A B O U T T H I N K I N G

A Publication by Cleveland Clinic Lou Ruvo Center for Brain Health

Cleveland Clinic Nevada

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KEEP MEMORY ALIVE

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

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25 YEARS OF FUNDRAISING LEADS TO ONE POWERFUL NIGHT FOR BRAIN HEALTH

Keep Memory Alive's 25th annual Power of Love® gala at Resorts World Las Vegas on October 16 brought top talent Anthony Anderson, Tori Kelly, Kenny Loggins, Demi Lovato, Bruno Mars, Marilyn McCoo and Billy Davis, Jr., AJ McLean, Wanya Morris and Shawn Stockman from Boyz II Men, Jordin Sparks and Charlie Wilson together to honor legendary musicians Smokey Robinson and Kenny "Babyface" Edmonds and raise funds and awareness for Cleveland Clinic Lou Ruvo Center for Brain Health.

Also in attendance were "Bar Rescue" star Jon Taffer, jeweler Steven Lagos, Las Vegas Raiders owner Mark Davis, Las Vegas Golden Knights owner Bill Foley, and Paul Mitchell Hair Care and Patrón Spirits Co-Founder John Paul DeJoria, the visionary who presented Larry Ruvo with Keep Memory Alive's very first fundraising check that launched the Power of Love gala 25 years ago.





Befitting the love-themed event, before Bruno Mars presented Keep Memory Alive's achievement award to Babyface, calling him his mentor and hero, he repeated advice the evening's honoree had given him for any time he's recording in the studio: "Make sure there's love in it."

Babyface shared his personal tie to Keep Memory Alive, saying, "My mother was losing her memory in her last years and there's nothing more painful than someone you love not remembering you." He thanked the Lou Ruvo Center for Brain Health for its support and counsel, and for "not just working to keep her memory alive, but to keep all of our memories alive."

As Smokey Robinson accepted his award from Anthony Anderson, he shared his personal experience of dementia, remembering Bobby Rogers of The Miracles: "We were born on the same day in the same hospital and sang together for 12 years. Every year on our birthday, we would call each other. He passed away five years ago, and I called him the year he passed, and he had no idea who I was. It's a horrible disease." **K.T. Lim** received a standing ovation when accepting the Keep Memory Alive Community Leadership award from Larry Ruvo and Keep Memory Alive Vice Chairwoman and Co-Founder Camille Ruvo, who acknowledged his support of caregivers who take care of the patients 24/7.

Celebrity chefs **Wolfgang Puck** and **Bobby Flay** prepared exquisite cuisine paired with wines from Southern Glazer's Wine and Spirits, followed by a showstopping dessert display from the Resorts World Las Vegas pastry team.

Guests bid on exceptional experiences and items during the silent and live auctions including a private dinner with Jon Bon Jovi in East Hampton, an opportunity to announce the Las Vegas Raiders live draft pick alongside Mark Davis at the 2022 NFL Draft, and a day of playing chess with Andrea Bocelli followed by attending one of his concerts.



Gala Grand Finale with Jordin Sparks, Wanya Morris, AJ McClean, Smokey Robinson, Babyface, Charlie Wilson, Marilyn McCoo, Billy Davis, Jr, and Kenny Loggins



Bruno Mars









THANK YOU TO OUR 2021 POWER OF LOVE SPONSORS:

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Dylan Wint, MD

DIRECTOR'S MESSAGE

Cleve

Dylan Wint, MD

Center Director, Cleveland Clinic Lou Ruvo Center for Brain Health

Camille and Larry Ruvo Chair for Brain Health

Las Vegas Legacy Chair in Neuroscience Education

Director, Education





Parkinson's disease: Discovered in 1817. No preventive treatments. No recovery, no cure. Perhaps to the annoyance of my family, I'm a bit of a history buff. So, it's been interesting to observe the speed at which we've been able to identify preventive options for COVID, compared to those in my "day job" as a cognitive disorders specialist.

The rapid discovery of vaccines for COVID-19 has been a boon to society worldwide, as we all await post-pandemic "normalcy." Our patients at Cleveland Clinic Lou Ruvo Center for Brain Health, in whom we've observed adverse changes in brain health due to social isolation, lack of exercise and other "side effects" of a worldwide plague, are no exception (see page 3).

Yet, thanks to many recent wins, we remain optimistic for a better future for families living with the neurodegenerative diseases treated at our center. For without research, there are no new treatments, preventions or cures (see page 7).

Not only has the Lou Ruvo Center for Brain Health built one of the largest Alzheimer's disease clinical trials programs in the country, having conducted more than **100 research studies** to advance new therapies for brain disorders towards FDA approval, we also recruited **700 new research participants** in a single year. And, in just 12 years, our clinician-scientists have **published more than 780 scientific papers** advancing the science of Alzheimer's, Parkinson's, multiple sclerosis, neuropsychology, brain trauma and clinical trials. The NIH has just awarded our center a second consecutive five year grant to continue growing Southern Nevada's first Center of Biomedical Research Excellence in collaboration with University of Nevada, Las Vegas (see page 5).

This comes on the heels of four recent NIH grants over the past two years, to:

- Better understand mechanisms of Alzheimer's disease risk and identify appropriate risk reduction approaches to benefit women
- Address disparities faced by individuals
 with dementia in rural settings
- Use biomarkers to predict dementia among individuals with Parkinson's disease
- Develop statistical models for using fMRI data to predict individuals at risk for Alzheimer's disease

And we're seeing progress: Two of the new drugs approved in 2019-2021 for neuromyeltis optica spectrum disorder (NMOSD) and MS were tested at our center.

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 (see page 29). And this research is made possible by grants and donor support, both public and private.

Thank you for your commitment to world-class care.

A B O U T THINKING

Cleveland Clinic Lou Ruvo Center for Brain Health

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About The Cover:

25 YEARS OF ENTERTAINMENT And Fundraising

This cover is a tribute to all the entertainers who have contributed their talents through the years to help raise funds to Keep Memory Alive. It's because of these generous people — true philanthropists in their own right — that Cleveland Clinic Lou Ruvo Center for Brain Health opened its doors to patients and their families in 2009, and has now delivered more than 220,000 appointments.

The Pandemic Derailed Us; How Do We Get Back on Track?

COVID-19 has precipitated a number of brain-related medical complications, including stroke and delirium/confusion. And many survivors of all ages are suffering from lingering confusion and "brain fog."

Dylan Wint, MD, Director, Cleveland Clinic Lou Ruvo Center for Brain Health, says brain diseases result from interactions between inborn factors (genetic susceptibility) and lived experience (environmental factors), and "The most universal recent lived experience is the COVID-19 pandemic."

While Dr. Wint and clinical colleagues across the center's cognitive, movement disorders and multiple sclerosis (MS) care teams have long spoken about the impact of modifiable lifestyle choices (see *Six Pillars sidebar*), never in our center's 12-year history has there been a better case study of the impact of the Six Pillars of Brain Health than that presented by the pandemic.

While COVID-19 may have longer-term effects that remain to be seen from secondary factors that affect brain health, here are some current observations from the team at the Lou Ruvo Center for Brain Health.

What have you seen in terms of the toll COVID-19 has taken on both patients and care partners?"

COVID-19 drastically changed how people interact and how they participate in vital and meaningful occupations.

"People I have worked with for many years in occupational therapy, whose symptoms were generally pretty stable, were suddenly coming in



with increased weakness, higher frequency of falls, and signs of depression and anxiety," says Shaina Meyer, OTR/L, Clinical Rehabilitation Manager.

"Beyond the worldwide devastation of COVIDrelated deaths, there have been silent effects on what we have lost in terms of social isolation, which has



really hit caregivers, a role that has always been isolating but has become much more so during the pandemic," says Aaron Ritter, MD, Staff Neuropsychiatrist.

"Having to shut down activities such as theater, day programs, clubs, and in-person visits with children and grandchildren really took a toll on caregivers, who felt their loved ones declined mentally, had to respond to patients' difficulty with



understanding/accepting/remembering changes in habits, and had to find things to do safely from home using technology to access online resources," says Dr. Wint. (See clevelandclinic.org/NevadaEvents for some options)

"We learned that living in lockdown in a care facility, isolated from family and friends to keep a resident 'safe,' was likely not the best plan of care," says



Ruth A. Almén, LCSW, Clinical Manager, Social Work Services. "What kind of quality of life is left if your body is alive but your brain has lost the will to function?"

Something's been stolen, but perhaps a social worker may help

"Many care partners tell us COVID has stolen much of the precious quality time remaining before their loved one's neurodegenerative disease takes the rest," says Ruth.





such as MS," says Le Hua, MD. "Our social services utilization has increased and, thankfully, we were able to deliver the care virtually to meet demand."

"I have been overwhelmed by patients' resiliency and blown away by the response to our online meetings, which have not only facilitated participation



by out-of-state patients, but also created unexpected intimacy and connectedness," says Sandy Chapman, LSW, MSCS, Case Manager, Social Work.

