

NEW THINKING ABOUT THINKING

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keepmemoryalive.org
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A Publication by the Cleveland Clinic Lou Ruvo Center for Brain Health

FACES OF CAREGIVING



Plus:

» HOW WE
DIAGNOSE
ALZHEIMER'S

» PROFILES IN
VOLUNTEERISM

» FRANK
GEHRY'S
LEGACY DRIVES
ATTENTION

KEEP MEMORY ALIVE

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



ALZHEIMER | HUNTINGTON | PARKINSON | ALS | MEMORY DISORDERS



There is much good news to share with all of you who have made the founding of the Cleveland Clinic Lou Ruvo Center for Brain Health possible. Those of you who have supported us financially, those who have supported us with their voices in the community, those who have entrusted loved ones to our clinical skills – you are the ones who have made the opening of this important Center possible, and I want to acknowledge the debt that we owe to all of you.

When I wrote to you in the last issue of *New Thinking About Thinking*, our clinical program at the Cleveland Clinic Lou Ruvo Center for Brain Health had just launched. Now, we are conducting more than 200 patient consultations per month, and we are increasing our capacity steadily. Patients and families have come from all of our neighboring states in the Southwest to see us in our Center, and a few have come from even further away. Our imaging bays are active for Magnetic Resonance Imaging as well as Computerized Tomography. We have plans to bring in PET technology in the near future.

We are bringing new health care professionals into the Center, and building the sort of interdisciplinary team that is required for the diagnosis and care of complex behavioral disorders.

I am very pleased to report that Susan Hirsch has accepted our offer to become Director of Social Services. Susan brings a prominent set of career experiences in the area of Alzheimer's disease program development, especially in the caregiving dimension of Alzheimer's disease and related disorders. She will expand and deepen the services that we offer to families and to caregivers.

Our research programs are off to a strong beginning. Under Susan Hirsch's leadership, this Fall we received national grants from the Rosalynn Carter Foundation to improve standards of care for caregivers. We received a large medical science

grant from the National Institute of Aging to expand our work in the prevention of Alzheimer's disease, under the leadership of Dr. Stephen Rao. We were fortunate to receive the Nelson Butters Award from the National Academy of Neuropsychology, recognizing our group's published work in cognitive assessment (see article in this issue "How We Diagnose Alzheimer's Disease") as the "Best Scientific Paper" published in the *Archives of Clinical Neuropsychology* in 2008.

Yet we have just begun. The work in front of us – to improve the diagnosis and treatment of the disorders that destroy cognition – will last for a generation. We will not be able to do this alone, yet our Center will play a prominent role in this work that lies ahead. We will become the first truly integrated center for brain health in the country, with multiple sites across the Cleveland Clinic system, and a breadth and scope beyond anything in today's university systems.

I am honored to be your Director. I hope you enjoy the remaining essays in this issue of *New Thinking About Thinking*. I look forward to keeping you informed of our progress.

Randy Schiffer, MD

Director, Cleveland Clinic Lou Ruvo Center for Brain Health



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CLEVELAND CLINIC NEUROLOGICAL INSTITUTE:

Our Commitment To You

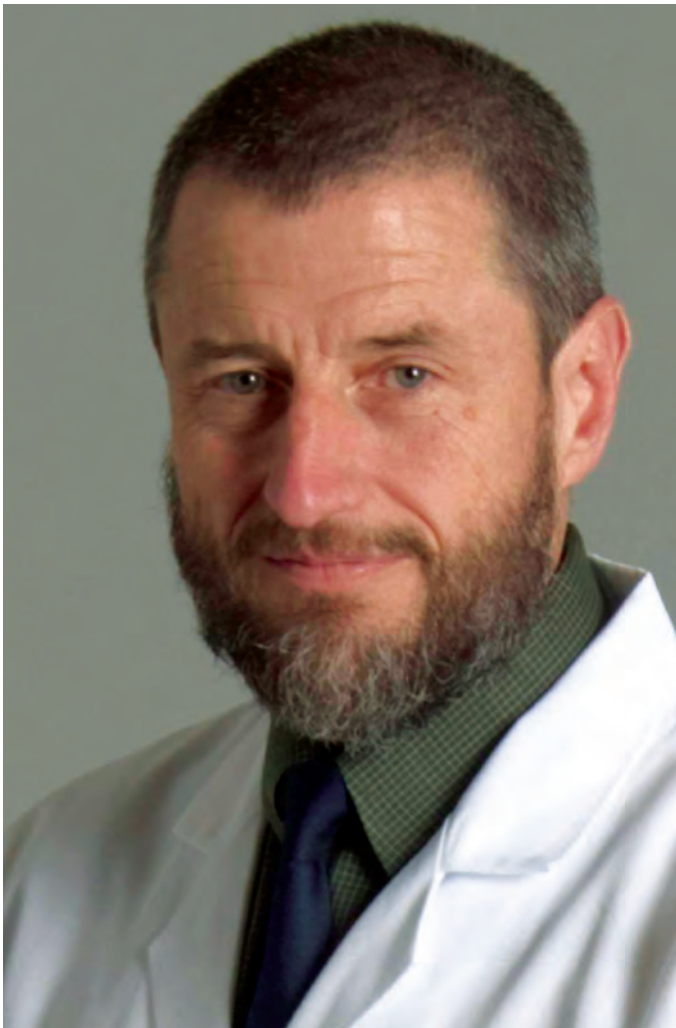
At Cleveland Clinic Neurological Institute, we keep working to enhance our monitoring of quality measures and outcomes because we view this initiative as a vitally important part of our clinical practice. Our work is incomplete, however, if we focus solely on the medical side and neglect a very visceral concern: *How do our patients feel?* Aware of the importance of patient satisfaction, we are working to incorporate measurement of this critical component of

the healthcare experience. This undertaking is rooted in the conviction that our responsibility to patients extends beyond diagnosing and treating their physical ailments.

We subscribe to a basic credo: *We will explain what will happen to you during treatment. We will manage your discomfort and pain. We will respond when you need us.* These simple precepts serve to remind us that the practice of even the most sophisticated medicine is a human endeavor.

We live this lesson every day at the Cleveland Clinic Lou Ruvo Center for Brain Health, where our staff sees patients and caregivers coping with dreaded diseases that impair the mind, mood, and movement. The quiet heroism of the people who carry these burdens is humbling. Our patients, their loved ones, and the Center's selfless staff and partners share a deep understanding of the power of compassionate care.

Advanced treatments, education, and groundbreaking research are central to our center's mission, but they do not fully define the scope of our responsibilities as healthcare professionals. We do justice to the people



who walk through our doors only when we combine these elements with sensitivity and empathy in our approach to patients and to their caregivers, whose needs too often have been overlooked.

The Cleveland Clinic Lou Ruvo Center for Brain Health will continue to offer the most innovative treatments and technologies, and we will encourage patients to enroll in clinical trials of medications with the potential to improve their lives. We will also remember the simple things. Who can overstate the value of a caring touch, a gentle reassurance or a supportive shoulder at just the right moment?

At the Neurological Institute, we believe our statistics support the assertion that, in terms of both outcomes and patient satisfaction, we rank among the nation's best. At the Cleveland Clinic Lou Ruvo Center for Brain Health, our patients, caregivers, employees, volunteers, supporters, and the community at large keep us focused on our goal to deliver the highest, most patient-centric level of neurological care.

Michael T. Modic, MD, FACR
Chairman, Cleveland Clinic Neurological Institute



HOW YOU CAN HELP: Pushing Toward Earlier Detection of Alzheimer's Disease through Clinical Trials

By Charles Bernick, MD, Associate Medical Director, Cleveland Clinic Lou Ruvo Center for Brain Health

When does Alzheimer's disease (AD) begin? Clinically we say it is when symptoms of memory loss reach a point where they impair one's daily function. Based on a number of lines of evidence, however, researchers now believe that by that point, most of the disease process has already occurred. It is estimated that we are currently spending most of our efforts treating the last 20% of the disease course, and that AD changes in the brain begin from 10 to 20 years before the diagnosis is usually made.

