

MADRC Reflections

News and Updates from the Michigan Alzheimer's Disease Research Center

From the Director

Just as spring weather encourages the growth of new beginnings, the current call for renewal for national Alzheimer's Disease Research Centers is spurring change and new direction for the MADRC.

As we complete our 20th year of continuous NIH funding, our efforts toward a successful application for renewal will secure operation from June 2010 through May 2015. In compiling information for this grant, we are emphasizing previous progress and proposing new research initiatives and community activities. During the current grant period, the MADRC has made great progress in enhancing the understanding of the development of Alzheimer's disease from the molecular perspective as well as diagnostic accuracy using imaging techniques. More information about these studies can be found in the article, "Research at Michigan Toward a Cure for Alzheimer's" on page 2. The MADRC has also contributed to the role of drug development and evaluation for patients with Alzheimer's disease. We are participating in several ongoing medication trials and publications are on the horizon for new medications resulting in part from studies in the MADRC such as Bapineuzumab.

MADRC accomplishments would not be possible without the commitment of our research volunteers. Individuals who participate in MADRC-supported studies have provided an invaluable contribution toward our understanding of Alzheimer's disease and related disorders. The MADRC will carry forward this momentum of knowledge by continuing to support exciting and innovative research projects during the new grant period.



Research highlights and future initiatives will be discussed at the MADRC Community Appreciation Conference: Advances in Diagnosis, Treatment and Prevention of Alzheimer's Disease on October 1, 2009. We hope to see you there!

Sid Gilman

Sid Gilman, M.D., F.R.C.P.
Director, MADRC

Welcome Edna

Dr. Edna Andrews Rose joined the MADRC in November 2008. She comes to the research center from the Atlanta, Georgia area. She holds degrees as a Registered Nurse,

a Masters in Social Work and a PhD in Social Work planning and Administration. Her prior research focus was on the Disproportionately Higher Incident of Alzheimer Disease in the African American Population. Dr. Rose serves as the Nurse Consultant for the research team here at MADRC and has been instrumental in shaping our center's minority outreach activities. She is married to Mr. Stanley Rose and resides in the Saline, MI area.



Research at Michigan Toward a Cure for Alzheimer's

The search for better treatments for devastating neurodegenerative diseases like Alzheimer's is increasingly urgent. With more and more Americans living longer lives, the prevalence of neurodegenerative disease in the population is forecast to reach crisis proportions in the coming decades. Nowhere is that challenge taken more seriously than at the University of Michigan, where researchers at one of the nation's first Alzheimer's Disease Research Centers are seeking to better understand Alzheimer's and related dementias, such as Lewy body disease, frontotemporal and vascular dementias.

As the mysteries underlying the brain deterioration seen in Alzheimer's and related neurodegenerative diseases begin to be revealed, physicians and researchers specializing in neuroscience at Michigan are beginning to see powerful new pathways to improved therapies. Their ongoing work offers many reasons for optimism.

How Do Our Nerves Produce Proteins?

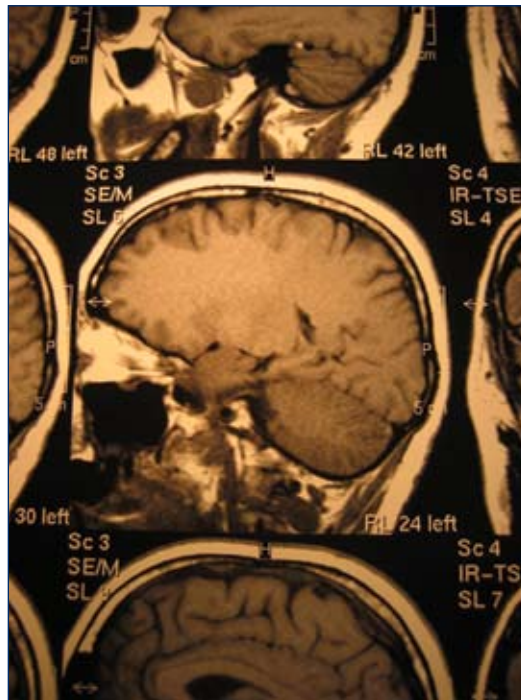
Why do some people get Alzheimer's and other people do not? A part of the answer has to do with proteins in the body. There are nerve-related proteins that seem to determine whether or not your body produces a larger protein called Amyloid Precursor Protein, and whether that protein, in turn, divides, to become the beta-amyloid protein that is one of the two key proteins related to Alzheimer's disease. The division of Amyloid Precursor Protein into beta-amyloid requires the presence of yet another protein called X11alpha.

