



Mount Sinai

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Icahn School of Medicine at Mount Sinai

Alzheimer's Disease Research Center



Mary Sano, Ph.D.

Director, ADRC

Hillel Grossman, M.D.

Medical Director, Clinical Core

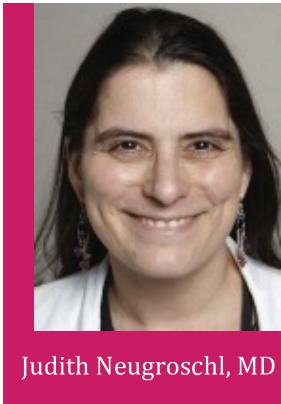
Margaret Sewell, Ph.D.

Editor, Director Educational Core

Kelly Pun, Assistant Editor



BACE Inhibitors



Judith Neugroschl, MD

The Mount Sinai ADRC is excited to announce our participation in a nationwide study of a new medication, MK-8931, on the progression of cognitive changes in mild to moderate Alzheimer's Disease (AD). Our current understanding of AD links the accumulation of a protein fragment, beta-amyloid, to progression of

the disease. There are two enzymes that are responsible for the formation of beta amyloid, and one of them is called BACE-1. These protein fragments spread throughout the brain and collect into the notorious beta amyloid plaques. This process interferes with many regions of the brain involved in memory, planning and thinking.

Previous studies with MK-8931, which inhibits BACE-1, have indicated that beta amyloid has been reduced by over 90% in the spinal fluid of healthy elders. These results suggest that MK-8931 may be able to decrease the beta amyloid in Alzheimer's patients, and research-

ers hope that the course of AD could be slowed by reducing beta amyloid plaque buildup. Researchers are hopeful that the drug will have positive effects on subjects with mild to moderate AD.

MK-8931 has undergone extensive safety review in the Phase I study and has precautions in place to ensure participants' health and safety and has been shown to be generally well tolerated.

Our study team will be led by Dr. Judith Neugroschl, who will work closely with other members of our ADRC team, including research coordinator Sabrina Lopez. Dr. Neugroschl states "We are very excited to be taking part in this study. We know that elevated beta amyloid leads to plaque formation, and this BACE-1 inhibitor should significantly lower the amount of beta amyloid fragments. We hope that by changing the amount of beta amyloid produced, we can impact the course of the illness, and that through this, and the other trials we are participating in, we will help find an effective treatment for this devastating disease." For more information on this study or other research programs at Mount Sinai's ADRC, please contact Sabrina Lopez at 212-241-5692.

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Easier Trails: Travel with People with Dementia

The bottom line for traveling with people with Alzheimer's is really simple: Expect the unexpected, remain flexible, and keep your sense of humor. You should try to plan and prepare for all eventualities as best you can, but no matter how well you prepare there will almost always be surprises. Build in extra time because, as caregivers know so well, a person with Alzheimer's can sometimes take a lot of time to do simple tasks. Regardless of your mode of travel, remember these three tips for traveling with a person who has Alzheimer's:

1. Use one packing checklist to be sure you have all the essentials you need for the person with Alzheimer's as well as for yourself.
2. Pack all the daily medications yourself for the person with Alzheimer's, and pack them for daily usage. Small plastic 3" x 2" pill bags that can be bought at most drugstores and big-box store pharmacies are perfect for this purpose. You can write on the bags or even apply different colored tape to distinguish morning, afternoon, and evening pill bags. Instead of having to take out pills from various bottles, you can simply hand one pill bag to the person with AD at the appropriate time of day. I also take several extra pill bags because it is quite easy for a person with Alzheimer's to drop and lose tiny pills.
3. Maintain toiletry bags to use solely when you travel. Each time you return from a trip, take a few minutes to replace or replenish used items. Then place toiletry bags away until it's time for your next trip.

Senderos Faciles: Viajando con las personas con demencia

Sin tener en cuenta el método de viajar, recuerde estos tres consejos cuando estas viajando con una persona con la enfermedad de Alzheimer's.

