A MESSAGE FROM MARY ANN MALACK-RAGONA, EXECUTIVE DIRECTOR/CEO

May is such a beautiful month. A month to honor all of our wonderful Moms and a month to honor all of those who have so bravely served our country so that Freedom can prevail for all. And best yet, May is the unofficial start of summer! For some it’s a sad month as we think about those we’ve lost due to Alzheimer’s disease or perhaps in the military, but that sadness must be replaced by the wonderful memories we all hold so dear to hearts.
I am excited to tell everyone that we are embarking on a new collaboration with UsAgainstAlzheimer’s. UsAgainstAlzheimer’s is a relentless force committed to stopping Alzheimer’s by 2020. Driven by the suffering of millions of families, UsAgainstAlzheimer’s presses for greater urgency from government, industry and the scientific community in the quest for an Alzheimer’s cure. Members accomplish this through effective leadership, collaborative advocacy and strategic investments.

ADRC has agreed to serve on the Planning Committee for the 4th Annual National Alzheimer’s Summit and Hill Day in Washington, DC. Mark your calendars and plan to join us on September 27th thru 29th where we will have the opportunity to learn from caregivers, political representatives, noted authors and researchers. We will also have an opportunity to visit with our U.S. Senators and Congressional Representatives to discuss issues of concern. There will be more to follow on this, as plans are in the preliminary stages, but if you have an interest in joining us for the National Summit please contact me and I will make sure I have you on our distribution list so that you get updated information. My email is: maryann.ragona@adrcinc.org.

ADRC looks forward to this new collaboration, as well as bringing our voice to Washington, D.C. in our quest to ensure A Future Free From Alzheimer’s.

Our Art Therapy & Music Therapy Programs continue to grow and we invite anyone caring for a loved one with Alzheimer’s disease to contact our office to inquire about programs that are available to you.

ADRC is also pleased to announce the launch of our Spanish Support for Caregivers which meets the third Saturday of every month at the Hispanic Counseling Center located at 344 Fulton Ave., Hempstead, NY. The Support Group meets from 10:30 a.m. to Noon. For more information please contact Licet Valois at (516) 435-6410.

Please remember that all of the programs and services offered at ADRC are at no charge to our families.
Our Walk Kick-off Breakfast is scheduled for Thursday June 9th, 2016 from 8:30 a.m. to 10:00 a.m. at Dave & Buster’s in Islandia. Online registration for our Walks is now open. Please visit us at www.adrcinc.org to reserve your place at our Kick-off Breakfast and/or to register for our Walk For Alzheimer’s.

We wish all of our Moms a Happy & Beautiful Mother’s Day filled with love, life and family.

Welcome Summer!
HONORING THE GREATEST GENERATION

by Dr. Cynthia Paulis

John Latini of Massapequa was thumbing through a World War II book on armored tanks in a book store when suddenly a picture caught his attention. The grainy black and white photo showed an armored tank amidst a city in ruins. Sitting on top of tank were five men, and front and center with a broad smile was young man that Latini recognized from old photos. It was his dad, John Latini. “My dad was 25 years old then and a tank sergeant. His tank was the first tank from Patton’s Third Army to reach the Rhine into Germany during the Battle of the Bulge.”

After the war John’s dad settled in Hicksville and with his wife raised four children. He served in the NY City Police force as a Lieutenant for 37 years and then retired. Latini, who was the youngest, noticed that sometime when his dad was in his mid-70’s he began to show early signs of Alzheimer’s although at that time they were not aware what was happening. “My dad had this amazing ability of always remembering a person’s name and face. Then later he started slipping but we just figured it was old age.”
His wife became the caregiver as the Alzheimer's progressed. Then tragically, while on vacation in Las Vegas, she collapsed and had a heart attack. Latini recalled the strange events which took place. "My dad at that time was in the mid stages of Alzheimer's. He was always a chivalrous type of man. When the paramedics arrived to do chest compressions they ripped open my mother's blouse and when my dad saw that he decked the paramedic knocking him across the room. The instinct to protect his wife was always there." Latini flew out to Vegas and was met by his brother, a Vietnam War Vet and also a police officer who was suffering from PTSD. "At that time my brother's meds were not adjusted properly. I remember sitting between my dad who had Alzheimer's and my brother who was threatening to kill the guy who kept opening up the overhead compartment, and my mother's body was in the cargo hold, and the plane was delayed. It was a really bizarre flight."