The risk of delaying treatment

"MS specialists have a good foundation in immunology and, because our treatments impact the immune system, even pre-COVID, we frequently counseled patients regarding infection risk and vaccinations," says Dr. Hua. "Thankfully, individuals with MS are not at higher risk of COVID-19 infection or complications Clinical Rehabilitation Manager Shaina Meyer offers advice on how to integrate the Six Pillars into your daily routine during the COVID-19 pandemic.

PHYSICAL EXERCISE

Gym closures and migration of exercise classes online took away the venue and/or the motivation for many. The safety and convenience of home delivery replaced the activity of going to the grocery or pharmacy.

Pro tip: Look for free exercise options with the opportunity to see people at a safe distance, such as a walk with the dog in a park or virtual group exercise classes.

MENTAL FITNESS

A heightened risk for depression during the pandemic led to apathy or lack of interest in participating in typical routines, thus reducing engagement in brain exercise.

Pro tip: Now might be just the time to learn something new or challenge a friend to online Scrabble.

FOOD AND NUTRITION

Less in-home cooking and more takeout haven't helped waistlines. We've all heard about pervasive weight gain since the onset of the pandemic.

Pro tip: Get back to the basics of fruits, vegetables, whole grains and lean meats. Consider going online, ordering a Mediterranean diet cookbook and enjoying a culinary adventure.

SOCIAL INTERACTION

For those with limited technical skills or inadequate equipment or internet speed, the shift of most social activity online resulted in social isolation.

Pro tip: The good old-fashioned phone is still a great way to stay in touch.

SLEEP AND RELAXATION

Erratic schedules honed during forced time off work and increased television binge watching have led to inconsistent or poor sleep habits.

Pro tip: Establish a regular bedtime and cease use of smart phones and other technology at least 30 minutes before.

MEDICAL HEALTH

Fear of COVID-19 and reduced access to medical appointments, particularly to annual screenings and other preventive care, have led to an increase in the severity of medical problems.

Pro tip: Providers are just as committed to reducing the spread of COVID-19 as you are. Mask up and make that appointment!

than the general public. So, I am surprised that some would delay or alter treatment of their MS due to the pandemic, given that not treating MS increases risk of long-time disability."

What's next?

"I am glad we are learning to live with COVID, which appears to be here to

stay, but it's still important that we do everything it takes to reduce the effects of infection," says Dr. Ritter. "For most, this will be getting the vaccine and boosters, while those who choose not to should remain socially distanced and vigilant about their overall health for the long haul."

Six Pillars of Brain Health: A Prescription for Reducing Risk

1: GET MOVING

People who exercise regularly have a lower risk of developing Alzheimer's disease.



2: "EXERCISE" YOUR BRAIN

Mental activity is just as critical as physical exercise in keeping your brain fit and healthy.



3: EAT MEDITERRANEAN

You are what you eat. Foods rich in antioxidants can help fend off the harmful effects of oxidation from lifestyle and environmental factors that damage your brain as it ages.



4: SPEND TIME WITH OTHERS

Staying connected with family and friends is important for brain health. Studies show those with the most interaction within their community experience the slowest rate of memory decline.



5: REST WELL

Getting a good night's sleep (6 hours or more is recommended) and managing stress are habits that could help you keep your brain young and nimble well into your golden years. Sleep disturbance should be investigated by your doctor.



Many common medical conditions are linked to declining brain function.



Learn more at HealthyBrains.org.



NIH Grant Accelerates Careers, Science in Southern Nevada

Less than a decade ago, "overlooked and underfunded" just might have described southern Nevada's relationship with the National Institutes of Health (NIH). However, a 2015 grant to Cleveland Clinic Lou Ruvo Center for Brain Health changed all that. And in 2021, the NIH renewed its commitment with a second grant.

The National Institute of General Medical Sciences of the NIH has awarded a grant expected to total \$11.3 million to fund Phase II of southern Nevada's first Center of Biomedical Research Excellence (COBRE): the Center for Neurodegeneration and Translational Neuroscience (CNTN).

This new five-year COBRE award builds upon a long-standing collaboration

between the Lou Ruvo Center for Brain Health and the University of Nevada, Las Vegas to continue the efforts of their shared CNTN. Aimed at establishing a translational neuroscience research infrastructure to develop innovative diagnostic methods and therapeutic interventions applicable across neurodegenerative disorders and in diverse populations, the CNTN has become an important local resource with potential national implications.

COBRE grants are part of the Institutional Development Award program, which supports faculty development and institutional research infrastructure enhancement in states with historically low levels of scientific research infrastructure and support from the NIH.

YOU CAN HELP

Private gifts make a difference. To help fund research at the Lou Ruvo Center for Brain Health, contact our development team at 702.263.9797 or DonateNevada@ccf.org.

Phase I: Successful growth

"Since receiving our initial funding in 2015, a promising group of junior investigators has leveraged the resources established by the CNTN to conduct highly innovative research projects, graduating from the CNTN program with independent funding and accelerated career growth," says Aaron Ritter, MD, of the Lou Ruvo Center for Brain Health, the CNTN's Co-Principal Investigator, who cites three examples:



On the heels of his contributions to the CNTN's Translational Biomarker Unit, neuroscientist Jefferson Kinney, PhD, was named

UNLV's Founding Chairman, Department of Brain Health. Now, he will oversee the CNTN's basic science projects and biomarker measurements, and is the Co-Principal Investigator of Phase II.



Jessica Kirkland-Caldwell, PhD, was promoted to Director of the Women's Alzheimer's Movement Prevention Center at Cleveland Clinic

in 2020 and, in 2021, secured NIH funding for research into the ways hormones and stress may influence women's risk for Alzheimer's disease.



Virendra Mishra,

PhD, received a grant from the NIH in 2020 to use biomarkers to develop a predictive mathematical model identifying individuals with

Parkinson's disease who may develop dementia, and was promoted to Assistant Director of the Lou Ruvo Center for Brain Health's Brain Imaging Department.

Dr. Ritter concludes, "This success of these individuals gives me great confidence that the renewal of our CNTN will allow us to continue to fulfill our mission of expanding both our translational neuroscience research capabilities in southern Nevada and our knowledge of neurodegenerative diseases."

Phase II: Introducing the CNTN's three new junior investigators



James Hyman, PhD, Associate Professor in the Department of Psychology at UNLV, is gathering real time neural activity, along

with biomarkers, from mouse brains following acute versus chronic inflammation episodes to better understand the impact of inflammation on behavior and memory-related brain network activity.



PhD, Assistant Professor in Geriatric Neuropsychology in Dr. Kinney's Department of Brain Health,

Samantha John,

is embarking on *Ethnoracial Characterization of Patient-Centered Outcomes*, a study of older adults at risk for neurodegenerative disease, to determine whether healthcare concerns and treatment outcomes differ according to racial and ethnic identity.



PhD, Staff Neuropsychologist at Cleveland Clinic,

Christina Wong.

is launching The Effects of Inflammation and Alzheimer's Disease

Risk Factors on Cognition in Older Adults to create a novel inflammatory composite score to examine the relationship between systemic inflammation and cognitive decline in non-demented older adults and in those with genetic or biological risk factors for Alzheimer's disease.

A Snapshot of Research Opportunities

WHY RESEARCH?

At Cleveland Clinic Lou Ruvo Center for Brain Health, our goal is not only to treat patients, but also to give you, your family and our community an opportunity to participate in clinical trials and research. In doing so, important contributors like you can help advance our knowledge of brain health and disease, while perhaps helping yourself or future generations. Together, we can frame a brighter future.

At the Lou Ruvo Center for Brain Health, we are pursuing answers to brain disease through four types of research. **Research** is a general, umbrella term; those research studies in which a potential new drug or a new device are used are called **clinical trials**. Some research is developed by our physicianscientists, while other times, we work alongside our partners in the pharmaceutical industry to answer important questions related to the diseases we treat.

Each study is reviewed by a panel of patient safety advocates called an Institutional Review Board (IRB) to ensure patients' safety and rights are protected.

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 CONTRIBUTION.

TYPES OF RESEARCH

PREVENTION TRIALS

Trials aiming to prevent the onset of brain disease

TREATMENT TRIALS

Clinical trials of potential new drug treatments for individuals with brain disease

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

LIFESTYLE: HEALTHYBRAINS.ORG

Research on the impact of life choices on brain health

WHAT TO EXPECT ABOUT PARTICIPATION

- Access a potential new drug treatment before it is widely available
- Initial study visit followed by ongoing study visits at routine intervals with prescribed assessments to monitor changes in your brain
- Access a potential new drug treatment before it is widely available
- Initial study visit followed by ongoing study visits at routine intervals with prescribed assessments to monitor changes in your brain
- No drug intervention
- Initial study visit followed by ongoing study visits at routine intervals with prescribed assessments to monitor changes in your brain
- Participate at your convenience via a website or app
- Opportunity to join a database of potential research volunteers for other studies
- Free, online self-assessment of your brain health, recommendations for brain-healthy lifestyle choices, and an opportunity to re-assess your brain health

• Prevent or postpone the development of a disease

RESEARCH GOAL

- Understand how safe a treatment is, or how a treatment works to slow down or stop the progression of a disease
- Better understand the development or progression of a disease
- Incorporate lifestyle recommendations and self-monitor changes in your online brain health assessment scores over time

WHAT HAPPENS TO THE INFORMATION WE GATHER ABOUT YOUR BRAIN?