This delay in recognizing AD may not have made much difference in the past, when there were no or only symptomatic treatments available. However, with the recent development and testing of new therapies that have the potential to slow disease progression, beginning treatment early in the disease process becomes imperative. With this idea in mind, there has been a major initiative in the research field to discover ways to detect AD in its earliest stages.

The Cleveland Clinic Lou Ruvo Center for Brain Health (CCLRCBH) is part of that research effort.

As a collaborator in the Alzheimer's Disease Neuroimaging Initiative (ADNI), a nationwide project funded by the National Institutes of Health (NIH), the CCLRCBH has been studying various neuroimaging techniques and biomarkers that may be able to track changes in the living brain as older people transition from normal cognitive aging, to mild cognitive impairment (or MCI, in which individuals have a memory deficit but generally function normally), to AD. Utilizing the latest brain imaging methods at CCLRCBH, researchers are investigating the role of MRI scanning to precisely measure volumes of particular areas of the brain, as well as PET scanning, which can image brain cell metabolism.

An exciting new technique with PET scanning is amyloid imaging. Amyloid is a protein that occurs in increased amounts in AD brains and is thought by many to play a role in causing the disease. By injecting a marker that tags amyloid, PET scanning can now reveal the amount of amyloid in one's brain—even before any symptoms develop.

ADNI has also focused on biomarkers for AD. A biomarker is a test that can be run on blood, spinal fluid, or other tissue that may reveal a disease. Just this year, ADNI made a significant step forward in developing a test to help diagnose the beginning states of AD sooner and more accurately by measuring levels of two proteins—tau and amyloid—in spinal fluid.

The CCLRCBH was an original member of the ADNI trial, which began by studying 800 people who ranged from normal to AD. To extend this research, ADNI was awarded \$24 million this year by the NIH. These funds will allow more people to participate in this ground breaking research, which is specifically targeting individuals with very mild memory impairment.

The research team at CCLRCBH is preparing to enroll new participants in this project. For more information about this or other studies at the CCLRCBH, or to inquire about participation, please contact the CCLRCBH at (702) 483-6000.



Introducing **DR. DYLAN WINT**

Dr. Dylan Wint will be joining the Cleveland Clinic Lou Ruvo Center for Brain Health from

Emory University Medical Center in February. Dr. Wint is an honors graduate from Stanford University, and an alumnus of the University of Florida Medical School. He is one of a small number of physicians in this country who are jointly trained in Psychiatry and Neurology. Dr. Wint is an expert in the areas of the psychiatric syndromes that specially affect people with neurologic diseases, and he will be setting up a clinical care and research program for such problems.

“Dr. Wint is a fantastic addition to the team, bringing the emotional, feeling side of the puzzle to the Center’s work in cognition,” said Dr. Randolph Schiffer, Director of the Cleveland Clinic Lou Ruvo Center for Brain Health.

Frank Gehry's Legacy:

Building Awareness of Neurocognitive Disorders

In order to shine the light on Alzheimer's disease (AD) and other neurocognitive disorders including Huntington's, Parkinson's, and ALS, Keep Memory Alive Chairman Larry Ruvo knew he needed a marketing tool that would capture the attention of all. By engaging architect Frank Gehry, Ruvo generated that highly captivating marketing vehicle in the form of a building that would house the work of his avocation, a Center for Brain Health. Be they impressed, intrigued, or skeptical of Gehry's design, they are engaged. They come in. They ask questions. They learn. In short, Gehry's architecture presents an idea and builds awareness; the work done inside builds toward a cure.

According to the Alzheimer's Association, delaying the onset of AD by five years cuts the diagnosis by 50%. Delaying the onset of the disease by 10 years eradicates the disease altogether. Until there is a cure, we know that the best method of addressing AD is early detection, which can be achieved only through awareness.



Cleveland Clinic Lou Ruvo Center for Brain Health, under construction, year end 2009

The Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas, Nevada, is not the first Gehry building to draw attention to the broader community in which it resides. In a 2002 article entitled "The Bilbao Effect," *Forbes.com* reported, "With its dramatic architecture, the [Gehry-designed] Guggenheim museum continues to be a major draw, attracting people who would otherwise not come. Bilbao estimates that its economic impact on the local economy in 2001 was worth 168 million Euro to the Basque treasury in taxes. This represents the equivalent of 4,415 jobs. A visitor survey revealed that 82% came to the city of Bilbao exclusively to see the museum, or had extended their stay in the city to visit it."

According to an economic impact study conducted in 2008 by the city of Bilbao, Spain, more than 11 million people had visited the Gehry-designed Guggenheim Museum since its opening 11 years before. Moreover, the Guggenheim Museum Bilbao is a leading European cultural institution in terms of self-financing, achieving around 65% of its financing from its own services rendered, again underscoring the power of the building itself as a marketing tool.

The media see it, too. On December 3, 2009, following his visit to MGM MIRAGE'S CityCenter and the Cleveland Clinic Lou Ruvo Center for Brain Health, *LA Weekly* Architecture Reporter Hugh Hart wrote, "Make no mistake: These buildings are very much about marketing. But instead of hawking fake identities borrowed from New York, Paris or Venice, this new generation of glass-encased

buildings parlays Nevada's most obvious natural resource, the unblinking sun, into nature-based spectacle." He continued, "There's not a stitch of kitsch to be found in the resort town's latest iteration of destination buildings."

That same week, *Bloomberg News* Architecture Critic James Russell visited the Center on a mission for his employer, also noting a personal connection through a loved one who suffers from a neuromuscular disease.

We know that the attention the Cleveland Clinic Lou Ruvo Center for Brain Health building has drawn from donors, prospective patients, prospective volunteers, the community, and the media has only amplified the initial investment, creating a more profound impact in the long run through the research, clinical trials, and treatment going on within the building's walls.

Keep Memory Alive CEO Maureen Peckman says, "Those with a trained eye realize the architecture is a symbol of hope, and is yet another extension of how we honor those with neurocognitive afflictions."

Perhaps *LA Weekly's* Hart best summed up Ruvo's marketing insight in writing, "[The building] flows out of the ground like a molten expression of intuition incarnate."

Here's a sample of comments reported by volunteers and employees of the Cleveland Clinic Lou Ruvo Center for Brain Health:

"Whether they think it is beautiful or strange, the building draws them in, wanting to know more."
—Dee King, Director of Volunteer Services

"I was driving by the building, and it struck me as beautifully unique. I saw the sign that read 'We still need help,' and dialed the number while driving. I had seen a couple of photos in the newspaper, but didn't know what was going on inside the building until I attended volunteer orientation a few days later. This is the first time I've ever volunteered, and after three weeks, it feels like the right thing to do. After all, I lost a grandfather to Alzheimer's."
—Amy Meskow, volunteer

"Dr. Bernick is wonderful. People need to come inside this building just so they can meet him."
—Jean Georges, volunteer and caregiver

"I'm frequently asked if the building is falling down. But really, I'm just glad it drew them in."
—Lynn Leavitt, valet parker

"I had a patient and caregiver who watched our building being built on TV, and the images drew them in. They told me now that they're here, they can't believe how incredible the structure is, and how different from a typical doctor's office with all the light and hope it provides."
—Joan Marie Farris, Medical Secretary

"A patient told me that they saw the building and then made an appointment. Now that they are here, they love Cleveland Clinic and feel our Center provides the best care available for Alzheimer's."
—Merena Tindall, Assistant Nurse Manager, R.N.