How does this process work? By using mice, cell cultures and various other techniques in the laboratory, Henry Paulson leads a team here at Michigan dedicated to sorting out the mysteries of these various proteins. Their goal, of course, is to figure out how the process works and then, how to stop it.

How Can We Diagnose Specific Dementias?

When a patient with dementia first visits a physician, the doctor does not know what is causing the dementia. Is it Alzheimer's? Lewy Body disease? A frontotemporal dementia? Something related to the blood vessels? Often it will take two or three years for the form of the dementia to be clearly understood. Earlier diagnosis would mean earlier and better treatment. But how? Two research projects that Kirk Frey and Roger

Albin are working on are aimed at speeding up accurate diagnosis of patients' dementias. The new technologies made possible by the invention of computers and the digitalization of images, including PET scans and MRIs, may be the key to helping physicians understand more about specific dementias quickly. The University of Michigan is leading the way in using imaging technologies to better understand many neurological conditions, including dementias. The Frey and Albin studies are using patient volunteers to see if the use of imaging technology can improve diagnosis and make it more accurate so that the right treatment



can begin sooner and possibly one day even prevent the development and progression of the disease.

If You Would Like to Help

The Alzheimer's Disease Research Center here at the University of Michigan is one of 29 across the country dedicated to treating patients and learning more about Alzheimer's, related dementias and memory disorders. These centers, including the one at Michigan, receive funding from the National Institute of Aging, which is part of the National Institutes of Health (NIH). NIH funding supports the studies described above.

Why then, with this NIH funding, would a gift towards Alzheimer's disease research matter? Private

See **Research** page 6.



Making a Difference in the Fight Against Alzheimer's

For three days in late March, I was among hundreds of Alzheimer advocates from across the country who gathered in Washington D.C. to call attention to the 5.3 million Americans with Alzheimer's disease (AD). I, along with Courtney McDonald, administrator of the Michigan Alzheimer's Disease Research Center (MADRC), and Mary Ellen Geist, author and caregiver, was fortunate to have the support of the MADRC to be able to participate in the Alzheimer's Association's (AA) Public Policy Forum and visit our local Michigan senators and representatives on the Hill to convey the message that they must support policies that will result in a change in the trajectory of this disease.

According to the Alzheimer's Association's 2009 "Facts and Figures", released the week of my visit in D.C., there may be as many as 16 million Americans with AD by the year 2050, tripling healthcare costs for those age 65 and older, if change does not take place. I am familiar with the devastating toll that AD takes on individuals struggling with this disease and on their families, having experienced it in my own family and that of innumerable patients.

At a senate hearing chaired by U.S. Senate Special Committee on Aging Chairman Herb Kohl of Wisconsin, I listened to the release of the "National Strategic Plan" prepared by the Alzheimer's Study Group (ASG). The group's leaders including former Speaker of the House Newt Gingrich, former Senator Bob Kerry, and former Supreme Court Judge Sandra Day O'Connor presented recommendations of the plan to fund research to halt Alzheimer's disease as well as recommendations to improve support to families and caregivers including long term care policies.

Along with the reports from the ASG and the AA, I sincerely believe that the collective voices of the advocates were heard. I am hopeful that we can continue to raise awareness about the importance of ending this disease. I urge individuals to write to their state and national senators and representatives in support of the recommendations of the ASG.

Nan Barbas, M.D., M.S.W. is Associate Professor in the Department of Neurology and Director, Cognitive Disorders Clinic.