Each study involves a collection of information about your health. Along the way and also at the conclusion of the study, we make every effort to provide you as much of this information as we are permitted, balancing a participant's interest in their personal health with the confidentiality and requirements of each unique research study. Regardless of what information our researchers are able to share with you, at the conclusion of your participation in the study, information gathered about you will be aggregated with that of other participants as we seek to understand the mysteries of the brain.

THE PATH TO PARTICIPATION

Prior to participation, all prospective research participants undergo:

- An Informed consent process with a research study coordinator to discuss the risks of study participation, and the variety and frequency of study visits and assessments
- A conversation around inclusion and exclusion criteria, a review of medical history, and an array of personal health assessments conducted at our expense to assess eligibility

Once accepted into the study, a research participant will undergo:

- Randomization, or impartial unknown assignment to one of the groups in the study
- **Study visits,** which follow a set protocol. The focus of study visits may include:
 - Examining the participant or monitoring adverse events
 - Dispensing the study drug
 - Evaluating medications the participant may be taking in addition to any provided as part of the study
 - Assessing study outcome measures

COST

There is no cost to participate in research at the Lou Ruvo Center for Brain Health. Rather, some studies may offer a stipend as a courtesy for participation.

HEALTHY? NOT HEALTHY? YOU CAN HELP PEOPLE JUST LIKE YOU

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.

Here at the Lou Ruvo Center for Brain Health we often say, *"If you have a brain, we may have a study that's right for you."* Feel free to test us on that.

JOIN OUR MISSION TO CHANGE LIVES, ONE BRAIN AT A TIME

Healthcare isn't one size fits all. To make sure new medicines and treatments work on everyone, we need people of all colors, ages and backgrounds to help us. With so many options from which to choose, perhaps one of our research studies might be of interest to you or someone you know.

Regardless of which study you select, you'll receive a baseline understanding of your current brain health before you begin participating in the study protocol or standardized steps of your study visits.

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
- Engage with us and find out which trial is a match for you or someone you know: 702.701.7944 or healthybrains@ccf.org
- Start your research participation journey now: healthybrains.org/research

Study Tests a Promising Treatment for Parkinson's Disease Symptoms

What if a simple pill could help individuals treat their Parkinson's disease motor symptoms without disabling side effects such as excessive daytime sleepiness, hallucinations or confusion?

"My patients would consider it a miracle," says Zoltan Mari, MD, Director, Parkinson's Disease and Movement Disorders Program at Cleveland Clinic Lou Ruvo Center for Brain Health. "And that's why I'm really excited about the potential learnings from the two TemPo studies for which our research team is currently recruiting participants."

TemPo is studying tavapadon, an investigational drug being considered for treatment of Parkinson's disease, through two different groups of participants ages 40 to 80:

- 1. Those who have never received levodopa ("treatment naïve")
- Individuals who are experiencing motor symptom fluctuation ("on/off periods") and will continue their normal doses of levodopa while in the study

The prospect of fewer side effects

Tavapadon is a dopamine receptor agonist, a drug that imitates the actions of dopamine. Tavapadon is hoped to selectively activate signals in the brain through dopamine receptors more effectively and with fewer side effects than currently available treatments.

In each of the two TemPo studies, participants will have a 50-50 chance of being on the investigational treatment or a placebo ("sugar pill"); neither the participants nor Dr. Mari, the study's principal investigator, will know to which treatment group the participants have been randomly assigned.



This photo was taken prior to the COVID-19 pandemic and does not reflect current PPE protocol.

Study participation involves:

- **Screening:** a visit to evaluate a prospective participant's suitability for the study
- **Treatment:** 27 weeks of taking the randomly assigned treatment, during which time the participant will engage in study-related tests and answer questions to determine health

and the effects (if any) of the assigned study drug

• Follow-up period: a final check-in with the research team

At the conclusion of the study, an optional open label extension will be offered: a 58-week period when participants will knowingly take the experimental tavapadon.

INTERESTED IN HELPING US LEARN MORE ABOUT PARKINSON'S DISEASE?

Contact the Lou Ruvo Center for Brain Health's research team at 702.701.7944 or healthybrains@ccf.org to see if you may be a fit for this study.







Cleveland Clinic

THE FUTURE OF HEALTHCARE SINCE 1921. IN NEVADA SINCE 2009.







Clinical care, research and no-cost family education and support services.

ALZHEIMER'S = FRONTOTEMPORAL DEMENTIA = LEWY BODY DEMENTIA HUNTINGTON'S = MULTIPLE SYSTEM ATROPHY = PARKINSON'S = MULTIPLE SCLEROSIS

Same-week appointments available

clevelandclinic.org/Nevada

Novel Therapies Bring Hope for Treating Progressive Multiple Sclerosis

Building on 2020, 2021 was a difficult year for most people. Those with demyelinating disorders such as multiple sclerosis (MS) were no exception. Fortunately, bright spots are on the horizon, particularly regarding future treatment options.

With the addition of four new therapies (ozanimod, ofatumumab, ponesimod, and monomethyl fumarate) in 2020-21, we now have more than 20 therapies available for MS.

"This presents 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 at Cleveland Clinic Lou Ruvo Center for Brain Health.

In search of the Holy Grail

Disease progression has traditionally led to increased disability. But for many, the natural progression of MS is exacerbated by MS attacks or relapses caused by the peripheral immune system, which refers to all the immune responses that take place outside the brain. As exciting as today's disease-modifying therapies are, they remain most successful in combating an attack, and much less so in slowing natural progression. And so, the Holy Grail in MS care — stopping disability progression in those who do not have active MS attacks — remains elusive.

Seeking a "twofer"

A recent scientific discovery in MS is the role of microglia in worsening disability. With this knowledge, scientists are working on identifying therapies that target the peripheral immune system



as well as the microglia, immune cells within the central nervous system found in MS lesions. (Lesions are a visible hallmark of MS that can be seen via an MRI scan of the brain.)

One class of drugs that can do both is known as BTK inhibitors, which have been used in oncology and rheumatology and are increasingly safer and better tolerated by patients. The MS community is very excited about the potential for BTK inhibitors to make strides in eliminating disability progression itself — rather than only combating an MS attack. If successful, BTK inhibitors would be a game changer for individuals with MS and their loved ones.



Do they work? We aim to find out

Cleveland Clinic Lou Ruvo Center for Brain Health is enrolling participants in Phase 3 trials evaluating the efficacy of BTK inhibitors in both primary progressive and secondary progressive MS, which presents an exciting opportunity for those with MS.

"Being in clinical trials allows participants to have early access to potential new therapies," says Le Hua, MD, FAAN, Sheila and Eric Samson Chair for MS Research and Director of the MS program. "It can add a sense of purpose, with participants knowing they may be helping others down the road traveling a similar journey with MS."

YOU CAN HELP

If you're interested in participating in MS research, please contact us at healthybrains@ccf.org or 702.701.7944.



COVID-19 Has Changed MS Clinical Practice in Unexpected Ways, Survey Shows

The COVID-19 pandemic has created unanticipated changes in healthcare delivery for people living with multiple sclerosis (MS). The virus' rapid evolution has resulted in a knowledge gap of how COVID-19 has affected MS clinical practice. Findings of a nationwide provider survey, recently published in the scientific journal *Multiple Sclerosis* and *Related Disorders*, reveal early learning aimed at closing that gap.

Carrie M. Hersh, DO, MSc, FAAN, Staff Neurologist and Director of the MS Health and Wellness Program, Cleveland Clinic Mellen Program for MS at the Lou Ruvo Center for Brain Health, Las Vegas, was among fellow specialists from the National Multiple Sclerosis Society's (NMSS) Health Care Provider Council who conducted the

INTERESTED IN RESEARCH OPPORTUNITIES?

We need both individuals with MS and normal controls. Learn more at clevelandclinic.org/NevadaResearch or contact our recruitment specialist at 702.701.7944 or healthybrains@ccf.org



survey of MS clinicians to understand how COVID-19 has impacted clinical practice patterns and other issues affecting them and their patients.

Providers disclose their concerns

The survey explored the pandemic's effects on clinicians' own general wellbeing, such as the availability of personal protective equipment (PPE).



This photo was taken prior to the COVID-19 pandemic and does not reflect current PPE protocol.

Moreover, the survey was unique in addressing MS specialists' perceptions of practice changes in the United States since the onset of the COVID-19 pandemic. Key observations focused on:

- Disease-modifying therapies, and how they're being used in clinical practice during the pandemic
- Telehealth services, with nearly half of MS specialists using virtual visits to provide more than 50 percent of their clinical care
- Redeployment of clinicians to COVID-19 frontlines, raising concern that the pandemic has caused challenges in the capacity of the MS workforce

The research was conducted in the summer of 2020, early in the pandemic.

"Further research is ongoing to explore these trends and develop consensus guidelines around best treatment practices for people living with MS during and after a global pandemic," says Dr. Hersh, whose learnings from leadership roles within NMSS and other national MS groups influence day-to-day care locally with patients.