1. Usa un lista de empacar para estar seguro que tienes todos los artículos esenciales para usted y la persona con la enfermedad de Alzheimer's.
2. Empaca todos las medicinas diarios de usted y la persona que tiene la enfermedad de Alzheimer's, y después empaca las medicinas para uso diario. Bolsas pequeños de 3 x 2 pulgadas disenado para almacenar medicinas pueden ser encontrado en la mayoría de farmacias y son perfecto para este propósito. Puedes escribir en las bolsas o poner diferente cinta de color para distinguir medicinas de la mañana, tarde y noche. En lugar de tener que sacar medicinas de diferente botellas de medicinas, simple puedes dar un bolsa a la persona con la enfermedad de Alzheimer's durante el tiempo de día apropiado. Siempre cargo extra bolas porque es fácil que un persona con la enfermedad de Alzheimer's bota y pierda medicinas pequeños.
3. Mantenga una bolsa de artículos de tocador solo para el uso de cuando viajas. Cada vez que viajas, toma un momento para rellenar los artículos usados. Después almacene la bolsa de artículos de tocador hasta el próximo viaje.

Portions of this article have been reproduced and translated with the permission of author Allan S. Vann. This article has also been published in the journal, *care ADvantage*, Alzheimer's Foundation of America and can be accessed at http://afacareadvantage.org/issues/ca_fall12.pdf. You can also read the complete blog entry and other pieces by visiting the website <http://allansvann.blogspot.com/>

SNIFF: The Study of Nasal Insulin to Fight Forgetfulness

The Mount Sinai ADRC plans to join other centers around the country to expand on exciting results that suggest that insulin may improve memory in those with Mild Cognitive Impairment or mild Alzheimer's disease. A study last year from Dr. Suzanne Craft, in a small group of patients, demonstrated that patients taking insulin did better on tests of memory and on functional abilities than those treated with placebo. Based on these hopeful results a larger and longer study is in the planning stages. Insulin has many interesting effects on the brain. For example, insulin receptors are found in the synapse, which is where nerve cells connect and communicate. Insulin may contribute to synaptogenesis, which means the growth of new synapses, a possible method for making better connections in the brain. Insulin also plays a role in the hippocampus, the area of the brain where memories are formed. Insulin may also be protective against toxic forms of amyloid, which form the brain plaques in Alzheimer's disease.

To test these possibilities, a clinical trial is in the planning stages. In this study insulin will be administered intranasally (that is, through the nose). The nasal passage is very porous, allowing drugs to have nearly direct access to the brain. This study will compare the benefits of intranasal insulin over a 1 year period. The study plans to recruit 240 people nationwide.

As with many trials for participants with memory problems, this study will require a study partner, someone to help the participant take their medications and to help



Mary Sano, Ph.D.

describe any changes that occur during the study. Not all studies are for all people. There are criteria for participation to maximize safety and to insure that we can measure the effect of the drug. For instance, subjects with diabetes who are currently taking insulin will be excluded to keep them safe from taking too much insulin. Also subjects who have serious trouble reading, writing or hearing would not be included, because we would not have a good way to determine if the drug was working.

The experts at the ADRC encourage people to consider participating in research and we have many studies to choose from. We encourage you to learn about opportunities, to decide what how much time you can give and ask questions of people you trust to help you decide if a study is right for you. Those who do take part report great satisfaction from knowing they made a contribution to knowledge that may help themselves, and others. For more information on available research at the MSSM ADRC please call us at 212-241-8329.

ADRC Studies Currently Enrolling

Alzheimer's Disease Research Center Longitudinal Study

This is a national study of healthy elders and those with memory problems that examines how memory disorders affect cognitive abilities and daily functioning over time. For those willing to be followed on a yearly basis, free memory and medical evaluations are available to two groups: healthy elders over 74 years old who may or may not be concerned about memory changes and those of any age who have a diagnosis of Alzheimer's disease and related diseases including Mild Cognitive Impairment. Participation in this research study does not include treatment; however doctors and psychologists will review test results, and provide a letter with a diagnostic impressions and recommendations. Participants will also be given information about other research opportunities as they become available, such as clinical trials, brain imaging studies, and surveys. For more information or to schedule an appointment, please contact **Kelly Pun at (212) 241-1514** or email at Kelly.pun@mssm.edu. Principal Investigator: Mary Sano, Ph.D. MSSM #84-119; MSSM approved through 3/31/14.

Trial of NIC5-15, a natural product in subjects with Alzheimer's disease

We are seeking Veterans and non – Veterans with Alzheimer's disease to participate in a research study of a natural product, NIC5-15 at the Bronx James J. Peters Veterans Medical Center. NIC5-15 is a natural product found in legumes and soybeans. In laboratory studies it interferes with the accumulation of a protein in the brain that is involved in the development of Alzheimer's disease. Researchers hypothesize that this may slow down the progression of the disease. Some study participants will receive NIC5-15 and some will receive a placebo (sugar pill). Participation in the study includes physical exams, neurological exams, blood tests, and tests of memory and thinking skills. Participation of 8 months is necessary. For more information please contact **Emily Exter at (718) 584-9000 ext 5179**, or email at Emily.exter@mssm.edu. Principal Investigator: Hillel Grossman, M.D. VA GRO#10-029 approved through 4/3/14.

