

Minnesota-North Dakota Support Group Newsletter

Published quarterly for our Support Group Facilitators
And their attendees.

October 2007

www.alzmdak.org
1 800 232 0851



Update: Major AD Research Initiatives

Exelon Skin Patch Approved

Exelon is a medication for people with mild-to-moderate Alzheimer's that aims to increase levels of the brain chemical, acetylcholine and improve memory functioning. Although some people do benefit from the medication, side effects of nausea, diarrhea, or vomiting can occur. Exelon also needs to be taken twice a day which can be inconvenient or difficult to remember. To remedy some of these problems, Novartis Pharmaceuticals (the maker of Exelon) has created a 24-hour skin patch that can be worn to allow a smoother, more continuous dosing of the medication. A new skin patch is applied each day and eliminates the need to swallow a pill twice a day. The patch lessens side effects and has been better tolerated than the pill form of the medication. Care partners also report that the patch is easier to use when helping their loved one manage medications. If you take Exelon, you may want to ask your doctor about the availability of the new patch.

Alzhemed Trial is Inconclusive

Over the past few years, there has been some publicity about Alzhemed, a promising drug under investigation that aims to lower levels of

the damaging amyloid protein in persons with Alzheimer's. In late August, the drug company Neurochem Inc. announced that the results of its much-anticipated large North American trial of the drug were inconclusive due to problems with analyzing the study data. The drug continues to be tested in European Union countries, however, and we will keep you updated as results from that study unfold.

Early Results from the Alzheimer's Disease Neuroimaging Initiative (ADNI)

ADNI is a study being conducted across the United States and Canada that is using magnetic resonance imaging (MRI), positron emission tomography (PET) scans, measurements of substances in body fluids, and neuropsychological testing to better track the progression of mild cognitive impairment (MCI) and the earliest stages of Alzheimer's. Some preliminary results of this study are helping scientists determine effective ways of diagnosing the earliest changes in the brain that could indicate a dementia so that future hopeful treatments can be delivered as soon as possible.

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Opportunities to get involved in Local Research

Are you caring for a parent with Alzheimer's disease or similar Memory disorder?

Researchers at the University of Minnesota School of Nursing are looking for volunteers for their new study, "Comprehensive Support for Alzheimer's Disease Caregivers." The goal of this study is to determine if flexible and comprehensive counseling and support can help adult children care for a parent's Alzheimer's disease or similar memory disorder. Participating adult children will be randomly assigned (like the flip of a coin) to receive the comprehensive counseling support program or regular care. All participants will take part in a series of in-depth interviews with Dr. Gaugler. All participants will have the opportunity to share their experiences about caring for their parents. Interested? Please contact Dr. Joe Gaugler 612.626.2485 or gaug0015@umn.edu. 6-150 Weaver-Densford Hall 1331, 308 Harvard Street SE Minneapolis, MN 55455

Support Group Facilitator

Training will be held on October 11th
From 1:00-5:00pm at the Edina office.
Please call Angie for more information
or to find out when a training may be
held in your region: 952.857.0522

We Can Help
1.800.232.0851
www.alzmdak.org

Preserving the Health of Alzheimer's Caregivers

The results of a study by Dr. Mary Mittelman and her colleagues on family caregiver support interventions were published in the September 2007 issue of the *American Journal of Geriatric Psychology* (Volume 15). The article, "Preserving Health of Alzheimer Caregivers: Impact of a Spouse Caregiver Intervention," reveals that caregivers of spouses with Alzheimer's disease who received enhanced support services, including individual and family counseling and support group participation, reported better physical health outcomes compared to family caregivers who had not received the intervention. These are the latest results from ongoing research on caregiver interventions conducted over the past 20 years. These findings suggest that "enhancing caregivers' social support, fostering more benign appraisals of stressors, and reducing depressive symptoms may yield indirect health benefits." For more information, visit

<http://ajgponline.org/cgi/content/abstract/15/9/780>

Conversation Starters!

I thought it may be beneficial to share some open-ended questions that may be useful to use for some of your meetings. The questions listed below may generate some fruitful discussion and bring some needed grieving for a few members.

- Caring for my loved one makes me feel _____.
- Doing _____ for my loved one gives me the greatest joy.
- When _____ happens to my loved one/family member, I get very upset/angry.
- I feel that _____ is the best sort of relief for the long hours of caregiving.
- When I see my loved one decline, I feel _____.
- I get the most support from _____ to get me through the difficult times.
- I feel frustrated when _____ happens with my loved one/family member.

If you have any other suggestions that have worked with your groups in the past please email me at Angie.Bizal@alz.org. Thank you!