To make an appointment with an MS neurologist, call 702.483.6000.

For Doctors, Medical School Is Only the Beginning

"What do you want to be when you grow up?"

"Doctor" is a common answer among children of all ages, influenced by the image of the kind, encouraging pediatrician who listens to their complaints and gives their parents a piece of paper bearing instructions that might help them feel better.

And so, from the basic human desire to help others springs the idea of becoming a doctor. Yet, our Cleveland Clinic Lou Ruvo Center for Brain Health doctors admit that after four years of medical school, another four years of residency, and a year or two of internship or fellowship, real-world doctoring extends well beyond what they learned in the classroom or in clinical rotations. Most interestingly, experiences outside the exam room affect patient care in the exam room.

In fact, what happens in the exam room is but the tip of the proverbial iceberg. Now, for what lies beneath the surface...



Carrie M. Hersh, DO, MSc, FAAN Staff Neurologist, Cleveland Clinic Mellen Program for MS at the Lou Ruvo Center for Brain Health, Las Vegas Director, MS Health and Wellness Initiative

"When I thought about being a doctor, I imagined perhaps doing research and maybe developing new treatments for patients. What I didn't realize — and what has actually become my primary research interest — is how important the concept of 'real world effectiveness' is in clinical research, in which we observe an approved drug treatment's varying success across an array of patients as we try to better understand why one works better in certain individuals than in others."



Le Hua, MD, FAAN Director, Cleveland Clinic Mellen Program for MS at the Lou Ruvo Center for Brain Health, Las Vegas Sheila and Eric Samson Chair for Multiple Sclerosis Research

"At the Lou Ruvo Center for Brain Health, the public relations team frequently asks doctors to talk to reporters about our latest research and what we can offer the community. I'm always surprised, and a little shy, when patients exclaim, 'I saw you on TV!' Yet, working with the media has challenged me to distill science down to digestible nuggets of information so that prospective patients and donors alike can understand what's new and exciting in the field of multiple sclerosis and, hopefully, share my enthusiasm for improving patient care."



Zoltan Mari, MD, FAAN Director, Parkinson's and Movement Disorder Program Ruvo Family Chair

"I trained at a public county hospital and then the National Institutes of Health, so, when I landed at my first 'real' job as a practicing physician, I was most surprised by how challenging it was to navigate the commercial insurance landscape. Patients aren't the only ones who have to learn about prior authorization and navigate the covered options versus the array of available treatment options. I guess that's why they call it 'managed care."



Jiong Shi, MD, PhD, FAAN Director, Clinical Trials Program Normal Pressure Hydrocephalus and Clinical Dementia Specialist Cognitive Disorders Team

"Never in medical school or elsewhere in my formal training was I exposed to research. Yet, when I started practicing, mentors engaged in research offered me the opportunity to participate alongside them. Now, research is my passion, and I'm honored to run the clinical trials program here at the Lou Ruvo Center for Brain Health. While there's been more progress in some disciplines than in others, it's heartening to see the approval of 10 new treatments for MS in the past three years."



Odinachi Oguh, MD Staff Neurologist Movement Disorders Team

"I never anticipated the psychological burden on physicians of diseases we treat. If we follow a patient long enough, they will die. As physicians, there's no structured forum in which to grieve or empathize with the family caregivers with whom we've built so much rapport over the years. As the physician lead for our center's continuous improvement efforts, it's something I'd like to change."



Dylan Wint, MD

Director, Lou Ruvo Center for Brain Health Las Vegas Legacy Neuroscience Education Chair Director, Education Neuropsychiatrist, Cognitive Disorders Team

"I'm frequently surprised how much time and effort my physician colleagues and I spend 'marketing' our ideas to gain financial support from public and private entities for our research and community education programs. Without such funding, we would never be able to expand our understanding of the brain."

Listen to the Powerful Voices of People With Brain Disease

Diagnosis is empowering because "it gives you clarity and options," in the words of members of Cleveland Clinic Lou Ruvo Center for Brain Health's Voice of the Patient and Family Advisory Council. This group wanted to showcase the diverse faces of disease, illustrating that "people with a brain disease are people first."

Thus was born the "I Am Powerful Project," a series of profiles of individuals who maximize life while managing brain disease.

If you're inspired to share your Cleveland Clinic Nevada story, please contact wolfn@ccf.org.

Nancy Nelson, 77 Diagnosed with Alzheimer's disease in 2013

If we were to meet, I'd want you to: Join me to spread positive awareness and dispel stigma attached to any Alzheimer's diagnosis. That's powerful.

My dad passed in 2002 from complications of Alzheimer's; nonetheless, I was surprised by my diagnosis at age 69. Yet, if I can help one person better understand the disease, I take that as a win and am OK with eventually following in my father's footsteps — but not just yet.

Early diagnosis has turned out to be a gift, giving me time to navigate uncharted water. People with cognitive impairment live life better for longer if they have a fighter's mentality. We must be partners in our own health. Besides reading, listening and heeding what I see and hear about dementia, I'm a published author, public speaker, an Alzheimer's advocate and activist, and am honored to have been named the 2018 Nevada Senior Citizen of the Year by the National Silver Haired Congress Nevada Delegation in partnership with the Aging Service Directors Organization.

Staying organized is important to me, but timeconsuming: I tell friends and doctors' offices alike to reach out with reminders about our plans to meet. When reading, I have to take detailed notes so I can later flip through for highlights or to reread a point I'm looking for. I've learned to laugh at myself, which helps.





The Lou Ruvo Center for Brain Health has empowered me by...

Making me feel special enough — and have strength enough — to try to make a difference through Alzheimer's advocacy.

James Sanders, 61

Diagnosed with multiple sclerosis (MS) in 2002

If we were to meet, I'd want you to: Not feel sorry for me. Just treat me like a normal person, because I am.

I was having balance issues and I knew something was wrong but, when I learned it was MS, I was shocked. I'd never heard of the disease, and no one could tell me how I got it. Since then, I've realized that while I have MS, it doesn't have to have me.

People with MS are often misunderstood. Yes, it's a debilitating disease that causes nerves and muscles to weaken, but you can function. Today, I enjoy preaching at our family's church, praying and reading scriptures, cooking and baking. Because of my balance challenges, I sit on my walker while I work in the kitchen. Before I start preparing any food, I arrange the tools and ingredients on the counter within reach.

Living my best life with MS is possible because of my faith in God and the love and support I receive from Ty, my wife and caretaker. She helps me with my MS, while I help her manage her arthritis.



The Lou Ruvo Center for Brain Health has empowered me by...

Providing doctors and rehabilitation therapists who can explain the array of treatments available. It's been a life changer.





The Lou Ruvo Center for Brain Health has empowered me by...

Providing the incredible opportunity for me to volunteer and give back to the HD community.



Yvonne Sweeten, 61 Diagnosed with Huntington's disease in 2015

If we were to meet, I'd want you to: Treat me like a normal person

Having friends and family with Huntington's disease (HD), I quickly went in search of a diagnosis when I myself began experiencing symptoms. There's so much hope for a cure today, due to the extraordinary work of doctors, scientists and pharmaceutical companies. I am a highly motivated person who has so much to look forward to in life, and I believed that knowing my status would help me get specialty care and make important decisions about long-term life plans.

People with HD are strong, courageous individuals, so I was particularly honored when the Huntington's Disease Society of America recognized my optimistic outlook with their 2021 Person of the Year Award.

I enjoy hiking, swimming, reading and watching old movies. Although planning and packing for exciting trips requires a lot of energy with my HD, travel remains a favorite activity.

Making His Wishes Known

We'll never know how the man for whom our center is named might have wished to be cared for. But we're certain that the late Lou Ruvo wouldn't have wanted to hurt Angie, his business partner and wife of 50 years. Yet, 27 years after his death, Angie still suffers back pain associated with lifting Lou after his multiple falls.

With less societal awareness of dementia in the 1990s and no family history, the couple never anticipated that Alzheimer's disease would enter their relationship. So, Lou and Angie, whom we consider Cleveland Clinic Lou Ruvo Center for Brain Health's first caregiver, never discussed a "what if" scenario for caregiving.



A new story for a new era

Fast forward to 2021, when awareness and education — such as that provided through more than 60,000 total visits to the Lou Ruvo Center for Brain Health's no-cost educational, therapeutic and support programs — can help to chart a better future for families.

In the wake of his diagnosis of Alzheimer's disease eight years ago, Chuck McClatchey, 68, and Bobbie, 72, his life and care partner, are collaborating today to make decisions about tomorrow.

People frequently ask, "Why do you do it? Are you planning to die?"

"You get a diagnosis, and now you're a person with dementia. But you remain a person first," Chuck explains. "I want to make the most important decisions now so that at the most horrible time, Bobbie doesn't have to do it by herself."