Markers of Transition to Alzheimer Disease in Veterans with MCI

This is a longitudinal study of aging veterans that will compare the results of memory and thinking tests as well as biological tests to see which are best at identifying who is at risk for developing Alzheimer's disease and their rate of cognitive, functional and global decline. To learn more about this project, please call **Christopher Van Hise at (718) 784-9000 ext 1704** or email at Christopher.vanhise@mssm.edu. Principal Investigator: Mary Sano, Ph.D. VA SAN#11-079 approved through 9/4/14.

Upcoming Trials

We are excited to announce that several new clinical trials will soon begin enrolling at our center. As detailed in the articles on pages 1 and 3, of this newsletter, the BACE study will examine the role of BACE inhibitors in the treatment of Alzheimer's Disease, while the SNIFF project will explore the use of intranasal insulin. For more information on these upcoming studies and other available research at the MSSM ADRC please call us at 212-241-8329.

ADRC Summer Internship Program



L-R: Interns Isabelle Avildsen and Pierce Janssen; Director Dr. Mary Sano; ADRC Supporter Robert Kahen; Interns Rebeca Teplitz and Samuel Charny

Thanks to ADRC supporter Robert Kahen, the ADRC was able to offer its second summer research college internship program in memory of Mrs. Moussa Kahen. Mr. Kahen's support towards future aging and memory researchers allowed our interns to attend educational lectures and outreach activities, while gaining hands-on experience with clinical and basic science research methods. All four interns were supervised by senior ADRC faculty on a variety of research projects that culminated in a presentation on August 1st to an audience of students and faculty. We proudly welcome these young academics to the field!

ADRC Goodbyes and Welcomes

We will greatly miss Gloria Benson who left in July to complete a master's program in neurocognitive psychology at the Ludwig Maximilian University in Munich, Germany. We are positive she will make a wonderful neuropsychologist!

Big congratulations to Judy Creighton, who completed her PhD in the neuropsychology program at Queens College. She recently took on a position at NYU. We thank Judy for all of her hard work and dedication over the years!

Helene Geramian began her doctorate in clinical psychology at Yeshiva University this fall. We wish Helene the best in her studies and are confident she will make an excellent psychologist!

Cleo McGovern started at SUNY Downstate in June for a joint program in medicine and public health. She is dearly missed at the ADRC, especially by her ADNI participants. Best of luck to the future Dr. McGovern!

And welcome to our new ADRC team members!

Lara Akinleye completed her degree at Tufts University in 2011, and she is the coordinator for the Brain Tissue Donation Program as well as the longitudinal study at the Bronx VA.

Jaclyn Pierce graduated from University of Richmond in May and is now acting as the study coordinator for ADNI-2.

Kelly Pun graduated from New York University in May 2013 and is the initial coordinator for the longitudinal study and administrative coordinator for the ADNI-2 study.

Christopher Van Hise completed the post-baccalaureate pre-medical program at Columbia University, and he is the coordinator for the MCI study at the Bronx VA.

2013 Walk to End Alzheimer's

Sponsored by the Alzheimer's Association, the 2013 Walk to End Alzheimer's was held on Sunday, October 20, 2013, at Riverside Park. We are still adding up our donations, but it looks like we will surpass the \$10,000 mark! If you are interested in participating in similar events and would like more information, please contact

Dr. Margaret Sewell at (212) 241-0188 or by email at margaret.sewell@mssm.edu



Kelly Pun helped coordinate this year's walk!

Caregiver's Corner

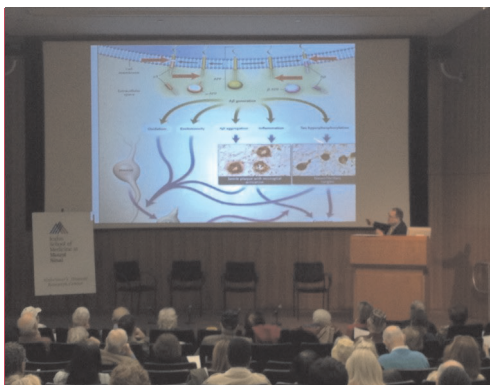
Resources for Patients and Caregivers (ENGLISH)