New Support Group Member Packets

First time Support Group attendees are people that we really need to pay extra attention to. They finally made the difficult decision to reach out for help and support. They found someone to stay at home with their loved one or maybe their loved one is at home alone, adding more stress to the situation. We want to make these new attendees feel as comfortable as we can while attending the Support Group.

This includes:

1. Make sure to welcome them to the group and acknowledge the fact that they are in a safe and confidential place.
2. Encourage them to share first. If they are not comfortable, tell them they can listen and feel free to ask questions as the meeting goes on.
3. Make sure everyone introduces themselves and explains why they are at the meeting. This may be difficult for seasoned group members if you have not had a new visitor for awhile.
4. Find time after the meeting to visit with them. How was their first experience? Would they care for additional information?
5. Give them a new visitor packet of information. I will be sending out these packets to the groups that return their surveys and agreements. Make sure everyone that is new receives one on their first visit.
6. Encourage them to attend the next meeting.

If you need more packets please call or email me at 952.857.0522 or Angie.Bizal@alz.org.

Helpful New Resources

A new booklet written specifically for people living with the Early stages of dementia is now available from the National Institute of Aging's Alzheimer's Disease Education and Referral (ADEAR) Center.

What Happens Next? was developed by the members of an early-stage support group at the Northwestern University Alzheimer's Disease Center in Chicago who chose to share their thoughts and feelings because they wanted to help others like themselves. The purpose of the booklet is to offer encouragement to those who have been diagnosed with early-stage dementia and to let you know that you are not alone. To preview **What Happens Next?** go to: www.nia.nih.gov/Alzheimers/Publications/WhatHappensNext.htm

You can order a FREE copy online or you can call ADEAR at 1.800.438.4380. Please pass the work along!

The National Institute on Aging (NIA), part of the Federal Government's National Institutes of Health (NIH), has primary responsibility for research into the cause of Alzheimer's as well as research aimed at finding ways to prevent and treat the disease. **The 2005-2006 Progress Report on Alzheimer's Disease "Journey to Discovery"** summarizes recent Alzheimer's research conducted or supported by NIA and other components of NIH. The 84-page booklet is beautifully illustrated and provides an overview of Alzheimer's, current trends in research and research advances, and emerging treatments. A section of the booklet is devoted to the impact of lifestyle, exercise, and diet on preventing and slowing of disease progression. The Progress Report also outlines a number of interesting research initiatives in genetics, brain imaging and mental and emotional health in aging and Alzheimer's. You can obtain a FREE copy of the Progress report by calling 1.800.438.4380 or by visiting www.nia.nih.gov/Alzheimers/Publications/ADProgress2005_2006/ Information taken from the Perspectives Newsletter Volume 13, Number 1.



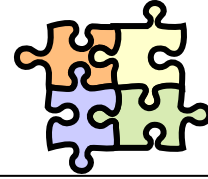
The “Advocacy in Action” Corner

November is Alzheimer’s Awareness Month. There are currently more than 5 million Americans living with Alzheimer’s and almost 10 million people caring for someone with Alzheimer’s or another dementia. The whole idea of advocacy (literally, giving VOICE on behalf of another) shouldn’t seem like a brand new idea to people who have cared for a someone with Alzheimer’s Disease. Any care partner who has struggled to find medical care for an individual with Alzheimer’s disease or told a long term care setting how to give better care for their loved one has been an advocate. We should recognize public policy advocacy as one of our most effective tools for fighting Alzheimer’s disease and its devastating effects on the care partner. We need to involve more people in the process of determining what public programs are needed to support our care partners and to do the work necessary to change public opinions. We need to use what we have—our care partners, passion, and the public opinions we can influence—to make our case. We need to mobilize our members, those in support groups, and friends in other organizations. Through meetings, letters, phone calls, and other public action, we can capture the attention of decision-makers and the media.

Learn how to become involved and make your VOICE heard. The Alzheimer’s Association of MN-ND will be holding “Advocates in Action” training from 3pm-5pm on November 15th. Call Angie at 952-857-0522 to register.

If you are interested in becoming an Alzheimer’s Advocate and cannot make the training, please email me your name, address and email address and I will add you to the E-advocacy list. There are many ways you can become involved! My email is Angie.Bizal@alz.org.

Putting the Pieces Together: Partnering with your Doctor



I have been visiting a few different Support Groups across the Metro this last month and I have come across a common theme. People have a hard time finding a physician they have confidence in and also have a hard time communicating with them. They may not be getting the answers that they need. They may not feel all the tests are being run. They are not being referred to resources in their community. I decided to speak with our Family and Community Education Manager Linnea Grey regarding this issue. She has a presentation that is all about “Partnering with Your Doctor.” The Alzheimer’s Association came up with this curriculum in 2005 when they began hearing the same complaints. This class is currently being presented across Minnesota and North Dakota. Keep updated on local education in your region through our website www.alzmnndak.org or you can check the list of classes on the last page of our newsletter every month. Please share these opportunities with your groups. I have also included with this email a few handouts for your attendees. I would appreciate it if you would copy these out and bring with to your next group. These handouts include:

- Minnesota-North Dakota Dementia Clinics
- Diagnosis of Alzheimer’s Disease
- Tips for visiting a doctor with someone with Alzheimer’s Disease.

