Imaging

Since establishing the brain imaging research team in 2014, the Lou Ruvo Center for Brain Health has engaged in robust data analysis to translate our neurologists’ medical learnings into publishable, actionable insights to share with the scientific community.

The team’s objective is to develop more advanced imaging methods and better data analysis approaches to find novel imaging biomarkers of neurodegenerative diseases such as Parkinson’s disease. One important known biomarker is loss of functional connectivity, which is observed as a loss of synchronization among certain regions of the brain.

A conventional MRI scan generates one image of the brain, which radiologists can view in cross-sectioned slices. Utilizing the more advanced imaging technique of functional MRI (fMRI), researchers collect the same image

every second for 10 minutes, yielding hundreds of images. These multiple data points provide insight into brain activity over time.

During a 10-minute resting-state scan, brain networks in healthy brains switch between active and inactive states every few seconds. In Parkinson’s disease, the brain imaging team discovered, the switching rate is reduced by about 20 percent for a majority of brain networks. This discovery yielded a new

imaging biomarker for Parkinson’s disease named frozen dynamics, a reference to the reduction in switching rates of resting-state brain networks.

“Imagine you’re in an exercise class where the instructor is doing a series of complicated dance moves but, as a member of the class, you always lag behind the instructor,” says Dr. Cordes. “That’s what’s happening to individuals with Parkinson’s. Their executive control network is lagging behind.”

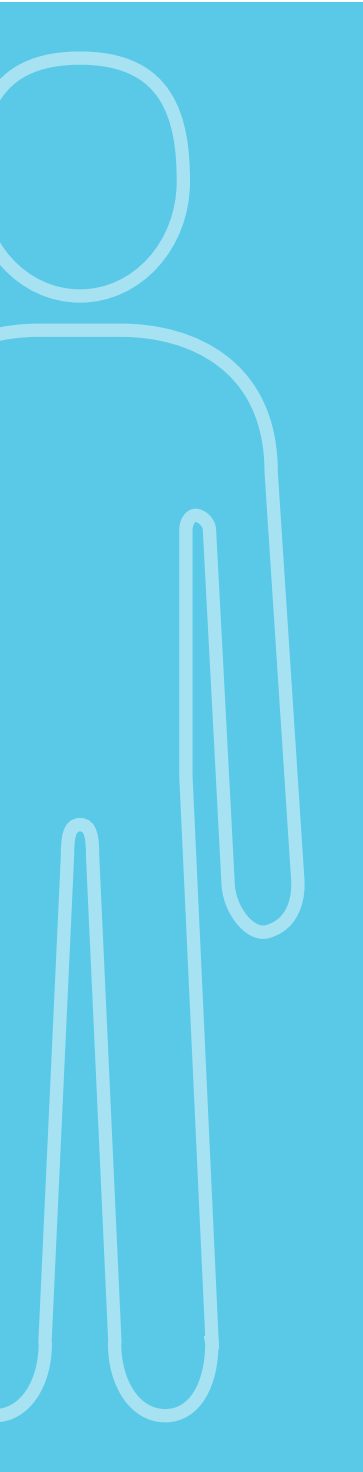
### Philanthropy Packs a Punch

Thanks to philanthropy, Dr. Cordes team’s research is expanding to look at other networks, such as how the default mode network (when the brain is at resting state) interacts with the executive function network. Preliminary results suggest that both networks show a fairly strong coupling or relationship: Just as with the instructor-student example, despite a time delay, a functional connection remains.

Yet, Dr. Cordes notes, all of this research comes to a screeching halt without philanthropy such as that from Lynn and Bill Weidner, who are particularly engaged in the scientific details of his team’s work. Generous donors cover a range of expenses, from team salaries to equipment to attendance at conferences where scientists exchange ideas that inspire new research years before publication in peer-reviewed journals.

“I can’t say thank you enough,” Dr. Cordes says. “We simply can’t do science without philanthropy.”

**You can support science.  
Call 702.263.9797.**



# Whole Body MRI Scan

A Whole Body MRI provides an overall snapshot of one's general health. A head-to-thigh scan, it may detect cancers in the earliest stages of formation, physical abnormalities, inflammation or obstructions.

.....