- **Mount Sinai ADRC** — Our website contains information about AD and our research programs, as well as resources for caregivers. You can also find previous editions of our newsletter here. www.mssm.edu/adrc
- **Alzheimer's Disease Education and Referral (ADEAR)** — A comprehensive website with AD information and resources from the National Institute on Aging. <http://www.nia.nih.gov/alzheimers/>
- **AARP Caregiving Resource Center** — Sponsored by the AARP, this website provides helpful information for caregivers and their families. <http://www.aarp.org/relationships/caregiving>
- **Family Caregiver Alliance** — Sponsored by the National Center on Caregiving, this website provides both caretakers and their loved ones with access to helpful information and resources. <http://www.caregiver.org>
- **Strength for Caring** — An online community providing important information while allowing caretakers to interact with and learn from one another. <http://www.strengthforcaring.com>
- **This Caring Home** — An interactive website with information and tips to make the home safer for individuals with Alzheimer's disease. <http://www.thiscaringhome.org/>
- **VA Caregiver Support**— An informative website providing support and resources for caretakers of veterans provided by the U.S. Department of Veterans Affairs. <http://www.caregiver.va.gov/>

Resources for Patients and Caregivers (ESPAÑOL)

- **Sobre el AD:** <http://www.alz.org/espanol/>
- **Recursos en español:** http://www.alz.org/espanol/resources/sitios_web.asp#organizaciones
- **Centro de asistencia para personas y con AD y desordenes relacionados (ADAC):** 212-659-8872

Participant Appreciation Day



Dr. Hillel Grossman discusses findings from autopsy research in relation to Alzheimer's Disease.

This year's 6th annual ADRC Participants' Appreciation Day was a success with over 100 participants in attendance as well as many ADRC students and staff members! After a welcome by event organizer and Education Core Director Margaret Sewell, Ph.D., ADRC director Hillel Grossman, M.D., updated the audience with "What we have learned from a century of autopsy studies in Alzheimer's Disease." The day also included an interview with Dr. Grossman and Ms. Alix Shulman* a volunteer research participant in the brain tissue donation program. After a raffle and lunch break, the audience broke out into sessions including a caregiver group led by the co-director of the Alzheimer's Disease

Assistance Center Mari Umpierre, Ph. D., a talk by Dr. Sewell on Maintaining Your Brain, and an art group session taught by Shelli Branscomb and Gloria Benson.

Before the day came to an end, ADRC Associate Director Samuel Gandy, M.D., Ph.D., spoke to the audience about "Type 2 Diabetes and Dementia: Alzheimer's, Mini Strokes, or Both?" as well as "The New Alzheimer's Brain: Pros and Cons". We are very thankful to all who participated. We look forward to seeing you again next year!

* See page 7 for the full interview with Ms. Alix Shulman

Participant Interview with Alix Kates Shulman



Pictured left to right: Hillel Grossman, M.D. and Alix Kates Shulman.

Dr. Grossman: You and your husband have been involved in Alzheimer's disease research for years. Can you tell us a bit about how you came to this involvement?

Ms. Shulman: After my husband, Scott, suffered from an aneurysm and placed on a heart and lung machine, he was diagnosed with TBI, traumatic brain injury. Since no further tests could be performed, research seemed like an opportunity to contribute and help others facing similar circumstances.

Dr. Grossman: I know that you and your husband are intending to donate your brains to our Brain Tissue Donation Program. Can you please tell us how you came to the decision to participate in this program?

Ms. Shulman: Once we became involved in research, it became obvious that we should participate in this program – we believe in the importance of science. My memoir, *To Love What Is*, is about caring for Scott following his TBI and it entailed a lot of research on brains; it became clear to me that for diseases like Alzheimer's, little is actually known. There is no known cause of Alzheimer's disease and there is no cure for the disease. So rather than bemoan this ignorance, we wanted to do something that would benefit the field of Alzheimer's research. We are too old to donate our organs, but we are never too old to donate our brains. I was pleased to learn that healthy brains are just as important as diseased brains. We'll give one of each.

Dr. Grossman: Was it a difficult decision to make to donate your brains?

Ms. Shulman: This decision was a no brainer!

Dr. Grossman: What, if any, reservations did you have about brain donation?

Ms. Shulman: We were only concerned with the practical difficulties of completing the donation at time of death. There are so many contingencies lurking. For example, what if I'm away when I die? What if his daughter is traveling?

Dr. Grossman: What do you hope will be gained from your decision to participate?