"Employees in both the post office and Home Depot have seen my Cleveland Clinic badge and said, 'Oh, you work in that unusual building.' It's amazing how much the building has aided the name recognition of the Cleveland Clinic Lou Ruvo Center for Brain Health."
—Beverly Bowen, Administrator



Keep Memory Alive's LeeAnn Mandarin routinely regales those touring the building with a lively story of her ride to its top

Cleveland Clinic Lou Ruvo Center for Brain Health Building Draws International Attention

On October 19, 2009, Libby Lumpkin, former curator of the Las Vegas Museum of Art, gave a tour of the Frank Gehry-designed building construction site to a group of architecture faculty and students from Zurich, Switzerland. “Even though the group was quite large—seven faculty architects and 18 graduate students—we worked it out to sneak them into the event hall for a few minutes during the construction crew’s break period. Construction Chief ‘O.B.’ Beyhoum helped get them equipped with hard hats and made sure all went well,” said Lumpkin.

Lumpkin also conducted an on-site seminar as part of a course on Las Vegas architecture given by one of the world’s leading architecture and design schools, the Swiss Federal Institute of Technology (Eidgenössische Technische Hochschule, Hönggerberg). She reports, “The group was ecstatic to be able to see the Life Activity Center under construction before the drywall was installed. The engineering of the hall is unique, with each section of steel manufactured in China and assembled like a jigsaw puzzle here in Las Vegas. The immense height of the ceiling, with the weight distributed along undulating lines, is a lesson in sophisticated engineering. With sunlight streaming through the window openings, it reminded the students of a cathedral. But there really is no precedent for the design.”

According to Lumpkin, international interest in the Frank Gehry-designed building is already high. “I’m hearing from more and more universities that

wish to arrange tours of the building. We are doing our best to accommodate tours for advanced students. It’s great to know that the Cleveland Clinic Lou Ruvo Center for Brain Health building will serve as one of the world’s top educational resources for many years to come, not only with respect to architecture, but to memory disorders.”

Most importantly, bringing people in the door drives awareness of the neurocognitive disorders that are treated within the building. Lumpkin reported that a couple of members of the group mentioned that they had family members affected by memory disorders. These students were gratified to see that the quest for a cure for these diseases would be housed in a building that symbolizes progress, hope, and excellence. They felt that the Gehry building will become an icon for the cause, in the way Louis Kahn’s Salk Institute building is now an icon for excellence in biological studies.



Students from Swiss Federal Institute of Technology



Jerry Springer visits with Larry Ruvo at the Center while in Las Vegas hosting America's Got Talent (photo by Erik Kabik)



Keep Memory Alive volunteers join Las Vegas Mayor Oscar Goodman at the Alzheimer's Association Memory Walk.



While in town performing in "Bronx Tale," Chazz Palminteri (R) tours the Cleveland Clinic Lou Ruvo Center for Brain Health with Michael Severino of Southern Wine & Spirits and the KMA board.



Larry Ruvo shows Former President of Mexico Vicente Fox and wife Marta around the new facility.



Barrett-Jackson Cruise-In offers up memories of nostalgic cars while supporting Keep Memory Alive.

Barrett-Jackson Cruise-In SUPPORTS KEEP MEMORY ALIVE

The second annual Barrett-Jackson Collector Car Auction took place October 8-10, 2009 in Las Vegas at Mandalay Bay Resort and Casino. For car enthusiasts, a highlight of the event was the 2007 Prudhomme Edition Shelby Super Snake concept car that was on site during the event, prior to this limited-edition Mustang being sold on the last day of the auction.

Proceeds from food concessions throughout the event benefited Keep Memory Alive in support of the Cleveland Clinic Lou Ruvo Center for Brain Health.

The Barrett-Jackson Auction Company was established in 1971 and is headquartered in Scottsdale, Arizona. Barrett-Jackson specializes in providing products and services to classic and collector car owners, astute collectors, and automotive enthusiasts around the world. Barrett-Jackson produces the "World's Greatest Collector Car Auctions™" in Scottsdale, Palm Beach, Las Vegas, and Orange County. Over the years, the company's commitment to charitable organizations continues to mount.

"We at Barrett-Jackson are proud and honored to work with the fine individuals at Keep Memory Alive," said Phil Neri, vice president of sales and marketing. "We hope to continue to build on the partnership we started in 2009."

Maureen Peckman, CEO of Keep Memory Alive said, "The dedication, professionalism, and passion of the leadership team at Barrett-Jackson assure me that with strong partnerships such as this, we will reach our ambitious goal of fostering enhanced treatments and ultimately the prevention of memory disorders of all kinds."

HOW WE DIAGNOSE ALZHEIMER'S DISEASE

Randolph B. Schiffer, MD and Donna Munic, PhD

The Cleveland Clinic Lou Ruvo Center for Brain Health treats all disorders that affect cognition, not just Alzheimer's disease. Still, Alzheimer's disease (AD) remains the most common disorder among the patients we see, and it is the one most often asked about by patients and families.

How do we know if someone has Alzheimer's disease? Our patients and their families are sometimes disappointed when we tell them that there is no simple test for AD – no blood test, or spinal fluid test, or brain imaging test that holds the answer to the question, “Doctor, do I have Alzheimer's disease?”

The answer lies in the skills and experience of the doctors who deal with Alzheimer's disease and related disorders. Even in this era of rapid expansion of medical technology, the “gold standard” for the diagnosis of Alzheimer's disease remains the clinical judgment of an experienced doctor.

The clinical history is the first step in our work at the Center – the unique story of each person we see: the pattern, pace, and quality of his or her symptoms. In these patterns we try to discern the signature of Alzheimer's disease, or perhaps the workings of another syndrome.

After the history, we examine the patient using standardized examination procedures to see if he or she shows abnormalities in physical or mental

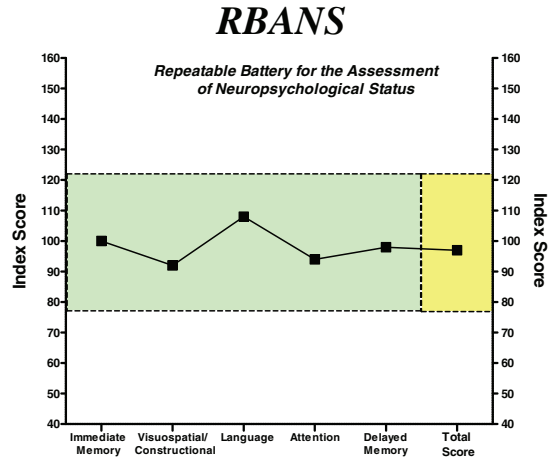
functioning. Among the mental functions, cognition is the most important marker for our diseases in the Center for Brain Health – the mental powers that have to do with knowing and thinking. It is impairment of these knowledge functions that constitutes the core symptoms of Alzheimer's disease, and of related disorders.

We test cognitive functions according to groups of similar functions, called “cognitive domains.” Domains are common sense-like sets of functions, such as “language,” “memory,” “executive-conceptual,” and others. The presumption here is that these cognitive groups share underlying neural networks in the brain, and that in time we will be able to understand those networks in molecular genetic terms, and to manipulate them medically in order to make people better.

There are many cognitive tests. We use various sets of these cognitive tests, depending upon the situation. The specific test that we use here in Las Vegas for the most difficult clinical questions is the RBANS – the “Repeatable Battery for the Assessment of Neuropsychological Status.” The RBANS gives us a graph pattern of an individual patient's performance according to expected norms for five cognitive domains (immediate memory, delayed memory, visuo-spatial, language, and frontal executive). It also provides an overall summary score.

