RESOURCES OF THE ALZHEIMER’S ASSOCIATION: RESEARCH & PROGRAM

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STANFORD UNIVERSITY

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State of the Science: Dementia Evaluation and Management among Diverse Older Adults and their Families
2013 WEBINAR SERIES

“Resources of the Alzheimer’s Association: Research & Program”

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Our speakers have no financial relationships to disclose and will not discuss off-label use and/or investigational use in their presentation.
About the Presenters

Resources of the Alzheimer’s Association: Research & Program

Heather M. Snyder, Ph.D., & Ruth Drew
Topics for Discussion:

- Landscape of Alzheimer’s disease
- Alzheimer’s Association mission
- Association research efforts
- Association programs and services
- How to access these resources

1 in 3 Seniors Dies With Alzheimer’s or Another Dementia

- More than 5 million people are living with Alzheimer’s disease.
  - Including 200,000 under the age of 65 with younger-onset.
- Cost of caring for people with Alzheimer’s and other dementias:
  - In 2013: ~ $203 billion
  - By 2050: ~ $1.2 trillion
Health Disparities in Underrepresented Populations

Although whites make up the great majority of the more than 5 million people with AD, African-Americans and Latinos are at higher risk.

- African-Americans are about two times more likely than whites to have Alzheimer’s and dementia.
- Latinos are about one and one-half times more likely than whites to have Alzheimer’s and dementia.

High Blood Pressure and Diabetes

- High blood pressure and diabetes are known risk factors for Alzheimer’s and other dementias among all groups.
- High blood pressure and diabetes are more prevalent in the African-American community; diabetes is more prevalent in the Latino community.
- Better management of these conditions may help reduce Alzheimer and dementia risk among African-Americans and Latinos.
Under Diagnosis of AD
Among African-Americans and Latinos

- Rate of AD and dementia in African-Americans and Latinos is higher than in whites, they are less likely than whites to have a diagnosis of the condition.
- Delays in diagnosis means not getting treatments early when available medications are more likely to be effective.
- Delays in diagnosis means less opportunity to make legal, financial and care plans while still capable.
- RESULTING IN MORE COSTLY CARE!

Caregiver statistics

Figure 7: Proportion of Caregivers of People with Alzheimer’s and Other Dementias vs. Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2009

Percentage

<table>
<thead>
<tr>
<th>Activity</th>
<th>Caregivers of people with Alzheimer’s and other dementias</th>
<th>Caregivers of other older people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting in and out of bed</td>
<td>54%</td>
<td>42%</td>
</tr>
<tr>
<td>Dressing</td>
<td>49%</td>
<td>31%</td>
</tr>
<tr>
<td>Getting to and from toilet</td>
<td>76%</td>
<td>31%</td>
</tr>
<tr>
<td>Bathing</td>
<td>31%</td>
<td>31%</td>
</tr>
<tr>
<td>Managing incontinence and diapers</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>Feeding</td>
<td>14%</td>
<td>14%</td>
</tr>
</tbody>
</table>
Alzheimer’s and Mortality

- 6th leading cause of death across all ages
- 5th leading cause of death for those aged 65 and older
- Only cause of death among the top 10 in America without a way to prevent, cure or even slow its progression.

Change in the Number of Deaths: 68%
Between 2000 and 2010

Our mission:
- Advance research
- Provide care and support
- Increase Concern & Awareness
- Public Policy & Advocacy Efforts

Our vision is a world without Alzheimer’s disease
National Plan to Address Alzheimer’s

Largest Non-Profit Funder of Alzheimer's Research in the World

- Over $300 million to >2,100 scientific investigations
- To date in 2013:
  - Awarded 5 Zenith Fellows Awards ($2.3M); 26 New investigator Research Grants ($2.6M); 2 Part the Cloud Translational Research Grant Program ($1.2M)
- Over 1,000 letters of intent received for 2013 All Investigators Program
- Community 5,500 peer-review volunteer scientists from nearly 60 countries
- Nearly 400 on-going research projects in more than 20 countries funded by the Alzheimer's Association
Programs to Promote Diversity in Research Community

• New Investigator Research Grant to Promote Diversity (NIRGD)
  – Per Year $60,000; Maximum $100,000/2 years

• Mentored New Investigator Research Grant to Promote Diversity (MNIRGD)
  – Per Year $60,000; Maximum $150,000/3 years

Fall & Spring Grant Cycles

• **New Investigators Program – Fall 2013**
  • Letter of Intent:
    • Open Date – January 2014
    • Deadline Date – February 2014
  • Application Deadline- April 2014
  • Review Process – April – June, 2014
  • Award Announcement - By August 30, 2014

• **Full Investigator Program – Spring 2014**

• [Alz.org/grants](http://Alz.org/grants)
International Society to Advance Alzheimer Research and Treatment

- Professional society for individuals interested in Alzheimer's and dementia science.
- Over 2,000 current members
- Benefits include:
  - Annual subscription to Alzheimer's & Dementia
  - Online career center
  - Reduced conference registration rates
  - CME/CE discounts
  - Monthly e-newsletter exclusively for members
  - Travel grants, hotel/ travel assistance at conferences, Car rental discounts
  - Peer networking opportunities
  - Professional Interest Areas (PIA)
  - Volunteer opportunities for ISTAART students