Ms. Shulman: Personally? I feel that brain donation is the most precious gift; it is more precious than giving money, because brains are scarcer. Brain donation is the final gift; it is from beyond the grave. I feel that giving your body to science adds meaning to death. Brain donation mitigates the sense of finality; like one's work, books, and/or children, brain donation is part of a legacy. It will keep us connected to the future and to life.

Dr. Grossman: Did you discuss this decision with your family?

Ms. Shulman: I have not only discussed this with my family, but with everyone I can. I am a writer and an activist. I believe talking is the best way to change taboos and attitudes. Whenever I discuss my memoir, *To Love What Is*, I plug brain donation. I also write about brain donation on my blog at Psychology Today: Love & Dementia (<http://www.psychologytoday.com/blog/love-and-dementia>).

Have you considered brain donation?

Brain donation is a priceless contribution to knowledge that leads to the development of more effective treatment for Alzheimer's disease. It is also critically important to be able to study brain tissue of individuals with no memory or other cognitive impairments. This allows scientists to compare normal and abnormal brain tissue, which will lead to a greater understanding of factors that may protect the brain from disease in aging.

To update your brain donation registration information or to learn about becoming a donor, please contact **Lara Akinleye** at **(718) 784-9000 ext 1729**, or email her at **Lara.akinleye@mssm.edu**.





**ALZHEIMER'S DISEASE
RESEARCH CENTER**
One Gustave L. Levy Place, Box 1230
New York, NY 10029-6574

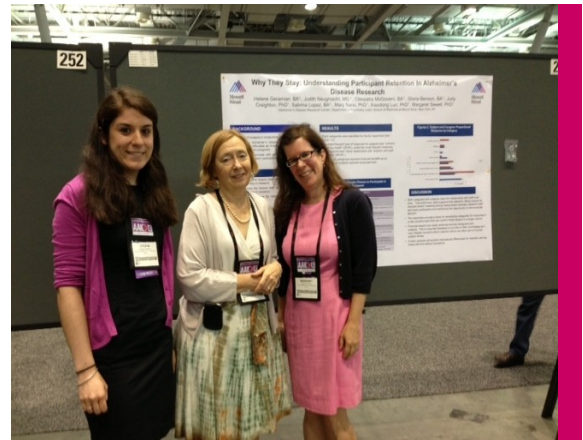
**Mount
Sinai**

Phone: (212) 241-8329
Fax: (212) 996-0987
Email: Margaret.Sewell@mssm.edu

Alzheimer's Association International Conference (AAIC) 2013

From July 13–18, several ADRC faculty joined the international AD scientific community in Boston to discuss new developments in the field at the Alzheimer's Association International Conference (AAIC). Members of our research staff also had the opportunity to present on important topics relevant to this rapidly developing field of research. These topics included:

- Detection of Mild Cognitive Impairment and early stage dementia with an audio-recorded scale
- Why They Stay: The Importance of Relationships in Understanding Participant Retention in Alzheimer's Disease Research
- Attitudes Towards Research in an Urban Minority Population



Pictured left to right: Helene Geramian, Dr. Mary Sano, and Dr. Margaret Sewell

You can learn more about this conference by visiting <http://www.alz.org/aaic>

Donations

Please consider supporting the research and care provided to all of the families within the ADRC

Enclosed is my tax deductible gift of

\$ _____.

Please note that this contribution is:

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Alzheimer's Disease Research Center
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New York, NY 10029-6574
Thank you for your contribution!

Contributions

With the help of volunteers like you, scientists and medical educators across the country are making strides against Alzheimer's disease. Unfortunately, there continues to be federal funding cuts to memory and aging research programs– including ours. With your gift, we are better able to serve the growing population of those living with memory disorders and their families. Your contribution supports our scientific research, as well as our education and training programs. We gratefully accept tax-deductible gifts and bequests that help all our scientific and educational endeavors and we can provide information on corporate or matched donations. Contact Jane Martin, PhD at (212) 241-8517 or by email at jane.martin@mssm.edu for more information.

Need a Memory Evaluation?

The ADRC's Memory & Aging Center (MAC) provides comprehensive evaluations for those who have memory complaints:

- **Experts:** Our team includes experts in geriatrics, geriatric psychiatry and neuropsychology, neurology, and radiology.
- **Quick:** The evaluation can be completed in one visit, including evaluation by a geriatric specialist, neuropsychological testing, and neuroimaging.

To make an appointment, please call (212) 241-1514