Our goal is to put your mind at ease by providing enhanced insight into your entire body. A Whole Body MRI at Cleveland Clinic Nevada involves two visits:

- 1. MRI scan**
- 2. Consultation with our family physician**

702.701.7948 | [LasVegasImaging@ccf.org](mailto:LasVegasImaging@ccf.org) | [ClevelandClinic.org/Nevada](http://ClevelandClinic.org/Nevada)

*Whole Body MRI scans are not typically covered by insurance.*



KEEP MEMORY ALIVE  
**MONTH OF MEMORIES**

**WE ARE SO  
PROFOUNDLY  
GRATEFUL**

that even during a pandemic, our community and friends came together to provide unwavering support to Cleveland Clinic Lou Ruvo Center for Brain Health's patients and caregivers.

**THANK YOU TO OUR SPONSORS**

7-11 Stores  
Carson Kitchen  
CHICA Restaurant  
Constellation Brands  
Constellation Brands Beer Division  
Crown Imports  
Delicato Family Vineyards  
Delmonico Steakhouse  
Deutsch Family Wine & Spirits  
Diageo Spirits  
El Super  
Ellis Island Casino & Brewery  
Emeril's New Orleans Fish House  
Empress Gin  
Fabulous Freddy's  
Fetzer Vineyards  
Fever Tree USA Inc

Foley Family Wines Inc  
Frederick Wildman & Sons  
Gerard Bertrand  
Green Valley Grocery  
Heaven Hill Brands  
Heavenly Pies  
Justin Vineyards & Winery  
King Ranch Market  
La Bonita Supermarkets  
Lawry's The Prime Rib  
Lee's Discount Liquor  
Mariana's Markets  
Moet Hennessy USA  
Mt. Charleston Lodge  
Patron Tequila  
Pit Stop

Smith's Food and Drug  
Short Line Express Market  
Southern Glazer's Wine and Spirits  
Sprouts Farmers Market  
Ste. Michelle Wine Estates  
Terrible Herbst  
Total Wine & More  
Trattoria Reggiano  
Treasury Wine Estates  
Trustworthy Brewing Co. & BBQ  
Village Pub  
Victoria Distillers  
Wagner Family of Wine  
Walmart Supercenter  
Yardbird Southern Table & Bar  
Yellow Tail Wines

**JOIN US NOVEMBER 1-30, 2021.**

Visit [keepmemoryalive.org/MoM](https://keepmemoryalive.org/MoM) to learn more.

# Community Support for Keep Memory Alive Continues, Even as Events Take on a New Look

With safety in mind, in March we decided not to rent our Keep Memory Alive Event Center, hold the annual rodeo at Shakespeare Ranch or any of the other one-of-a-kind evenings the Keep Memory Alive team stages. We're more grateful now than ever to the community for collaborating with us on creative approaches to fundraising.

**Here are a few examples. If you have a fundraising idea, please contact Keep Memory Alive at 702.263.9797.**

## Las Vegas Raiders Kick Off the Season with a Gift

On September 21 when the Las Vegas Raiders played their inaugural game in Allegiant Stadium against the New Orleans Saints, one man was conspicuously absent: Las Vegas Raiders Owner and Keep Memory Alive Board Member Mark Davis, who pledged not to be in the new stadium until COVID restrictions allow games to be fully open to fans.

Instead, he hosted a watch party at the team's Henderson headquarters, using the occasion to make a \$250,000 gift to Keep Memory Alive.

"All of us at Keep Memory Alive and Cleveland Clinic Lou Ruvo Center for Brain Health are extremely grateful for both the Las Vegas Raiders' and Mark Davis' wonderful donation," says Keep Memory Alive Chairman and Founder. "The funds could not have come at a better time, as COVID-19 has put a hold on so many of our in-person fundraising efforts, including our annual rodeo in Lake Tahoe and a celebrity poker tournament."



Larry Ruvo, left, and Mark Davis

## Clark County Medical Society Alliance Names Cleveland Clinic Nevada a Charity of Choice

"Every 65 seconds, a new brain develops Alzheimer's; two thirds of them belong to women," the Clark County Medical Society Alliance (CCMSA) proclaimed on its Facebook Page while announcing Cleveland Clinic Lou Ruvo Center for Brain Health as the beneficiary of a fall luncheon and April 2021 fashion show.

Funds benefit the Women's Alzheimer's Movement Prevention Center at Cleveland Clinic, the first

prevention center in the nation exclusively for women. "Together, we will raise awareness towards women's Alzheimer's. Donations will support prevention, research, programs for caregivers and educational outreach from HealthyBrains.org."

