



Brain Facts Support Brain Donation: Why it's Important to Think About It

The National Institute of Neurological Disorders and Stroke describes over 400 different brain disorders. While many of these conditions are rare, others like Alzheimer's, Parkinson's and autism affect millions of people at different ages.

Parkinson's disease (PD) is a chronic and progressive movement disorder, meaning that symptoms continue and worsen over time. Nearly one million people in the US are living with PD. The cause is unknown. Although there is presently no cure, there are treatment options such as medication and surgery to manage its symptoms.

Some disorders affect brain development in children. Autism is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASD). Children with autism have difficulties with social interaction, display problems with verbal and nonverbal communication, and exhibit repetitive behaviors or narrow, obsessive interests. Autism varies widely in its severity and in some cases, the symptoms may go unrecognized, especially in mildly affected children or when more debilitating disabilities mask it. Scientists are not certain what causes this condition, but it is likely that both genetics and environment play a role.

Schizophrenia is a severe and debilitating brain and behavior disorder affecting how one thinks, feels and acts. People with schizophrenia can have trouble distinguishing reality from fantasy, expressing and managing normal emotions, and making decisions. Their thought processes may also be disorganized and they have difficulty engaging in life's activities.

Schizophrenia affects men and women equally. It occurs at similar rates in all ethnic groups around the world. Symptoms such as hallucinations and delusions usually start between ages 16 and 30. Men tend to experience symptoms earlier than women. Most of the time, people do not get schizophrenia after age 45. Schizophrenia rarely occurs in children, but today, the awareness of childhood onset schizophrenia is increasing.

The only way to accurately diagnose many brain disorders that effect us across the lifespan, including Chronic Traumatic Encephalopathy (CTE), is by studying

the brain after death. In 2008, the Concussion Legacy Foundation partnered with Boston University and the Veterans Administration to found a Brain Bank. These researchers have revolutionized our understanding of CTE, but more donations from those who suffer with CTE and other traumatic brain injuries are needed.

With recently appropriated funding from Congress, the National Center for Post-Traumatic Stress Disorder (PTSD) is leading a research consortium to develop a national brain bank. This effort will be the first brain tissue repository dedicated to researching the physical impact of stress, trauma and PTSD on the brain. The University of Miami Brain Endowment Bank™ is supporting this important effort.

The University of Miami Brain Endowment Bank™ is one of six national brain repositories chartered by the National Institutes of Health (NIH) in 2013. Our mission is to support scientists and doctors who are working to understand the cause of many diseases that affect the human brain. By providing samples of donated brain tissues, we can help them develop new treatments and ultimately find the cures for diseases that affect our brain. Brain donations from unaffected healthy donors are needed for comparison. And, scientists need to study the brain across the lifespan, from childhood to old age.

A brain donation after death can provide tissues to hundreds of qualified researchers who have dedicated their lives to make ours better. It is important to use your intellectual power and to make the most of your brain. But when the end inevitably comes, why let such a precious resource go to waste? Your gift can make a difference and lead to the next scientific breakthrough. A gift of a brain donation after death supports the health and well-being of the next generation - your children and grandchildren.



*Deborah C. Mash PhD
Founder and Director, UM Brain Endowment*

DONOR PROFILES

Most people understand the importance of organ donation and how it can save lives, but a brain donation is a special gift.

At the Brain Endowment Bank, we have the unique opportunity to connect with our donors and their families who share a common vision. We welcome these friendships and the opportunity to learn from our donors and their family members about the disease process. We also learn why some people age “razor sharp” into the eighth, ninth and tenth decade of life. Our friendship does not end after the final gift of a brain donation. We extend comfort to the family and work to provide families with the answers that they seek. This information comes from the neuropathology examination of the brain. We share with you three stories: Martin Caplan, Cecil Pittman and words from the family of Alexander Merrill Seyl.

Cecil Pittman (1947-2016)

Cecil Pittman was a U.S. Marine Corps veteran, an active community member who served on local boards and a loving family man who raised three children with his wife Patricia (Trish). Diagnosed in 2009 with Lewy body dementia (LBD), this disease, coupled with Post-Traumatic Stress



Disorder (PTSD) from two combat tours in Vietnam, lead to his aggressive mental decline. This gentle giant of a man, became aggressive and combative, suffering from tormenting hallucinations and paranoia that plagued him until the end. The Pittman family made the decision to donate his brain to help promote research for a cure for this devastating brain disease.

Trish Pittman, Cecil's wife and caretaker, is a dedicated advocate for people diagnosed with Lewy Body Dementia. It is her mission to find the cause and ultimately a cure.

“Cause, Cure, Care” is her motto.

She shares her passion with us, and this is why she made the decision to donate his brain to support research for a cure.

“Over the past 45 plus years of knowing and being married to Cecil, we recall the good times, the great times, and lately, the not so good times. We are committed to raising awareness of this cruel form of dementia. Many families are affected by loved ones diagnosed with some type of dementia later in life and much needs to be done,” said Trish Pittman.



The Pittman family is sponsoring the 2nd annual **Cecil Pittman Golf Tournament** to be held on October 10, 2016 at Flat Creek Country Club in Peachtree City, Georgia. This year's proceeds will benefit the **University of Miami Brain Endowment Bank** and the research on Lewy Body Dementia. Please participate in the tournament or make a donation to support this event. Call 305-243-6219 or 1-800-UMBRAIN or brainendowmentbank.org.