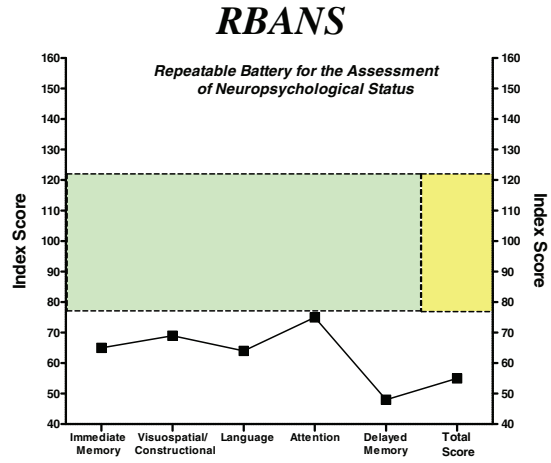
For example, here is a normal RBANS profile:

Name: Mr. X
Age: 72 years old



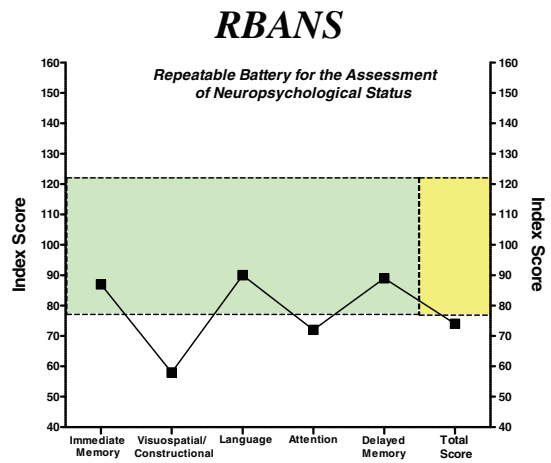
Here is an RBANS profile for Alzheimer's disease:

Name: Mrs. X
Age: 81 years old



Here is an RBANS profile for a non-Alzheimer cognitive loss syndrome:

Name: Mr. Y
Age: 60 years old



Once we have completed the cognitive assessment, we then sit down with the patient and his or her family and review the results with them, explaining what we can and cannot conclude from diagnostic assessment. After that, we move to treatment planning – but that will be the subject of a later essay for this Journal.



APPROACHES TO ALZHEIMER'S

By George P. Scollins, Jr.

Twenty-one months ago I was diagnosed with Alzheimer's disease (AD). Since that time, I have learned a number of approaches that may help others. My major purpose in sharing this information is to communicate effective ways to face the realities of AD.

APPROACH #1:

Do your best to make use of valuable time

Avoid feeling sorry for yourself. Instead, focus on remaining positive and learning about participating in research studies, especially brain and dementia research studies. A song from the Second World War seems especially germane to a positive approach: "Accentuate the positive, eliminate the negative, latch on to the affirmative, but don't mess with Mr. In-between." To illustrate my last remark, Jonah in the whale, Noah in the ark. What did they do when everything seemed so dark? They accentuated the positive, eliminated the negative, latched on to the affirmative, but did not mess with Mr. In-between.

APPROACH #2:

Take care of important financial affairs

Make use of services of an elder care attorney who is experienced in dementia-related issues. Establish a healthcare proxy, living will, and power of attorney so your wishes will be acted upon. The earlier you complete these items, the easier it will be for those you have delegated to carry out your wishes.

APPROACH #3:

Keep your mind as alert and active as possible

There are numerous ways to keep your mind active with regular activities, such as working crossword puzzles and memorizing items. The AARP website (aarp.org) is among the better sources for these activities, such as "brain aerobics."

[Information on these activities is also available on keepmemoryalive.org.]

APPROACH #4:

Stay healthy with exercise and proper diet

Studies have shown that regular exercise, when combined with a healthy diet, is helpful in keeping your mind alert and able. Your doctor should be consulted if you plan to expand your physical activity level. Many health tips stress that what is good for your heart is good for your brain, including your ability to think and remember. Good sleeping habits help the body respond better to mental activities.

APPROACH #5:

Volunteer to participate in Alzheimer's research

Boston University and other medical schools are looking for volunteers to participate in studies. Even though participation may not improve your condition, it may help others now and in the future. Positive approaches certainly should take precedence over feeble or no effort to confront the realities of your situation.

[For information on participation in Cleveland Clinic Lou Ruvo Center for Brain Health clinical trials, call 702-483-6000.]

APPROACH #6:

Remain as active and social as possible

Maintain contacts with old and new acquaintances. Outreach to others will greatly expand your horizons and outlook. Reaching out to others who have Alzheimer's may serve you well in viewing your own situation from a different perspective. It will assist others in becoming more positive under trying conditions.

APPROACH #7:

Become as knowledgeable as possible about the status of Alzheimer's research

Seek out this information and ask your healthcare professionals to interpret it for you. The amount of research in this area is staggering. One source of information is the Alzheimer's Association. Meetings are regularly scheduled by local chapters, which are useful to keep abreast of developments. Periodic appointments with your neurologist are crucial in understanding your condition. The tests that accompany these visits provide ongoing assessment of where you are with the disease.

[Visit the Cleveland Clinic Lou Ruvo Center for Brain Health Library, which houses a comprehensive collection of books, videos, DVDs, and other materials that can be taken out on loan. Trained volunteers are able to assist with locating materials in the library in Las Vegas and online from anywhere.]

APPROACH #8:

Recognize and accept that changes in your emotional and cognitive state are a reality of living with AD

One major reality is recognizing that your care partner often has a clearer understanding of your emotional and cognitive status than you do. As a result, you become more aware of changes and their insights help you adjust in a positive manner.

APPROACH #9:

Get help from support groups, family, and friends

One of the most positive results of writing this essay has been a deeper understanding of myself and the positive responses I have had to the condition. I more deeply appreciate the help provided by my care partner and wife, Patricia, and the value of speaking at programs and to caregivers. As a result, my confidence in living with the condition in a positive manner has expanded. My appreciation of the support group leaders and the contribution of the support group members is even more significant.

[For more information on the Cleveland Clinic Lou Ruvo Center for Brain Health's weekly caregiver support groups, call 702-483-6000.]

APPROACH #10:

Accentuate the positive

The most significant aspect of this experience is the way I changed myself over this period. I find myself crying at heart-rending television programs and movies. Newspaper articles or senseless violence produce a new, but similar type of effect. My desire to help others is expanding, as is my determination to stay positive despite the realities of Alzheimer's. Again, the lyrics of that bygone song remain deeply embedded in my mind. "You've got to accentuate the positive, eliminate the negative, latch on to the affirmative, but don't mess with Mr. In-between." Remain positive, it does make a difference!

ABOUT GEORGE SCOLLINS:

As a special education administrator in four different school districts over 25 years, George Scollins has spent much of his career educating and advocating for others. Today, despite a diagnosis of AD, Mr. Scollins continues his life's work through this article, "Approaches to Alzheimer's." It is just one way he and his wife, Patricia, are helping others who are coping with AD. Mr. Scollins was prompted to write the essay when he saw members of his support group struggling with their symptoms, but often reluctant to seek medical attention. Mr. Scollins urges others to see a physician, get a diagnosis, and move on.

In their fight against AD, George and Patricia Scollins have participated in several research studies at BU ADC. Mr. Scollins is determined that "whatever happens is going to be positive, not negative."

Thanks to George and Patricia Scollins for their permission to reprint George's essay from BU ADC Fall, 2006 Bulletin in this issue of New Thinking About Thinking. We are also grateful to Angela L. Jefferson, PhD, Associate Professor of Neurology and Director, Education and Information Transfer Core, Boston University School of Medicine, Alzheimer's Disease Center for permission to reprint.