I decided to attend the 2009 Public Policy Forum in Washington D.C. for the simple fact that - like the more than ten million people across the U.S. taking care of someone living with Alzheimer's - I couldn't stand it anymore: my father, suffering with Alzheimer's disease for fifteen years; my mother's life and livelihood sapped away by being his caregiver for a decade and a half; the sorrow and sadness my two sisters and their families were experiencing due to the heartbreaking daily grief of my father's slow demise; and my own life - turned upside down- by quitting my job to come home to help my mother take care of my father four years ago. A similar story is being told over and over again by families across the U.S.. And so many families suffer much more than my family does. I decided I had to do everything within my power to help find a cure for the disease and help caregivers whose lives are often destroyed when their loved ones are diagnosed with the disease.

One of the most moving moments for me was when Maria Shriver and Sandra Day O'Connor delivered their address during the Senate Hearings. Maria, the executive producer for the documentary series called The Alzheimer's Project, which will air in May, talked about how much it hurt that her father no longer knew her name. That's what I had experienced with my father, too, and I felt linked to her in a new way. I felt honored that she had chosen to tell my father, Woody's, story (he is featured in one of the documentary series called "The Memory Loss Tapes") and I suddenly realized how important it was that his story will go out into the world to help others.

For the first time in a long while, hope filled the room.

I feel this is important work. I will carry it on as I tell my father's and my family's story throughout the coming months, and I hope to be back at the Public Policy Forum next year.

Mary Ellen Geist, a former broadcast journalist, is the author of the book "Measure of the Heart: A Father's Alzheimer's, A Daughter's Return". You can reach her at maryellengeist.com



Share Your Story

by Sarah Middlemas, B.S.
Masters of Public Health student
A Visit with Alberta Sabin,
research volunteer with MADRC

Early in December, eighty-one year old Alberta Sabin was outside her garden apartment at the Chelsea Retirement Center (CRC) and found herself enjoying the big beautiful fluffy snowflakes falling from the sky. After studying the detail of each flake that landed on the sleeve of her coat, she determined the snow to be of the perfect packing variety. She was going to do something she had not done for years- she was going to build a snowman! Alberta began by rolling the snow into three separate balls and soon enough, a snowman took shape. But Alberta didn't stop there, after her snowman was assembled, her neighbor snapped a picture of her creation and Alberta went on to personalize her snowman by writing a short story in her creative writing group that meets bi-monthly at the CRC. This is a perfect demonstration of Alberta Sabin's spirit- she takes a situation (like a snowy day) and makes the best of it and then some!

Alberta came to CRC about five years ago when she started experiencing some difficulties with her memory. "I could see things happening that I wasn't pleased about. I saw what happened to my mother and grandmother both whom had dementia in their early 70's. For her protection I had to put my mother in a nursing home. She hated me for it, and it took several months for her to reconcile herself to the idea that it was a pretty good place to live." After experiencing this difficult situation, "I made the decision that I was going to choose my own nursing home and while I don't need nursing care yet, I didn't want my kids to have to go through what I did."

A couple of years later, with the encouragement of her children, Alberta became involved with the University of Michigan's Memory and Aging Project (UM-MAP). Alberta's biggest motivation for participating in research is the hope it will lead to helping others someday. As a volunteer in the UM-MAP study, Alberta recently decided to donate her brain for research. She



"My life began with a beautiful snowfall in December" — excerpt from *My Name is Cycle* by Alberta Sabin

said, "I am signing up for it. After I'm dead, I have no more use of it. If it will help them to learn more about what's going on in the brain, then I would feel as if I was making a good contribution." This decision of Alberta's is very important because at this time, there is no other way to definitively diagnose conditions that cause progressive dementia than to examine the brain upon death. The opportunity to examine and learn from a donated brain (and compare it to a donated brain from someone without dementia) is a significant contribution to science.

Many people are hesitant to participate in research. Yet, when I asked Alberta about her research participation, she once again exuded her positive attitude and viewed it as getting to do "a lot of fun things." The UM-MAP study also involves annual memory testing



and while some folks can get intimidated by testing, Alberta isn't one of them. At one time in her life she might have been concerned, but she now finds it interesting. "If I do [perform badly on a test] maybe they'll be able to find out why. That's why I'm eager to be a part of the study because I hope things will be learned and that will help other people."