ISTAART Professional Interest Areas

- Alliance of Women
- Anesthesia, Surgery, & Cognition
- Atypical Alzheimer’s Disease
- Blood Based Biomarkers
- Down syndrome & Alzheimer’s disease
- Electrophysiology
- Neuroimaging
- Neuropsychiatric
- Psychosocial Understanding & Intervention
- Technology
- Vascular Cognition
Convening & Connecting Scientists Around the Globe

A first-of-its-kind, free, confidential, online and phone-based tool that provides comprehensive clinical trial information and an individualized trial matching service for people with Alzheimer’s and related dementias.
How TrialMatch® Works

1) Individual completes a profile online or over the phone

2) Database takes the information in the profile, compares it to the match criteria housed in the database and presents a list of potential match trials

3) Individual selects trials most interested and connect with a TrialMatch Coordinator to get the contact information for the trial site.

4) Over the following weeks and months, TrialMatch Coordinators follow up with constituents to assist with challenges or questions that come up and to track outcomes.

National Alzheimer’s 24/7 Helpline

• 1 national 800# (800-272-3900)
• National Contact Center partners with 80 chapters
• 24,000 calls/month
• Calls taken by:
  • General information specialists
  • Masters prepared Care Consultants
National Alzheimer’s 24/7 Helpline

- Language translation line provides 170+ languages
- Spanish line
- 12 bilingual agents (Spanish, Korean, Mandarin)
- Brochures and topic sheets available in Spanish, Vietnamese, Mandarin, Japanese, Korean

Chapters Provide Local Programs

- Helpline Calls
- Community Education Programs
- Support Groups
- Early Stage Engagement
- Care Consultations
- Diversity and inclusiveness outreach
- Local/regional conferences, Walks, Public Policy/Advocacy
Online Resources: alz.org

Comprehensive website providing:
- Disease and caregiving information
- Research and clinical trial data
- Access to national, chapter and online programs and resources
- Interactive brain tour translated into 14 languages
- Spanish and Asian portals
- Safety Center

Online Resources:
Spanish and Asian portals

Information and brochures available in Spanish, Mandarin, Korean, Vietnamese and Japanese
Online Resources: Caregiver Center

Resources for:
- Personal care
- Medical care
- Behaviors
- Safety issues
- Care options
- Legal and financial planning

Online Resources: ALZConnected

- Active social networking community
- For people w/ Alzheimer’s & their families
- Public and private groups
- 40K visits/month
- Discuss unique challenges
- Message boards
- Peer support
Online Resources: Alzheimer’s Navigator

- Personalized surveys to help navigate care needs
- Create customized action plan
- Link to information, support and local resources

Online Resources: Alzheimer’s Care Team Calendar

- Post items for which assistance is needed
- Friends and family sign up for specific tasks
- 10,275 volunteers are lending a helping hand to families coping with Alzheimer’s in more than 3,078 communities

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Online Resources: Community Resource Finder

- Access comprehensive listings of resources, community programs and services
- Search by category and proximity
- Sort by specific needs and preferences
- Create a list of the resources you need near you

Online Resources: E-Learning Courses

- Know the 10 Signs: Early Detection Matters*
- The Basics: Memory Loss, Dementia and Alzheimer's Disease*
- Legal and Financial Planning for Alzheimer's Disease
- Living with Alzheimer's for People with Alzheimer's
- Living with Alzheimer's for Caregivers (Early, Middle and Late Stages)
- Living with Alzheimer's for Younger-Onset Alzheimer's
- Take all our core family education programs online
- Any time, at your conveniences
- Available in Spanish
Online Resources:
Dementia and Driving Resource Center

Online Resources:
Caregiver online training

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Online Resources: Virtual Library

• Nation’s largest library devoted to Alzheimer’s disease
• Fast librarian assistance through chat, email or phone
• Quick access to info through resource lists, catalog and links

Summary

• Urgency of Alzheimer’s
• Research efforts: IRGP, ISTAART, AAIC, TrialMatch
• Programs and services: Chapter network, ALZConnected, Alzheimer’s Navigator, E-Learning
• Alz.org or 800-272-3900
Contact us. We’re here to help!

24/7 Helpline 800-272-3900

www.alz.org

www.alz.org/research

THE END OF ALZHEIMER’S STARTS WITH YOU

alzheimer’s association

alz.org
Q & A

- We will have some time at the end of the presentation to answer your questions. If you have any questions, please use the “Chat” feature located on the right side of your screen. Please send your chat to everyone if possible.
- After the Q and A, We would like to ask each of the participants to answer the short evaluation questionnaire.

Please complete our short survey. We appreciate your feedback.

NOTE: Continuing Education Participants must complete a final survey in order to receive CEU/CME credit

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Final Question
Thank You for Participating!

Reminder: Please complete our short survey.
We appreciate your feedback.

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