PROFILES IN VOLUNTEERISM: SUSAN VAN GORDER

“I volunteer because it’s a good feeling,” says Susan Van Gorder. “You see people arrive needing answers, and leave looking satisfied, relieved, and even hopeful.” Susan has a personal connection with the quest for answers and for hope: her husband of 45 years, Matt, was diagnosed with Parkinson’s in 2008, and Susan says that volunteering at the Cleveland Clinic Lou Ruvo Center for Brain Health helps her as a caregiver.

“The Center has a caregiver support group every Wednesday,” reports Susan. “The caregivers arrive for group sometimes looking sad or tired. Then, when greeted by our little puppy, Jordan, they begin to look more relaxed. When group is over and they step off the elevator, they can’t wait to talk about their experience. They appear calm and relieved, as if some weight has been lifted off their shoulders. You can tell they feel as if they’ve finally found the right place.”

When she wants the weight of the world removed from her own shoulders, Susan heads to the gym. While her husband goes six days a week because the exercise helps reduce the symptoms of his Parkinson’s, Susan accompanies him at least five days. She likes the exercise ball, while her husband enjoys weightlifting. Both agree that time spent on the treadmill is purely a necessary evil! Outside of it all, Susan is most proud of being the only adult able to successfully shop for her 12-year-old granddaughter.

When asked which of the many volunteer hats she most enjoys at the Center, Susan says, “Most of all, I enjoy that there’s no such thing as ‘I’m just a volunteer.’ [Director of Volunteer Services] Dee King has a knack for making all of her volunteers feel appreciated and needed.”

Susan met Dee King while volunteering at a local hospice where Dee was director of volunteer services, then followed Dee to the Cleveland Clinic Lou Ruvo Center for Brain Health. Susan herself has a knack for making employees and fellow volunteers feel cared for, routinely checking to see who has been to the gym that day and making certain that everyone has packed healthy choices for lunch.

Susan reports, “I enjoy meeting and working with other volunteers. Everyone is so interesting. It’s fun to exchange experiences with them.”





PROFILES IN VOLUNTEERISM: JEAN GEORGES

Jean Georges knows full well the physical toll of being a caregiver. Two years ago, while at the Mayo Clinic with her husband, Leonard, for his routine Alzheimer's/vascular dementia visit, she suffered a stress-induced heart attack. Despite having been told for years during annual physicals that she was the picture of heart health with low cholesterol, a healthy diet, and plenty of physical exercise, Jean found herself undergoing a quadruple bypass the next morning.

Jean, who has since recovered fully, is delighted that the Cleveland Clinic Lou Ruvo Center for Brain Health has come to Las Vegas. Now, rather than traveling to Mayo, her husband is being treated locally by Dr. Bernick. Jean herself attends the weekly caregiver support group at the Center. But being a full-time caregiver is not enough for Jean. She feels compelled to educate others on the subject of dementia, and says, "I talk about my husband's disease because it gives others permission to talk about it. I want to educate people so that they, too, can heed the early warning signs. Early detection is critical, and something that I wasn't aware of myself."

Jean says that volunteering at the Center is a wonderful way to continue that education, adding, "I'm just

thrilled to be a part of what is going on within these walls. It's truly first class. Things are going on here that I feel will bring a solution to dementia."

Given her lifelong interest in reading and in education, it's not a surprise that when presented with the array of volunteer opportunities at Cleveland Clinic Lou Ruvo Center for Brain Health, Jean chose the library. She says it's full of knowledge about the various forms of dementia, and contains helpful information for caregivers themselves. She is proud that the Center's collection is already believed to be the largest of its kind in the state of Nevada.

"Alzheimer's is a terrible disease, but a fascinating one," Jean proclaims. "It's another frontier, and I've been fascinated by frontiers since my husband and I moved to Las Vegas 50 years ago when the city itself was a frontier. The Cleveland Clinic Lou Ruvo Center for Brain Health is now an oasis in the desert."

She says that back when her husband was first diagnosed over six years ago, prevailing philosophy at the time dictated that the Alzheimer's patient not be told of his condition. Jean comments, "If the patient knows, the couple can walk down the road together. If not, the burden is entirely on the caregiver."

DEE KING DIRECTOR OF VOLUNTEER SERVICES



A finance professional by training, years ago Dee King was working full-time as a credit manager at a private company while volunteering for a local hospice. As a volunteer, she facilitated bereavement groups, spoke in the community on behalf of the organization, and provided in-home assistance to patients and families. “My kids were growing up, and the nurturing part of my soul wasn’t being nourished anymore. The hospice was just what I needed,” explains Dee.

Dee became so passionate about the organization that when a full-time paid role opened up for an assistant director of volunteer services, she sold her house, moved to a small condo, and re-prioritized her personal life so that she could afford to take the pay cut required to turn her avocation into her profession at a non-profit. Through it all, she continued to volunteer for AIDS-related causes, including AFAN in Nevada.

Dee says she has frequently been asked how she deals with all of the sadness surrounding hospices and AIDS, to which she routinely replies, “You can’t change what’s happened in the past or in the future, but you can make a positive difference during the time you are involved with a family.”

The ideal volunteer is reliable, passionate, committed, and able to connect easily with strangers. When volunteers join the Cleveland Clinic Lou Ruvo Center for Brain Health, they typically tell Dee that they are surprised by how friendly the staff and volunteers are, and how much they have in common with other volunteers. A common bond is not surprising, given that more than 50% of volunteers are or have been caregivers to loved ones with various forms of dementia.

As Director of Volunteer Services for the Cleveland Clinic Lou Ruvo Center for Brain Health, Dee has taken the program from 0 to 70 volunteers, and along the way has created a three-hour volunteer orientation, including a module on Four Seasons hospitality training. Dee interviews prospective volunteers with a keen matchmaking eye, explaining, “My delight comes through interacting with volunteers, and getting to know each one well enough to match them with roles they truly find fulfilling.” Interested in getting to know Dee and her team of volunteers? She just may have the perfect role for you, too.

Interested in joining us at the Cleveland Clinic Lou Ruvo Center for Brain Health?

We're always on the lookout for upbeat, enthusiastic, passionate, and smart individuals.

For a volunteer role:

We have some work-from-home opportunities as well as opportunities at the Center. We can help you design your own, or you may choose from: Lending library • Patient hospitality • Caregiver support • Health and fitness • Newsletter editor • Community events/ Health fairs • Arts & crafts • Fundraising events • Power of Love gala • Office work (mailings, etc.) • Scheduling volunteers

The vision of the volunteer program at the Cleveland Clinic Lou Ruvo Center for Brain Health is recruitment, empowerment, and continuing education opportunities for citizens with diverse cultural and racial backgrounds and skill sets. The volunteer program will engage community involvement in the expansion, enhancement, and delivery of the compassionate, quality services of the Cleveland Clinic Lou Ruvo Center for Brain Health, setting the "gold standard" for volunteer services in Nevada.

Contact Dee King via phone at 702-263-9797 or dking@keepmemoryalive.org. You may also contact us via the "Volunteer" page of www.keepmemoryalive.org.

For a paid role:

All jobs are posted at: www.clevelandclinic-jobs.com. Type in the keyword "Las Vegas" to find the open jobs at the Cleveland Clinic Lou Ruvo Center for Brain Health.



Volunteers Donna Achrem and her pet therapy dog, Jordan, greet participants during the Center's caregiver support group each Wednesday.

Keep Memory Alive Volunteers

By Dee King, Director of Volunteer Services

- O**pen their hearts and take the risk of sharing another's loss.
- P**articipate in life, rather than just showing up for it.
- P**ractice "daily acts of kindness." A smile is the shortest route to another person.
- O**rganize their lives to make time to be active in their community.
- R**ecognize the talents, time and spirit that they have to share with others.
- T**reasure the opportunity for personal growth.
- U**nderstand the importance of "being there."
- N**ourish their souls through activities to enrich another's human experience.
- I**nspire others to see the goodness in themselves and the world around them.
- T**reasure the personal growth that flourishes with service to others, and realize ...
- Y**esterday is gone, tomorrow is a day away, and today is the day to make a difference.