Just as Alberta has demonstrated flexibility with testing procedures, she has also learned to incorporate some specific strategies into her life to accommodate some of her memory changes. She is proud that implementing these coping strategies has allowed her to maintain her independence. Perhaps the biggest strategy Alberta has found helpful is writing everything down. That way, she can refer back to her notes as she needs to be visually reminded. She thinks that email is a wonderful tool and an extremely effective way for her to communicate with family and friends. Again, because of the way it provides a record of the message so she can refer to it later. If someone calls her on the telephone she often finds herself asking for the information to be sent by mail or email, so that she can look at a printed copy and use it as a reminder tool.

Alberta has implemented some additional coping strategies when it comes to cooking for her and her husband. "I'm very strategic about cooking. When baking, I put all the ingredients out, pre-measure, and make sure everything is in a certain place. Then when it comes time to put it all together, I don't have to wonder whether I put in a certain ingredient yet." She also keeps her favorite recipes taped to the inside of her cupboard doors so they are always easy to find.

In addition to participating in the UM-MAP research study, Alberta has found it helpful to cope with her memory changes by staying both mentally and physically engaged. She likes to go for walks, perform stimulating brain activities such as crossword puzzles and creative writing exercises, volunteer at Towsley Village (the memory care center located on CRC campus) and is a member of the CRC chimes choir. A tool that Alberta has found most helpful in maintaining her active lifestyle is her daily calendar. She uses colored pens to highlight activities that are 'a must,' so they stand out

on the page. She refers to it several times daily. "That's the way I cope, without it, I would be in a frenzy all the time."

Alberta Sabin has found that incorporating these simple coping strategies into her daily routine has allowed her to maintain a full schedule filled with many enjoyable activities. As we leave behind Alberta's personalized story of a snowman in the winter, we will look forward to hearing her ring in the fresh sounds of spring as she plays with the chimes choir in this year's CRC spring program.

Share Your Story is an ongoing opportunity for research volunteers to learn from each other. Please contact Cassie Starback, MSW at (734) 936-8764 or at cassiem@med.umich.edu if you are interested in sharing your coping strategies and care tips. We would love to learn from each of you.

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Lisa Bain (734) 936-6267, pager #9198

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Save the Date

MADRC Community Appreciation Conference: Advances in Diagnosis, Treatment and Prevention of Alzheimer's Disease

An informational event for research volunteers, caregivers, professionals and the interested public

October 1, 2009
8:30 am – 4:00 pm
Marriott Hotel - Ypsilanti


Registration information will be mailed to you soon.



MADRC Community Appreciation Conference
Advances in Diagnosis, Treatment and Prevention of Alzheimer's Disease

Thursday, October 1, 2009
8:30 am – 4:00 pm
Lunch provided

Marriott Hotel
1275 S. Huron Street
Ypsilanti, MI 48197



Research

From page 2.

support is essential to helping younger researchers explore their most promising ideas. These ideas may have great merit and be very worthy of study, but it will usually take several years of work in the laboratory before they can compete for federal funding. By funding such work yourself, you make possible the exploration of novel thinking that may one day lead to the breakthroughs that will spare us the suffering of so many kinds of neurological degeneration. The studies described above run by senior researchers at Michigan, now funded by the NIH, evolved from that kind of thinking.

The University of Michigan Alzheimer's Disease Research Center would like to thank you from the bottom of our heart for your interest in Alzheimer's disease. Whether you are a study participant, a professional, or have donated a financial gift, you are the reason why we are able to conduct this research.

Giving Opportunities

If you would like to support the MADRC in memory of a loved one or simply to further Alzheimer's and memory disorders research, please know that we welcome all gifts. Your contribution will be used to advance our efforts to prevent, treat and cure Alzheimer's disease and related disorders.

Gifts can be made directly, or through an estate or planned giving vehicle. If you have interest in supporting this work and related research in Alzheimer's and related dementias, or have additional questions about ways of giving, please contact Maria Grupe at (734) 998-7251 or mgrupe@umich.edu.

Please make checks payable to the University of Michigan and indicate MADRC in the memo line. Gifts should be sent to:
MADRC, University of Michigan
300 N. Ingalls, Room 3D05
Ann Arbor, MI 48109-0489
Attention Sid Gilman, MD, FRCP



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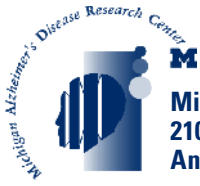
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