"Standup for our mission towards a healthier Southern Nevada!" the CCMSA encourages its social media followers.



L to R: Shirley Musni, Cindy Choi (co-Presidents CCMSA), and Cleveland Clinic's Dr. Jessica Caldwell and Jody Ghanem



## A Penny for Your Thoughts: The Change That Makes a Difference Goes Virtual

With COVID-19 forcing the Clark County School District to reimagine the 2020-2021 school year as an exclusively online experience, charitable support followed suit. November 16-19, Wilbur & Theresa Faiss Middle School, Victoria Fertitta Middle School and Sig Rogich Middle School returned to support Keep Memory Alive's annual A Penny for Your Thoughts school campaign, with Irwin & Susan Molasky Junior High School joining for the first time. Together, the schools shattered previous records.

A Penny for Your Thoughts is a fun and easy virtual or in-person fundraising campaign that helps fund caregiver support programs. In addition, the fundraising

program engages participants in philanthropy and shares the importance of supporting research and treatment for those suffering from brain diseases.

Each participating school received a branded, online fundraising toolkit, and support from the education and fundraising teams at Keep Memory Alive.

"We received excellent feedback on our new, online brain health education videos," says Anna Robins, Senior Director of Special Events at Keep Memory Alive. "Some teachers even integrated a week of brain health into the curriculum."

Better brain health is a win for people of all ages.

### HAVE A PENNY? GIVE A PENNY

Do you know a workplace, business or school that would like to help? Please contact us at 702.263.9797.



**A PENNY FOR YOUR THOUGHTS**  
THE CHANGE THAT MAKES A DIFFERENCE  
BENEFITING CLEVELAND CLINIC LOU RUVO CENTER FOR BRAIN HEALTH

## Fox5 Las Vegas "Heat Is On"

More than 89 days of 100+ degree heat? Not exactly what most of us hope for in a summer. However, if someone were to give you \$20,000 to commemorate that heat, perhaps you'd think differently?

That's exactly what happened to Cleveland Clinic Lou Ruvo Center for Brain Health. Through Fox 5 Las Vegas' "The Heat Is On" promotion, Cleveland-native-turned-Las-Vegan Tommy DeMore of Universal Solar Direct and Universal Windows Direct

committed to donate \$100 per day that the temperature in Las Vegas rose above 100 degrees.

Although that promise was calculated to total a hearty \$8,900 for our center, in honor of his mother who is battling late stage Alzheimer's, Mr. DeMore more than doubled his donation, presenting a \$20,000 check live on TV to Cleveland Clinic Nevada Administrative Director Erick Vidmar and Marwan Sabbagh, MD, Director.



L to R- Erick Vidmar, Marwan Sabbagh and Tommy DeMore



# FOR EVERY CARE IN THE WORLD

It started with four physicians who wanted to create an institution unlike any other. One devoted to shared clinical expertise, innovative research and the education of future caregivers.

It started with four physicians in Cleveland, Ohio. We are now over 60,000 Caregivers across the globe, dedicated to providing world-class care. For every patient. Around the world.

**100**  
YEARS  
EST. 1921

 **Cleveland Clinic**



“What does the  
building mean?  
It symbolizes hope.”

-Frank Gehry



We look forward to welcoming  
you back to the Keep Memory  
Alive Event Center.

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**KEEP MEMORY ALIVE EVENT CENTER**  
888 W. Bonneville Avenue  
Las Vegas, Nevada | 89106  
[kmaeventcenterlasvegas.com](http://kmaeventcenterlasvegas.com)  
702.331.7043

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A 501(c)3 Organization  
Proceeds benefit Cleveland Clinic  
Lou Ruvo Center for Brain Health

REMEMBERING

# Sheldon Adelson

We are deeply saddened by the January 2021 loss of Sheldon Adelson, an unwavering supporter of Keep Memory Alive and recipient of the Community Leadership Award at our 2020 Power of Love® gala. Sheldon and his wife, Dr. Miriam Adelson, are known for their philanthropic efforts throughout the world spanning medical research, education and many Jewish causes and organizations.

Mr. Adelson was a pioneering business executive and one of the world's most successful entrepreneurs.