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Memorable experiences available through our silent and live auctions. Join us for the opportunity to bid on truly priceless items, including:

- Lunch with Architect Frank Gehry at his studio – Los Angeles
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Your opportunity to keep memory alive awaits...Saturday, February 27, 2010.
To RSVP, please call 702-263-9797.

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AN EVENING TO REMEMBER SO OTHERS WILL NEVER FORGET.

Please join Keep Memory Alive and **Chefs Wolfgang Puck and Thomas Keller** for a memorable evening full of celebrity guests, flowing champagne and an unforgettable surprise headliner. Bid on luxury items, including one-of-a-kind jewelry and travel excursions, during silent and live auctions. And join us in **honoring Stacie and Chuck Mathewson, Chairman Emeritus, IGT.**

All proceeds benefit the Cleveland Clinic Lou Ruvo Center for Brain Health and their tireless efforts in the battle against Alzheimer's, Huntington's, Parkinson's, ALS and memory disorders.

Seating is limited.

For information, visit keepmemoryalive.org or call 702.263.9797.

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

KEEP MEMORY ALIVE
Supporting the Mission of the Cleveland Clinic Lou Ruvo Center for Brain Health
ALZHEIMER | HUNTINGTON | PARKINSON | ALS | MEMORY DISORDERS

BELLAGIO
LAS VEGAS

EVENTS

The Leon Thal Symposium (LTS) 2009 on the Prevention of Dementia was held October 27th - 28th in Las Vegas. This annual commemorative think tank celebrates the efforts of the late Dr. Leon Thal, a leading investigator into the cause, prevention and treatment of Alzheimer's disease (AD). The LTS assembles leaders in the field who have been inspired by his efforts and encourages further development of strategies to move AD prevention forward.

At the time of Dr. Thal's death in 2007, he was poised to shift his focus from treating to preventing AD. He and other leaders in the field realized that by the time symptoms are recognizable, the disease has progressed much too far to be reversed or even slowed appreciably.

In 2008, the LTS formulated a plan that was incorporated in large part into the Alzheimer's Study Group's National Alzheimer's Strategic Plan. This plan was presented to

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WINNING THE LONGEVITY REVOLUTION:

the 111th Congress and the Obama administration in March, 2009. The recommendations were incorporated into the Alzheimer's Breakthrough Act of 2009 (S. 1492 and H.R. 3286), legislation that by fiscal year 2010 would double the funds allocated for Alzheimer's research by the National Institutes of Health. The bill also calls for a National Summit on Alzheimer's, which would bring together scientists, policymakers, and public health professionals to move the enterprise forward.

Actionable recommendations of the LTS 2009:

1. Establish a national registry

The 2009 symposium was charged with planning a national initiative to establish a database registry that would help characterize the natural history of AD and other dementia-related diseases throughout a person's lifespan—particularly in the years prior to the development of symptoms. Such a registry would facilitate the validation of assessment tools that are urgently needed to anticipate preventive and

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LEON THAL SYMPOSIUM

CARING FOR THOSE WHO CARE

By Susan Hirsch, MSW and Donna Munic, PhD

- After caring for her husband with dementia for five years, Mrs. M. had a stress-related heart attack.
- Mr. G. feels lonely and overwhelmed caring for his wife, with no family close by and few friends who still call to see how he is doing.
- Ms. R. is grateful that, even though her mother has Alzheimer’s disease, the family has drawn closer as together they figure out how to provide care and support for both parents.
- Mr. H. wishes that he knew some tips for making the daily ritual of bathing his wife less stressful.

THE COMMON THREAD:

Each is a caregiver who provides care, love and support to a family member. Larry Ruvo, Founder and Chairman of Keep Memory Alive, understands the challenges of caregiving first-hand. His mother, Angie Ruvo, spent years as the primary caregiver for her husband, Lou. In addition to the stresses of caregiving, her physical health was impacted by months of improperly lifting her husband. Immediately following Lou’s death, Angie was admitted to the hospital to undergo complex back surgery. She now lives with chronic pain, an end result of being a loyal, caring, and loving wife. This firsthand experience led to Larry’s commitment to ensuring that caregivers receive the support they need to care for their own well-being during such times of extraordinary challenge.

WHO ARE CAREGIVERS?

Each of us during our lifetime will be called upon to offer care and support to a loved one. Often, we do not think of ourselves as doing anything special – just being a loyal spouse like Angie Ruvo. However, those who take on this role know that caregiving takes time, energy, resources, and—in the case of an illness impacting cognitive functioning—education to understand more about the course of the disease. At times, caregivers experience feelings of frustration, isolation and the sense that no one truly understands their situation.

Statistics bear out just how many experience the challenges of being a caregiver. Nationally, there are more than 34 million caregivers. Here in Nevada, an estimated 260,000 caregivers provide more than 280 million hours of care annually, based on data from the Family Caregiver Alliance.

“There are only four kinds of people in the world – those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who need caregivers.”

- Former First Lady Rosalynn Carter

WHAT WE OFFER:

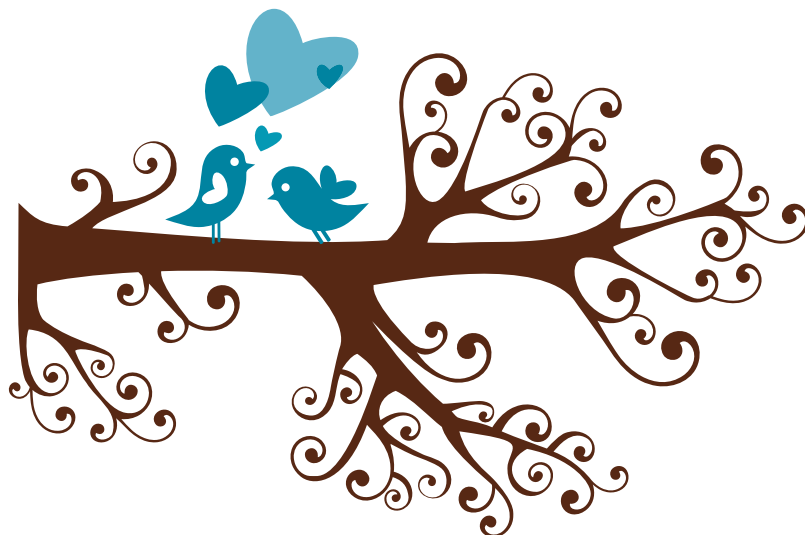
The Cleveland Clinic Lou Ruvo Center for Brain Health (CCLRCBH) views caregiver services as an integral part of its mission. Complementing excellent medical care, our focus on caregivers affirms that neurocognitive diseases impact not just the patient but everyone involved in offering care and support. Our goal is to provide supportive services and programs to caregivers and family members, maximizing their knowledge, skills and capacity to provide care.

With the input of caregivers themselves, we seek to build a comprehensive, innovative and collaborative model that incorporates:

SOCIAL WORK – *individualized assistance to plan for care of a loved one over the course of the illness including assessment, care planning, and counseling.*

Highlights:

- CCLRCBH was awarded a grant from the Rosalynn Carter Institute for Caregiving to implement a successful evidence-based counseling program, the New York University Caregiver Intervention. The program consists of a series of initial counseling sessions, support group participation, and *ad hoc* counseling as needed. The intervention has been shown to reduce caregiver symptoms of depression, improve caregiver satisfaction through their support network, and delay placement of a loved one in a facility for a year and half.
- Trained professionals are available to meet with caregivers and family members to assess needs, develop a care plan, assist with connections to community resources, and provide counseling related to the emotional impact of caregiving.