Latini's sister then moved into the home and became the new caregiver. "My dad went to the funeral but I don't know if he didn't understand what was happening but he didn't seem to show any signs of emotion. He stood there stoic. He seemed to go downhill, however, after my mom died. I never really knew to what extent my father knew what was going on. That his wife of so many years was gone. I think that was the last straw and my father regressed more because my mom was such a presence in his life. My dad was later incontinent. Here was this strong man now in diapers. I would hear stories from my cousins who are a lot older than I am that my dad was real athlete, a gymnast who could do a back flip from a standing position. It was sad to see this tremendous change."

The one thing that Latini recalled was how grateful and appreciative his dad always was for what he had. "He would ask a lot of questions and look around the room and say, "Is this my home? Do I live here? We would say yes and he would smile and say, "That's amazing." My dad, when he was cognitive, was grateful for how he started and what he became, being a police officer and being able to have his own house. He was the kind of man who always picked up bottles to return and was so grateful that his life turned out so well after the depression. That's why it was so strange when he didn't recognize his own home."
Latini's dad was born in America but soon reverted to his Italian roots. "The one thing he would start to do was speak in Italian and then sing songs in Italian which we always found very humorous."

As his Alzheimer's progressed he later went into an assisted living facility in Lynbrook for the last year of his life. "I don't think they took very good care of him because he started to develop bed sores so it was very tough to see this. He became very ill, had pneumonia, a stroke and then a heart attack and died at the age of 83."

Latini recalled a time when his father and his uncle Fiori, who served in the Navy, were flown down to visit the WWII wall in Washington D.C. "My uncle also developed Alzheimer's. When they were there someone interviewed them and you can tell that they no longer had any of their faculties."

Latini reflected on what was the hardest part of watching his dad go through Alzheimer's. "Here was this man who led such a vibrant life, he was a commander in the police department who had the respect and command of so many people and to see that he didn't even know where he was anymore. He didn't recognize his house and he didn't even recognize my sister who was his caregiver all the time. He did recognize me but even people who were in his daily routine he didn't recognize. My children were very young at the time so he never got to enjoy them or get to know them as a grandfather. I was the youngest of four children so there was a 20 year age difference between my older brother and me."

Latini shared his father's stories of WWII. "That generation never really talked much about the war. They came home, raised a family and moved on. There was one time I saw a picture of my dad on top of a tank when he was going either through Belgium or France. He has his finger in a hole through his helmet. Apparently a sniper shot at him, and there is a gap between the top of your head and the helmet. The bullet passed through that gap. There is a picture of him with his finger in the hole smiling, like I really dodged the bullet. I asked what happened. My dad said well there was a sniper but I got him."
Latini continues to search for his dad. “Whenever I see a movie on WWII or go to a bookstore I look for him. I often said to my wife that one of these days I will walk into a bookstore and find him. Then one day when I was in the bookstore flipping through a book on armored tanks I saw the picture. I felt it was a fitting tribute, there it is, I knew someday my dad would make it into history forever. As my dad progressed with the Alzheimer’s he became more confused but he was always very happy. I can only hope that in his mind he went back to a happier time and place with whatever memories he had.”
UNLOCKING THE MYSTERY OF ALZHEIMER’S DISEASE

by Dr. Cynthia Paulis

Peering through a microscope, Allison B. Reiss, MD, Head, Inflammation Section of Winthrop University Hospital Research Institute and Associate Professor of Medicine at Stony Brook University School of Medicine, hopes to unlock the mystery of Alzheimer’s disease which causes brain cells to wither and die. She is currently running a pilot program to find a cure for this dreaded disease which affects so many millions of people around the world.