ABOUT LEWY BODY DEMENTIA

Lewy Body Dementia is a progressive neurodegenerative dementia closely associated with Parkinson's disease (PD). Both primarily affect older adults. Its primary feature is a more rapid cognitive decline than with PD. Symptoms include impaired analytical or abstract thinking, fluctuations in cognition, attention or alertness; problems with movement, tremors, stiffness, slowness and difficulty walking. Other symptoms are visual hallucinations, sleep disorders, behavioral and mood changes. The disorder is diagnosed by examining the brain for the presence of Lewy bodies in the neurons. These are only detectable in the brain after death. This examination confirms the diagnosis given during life.

Alex's Story

A Powerful Story of a Mother's Love and Her Lasting Gift

By Michelle Seyl

I'll never forget the day I found out I was pregnant with our precious angel, Alexander Merrill. I was at work and started feeling very ill. When I got home my husband took one look at me and knew. I didn't believe him. We had been trying to have a baby for a couple of years - since he returned from the war in Afghanistan. Little did we know what a beautiful gift was coming our way.

At ten weeks, I visited my doctor, who performed a blood test for Trisomy 13, 18 and 21, or Down's Syndrome. We then had our first ultrasound and the doctor noticed something abnormal on the screen: a little fluid around the neck of the baby. She explained that this was characteristic for Trisomy 21. It didn't matter to us. We were delighted that another child would be joining our four beautiful sons. Although I was happy, I was nervous about the test results. I wanted our baby to be healthy. The call came a few weeks later. We were told we were having another boy, but our baby tested 82% positive for Trisomy 18. The minute I got off the phone I looked up Trisomy 18. I will never forget the words: "incompatible with life."

It is a rare chromosomal abnormality that causes malformation of the major organs. The more I researched, the more I realized how little information there was about it. I was devastated to learn that



our baby boy had only a small chance of being born alive, let alone living to his first birthday. I told myself that whatever time we had with him was a blessing. I joined other "Trisomy Moms" and was inspired to donate.

During the pregnancy, I saw a specialist, who allowed my husband and me to see our baby boy once a month by ultrasound. Those appointments were bittersweet; we never knew when he might be born. On May 21, 2015, I gave birth to Alexander Merrill. I held him as he cooed. It was the most beautiful sound in the world. We spent six amazing hours with our little angel. When the recovery team came, we knew that Alex's gift would make a real difference. We donated our precious baby boy's brain to the **University of Miami Brain Endowment Bank** to assist with research in Trisomy 18. We also donated his lungs to assist in research into the treatment of cystic fibrosis.

One day there will be a cure for Trisomy 18. Through donation, scientists will be able to do the research and hopefully cure this condition. It may not happen in my lifetime, but I know that our sweet baby boy, Alex, will change this world with his very short life.

Martin Caplan (1918-2016)

Mr. Caplan registered with the UM Brain Endowment Bank in 1992. He was a strong supporter of us, encouraging others to consider his final gift of a brain donation. His granddaughter, Debra Caplan, provides his story.



My grandfather Martin ("Marty") was born in 1918 to Michael and Sophie Caplan and grew up in Philadelphia. He served in World War II as a cartographer and received a Silver Star for his bravery in rescuing fellow soldiers during a battle. Marty was first married to Mildred Kouser, my grandmother; later he married Marie Benshabat. He had two sons, Murray Caplan and Zev Caplan. He ran Tile Town, a floorcovering business with nine stores across Philadelphia and South New Jersey. Upon retirement, he moved to Hollywood, Florida where he lived for more than three decades, with a brief stay in Israel in the 1970s. Marty loved the music of his youth, especially big band and Broadway hits of the 1930s, 40s and 50s. He was extremely intelligent and fiercely independent, even in his late 90s. Marty Caplan will be missed by many of us.

Brain Bank Research Focuses on Recent Algal Blooms

Florida has been affected by massive algal blooms in Lake Okeechobee this summer. And our scientific research has been profiled in recent news reports. Blue-green algae have been implicated in the development of some neurodegenerative diseases, but while there are links to blue-green algae, there is a need for more research

On June 22, CBS News Channel 12 in Martin County reported that algae blooms in the lake are invading waterways extending 30 miles to the Intracoastal Waterway. Lake Okeechobee is critical to local, state and national environmental health. It is the largest freshwater lake in Florida and the second largest in the continental United States after Lake Michigan.

The investigative reporter credited Deborah Mash and a team of scientists at the University of Miami with making the connection between diseases like Alzheimer's and the blue-green algae now invading the Treasure Coast. "Scientists are now concerned that people living by bodies of water that are known to have high algae bloom activity may be at risk for certain neurodegenerative disorders, like ALS and Alzheimer's dementia," Dr. Mash said.

The research is focused on an amino acid known as beta-methylamino-L-alanine, BMAA. Amino acids are the building blocks of proteins; there are 20 of them that the human body can make and then combine in various manners to form the proteins in our bodies. However, there are other amino acids that don't regularly get incorporated into proteins - BMAA is one of these. If BMAA from the diet gets incorporated into proteins then it may impair their function. Researchers found BMAA in the brains of North Americans who had Alzheimer's disease, and in the

brains of victims of ALS and Parkinson's dementia in Guam.

Dr. Mash has collaborated with Paul Alan Cox and his team, who are at the forefront of BMAA research. Paul Cox is credited with making the BMAA connection to neurodegenerative disease. Working together, they are studying how this neurotoxin in algal blooms may cause damage to the brain. Monkeys fed BMAA in their diet, develop pathology in the brain that is similar to Alzheimer's disease and ALS.

"We see the BMAA theory as complementary to current genetic research, and are very open to the possibility that other environmental factors may be involved," said Paul Cox of the Institute for Ethnomedicine and leading proponent of the BMAA hypothesis. "More research is needed, but people should be aware that toxic algal blooms should be monitored as more information about the public health risks unfold."



500 Reasons Why We "Lobe" You Campaign

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Thank you for your support and grateful intention!