EDUCATIONAL PROGRAMS – *a comprehensive curriculum designed to increase the knowledge and skills needed to care for a loved one.*

Highlights:

- Our caregiver library, with more than 1,000 books and videos as well as on-line resources, is open to caregivers, patients, family members, and the community-at-large. The library is staffed by specially trained volunteers.
- Watch for our calendar of caregiver education classes, featuring programs both at the Cleveland Clinic Lou Ruvo Center for Brain Health and throughout the community. Topics will include taking care of the caregiver, building communication skills, financial and legal planning, and coping with challenging behaviors.

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SUPPORTIVE SERVICES – *informal support for caregivers, families, and individuals with neuro-cognitive diseases.*

Highlights:

- The Caregiver Support Project convenes a weekly support group for caregivers. Learning and sharing are hallmarks of this experience as caregivers gain new understanding and support each other.
- CCLRCBH has been chosen to participate in an Administration on Aging grant awarded to the State of Nevada to develop support groups that focus on providing intensive education along with emotional support. Our role is to evaluate the effectiveness of this intervention as it is implemented throughout our state.

SUPPORTING CAREGIVERS – Former First Lady Rosalynn Carter declared, “There are only four kinds of people in the world – those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who need caregivers.” We invite you to join with us in offering support to those who are caring for loved ones with neurocognitive diseases. Encourage a caregiver to check out the services we offer. Volunteer at our library. Lend a hand or offer a word of hope because someday, chances are, we will all be caregivers.

For more information, contact Susan Hirsch at 702-483-6000 or e-mail hirschs2@ccf.org.

COMMUNITY PROGRAMMING, FALL 2009:

The following programming was provided by the staff of Cleveland Clinic Lou Ruvo Center for Brain Health except as otherwise noted.

AT NATIONAL CONVENTIONS:

Taking Care of Self

American Postal Workers Union (APWU) National Retirees Conference
Donna Munic, PhD

Staying Sharp: Ask the Experts about Keeping Your Brain Young

AARP Vegas@50+
Donna Munic, PhD
Maureen Peckman, Moderator
Randolph Schiffer, MD

GREATER LAS VEGAS COMMUNITY:

“The Family Caregiver” presented by UNLV College of Fine Arts Gerontology Program, Division of Educational Outreach, Osher Lifelong Learning Institute and the Cleveland Clinic Lou Ruvo Center for Brain Health.

Role of the Caregiver

Susan Bobby
Douglas Hill, Associate Director, Senior Adult Theatre Program, University of Nevada, Las Vegas and the student performers from the Senior Adult Theatre Program
Susan Hirsch, MSW
Ann McDonough, PhD Dean, Academic Success Center Director of Gerontology, University of Nevada, Las Vegas

Taking Care of the Caregiver.

Michele C Clark, RN, PhD Associate Professor UNLV School of Nursing
Susan Hirsch, MSW
Dr. Sandra Owens-Kane, LCSW Associate Professor & Hartford Faculty Scholar of Geriatric Social Work University of Nevada, Las Vegas, School of Social Work

Caregiver Survival Skills and Behaviors & Communications

Donna Munic, PhD
Christine Terry, Program Manager, Alzheimer’s Association, Desert Southwest Chapter, Southern Nevada Region

Holiday Stress

Temple Sinai, and again at Adult Day Care Center of Henderson Donna Munic, PhD

2009 Triad Senior Education Seminar in Gardnerville, Nevada

Sponsored by the Douglas County Nevada Triad
Susan Hirsch, MSW
Maureen Peckman

TO LEARN ABOUT UPCOMING COMMUNITY PROGRAMMING, PLEASE JOIN THE KEEP MEMORY ALIVE GROUP ON FACEBOOK OR FOLLOW US ON TWITTER.



A Note from a Valued Community Partner: Prime Time Parkies Do Lunch

By Claire Rose Bernard Executive Director, eLayne Library

It's lunchtime on Tuesday at the Huntridge Drug Store Diner and four friends have convened to discuss the one thing they all have in common: Parkinson's disease (PD). They are the Prime Time Parkies. Started by Bruce Layne, a successful Las Vegas businessman, the group—comprising Pete Becker, Ron McLean and Don Shephard—began meeting a few years ago and recently accepted its only non-Parkinson's member, Dr. Randy Schiffer of the Cleveland Clinic Lou Ruvo Center for Brain Health.

The Prime Time Parkies are now an integral part of the eLayne Library, the Parkinson's non-profit that Bruce recently started. The eLayne Library will work on two levels. On the one hand, it is becoming a digital library for researchers and scientists to store, query, and compare data, actively steering collaboration across stakeholder categories through moderated debates, grants, and virtual symposia.

On the other, eLayne is developing a virtual Parkinson's community—a place for patients, caregivers and doctors to catch up on the latest PD information, share their stories and tips, and become empowered in the fight against Parkinson's through myriad opportunities from self-reporting to creating local micro-communities.

Thanks to the internet, everyone can join the Parkies in their weekly chats. Through our web site (www.elaynelibrary.org), we let you know in advance if there will be a special guest and if so, you can send your questions in to be answered on the show.

But the best way to understand the Parkies is to hear them in their own words in a lively lunchtime discussion.

Bruce starts out. "When I was diagnosed, 10 years ago, the doctor said, 'You've either got a brain tumor, or a stroke, or MS, or Parkinson's disease.' I said, 'What's the other option?'"

Ron picks up the thread, "We were all going to different doctors, getting different information, taking different medication, that's how it originally started."

Pete jumps in, "As an attempt to consolidate the experience and knowledge."

Bruce adds his two cents, "So we don't feel so fearful."

Ron elaborates, "So you're not out there dog paddling along by yourself."

"There's some comfort in that," **Bruce** agrees. "We all have a common disease and nobody really wants to hear it and you don't want to talk about it with strangers, but it's a common bond. We bring newly diagnosed people to lunch, answer their questions—"

Pete interjects, "We can't seem to get any chicks, though." "Well we had one, but you scared her off!"

"Man, that's a sad commentary on our social skills."

Ron refocuses the group, "The thing is, we've avoided the politics of big organizations. We just get together and talk, we have no agenda—"

"Clearly," clamors **Pete**. (As you may have noticed, Pete's the one with the quick jabs.)

Ron: "Clearly we're incapable of having an agenda."

Don agrees, "I think you are right there."

"Of course. I'm glad you recognize that, Don," says

Ron. "I picked up Don the other day to go to exercise class and he asked me how I was doing. I said, 'Wonderful.' 'No you're not', he said. 'Yeah, but who wants to hear it?' 'I do,' he said."

Don smiles, changing the subject. "She's got us singing now, in exercise class."

Pete: "I might come back just to hear you guys sing."

Ron: "That might not be worth the trip."

They chuckle and **Bruce** chimes in, "I took stand-up comedy lessons to keep my mind sharp and guitar lessons to...well, whatever that was for—"

Pete volunteers, "Chet says he's gonna take tai chi."

"I did that, too," offers **Bruce**.

"Bruce, you get the award for quackery."

"I'll try anything once."

"That's what comes from having relatives who were chiropractors."

The group laughs.

But, at the end of the day, it is Dr. Schiffer who puts it best,

"The common thread is the friendships here. When Bruce Layne first told me about this group, I said, 'It sounds like Cheers.'" I really wanted to see it, because friendships can be great medicine."