The couple's comprehensive approach to planning has spanned:



• Establishing advance directives: Selecting a certified elder law attorney and drafting power of attorney, healthcare power of attorney and wills. *Tip: These documents can vary by state, so be sure to review them if you move.*



• **Downsizing their home:** Thinning out 2,500 square feet of household belongings and downsizing to a two-bedroom senior apartment. *Tip: Keep the items that spark the fondest memories; for Chuck, that is pictures of airplanes flown during his 20 years as an Air Force pilot.*



• Shopping for memory care communities: Worrying about injuring or offending someone unintentionally if he loses his judgment due to declining cognition is a great concern for Chuck, who wanted to evaluate congregate living options. *Tip: Ask how the facility manages difficult behavior, which might include medication or restraints.*



Planning for burial: Choosing the Veterans Administration cemetery where both have former spouses interred was important to Chuck and Bobbie. *Tip: Consider which final resting place seems like the best match for you and your family.*

Living well while controlling your "inevitable"

Bobbie, who lost her first husband all too quickly to pancreatic cancer, appreciates Chuck's desire to plan for the inevitable.

"It's not the easiest thing to do. You're looking death in the face and making plans for it. However, if you want your wishes to be carried out, you have to put them down on paper under the guidance of a lawyer," says Chuck, who believes financial and healthcare planning "isn't just for millionaires" and advocates for engaging a trained legal expert rather than using free, online, do-it-yourself toolkits. "Whether or not you have dementia like I do, we're all going to die. Don't wait for the inevitable to happen."

For those interested in sharing ideas about living well with dementia, Chuck leads weekly online conversations through Dementia Friendly Nevada's Dementia Conversations: dementiafriendlynevada.org/ dementia-conversations.





SHARE-ing Your Wishes With a Loved One

Facilitated under the guidance of Lucille Carriere, PhD, Angie Ruvo Endowed Caregiving Chair and health psychologist, SHARE is an evidence-based program available at no cost to patient-care partner pairs. The program's goals are to:

- SUPPORT patients and care partners and help them communicate effectively and plan for the future
- Promote HEALTH and well-being and decrease stress
- Encourage participation in fulfilling ACTIVITIES
- Learn about available RESOURCES that reflect their values and preferences
- · Provide EDUCATION about dementia and how to manage changes that lie ahead

If you or someone you know might benefit from the SHARE for Dementia program, ask a Cleveland Clinic neurologist for a referral by sending a message via MyChart or calling 702.483.6000.

Near or Far, Bringing Support Where You Are

After searching online for a support group for family members of those with frontotemporal dementia (FTD), Robin Jennings identified a group based near her home in Las Vegas. It was pre-COVID, so the group met in person in the evenings, after her work in a law office wrapped up.

"Group members were so welcoming right from my first meeting, when they asked what I knew about FTD," remembers Robin. "Pretty much what's in the book, 'What If It's Not Alzheimer's," I replied."

"Oh, you mean the book by Lisa Radin? THAT Lisa Radin?" they said, gesturing across the circle of chairs to a woman Robin immediately recognized from a photo in the book that bears the subtitle, "A Caregiver's Guide to Dementia."

Robin Jennings, left, and Jean Harmon



A caring community

It was then that Robin knew she had found "my people" at Cleveland Clinic Lou Ruvo Center for Brain Health, as the author's advice had been guiding her remote caregiving of a mother with FTD, Jean Harmon. Although Jean remains in the care of a neurologist in Albuquerque and has seen a center neurologist only once, the no-cost support group continues to be Robin's community for FTD advice and fellowship.

"For some care partners, the most difficult task is getting to that first support group," says Ruth Almén, LCSW, Clinical Manager, Social Work, who co-facilitates the group. "For others, it's asking for help, which is unfortunate, as our friends, family and community are often just waiting to give meaningful support, but don't want to be pushy. It's a real gift to be able to assist people you care about."

Robin has found Ruth and the social work team are an invaluable resource for getting the help she didn't know she needed, "both financially and emotionally."

And the support group? "They provide a caring, empathetic shoulder to cry on, a sounding board for decisions you need to make and, quite often, the comic relief you need to keep on going," says Robin.

MORE ABOUT OUR PROGRAMS

For a complete list of educational, therapeutic and support programs, visit clevelandclinic.org/NevadaEvents.



Expanding the circle

Unexpectedly, COVID ended up being a boon, forcing the group's meetings to move online and thereby allowing family members from across the country to participate.

"It has helped my stepfather, Ed Harmon, immensely to be able to 'meet' the group, share experiences and learn from other people who have become friends, rather than receiving a summary of the meeting from me after the fact," says Robin. "It has been wonderful to see how he has learned and progressed, becoming an awesome caregiver!"

While traveling through Albuquerque, one of the Las Vegas care partner group members and her husband met up with Ed.

"He was thrilled," says Robin.





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CARING FOR CARE PARTNERS

Doctor's Orders: Home Health vs. Hospice vs. Palliative Care

After a Serious Illness: Which Level of Care?

Discharge from unanticipated hospitalization brings with it the excitement of "getting out" as well as the challenges of navigating the myriad decisions about what comes next. Layer on the ongoing management of a chronic neurodegenerative disease and we all might wish we had a medical degree to enhance our understanding.

In fact, it's typically social workers or case managers who can provide the information we seek and present options to consider, and who are most familiar with available resources — many of which are available at no cost.

Safe plan of discharge

"It's rare that an individual can walk out of the hospital and return to their previous life without some transitional assistance. It's very important to know, too, that ethically, hospitals cannot discharge an individual until a safe plan for care has been established for them at their place of residence," says Ruth Almén, LCSW, Clinical Social Work Manager at Cleveland Clinic Lou Ruvo Center for Brain Health.



NEED HELP, BUT HAVEN'T HAD A TRIGGERING HEALTH EVENT? CONSIDER A PCA

Home health, hospice and palliative care are based on medical necessity. If you simply would like a little assistance with day-to-day activities, from housekeeping to bathing to shopping to managing appointments to companionship, a personal care assistant (PCA) can lighten the load.

Services are available from a few hours of help a week to full-time assistance. A social worker can provide a list of agencies to consider and questions to ask as you vet them, as well as insight into any possible financial assistance from community resources, as PCAs are not typically covered by insurance.

She explains: "While that may look a little different for each person, in general, home health helps an individual continue treatment and recovery and hone any skills necessary to stay safe and independent where they live, while also offering training for family on how to help. Hospice helps patients and their families prepare physically, emotionally and spiritually for the end of life, with a focus on quality of life. Anyone with a lifelimiting illness may qualify for hospice or palliative care to increase comfort."

The good news is that when physical need is demonstrated, Medicare, Medicaid and most private insurers cover most of these services.

It's hospice, not the Grim Reaper

Hospice care aims to help you be comfortable throughout the rest of your life and to give you choices about your care.

It's important to remember that you have the final say about enrolling in hospice or continuing treatment. Hospice agencies typically wish to meet to explain their services and answer your questions, with no expectation of a commitment at that first meeting. They want to be sure you have all the information you and your family need to make an informed decision about your care. If you enroll, you can always change your mind and discontinue hospice.

Then there's palliative care

People often confuse palliative care with hospice. Both types of care ease the symptom distress that severe illness can bring: pain, fatigue, depression and more.

The difference is in the overall approach to care. You can begin palliative care for a serious illness while also receiving curative or life-prolonging treatment. Palliative specialists work in tandem with other medical specialists as an added layer of support to help you feel as well as possible.

Making those important decisions

Just because you or your loved one must deal with a chronic illness doesn't mean you have to live with discomfort, pain or anxiety. Talk with care providers and family and determine your goal: Is it physical improvement or comfort care?

Regardless of which option you choose, don't sacrifice quality. Look for accredited providers with demonstrated track records of providing the level of care you desire, and ask those you trust for recommendations.

If you don't have a social worker on speed dial, it may be time to identify one. Contact your Cleveland Clinic neurology team via MyChart or at 702.483.6000 for an introduction to a social worker.



HOME HEALTH

DESIGNED FOR PEOPLE WHO:

- **Don't need the 24/7 care** offered in a skilled nursing facility or long-term acute care facility?
- Need help recovering from or learning to manage a new health condition at home
- Have mobility or functional issues
- Have difficulty leaving their home
- SERVICES INCLUDE:
- Skilled nursing: Monitoring patients' vital signs and managing home treatments, from oxygen to wound care to incontinence, and chronic conditions, such as diabetes or a neurodegenerative condition
- Physical, occupational and speech therapy: Helping patients regain mobility, function and quality of life
- Home health aide: Assisting with activities of daily living
- Social work: Connecting patients and families to resources that help meet their financial, transportation, emotional, safety and other needs so they can live at home as long as possible



- Have a terminal illness and life expectancy of six months or less
- No longer benefit from curative treatments
- Choose medical care focused on comfort and symptom management



PALLIATIVE CARE

- Are still being treated for a serious illness, with an eye toward improving
- Seek to comfortably mitigate the side effects of treatment

- Medicine and other treatments to ease symptoms
- Mental health support, such as counseling to cope with feeling lonely or afraid
- Programs that improve quality of life, such as art and music therapy
- Spiritual care for patient and family
- Emotional support for family and loved ones

- Reduction of the symptom distress severe illness can bring: pain, fatigue, depression and more
- Care team that can include patient's medical team, loved ones and a social worker

CARING FOR CAREGIVERS

Lightening the Load: New Workshop Aims to Increase Caregiving Skills

Former First Lady Rosalynn Carter, who was only 12 when she began caring for a father terminally ill with leukemia, speaks from experience: "Caregiving is hard, even on the good days when it brings joy and fulfillment. It requires dedication, determination and time."