A true rags-to-riches story, Mr. Adelson's business career spans more than seven decades and included creating and developing to maturity more than 50 different companies, including the COMDEX trade show for the computer industry.

His experience in the trade show business and his innate ability to challenge the status quo enabled him to lead the transformation of Las Vegas from a gaming-centric regional location into an international business and leisure destination.

When Camille and Larry Ruvo had an idea that would help change the course of how neurodegenerative diseases were treated, Dr. Miriam and Sheldon Adelson were immediately on board and instrumental in supporting Keep Memory Alive in its earliest days. We are grateful for their support, friendship and the incredible legacy Sheldon leaves behind.

Our sympathy is with Dr. Miriam Adelson and the entire Adelson family, as well as Las Vegas Sands Corp. We will forever keep Sheldon Adelson's memory alive.

Sheldon and Dr. Miriam Adelson



As Larry Ruvo told the *Las Vegas Review Journal* on January 12, "It's a sad day for Las Vegas, a sad day for the charitable world, a sad day for Israel, and a sad day for my family. He is a man I truly, truly respected and admired. His charity work will be his legacy. Sheldon Adelson should have a statue on the Strip. He was that extraordinary."

## REMEMBERING

# Siegfried Fischbacher

Our heart is heavy with the January 2021 loss of Siegfried Fischbacher, a Las Vegas icon and tremendous supporter of Keep Memory Alive. Siegfried and his beloved onstage partner, Roy Horn, dazzled many with their magic and helped solidify Las Vegas as the Entertainment Capital of the World.

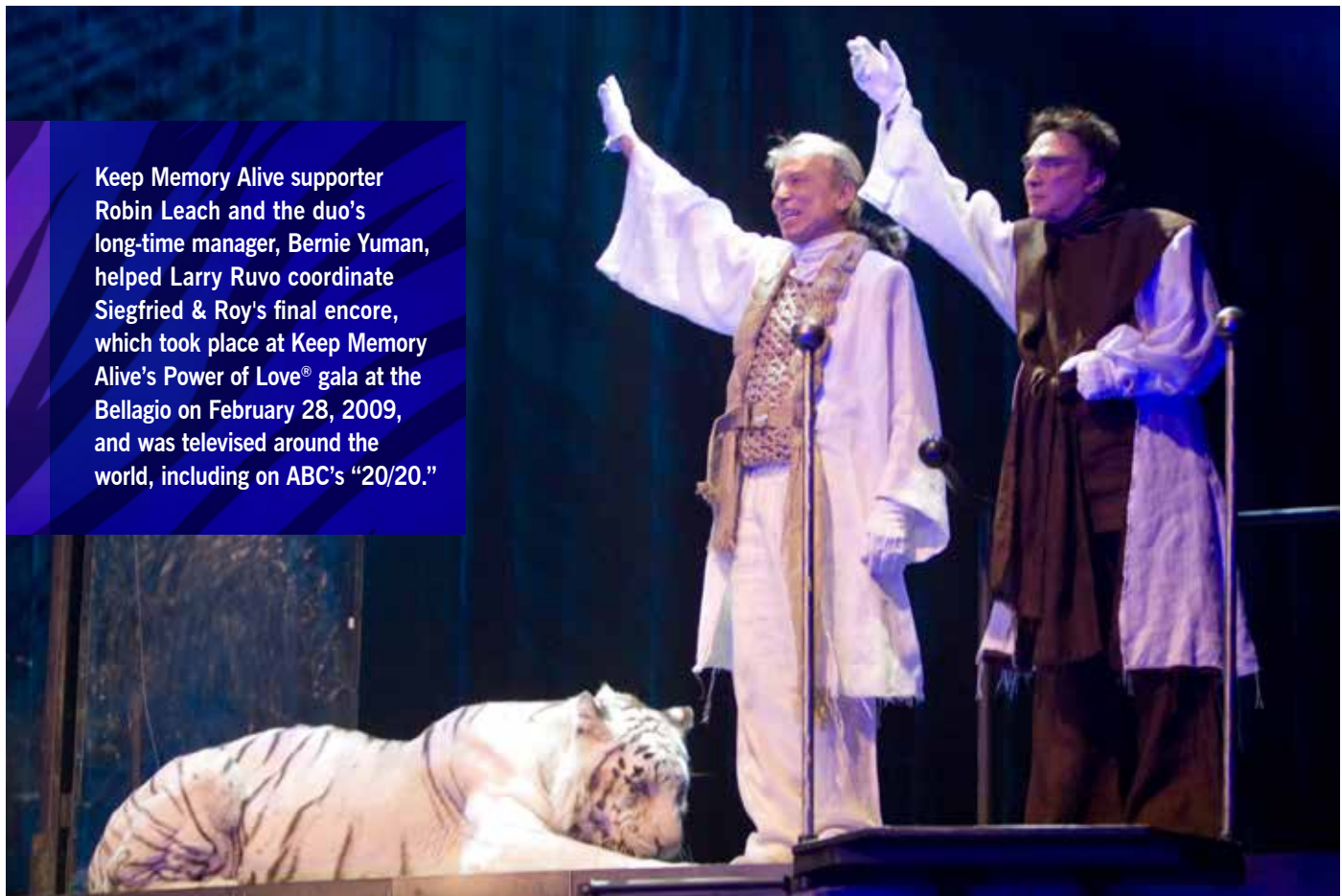
Yet, equally as impressive as their onstage talents was their compassion for others. The kindness and generosity they displayed to animals, their fans and charitable causes and organizations were no illusion.