We'll Parkie High Five to that. For more details on the Parkie High Five, please visit www.elaynelibrary.org.

eLayne is an online Parkinson's community. Thanks to Bruce Layne and eLayne's philanthropic support, in 2010 the Cleveland Clinic Lou Ruvo Center for Brain Health will be conducting Parkinson's research through a forced exercise initiative designed by Cleveland Clinic biomedical engineer Jay Alberts, PhD. To participate or find out more about the research, which involves cycling on stationary bicycles, please call the Center at 702-483-6000.

Life Activity Center to Open in May 2010:

Create a memory and help us preserve memory



*It began with a simple wood block and a crumpled sheet of paper
Its space defined...its undulations
captivating.... its form intriguing*

Embark on a Frank Gehry-designed experience. Conveniently located at the intersection of I-15 and I-95 in the urban Las Vegas arts and science community of Symphony Park, the Cleveland Clinic Lou Ruvo Center for Brain Health and its Life Activity Center (LAC) present a unique environment in which to host your private function. Gehry's design for our LAC includes up-lighting and 199 windows in an undulating, surrounding stainless steel trellis canopy, creating a truly one-of-a-kind experience day or night.

Accommodating 500 seated or 900 standing, the LAC will provide only the finest in creative design, world-class cuisine, superior wines, and exceptional personalized service.

The LAC is perfect for:

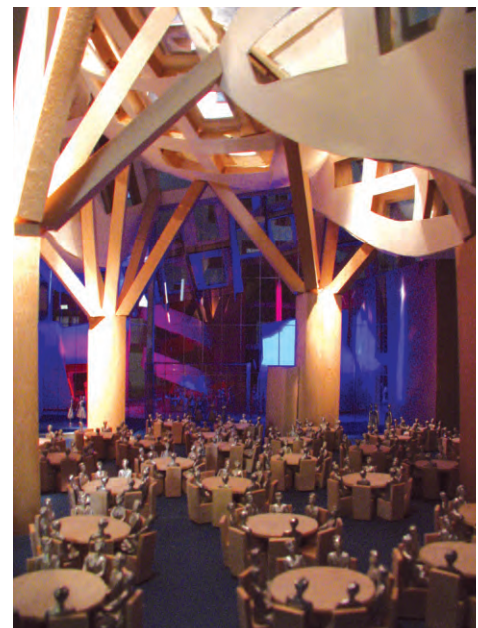
WEDDINGS ■ BAR MITZVAHS ■ BIRTHDAYS ■ REUNIONS ■ CELEBRATIONS OF LIFE ■ TRADE SHOWS

Recognized for our commitment to patients, the Cleveland Clinic Lou Ruvo Center for Brain Health applies these same principles to each and every gathering at LAC, offering the ultimate in hospitality with a focus on detail and personalized, individual attention, resulting in an unrivaled guest experience.

Creating your memory at the LAC helps us preserve memory for others. Special event revenues collected by Keep Memory Alive support the Cleveland Clinic Lou Ruvo Center for Brain Health's core mission: enhanced treatments and ultimately the prevention of neurocognitive disorders.

The Life Activity Center: **creativity at play**

Bookings have already been confirmed for 2010. Contact us at (702) 263-9797 or via email at LAC@keepmemoryalive.org to discuss availability.





KEEP MEMORY ALIVE WAS BORN 14 YEARS AGO OVER A DINNER LARRY RUVO HOSTED FOR FRIENDS AND FAMILY.

Create unforgettable memories for your friends, family, and colleagues in our new **Frank Gehry-designed Life Activity Center.**

WEDDINGS ■ BAR MITZVAHS ■ BIRTHDAYS ■ REUNIONS ■ CELEBRATIONS OF LIFE ■ TRADE SHOWS

Create a memory and help us preserve memory. Special event revenues collected by Keep Memory Alive support the Cleveland Clinic Lou Ruvo Center for Brain Health and its quest for the cure.

Embark on a Frank Gehry-designed experience with Keep Memory Alive. Accommodating 500 seated or 900 standing. **The Life Activity Center: creativity at play**

Beginning May 2010.

Contact Christina Moon at 702-263-9797 to discuss availability.

KEEP MEMORY ALIVE

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

ALZHEIMER | HUNTINGTON | PARKINSON | ALS | MEMORY DISORDERS

(cont. from page 22)

therapeutic trials. The lack of these tools has been the limiting issue for advancing the concept of prevention.

The goal of establishing a ‘National Registry’ of asymptomatic volunteers at risk for dementia will be to recruit large numbers of healthy people willing to undergo a minimal set of assessments to establish a baseline dataset. From this group, subgroups could be selected for additional studies to evaluate different methods of identifying the earliest predictors of disease. Such tools and knowledge are needed to select at-risk individuals appropriate for preventive and therapeutic trials, and to demonstrate whether a therapeutic agent is having a positive effect so that future preventive and therapeutic trials can be accomplished in a reasonable time frame.

2. Compare screens to determine which are best

Consensus was also reached on the probability that multiple screening approaches will be required in order to identify individuals who are at high risk for developing AD. A workgroup will be formed to further evaluate the screening approaches discussed above and to formulate a plan to evaluate which combination of screens would be needed at baseline, and then which assessments might be added for smaller subgroups of subjects. A National Registry and Clinical “Test Bed” might enroll 10,000 households across the United States to participate in non-invasive home monitoring techniques; provide saliva samples for whole genome sequencing; participate in home assessments of diet, lifestyle, and family, medical, and social histories; and collect water, soil, and air samples in the home. These households could then be divided (either randomly or by some pre-determined criteria) into subgroups to undergo: a) wet biomarker studies and structural imaging, b) cognitive testing, c) functional imaging, and d) other tests.

3. Address public misunderstandings about AD

Despite the huge public health implications of the growing AD problem, there is a high level of public misunderstanding about AD and healthy brain aging. For example, “brain games” have been successfully marketed as effective in slowing dementia despite a lack of scientific evidence, while the effectiveness of exercise, which has been documented, is less widely accepted. Because a person’s level of understanding correlates with his or her willingness to participate in clinical trials and because recruitment for trials is so important, the need to address public understanding of the issues is critical.

4. Go global - Extending the registry beyond the United States

While the current effort is to establish a registry in the United States, the problem of AD is a global one, and will require worldwide cooperative efforts if it is to be addressed effectively. Among the participants at the workshop were those who represented studies underway around the world. A European Union / North American collaboration was initiated in Barcelona last year. A global initiative is also underway in Canada, which has so far developed a partnership with France and is now in discussions with other European countries and the United States. Studies in Canada and some other countries will benefit from the presence of national health systems that ensure care and treatment for all citizens. In France, President Nicolas Sarkozy unveiled a five-year plan in 2008 to invest \$2.4 billion in a foundation for AD research. A prevention trial of omega 3 fatty acids plus physical and cognitive treatments targeting patients at risk for dementia is also underway in France.

Conclusion

The longevity revolution in combination with the baby boom generation has created the conditions for a tsunami of individuals developing AD in the coming decades. With this in mind, AD researchers around the world have recognized the urgency of identifying preventative strategies as soon as possible. We are now at the point of needing specific recommendations and a plan for implementing those recommendations in the next few years. If Leon Thal were here, he would be leading this effort. In his memory, the Cleveland Clinic Lou Ruvo Center for Brain Health has brought together collaborators from across the nation and beyond, with a singular focus on preventing AD. This symposium represents another step forward on the path to prevention, but will require the sustained effort of all stakeholders to ensure continued progress.

Donna Thal presents the Leon Thal Prize to Virginia Lee, PhD, and John Trojanowski, MD, PhD, of the University of Pennsylvania.



**Where did
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physicians refer
their patients
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KEEP MEMORY ALIVE

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



ALZHEIMER | HUNTINGTON | PARKINSON | ALS | MEMORY DISORDERS



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Go to keepmemoryalive.org to learn how you can invest in memories and support the work of the Cleveland Clinic Lou Ruvo Center for Brain Health.