Trained as a board certified internist, Dr. Reiss is integrating medicine and science as a way to understand the mechanism of Alzheimer’s. “For years I was an Internist at NYU looking at how cholesterol affects Alzheimer’s patients. Inflammation and lipid metabolism underlies so many diseases; it gives me a wide range of possibilities where I can apply my skills.” After receiving a grant, Dr. Reiss is heading a pilot program looking at how cholesterol affects Alzheimer’s. Working closely with the geriatricians and neuroscientists she is hoping to make a breakthrough.

“I always liked to solve puzzles and problems, that’s what I love about research. Alzheimer’s to me is not only personal because of all the suffering it causes, but it is also intellectually a challenge to figure it out and to try to do something about it. I read the literature to see what is going on but it is the same old thing. The doctors working on it seem so helpless. We seem to be getting closer to prediction but what good is prediction if you can’t do anything about it. Why does a person want to know if they are going to have Alzheimer’s if we can’t help them?”

Thinking outside of the box Dr. Reiss has decided to take on the challenge through a different set of skills. “My philosophy of Alzheimer’s always has been that it is not a brain disease but a systemic disease. It is through your whole system that this happens. It’s not just that the brain gets sick and everything
else is fine. It is all connected. I think a lot of research in Alzheimer’s tends to isolate it. The people who study it tend to be experts in the brain but they are not thinking of everything. My experience is that I am a trained molecular biologist with an interest in neurology. By putting all of our heads together we can do something different.”

During the time that Dr. Reiss was developing this new approach, over in England Axol created Human Neural Progenitor Cells (hNPCs) which can be purchased for research. “You can’t take brain cells from people with Alzheimer’s but you can take peripheral cells from people affected by the disease and those without,” commented Dr. Reiss.

“Dr. Allison Reiss is in the center. On her right with short brown hair is Lora Kasselman and on her left with long hair is Nicolle Siegart. They are students working in the program.”

These (hNPC ) which are fibroblasts are then differentiated into markers of cerebral cortical neural stem cells. The Axol (hNPCs), according to their company’s literature, “Are capable of generating a spectrum of cortical
projection neurons that are electrically active and have the ability to form functional synapses and circuits in vitro. Cerebral cortical neurons are implicated in numerous diseases including Alzheimer’s, autism, epilepsy and stroke.”

Translated what this means is that these cells can then act exactly like brain cells. When the synapses or connections of the brain which transmits information gets clogged with protein or amyloid it causes the cells to wither and die, taking with it the person’s history, memory, personality.

“These hNPCs which are like neurons can be grown on a dish and then you can use them as fully human cells to work with human material now from people who are enrolled in the study. That’s where you get the personalized element. We are enrolling patients with Alzheimer’s and those without who are over 65 years old. We are taking from these patients the platelet rich plasma the same type that people are using to help sports figures heal injuries. It’s full of platelets and growth factors and distills out important elements in the plasma that I believe are crucial for Alzheimer’s. The reason I like the plasma is that the platelets have the amyloid machinery. The machinery and the production of amyloid occur only in a few cell types and coincidentally one of those cell types is platelets.”

These hNPC’s have an added value. “For purposes of study where I can’t go and take a piece of someone’s brain and look at their amyloid production in their brain cells, here I can get platelets so easily from my patients with a blood sample.” Then she adds the platelet rich plasma on to the neurons that are Alzheimer and then she can observe the production of amyloid and the toxicity to the cells. Amyloid is toxic to neurons, not so much to the fibrils. Dr. Reiss explained what she hopes to learn from this study. “We want to compare how the machinery will work when you have an Alzheimer environment in the neuron combined with an Alzheimer environment in the platelet as opposed to normal neurons and normal environment. Then we are going to look at normal neurons and see what Alzheimer’s platelets do to those. How much of the outside influence will hurt a neuron that is not genetically predisposed.” The program has been going on for a year and a half.
“What we want is a predictor of who is going to get Alzheimer’s so when we start to see the patterns that are ominous in the patients we can start to look at outside family members and see if we see that. While that is interesting what is more important is to try to start treatment so we can avert some of the toxicity. So if you see an Alzheimer’s person, platelet rich plasma on those neurons and then you introduce a drug or a treatment and see a difference you get into that realm of personalized medicine where you can predict hopefully if a drug will be good for that person.”