Before Cleveland Clinic Lou Ruvo Center for Brain Health opened its doors, Siegfried & Roy were supporters of Keep Memory Alive and remained steadfast as our mission to deliver world class care for neurodegenerative diseases came to fruition. We were honored to assist Siegfried in his role as a caregiver to Roy, and to celebrate him with our inaugural Caregiver Award at the 21<sup>st</sup> annual Power of Love<sup>®</sup> gala.

Both Roy, who passed away in May 2020, and Siegfried will be greatly missed, but their magic will live on forever.



**“I am eternally grateful for their support and the legacy they leave behind. Siegfried & Roy will be greatly missed, but their magic will live on forever,”** says Larry Ruvo, Chairman and Founder of Keep Memory Alive, pictured here touring Siegfried Fischbacher, left, and Roy Horn, center, in January 2009 prior to the Lou Ruvo Center for Brain Health’s opening.



**Keep Memory Alive supporter Robin Leach and the duo’s long-time manager, Bernie Yuman, helped Larry Ruvo coordinate Siegfried & Roy’s final encore, which took place at Keep Memory Alive’s Power of Love<sup>®</sup> gala at the Bellagio on February 28, 2009, and was televised around the world, including on ABC’s “20/20.”**

# Recognized for Excellence

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.**

## 2019 Research Awards

(Neurological Institute, Cleveland Clinic, November 2020)

**Liliana Dumitrescu** (*Rising Star*)

**Nancy Caputo and Michelle Sholar**  
(*Above and Beyond*)

**Nadia Fulkerson** (*Outstanding Leadership in Clinical Research by Research Management or Finance*)

## Nonprofit of the Year

(Nevada Women's Chamber of Commerce's Nevada Women's Hall of Fame, November 2020)

**Cleveland Clinic Lou Ruvo Center for Brain Health**

## Battle Born Business Campaign (September)

As a result of our operational response to COVID-19, Cleveland Clinic Lou Ruvo Center for Brain Health was featured in Governor Steve Sisolak's Battle Born Business Campaign. The campaign highlighted businesses throughout Nevada that have taken creative measures to stay safe and stay open.

The Lou Ruvo Center for Brain Health was selected for our efforts in bringing both patient appointments and our free educational and support programs to virtual platforms (see page 31).



## ISMRM Magna Cum Laude Merit Award

(ISMRM conference, August 2020)

**Zhengshi Yang**, for his abstract on neuroinflammation in Alzheimer's disease and the GE180 study

## Certified Medical-Surgical Registered Nurse

(Medical-Surgical Nursing Certification Board, May 2020)

**Nurah Ali, CMSRN**

**Fellow** (American Academy of Neurology, 2019-2020)



Carrie M. Hersh, DO, MSc, FAAN



Le Hua, MD, FAAN



Zoltan Mari, MD, FAAN

## 2020 ALZHEIMER'S AWARD

(*Journal of Alzheimer's Disease*, July 2020)

Each year, the associate editors of the journal select the best article from the previous year's volumes. The 2020 award goes to Justin B. Miller, PhD, ABPP/CN, and Aaron Ritter, MD, for *The Pathology of Rapid Cognitive Decline in Clinically Diagnosed Alzheimer's Disease*.