The Rosalynn Carter Institute for Caregivers (RCI) was established in 1987, and is anchored in the former first lady's belief that there are only four types of people in the world: those who have been caregivers, who are caregivers, who will be caregivers and who will need caregivers.

No Time Off on This Job

At Cleveland Clinic Lou Ruvo Center for Brain Health, our aim is to support all types of caregivers with a robust array of tools for use in their day-to-day labor of love.

"Introducing RCI's evidenced-based program, Dealing With Dementia, to our

center's care partner community adds to our existing skill-building programs, Improv for Care[™] and Powerful Tools for Caregivers," says Lucille Carriere, PhD, Director of Behavioral Health and holder of the Angie Ruvo Endowed Caregiving Chair.

We share with RCI the belief that when individuals are diagnosed with Alzheimer's disease or other types of dementia, their entire support system faces the implications of these complex diagnoses. Dealing With Dementia, a four-hour workshop supplemented by the "Dealing With Dementia Guide," a detailed workbook, provides education and takeaways for hands-on caregiving skills, as well as the ever-elusive caregiver self-care.

"We always advise care partners to take care of themselves first because if they succumb to injury or illness, they will be less able to support their loved one," says Dr. Carriere. "And unlike other 'jobs,' caregiving doesn't allow for sick days."

INTERESTED IN BUILDING YOUR CAREGIVING SKILLS?

Dealing With Dementia is offered to participants at no cost, thanks to funds raised by the Clark County Medical Society Alliance throughout 2021.

If you're interested in participating in Dealing With Dementia, please contact LouRuvoSocialServ@ccf.org or 702.271.9563 for information on upcoming sessions of this online workshop. A full list of our educational, therapeutic and support programs is at clevelandclinic.org/NevadaEvents.



"Dealing With Dementia presents strategies and approaches for addressing the challenges of dementia in a healthy way" says Tiarra Atkinson, LCSW, Behavioral Health Outpatient Therapist and Co-Facilitator of the workshop.



"I'm thrilled that Dealing With Dementia provides each attendee with a resource workbook to use at home as they navigate the twists and turns of their family's journey with dementia," says Verla Niebuhr, Program Manager, Caregiver and Community Education, and Co-Facilitator of the program.





THE **POWER** OF PREVENTION

We Help Women Reduce Their Risks for Alzheimer's

Up to 40% of Alzheimer's disease cases may be preventable by making lifestyle changes. Of the 6.2 million Americans with Alzheimer's, two-thirds are women.

In collaboration with Maria Shriver, we opened the nation's first Alzheimer's prevention clinic specifically for women — The Women's Alzheimer's Movement Prevention Center at Cleveland Clinic.

Help Us Prevent Alzheimer's

In its first year, our prevention clinic saw patients from 40 states and is already booked through 2022 as it awaits further philanthropic support.



DonateNevada@ccf.org







WomenPreventAlz.org

Caregiving: Music Puts Words to a Thankless Job

A 24/7 "job" with no pay or vacation days sounds daunting but a "thank you" can go a long way, notably for caregivers to individuals with dementia. Add music to those thanks, and you just may have the gift of understanding. Understanding what it's like to care for someone with a memory disorder.

That's how Linda Loane felt when her husband, Jim, invited her to his session with Cleveland Clinic Lou Ruvo Center for Brain Health music therapist Becky Wellman, PhD, and broke into a song he had written for Linda, calling out her tireless caregiving efforts on his behalf.

The lyrics, "It gets harder day by day. I see your struggle. And dedication just for me," struck a chord with Linda, whose caregiving burdens have progressed over the past seven years along with Jim's Lewy body dementia, which has entered their relationship as a third participant of sorts, which the couple refers to as "Lewy."

"This song," says Linda, "it's not Lewy talking. It's Jim. The kind, considerate man I married 46 years ago."

Says Dr. Wellman, "Quite a few patients write songs for their families." She collaborates with her patients, providing the musical score.

For patients and care partners alike

For Beth Holladay, 70, music is more than a pastime or form of entertainment. Its melodies and rhythms link her to treasured feelings and memories that Alzheimer's, a progressive neurological disorder, is slowly taking from her.





Linda's Song

I always knew you were a strong woman It's part of what drew me to you It's like I had a premonition That I would need you to be someday

Caregiving is not for wimps It gets harder day by day I see your struggle And dedication just for me

Making all the phone calls Dealing with insurance and pills Making appointments Driving me everywhere

You take care of everything And everyone Never thinking of yourself You're a blessing to all you meet

The "we" is now just "you" I cannot help the way I'd like While my love stays strong My mind and body fail

Dementia stole our life Our love and family Tomorrow is always a question Who will I be?

My memory will fail I'll fall, I'll make mistakes But somewhere in my addled brain I'll always love you

I always knew you were a strong woman It's part of what drew me to you Like I had a premonition That I would need you someday



Beth's 90-minute daily group music therapy sessions are restorative as well for Jim, her husband of 45 years and her primary caregiver. Jim — who has spent most of his career in music, including years on production crews for Billy Joel, Neil Diamond and other performers — will often take time during the therapy sessions to make phone calls, complete chores or just relax from his nearconstant caregiving duties.

The science behind the music

"Living with a memory disorder is very difficult. Imagine not being able to form new memories. It's very anxiety provoking," says Aaron Ritter, MD, the behavioral neurologist who has treated Beth since she and Jim moved to Las Vegas from California in 2016. "One of the goals of treating Alzheimer's disease is to help a person adjust their environment to more closely align with what their brain is capable of doing. Research has consistently shown that music and, more specifically, music therapy, can help the brain function better."

Dr. Wellman explains that music therapy can help with memory, improve lung function, reduce blood pressure, increase self-esteem, lower anxiety and more. Before beginning music therapy which, until her disease began to progress, included guitar lessons from Dr. Wellman — Beth often suffered from panic attacks and severe anxiety, both of which are common in individuals with Alzheimer's disease.

"Now, if creating a playlist she can use at home to manage her mood makes her and Jim's lives a little less stressful and her burden a little less overwhelming, then that's what I'm going to do in the hour I have with Beth in our individual sessions," says Dr. Wellman.

Community support

Beth also takes great joy in singing along to songs chosen by other members of the music therapy group.

"We all have (cognitive) issues, and music sort of draws us together," she says.

Dr. Ritter believes Dr. Wellman's music therapy program could be a model for chronic diseases: "When it comes to managing disease, I think most people don't just want medications. In our field, people want to know the concrete steps they can take to help their brain function better. I tell everyone that it's important to be part of a community, to share experiences and do things to keep physically and cognitively active. Music therapy is a part of that."

Interested in trying out music therapy? Group sessions are free and meet every weekday afternoon. Learn more at clevelandclinic.org/NevadaEvents.



"My wife, Kikie, and I are the products of '50s and '60s music. I can't remember names, but give me a '50s or '60s song and I'm there. We really enjoy singing and we thought for people of our age, who may have Alzheimer's or another form of dementia, this type of therapy might really be something," says music therapy supporter Robert Priddy.

Adding to the Priddy Family Foundation's 2018 gift, the family pledged a gift in 2021 to fund general operations and allow for the purchase of new instruments and expansion of the program over the next five years.

PHILANTHROPY AT WORK

The VPAC: a "Suggestion Box" on Steroids

Patient-centric in action, the Voice of the Patient Advisory Council (VPAC) comprises patients and family members who advise from the perspective of personal experience, offering real-time feedback and creative approaches to specific opportunities for improvement at Cleveland Clinic Lou Ruvo Center for Brain Health.

Since the VPAC's launch in May 2015, "Let's run it by the VPAC" has become a common refrain among center leadership.

"It's nice to be part of the solution, not just complain about a problem," says Chuck McClatchey. Fellow VPAC member Yvonne Sweeten says, "Our group is a way to give back to an organization that's done so much for all of us."

Dylan Wint, Center Director, says "As I always tell my trainees, patients and care partners are the people best equipped to tell us what they need. Our role should be providing opportunities to hear them and collaborations to meet those needs."

An antidote to fear

Recognizing that many shy away from seeing a doctor for fear of receiving a diagnosis, the 2020-21 VPAC cohort suggested highlighting individuals who have found that knowledge is power and, armed with a specific diagnosis, have chosen to manage their condition rather than allowing it to manage them. Thus was born the "I Am Powerful" profiles (see page 15) that have been rolling out on social media.

VPAC member Len Hutchinson says the VPAC is "an opportunity to have your ideas heard. It's like a suggestion box on steroids."