This test system will help to determine if the medications out there are of any help in stopping or slowing down the disease. “The goal here is to set up a model not just for our lab but for other labs as well so we can get a broad swath of Alzheimer’s patients and do a longitudinal study to see if there are changes in the activities of drugs and this Alzheimer’s machinery as the disease progresses, to be able to catch it early and to be able to test new and innovative treatments as drugs develop. This is a pilot study on learning about the differences in all of the important proteins in keeping a neuron healthy versus a deteriorating one in Alzheimer’s. This will give us a snapshot of the key differences between all of the proteins in the machinery of a person with Alzheimer’s verses a person without Alzheimer’s. Once we get that pinpointed we can unravel and reveal some new proteins we didn’t know about and we can use drugs and treatments to see which proteins we can change and improve the results for the cells. We can keep brain cells alive and healthier longer because in Alzheimer’s there is a lot of destruction and death of brain cells. We want to prevent that so we have to go back to the basic biology of the cell to compare and see which ones are vital, which ones are going astray in Alzheimer’s and how we can protect against that.”

Dr. Reiss also has a theory on how cholesterol affects Alzheimer’s patients. “Cholesterol is shuttled back and forth from the blood brain barrier which is a fairly closed system. We do know that in every cell the membranes that keep the cell in tact are made almost completely of cholesterol and the composition of that membrane can vary a bit. I believe that abnormal cholesterol handling and abnormalities in the membrane leave the cell vulnerable to the toxic effects of amyloid and tau (proteins that over accumulate and cause the cell to become very ill and die). We want the cell to be able to fight back against the
amyloid and the tau and keep itself intact. The key to that is having a membrane that is healthy and keeps the cells integrity. When the cholesterol transport is not proper the cell becomes very vulnerable. Part of our experiment is studying the cell’s cholesterol metabolism and compare healthy and non-healthy.

Dr. Reiss reflected on what she hopes to gain from this study. “I think big. My objective is to expand the study and ultimately to get a better understanding of Alzheimer’s so we can predict who is vulnerable so we can avoid it, avert it and prevent it. We want to do something to stop Alzheimer’s disease.”
IRREVOCABLE TRUSTS
by Nancy Burner, Esq.

Despite what many people think, it is possible to protect assets to pass on to the next generation and still receive long term care at home or in a nursing facility from the Medicaid program. One of the ways we can protect these assets is by creating an Irrevocable Trust, often referred to as Medicaid qualifying trust. The client who creates the trust is called the grantor. The grantor puts assets they are looking to protect into the trust by changing the ownership of the asset. While not entitled to receive principle from the trust, the grantor can receive all income generated by trust assets. Any person other than the grantor or their spouse can be named as trustee to manage the assets that are held in the trust. The trust document will list your wishes for distribution of assets after your death just as would be done in a last will and testament. Once you have transferred assets into a properly drafted Irrevocable Trust and they have been there for a period of five years, they will be considered unavailable if you need to apply for Medicaid to assist with the cost of your nursing home care. The assets are deemed protected the month after funding the trust if you are applying for Medicaid to assist with the cost of home care. A trust can own various types of assets including, real property, brokerage accounts, life insurance, and non-qualified annuities. In addition to the benefit of asset protection, the trust will also provide for orderly management of your assets during your lifetime as well as avoidance of probate at death. In a properly drafted trust the grantor has the right to change beneficiaries and trustees at any point giving some flexibility to the otherwise ominous sounding “irrevocable trust.” As the foregoing demonstrates, Irrevocable Trusts can be a beneficial yet flexible tool for Medicaid planning.
The attorneys at Nancy Burner & Associates, P.C. represent clients in **Suffolk and Nassau Counties, including the Hamptons and Eastern Long Island, as well as throughout New York City**, concentrating in the areas of Estate Planning, Elder Law, Trust and Estate Administrations and Guardianships.
VINCENT RUSSO, ESQ.
INDUCTED INTO FRIAR’S CLUB

Vincent J. Russo, Esq., a good friend and supporter of the Alzheimer’s Disease Resource Center, was recently inducted in the prestigious New York Friar’s Club. Russo is the creator and co-host of the Telly Award winning show Family Comes First, and an attorney, visionary and pioneer in the fields of Elder Law and Special Needs.