Justin B. Miller, PhD, ABPP/CN



Aaron Ritter, MD



ANNIVERSARY

LET'S CELEBRATE  
THE POWER OF LOVE

SATURDAY, OCTOBER 16, 2021  
LAS VEGAS

More information to come: [KEEPMEMORYALIVE.ORG/POL](http://KEEPMEMORYALIVE.ORG/POL)

**KEEP MEMORY ALIVE**

Supporting the Mission of Cleveland Clinic Lou Ruvo Center for Brain Health

ALZHEIMER'S | HUNTINGTON'S | PARKINSON'S  
MULTIPLE SYSTEM ATROPHY | MULTIPLE SCLEROSIS



**Cleveland Clinic**

Lou Ruvo Center for Brain Health

# KEEP MEMORY ALIVE

Supporting the Mission of Cleveland Clinic Lou Ruvo Center for Brain Health

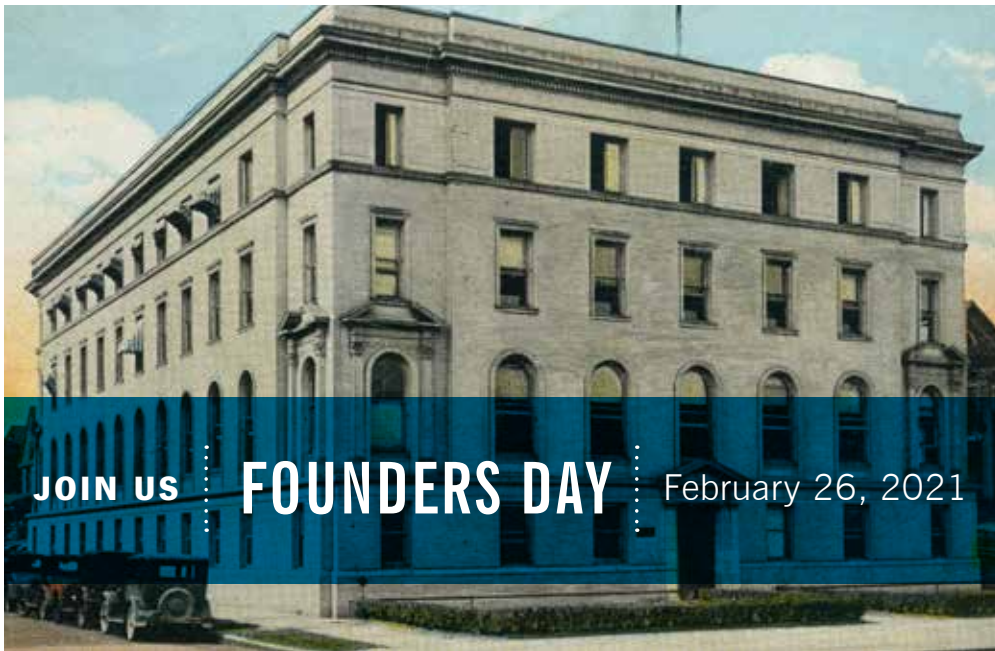


ALZHEIMER'S | HUNTINGTON'S | PARKINSON'S  
MULTIPLE SYSTEM ATROPHY | MULTIPLE SCLEROSIS



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Las Vegas, NV 89106  
Office 702.263.9797  
Toll free 888.268.9797

keepmemoryalive.org  
clevelandclinic.org/Nevada



**JOIN US** for a year of celebration, starting with the 100th anniversary of Cleveland Clinic's opening in 1921.

**WHEN:** Friday, February 26, 2021  
6:00 p.m. – 7:00 p.m.

**LOCATION:** Virtual

**RSVP:** To receive updates and information on how to watch virtually: [clevelandclinic.org/foundersday](https://clevelandclinic.org/foundersday)

**Global Founders Day Keynote Address**

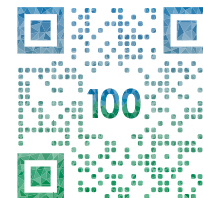
Remarks from Cleveland Clinic CEO and President, Tom Mihaljevic, MD

**World Premiere of the CNN Film —**  
“A Century of Care”

**100**  
YEARS  
EST. 1921



**THE FUTURE  
OF HEALTHCARE  
SINCE 1921.**



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