Everyone has a voice

Nothing irks VPAC members more than patients and families saying they don't know about the no-cost educational, therapeutic and support programs offered daily at the center (clevelandclinic.org/NevadaEvents). So, they crafted an online overview (clevelandclinic.org/NVpatientguide) to guide patients through the journey of a degenerative brain disorder, and have been actively seeking additional ways to communicate these resources, such as distributing key materials as visitors leave the building after an appointment.

VPAC members build rapport during their shared year of service and say the group "feels like family." As with any family, there are as many opinions as members. Yet, when asked to describe the VPAC, all agreed: Everyone has a voice and is listened to. They talk, discuss, disagree and then smile as the meeting ends.

NEEDED: VPAC VOLUNTEERS

We're currently recruiting patients and family members to join the sixth VPAC cohort for a Spring 2022 start. We seek passionate, committed individuals who, if selected, are able to serve for a year in this ongoing focus group.

The VPAC has 12-18 members who meet online monthly for $1\frac{1}{2}$ hours at lunchtime and occasionally engage in small assignments from home in preparation for a meeting. The group's goal is improving the patient experience for all — not just for its members.

If you're interested in being considered for this volunteer role, please ask your Lou Ruvo Center for Brain Health provider for a referral to the VPAC's facilitator.



A Vital Force in Nevada's Economy



Estimated Impacts: State of Nevada

Cleveland Clinic's contributions to the communities in which it serves extend beyond the world-class care of neurological diseases for patients to the support of our state and local economies to benefit all Nevadans.



\$48.9 million



\$22 million

341

213

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\$5.7 million

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\$1 million in visitor spending



\$6.3 million



\$20.5 million in household spending

households supported

Read the full report: clevelandclinic.org/economicimpact

(Source: A Vital Force in Our Nation's Economy, ©2021 The Cleveland Clinic Foundation)

Driven to Donate: Robert T. Bigelow

Life can sometimes be mundane but, growing up in Las Vegas, it was anything but, says Robert T. Bigelow, who remembers "sound barriers being broken every day and residents' windows routinely shattered. Between Nellis Air Force Base, the Nevada Test Site and growing intrigue around UFOs, Las Vegas was laden with excitement."

As an adult, his approach has been to focus on areas that are poorly understood because "a challenge, whether presented by a hobby or scientific research, makes life exciting."

That's why Robert, Founder of Bigelow Aerospace, and his late wife, Diane M. Bigelow, began supporting Cleveland Clinic Lou Ruvo Center for Brain Health: "It's a world-class facility that addresses crucial health issues for which societal demand is growing," he says.

Having lost Diane to a terminal illness in February 2020, Robert understands all too well the importance of early detection and care which, in the realm of neurodegenerative diseases treated at the center, "might help defer and delay their impact on people," he says.

Keeping her memory alive

Diane, who looked forward each year to buying a table at Keep Memory Alive's Power of Love[®] gala, was the instigator of the couple's giving to the Lou Ruvo Center for Brain Health.

"Now, I continue in her memory. She's still part of what I do," says Robert, a



2021 inductee to Cleveland Clinic's 1921 Society (see sidebar).

But it was the thrill of test-driving a Lamborghini Urus SUV with his granddaughter that inspired Robert to purchase the car and donate it to be auctioned live at the 2021 gala. He took great joy in surprising even Larry Ruvo by grabbing the microphone from the auctioneer, waving a one-kilogram gold ingot at the crowd and announcing that he was placing it in the glove box, adding to the excitement among bidders.

Robert, who says his parents' modest income didn't leave much extra at the



end of each month, now takes great pride in giving back to his hometown, and hopes others will do likewise: "If the world helps you make some money, share it. Even if it's only \$20, giving can make you feel really good."



THE FUTURE OF Healthcare since 1921. In Nevada since 2009.







1921 Society

For 100 years, Cleveland Clinic has delivered exceptional care and breakthrough discoveries that have changed the course of healthcare. Founded in 1921 by four physicians returning to Cleveland, Ohio, after service in World War I, Cleveland Clinic has grown into a global enterprise caring for more than 7 million patients annually, and is consistently ranked among the top hospitals in the world.

Philanthropy has been instrumental in this growth over the last century. Compassionate benefactors have provided crucial resources to seed discoveries, build leading-edge facilities, and deliver care that has changed and saved lives.

Cleveland Clinic established the *1921* Society to recognize their dedication and thank them for their commitment to our patients and communities. The society consists of donors who have made lifetime gifts of \$1 million or more. Since its founding in 2005, induction ceremonies have welcomed new *1921 Society* members; today, more than 600 individuals, families, corporations and foundations are in this remarkable group.

Our donors view Cleveland Clinic as the place to make a meaningful investment, and the impact of *1921 Society* members' leadership gifts has multiplied over time.

If you share that passion for changing and saving lives and wish to make a gift of any size, please contact Cleveland Clinic Nevada's development team at DonateNevada@ccf.org or 702.263.9797.



SUPPORTING SCIENCE

"It's only when you are a patient and you meet the doctors and nurses, that you see the care they take and how wonderfully well the Clinic is run, that you realize how terrific it is and that you really want to support Cleveland Clinic in every possible way that you can."

— Sheila and the late Eric Samson, inducted into the 1921 Society, 2006



Le Hua, MD, FAAN, Sheila and Eric Samson Chair for Multiple Sclerosis Research, and Director, Cleveland Clinic Mellen Program for MS at the Lou Ruvo Center for Brain Health, Las Vegas

Scanning Your Way to Peace of Mind

30 years ago, an otherwise-healthy family member underwent full-body imaging. "I doubt it was anywhere near as good as today's technology, but the procedure nonetheless found a cancerous tumor. He had it removed and is still alive today," says Nicole Taffer, who at 48 decided such imaging would "be a great, early mile marker for me, too."

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 as well as physical abnormalities, inflammation or obstructions. This exam is useful for individuals who aren't experiencing health complaints, yet seek the peace of mind that a noninvasive overview of their current health can provide.

Here's how to use the findings from your whole body MRI scan:

1. The scan

Your whole body MRI can serve as your new imaging baseline. Images made at Cleveland Clinic Nevada are backed by the full resources of Cleveland Clinic's Imaging Institute, which is staffed by board-certified subspecialty radiologists.

2. Consultation with your referring provider

Review the interpretation of the scan with your referring provider to discuss any notable findings and coordinate with your preferred specialists to determine if further tests are necessary.

A painless process

"Whole body MRI, which is not typically covered by insurance, has been a useful addition to Cleveland Clinic Nevada. It helps guide a patient's primary care physician to evaluate potentially troublesome yet asymptomatic issues

The Whole Body MRI Exam Covers:

HEAD brain, sinuses, nasal cavities, mouth

NECK major arteries and soft tissues, lymph nodes and thyroid

CHEST

lungs (utilizing low-dose CT), lymph nodes, heart, large blood vessels

> SPINE spinal cord, vertebrae, discs

ABDOMEN kidneys, liver, spleen, adrenal glands, gallbladder and pancreas

PELVIS

uterus, ovaries, prostate

To learn more about a whole body MRI, contact the Cleveland Clinic Nevada imaging team at 702.701.7948 or LasVegasImaging@ccf.org.

before they become problematic," says Erick Vidmar, Administrative Director, Cleveland Clinic Nevada.

Most screening MRI findings in asymptomatic individuals are incidental and of little clinical consequence, which may be just the reassurance a patient wants. Nicole was shocked when her MRI uncovered a small aneurysm in her brain, but says, "Because it was detected so early, my primary care doctor is confident it can be managed "

Her takeaway? "I would encourage anyone to do this scan. It's a great source of reassurance."

IOST YOUR EVENT IN AN ARCHITECTURAL AND CULTURAL LANDMARK













KEEP MEMORY ALIVE EVENT CENTER



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

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

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

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

For information about date availability or to schedule a site visit, please contact KEEP MEMORY ALIVE EVENTS TEAM

702.263.9797 or email eventcenter@keepmemoryalive.org



ON THE SCENE

Visitor Photo Gallery



L to R: Michael Severino, Chef Bobby Flay and Dr. Dylan Wint



Baptist Health South's Luis Rios, Jess Berrin, Nate Ortz, Dr. Michael McDermott

Dr Rafael Pelayo and Dr. Alex Jungreis









L to R: Bobby, Malissa, Rosemary Shriver



Honoring ANNE MARIE MARTIN

Anne Marie Martin — or "Annie" as she preferred to be called — volunteered at **Cleveland Clinic Lou Ruvo Center for** Brain Health for nearly 10 years in clinic operations, administrative areas, at fundraising events and educational conferences, but always said her favorite role was opening the front door and greeting patients and families.

"It's not easy because you don't know who's coming through the door or what challenges

they're facing but, no matter what, we treat everyone with dignity, class and respect," she told New Thinking magazine in 2018.

After Annie passed in 2021, her husband, Ed Martin, and family gathered to honor her with a plaque on the center's donor wall.

For information on how you can honor a loved one, please contact DonateNevada@ccf.org or 702.263.9797.





Event Hosts Help Raise Funds and Awareness for Keep Memory Alive

Throughout 2021, the Keep Memory Alive special events team was busy collaborating with enthusiastic community supporters. Here are but a few examples.