If you have any suggestions about future topics please let me know at Angie.Bizal@alz.org.

Physician Champions:

The Alzheimer’s Association of Minnesota and North Dakota is challenging our local physicians to become Alzheimer’s “Physician Champions”. This includes physicians that are willing to partner with us to promote early diagnosis in their patients and refer them to community resources. If you feel that you or someone in your group knows of a physician that provides quality dementia care and may be a possible candidate to be a “Physician Champion”, please send me their name and contact information to Angie.Bizal@alz.org and we will be in contact with them. This can be confidential.

Thank You!

Research Cont. from page 1.

Scientists are learning more about the use of MRI and PET scans in the detection of early brain changes and may be able to use these tools more effectively in the future to assist with diagnosis, track progression, and evaluate benefits of drugs under investigation.

Gene for Frontotemporal Dementia

Scientists have discovered genetic mutations that cause a form of familial frontotemporal dementia (FTD). FTD usually affects people between ages 40 and 64 with symptoms that include changes in personality and social behavior, as well as thinking and judgement. Twenty-to-fifty percent of people with FTD have a family history of this specific dementia. The important discovery of this gene, called progranulin, or PGRN, can influence future approaches to developing therapies for people living with FTD.

Information taken from the Perspectives Newsletter-Volume 13, Number 1. To get on the email list for this publication, please visit <http://adrc.ucsd.edu/newsletter/news1.htm>.

Community and Family Education Opportunities

North Dakota

After the Diagnosis

October 11, 2007 6:30-7:30pm

MeritCare 801 N. Broadway Fargo, ND Cafeteria Room

Call Gretchen for more information 701.277.9757

Maintain Your Brain

October 2, 2007 7:30pm

Lord of Life Lutheran Church Bismarck, ND

Call Kristi for more information 701.258.4933

October 6, 2007 12:30pm

Trinity Lutheran Church Bismarck, ND

Call Kristi for more information 701.258.4933

Caregiving Issues

October 11, 2007 7:00pm

Ramkota Hotel, Bismarck, ND

Part of the Geriatric Health Care Conference– Family Session

For more information visit:

[http://www.st.alexius.org/events/events_detail.asp?](http://www.st.alexius.org/events/events_detail.asp?EventID=116&EDID=3)

EventID=116&EDID=3

Metro Area

Partnering With Your Doctor

October 2, 2007 6:30-8:30pm

St. Joseph's Hospital 69 Exchange St. W Saint Paul

Schefer Hall-please call 952.857.0538 to register.

Maintain Your Brain: How to Live a Brain Healthy Lifestyle

October 11, 2007 6:30-7:30pm

North Memorial Hospital 3300 Oakdale Ave N Robbinsdale

Ridgeview Conference Room. Please call 952.857.0538 to

register.

Legal Planning Issues

October 16, 2007 6:30-8:30pm

St. Joseph's Hospital 69 Exchange St. W Saint Paul

Schefer Hall-please call 952.857.0538 to register.

Understanding Memory Loss

October 25, 2007 6:30-8:00pm

North Memorial Hospital 3300 Oakdale Ave N Robbinsdale

Ridgeview Conference Room. Please call 952.857.0538 to

register.

Financial Planning Issues

October 30, 2007 6:30-8:30pm

St. Joseph's Hospital 69 Exchange St. W Saint Paul

Schefer Hall-please call 952.857.0538 to register.

Savvy Caregiver Workshop

Length: 12 hours (Six 2-hour sessions)

Mondays, October 29-December 3, 2007 6:30-8:30pm

Alzheimer's Association Office

4550 W. 77th Avenue S Suite 200 Edina, MN

Please call 952.857.0538 to register.

Visit our Support Group Facilitator Website

The Alzheimer's Association has designed a website specifically for you as Support Group Facilitators.

You can find links to attendance forms and marketing flyers, information for Support Group Attendees, information on Green-Field Library, and much more!

www.alzmdak.org/sg

Green-Field Library News Update

The Minnesota-North Dakota Chapter is the only chapter that allows our volunteer facilitators to order resources directly through Green-Field library. In last month's newsletter, I provided directions on how to do that. However, we realized we missed a step. Make sure to let **them know that you are a facilitator with the Minnesota-North Dakota Chapter and you have received permission from me Angie Bizal**. If you are sending an email, please cc: me on that message Angie.Bizal@alz.org. Let me know if there are any other questions.