The Friars Club was founded in 1904 and has evolved into one of New York’s most exclusive clubs, home to legendary comedians, actors, musicians, writers, directors, producers, journalists, broadcasters, entrepreneurs and athletes. The club is known for fostering and promoting strong social and professional bonds among its membership through celebrity roasts and philanthropic efforts.

Russo has been involved with the organization for the past 10 years in a networking capacity. He shared his thoughts on his recent induction. “I am honored and excited to become a member of the Friars Club and look forward to continuing the traditions of the Friars Club and the Friars Club Foundation. This is a wonderful opportunity to be involved in the entertaining and performing world whose members are also very generous to charities through the Friar Foundation.”
Mary Ann Malack Ragona, ADRC Executive Director & CEO, has high praise for Mr. Russo. “Vincent Russo has been such a great friend to our organization and helps ADRC and our families in so many ways. We could not be more pleased to see that such a well-respected and admired attorney has received this prestigious award. Congratulations to Vincent Russo who has been a true advocate for our Alzheimer’s families. This is an honor that is so well deserved.”

2016 Calendar of Events

June 9th, 2016  Walk For Alzheimer’s Kick-off Breakfast
               Dave & Buster’s, Islandia, NY

June 23rd, 2016 12th Annual Art Expression Program
                 Tea & Art Exhibit
                 ADRC, Bayshore, NY

July 16th, 2016 4th Annual Alzheimer’s Regatta Event &
                 Awards Dinner
                 Sagamore Yacht Club, Oyster Bay, NY

July 18th, 2016 ADRC’s Annual Golf Classic
                 Huntington Crescent Club, Huntington, NY

July 28th, 2016 Art for Alzheimer’s
               Parrish Art Museum, Water Mill, NY – 6pm to 8pm

September 10th, 2016 14th Annual West End Walk For
                      Alzheimer’s
                      Marjorie Post Park, Massapequa, NY

October 15th, 2016 5th Annual Westhampton Beach Walk
                    For Alzheimer’s
                    Main Street & the Gazebo, Westhampton Beach, NY
                    (pending Village approval)

December 8th, 2016 11th Annual Walk Holiday Awards
                    Luncheon
                    Milleridge Inn, Jericho, NY

December 15th, 2016 33rd Annual Gala & Awards Dinner
                    Venue to be determined
ADRC’S 14TH ANNUAL WALK KICK-OFF BREAKFAST

Thursday – June 9th, 2016
8:30 a.m. to 10:00 a.m.

Dave & Busters
1856 Veterans Memorial Highway
(Walmart Shopping Center)
Islandia, NY

Register online or RSVP to
info@adrinc.org by 6/1/2016

To make a phone reservation please call:
Mary Ann Malack-Ragona
Phone: (631) 820-8068
Alzheimer’s Disease Resource Center
Invites You To
ART FOR ALZHEIMER’S
(Celebrating Paint At The Parrish)
Honoring
The Parrish Art Museum
Thursday, July 28th, 2016
6:00 p.m. to 8:00 p.m.
Alzheimer’s Disease Resource Center Inc. Mission Statement
To support research that may lead to a cure for Alzheimer’s Disease, to provide care, support and education programs for families in need, and to be the voice for families who are coping with Alzheimer’s Disease and/or other Dementias.

Alzheimer’s Disease Resource Center Inc. | Main Office
45 Park Avenue, Bay Shore, New York 11706

Satellite Office: 33 Flying Point Road, Suites 121/122
Southampton, New York 11968

© 2016 Alzheimer’s Disease Resource Center Inc.
All rights reserved. www.adrcinc.org | 631.580.5100