Fox5 Las Vegas "Heat Is On"

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 to Cleveland Clinic Lou Ruvo Center for Brain Health \$100 per day that the temperature in Las Vegas rose above 100 degrees.

After 87 days in the triple digits, that pledge was calculated to total a hearty \$8,700 for our center. However, to honor of his mother's battle with Alzheimer's, once again this year Mr. DeMore more than doubled his donation. When receiving the \$20,000 check live on TV, Dylan Wint, MD, the center's director, dubbed Mr. DeMore a "benevolent scofflaw" for bending the rules of Fox5's promotion to make an even larger impact on patient care and research.



Whiskey on The Rocks

Launched in 2017 and on hiatus in 2020 due to COVID, on October 14, 2021, Total Wine and More resumed is popular Whiskey on the Rocks at Red Rock Resort Casino, Resort and Spa in Las Vegas. The event featured a great array of whiskey vendors outside around an exclusive 21+ pool area, The Pond. More than \$20,000 was raised, including a \$10,000 donation from whiskey supplier, Edrington.





Audi Henderson Lake Las Vegas Classic

Despite a COVID cancellation in 2020, on November 5 and 6, 2021, golfers, foodies and other loyal event-goers returned to the magnificent Reflection Bay Golf Club at Lake Las Vegas.

On Friday, golfers experienced the Jack Nicklaus Signature Design course. The festivities continued on Saturday at an event known as "The Feast": an evening of dancing on the beach, an abundance of food and beverage from some of Las Vegas' finest restaurants, and a silent auction.



HENDERSON, NEVADA

Month of Memories

Keep Memory Alive's annual Month of Memories is a community-wide initiative in support of National Alzheimer's Disease Awareness & Family Caregiver Month. Each November, Keep Memory Alive rallies Las Vegas businesses to raise awareness of and funds for this devastating disease that affects so many patients who come through our doors at Cleveland Clinic Lou Ruvo Center for Brain Health. We also honor their friends and family who serve as dedicated care partners.



PARTNERS IN GENEROSITY

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

Atomic Liquors Big Dog Brewery Bin702 Carson Kitchen

The Golden Tiki

Honey Salt Nacho Daddy Stoney's Rockin' Country Therapy Trattoria Reggiano -Downtown Summerlin

[Yellowtail] was inspired to continue its support beyond November, donating \$1 to Keep Memory Alive for every bottle of wine sold in Nevada through December 31.

JOIN OUR TEAM OF COMMUNITY FUNDRAISERS

Contact info@keepmemoryalive.org or 702.263.9797



HEROES AND HEROINES: A Labor of Love for Longtime Volunteers

Twenty-five years of the Power of Love® just wouldn't be possible without loyal volunteers.

"As the gala has grown over the years, so has our volunteer force. For at least the past decade, we have had more than 100 volunteers at each gala, each serving at least eight hours the day of the event," says Anna Robins, Senior Director, Keep Memory Alive, the creative and logistical powerhouse behind the Power of Love. "They're on their feet and running, creating a smooth, refined guest experience from check-in through the silent and live auctions to distributing the goodie bags as guests leave."

Meet a few long-term gala volunteers, in their own words:



Abbie Franks Power of Love volunteer: since 2007 Roles: check-in and live auction runner

"As a teen, I served as a candy striper in our local hospital, learning by example from my parents about the importance of volunteering in the community. I've been touched closely by neurodegenerative disease, with my best friend since birth dying of ALS at age 52. Volunteering at the Power of Love always makes for a long day but it's for a great cause."



Marilyn Drake Power of Love volunteer: since 1997 Role: jewelry section, silent auction

"Both my mother-in-law and mother have had dementia, so I'm glad Cleveland Clinic is doing research, which will perhaps help the next generation escape what previous generations have endured. I also appreciate their commitment to supporting family caregivers."



Ruth Mormon Power of Love volunteer: since 2010 Role: jewelry section, silent auction

"Volunteering at the Power of Love is a great opportunity to be part of the local community and, of course, it's always fun to bump into guests we know and to serve alongside my friend and former colleague from The Meadows School, Marilyn, who initially recruited me to serve at the gala."

Steven Tyler



Each year, when I arrive at the Power of Love venue...

"It's magical, like stepping into a fairy tale land." — Ruth

"I'm struck by the cleverness, how they make an arena or a tent look so warm, inviting and festive. It's magnificent!" — Abbie

Celebrity encounters

"As the announcer was calling guests to head to the dining room and Ruth and I were waiting for the last of the stragglers to leave our jewelry station, up to our booth comes Steven Tyler from Aerosmith. He chatted with us and was the nicest person." — Marilyn

"I love the LAGOS jewelry, and maestro Steven Lagos himself attends the gala each year. He's so charming, and always stops by to see Marilyn and me and, of course, the items he has donated." — Ruth

"One year, I got to check in Danny DeVito and Rhea Pearlman. He graciously thanked all volunteers and shook everyone's hand." — Abbie

2021: The 25th annual Power of Love was special because...

"Getting out after enduring 18 months of a pandemic made it seem as if life is getting back to normal." — Marilyn

"Twenty-five years is a long time. Just think of all the good that's been done over all those years. It's become a tradition. I see the same faces, year after year, as well as newer, younger people. People seem to support Keep Memory Alive more fully each year." — Ruth



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Steven Lagos

Rhea Pearlman

and Danny DeVito

JOIN OUR EVENT VOLUNTEER RANKS

"The Keep Memory Alive team behind it is fantastic. We all share one goal: Raise as much money as possible. You can be a part of it." — Abbie "The funds raised are used primarily for the research and care of patients and family members. Not to administration. Keep Memory Alive puts their money where their mouth is." — Marilyn "Volunteering for Keep Memory Alive is part of being a Las Vegas resident. You're giving back to the community, but you're also getting to experience the glamor and entertainment of an over-the-top Vegas event." — Ruth

specialevents@keepmemoryalive.org or 702.263.9797

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.

Named to the Governor's Task Force on Alzheimer's Disease

(Aging and Disability Services Division, Nevada Department of Health and Human Services, 2021)

Dylan Wint, MD

Best Conference Center, Silver Winner, 2021 Stella Awards

(Northstar Meetings Group, November 2021)

Keep Memory Alive Event Center

Certificate in Vestibular Rehabilitation

(American Physical Therapy Association and Duke University, November 2021)

Michael Gevertzman, PT, DPT

2021 Angel Awards Nonprofit of the Year

(Vegas INC, September 2021) **Cleveland Clinic Nevada**

The BizBash 500, Corporate Event **Producers & Strategists category**

(BizBash, September 2021) Anna Robins

Top Doctors

(KNPR's Desert Companion, August 2021) Le Hua, MD, Zoltan Mari, MD, and Dylan Wint, MD

Pinnacle Award, Issues Management category

(Public Relations Society of America, Las Vegas Chapter, November 2021) MacKenzie Ruta, APR & Nicole Wolf, APR



INAUGURAL RESEARCH PILOT AWARDEES NAMED IN DECEMBER 2021

A newly established funding mechanism designed specifically to support the gathering of novel, early-stage pilot data for use in pursuing future larger external funding, the 2021 Research Pilot Awards were open to all Cleveland Clinic Nevada staff.

All applications were evaluated by three reviewers and scored in a manner consistent with the NIH scoring system, which considers:

- Significance and Innovation
- Project approach/methodology
- Clarity of plan for applying for future external funding

The top 2 scoring applications have each been awarded \$25,000 in funding for one year. Recipients are:

CARRIE M. HERSH, DO, MSC, FAAN Staff Neurologist and Director of the

MS Health and Wellness Program,

Cleveland Clinic Mellen Program for MS at the Lou Ruvo Center for Brain Health, Las Vegas



Fatigue, a very common symptom in multiple sclerosis (MS), is difficult to treat even with available medications. Dr. Hersh's research aims to evaluate the impact of adaptive yoga on MS-related fatigue.

VIRENDRA MISHRA, PHD

Assistant Director, Brain Imaging Research

Freezing of Gait (FoG) is a disruptive phenomenon that can cause individuals with Parkinson's disease to literally freeze in their tracks.

Dr. Mishra's project aims to compare the impact of structured physical therapy interventions with use of virtual reality simulating those same interventions.



2022: KICKING OFF THE NEXT 25 YEARS OF PARTIES WITH A PURPOSE

Join Keep Memory Alive throughout the year for bespoke, curated events featuring world-class food, wine, and spirits crafted by celebrity chefs and master mixologists.

Together, we'll raise funds for world-class healthcare at Cleveland Clinic Nevada.

keepmemoryalive.org | 702.263.9797

KEEP MEMORY ALIVE





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keepmemoryalive.org clevelandclinic.org/Nevada



JOIN US ONLINE DAILY FREE EDUCATIONAL, THERAPEUTIC AND SUPPORT PROGRAMS

- Mind in Design: An Artmaking Class for Everyone
- Conversations to Remember
- The Learning Arts
- Group Music Therapy
- Rhythmic Reminiscence
- Support Groups
- Lunch & Learn
- Skill-Building Sessions

View our online events listing: ClevelandClinic.org/NevadaEvents