A call to action: What you can do about Alzheimer’s disease

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The “first” face of Alzheimer’s disease: Auguste D.
Alzheimer’s disease is a progressive neurodegenerative disease

Taken from: http://hubpages.com/hub/My-Simple-Theory-on-Alzheimers
What are the challenges to successfully treating this disease?
We need to diagnose the disease sooner and with greater accuracy
Even a “super” drug is unlikely to have a benefit if the cells are already gone.

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Neurological Progression of Alzheimer’s Disease

- **Presymptomatic period**
- **Clinical Diagnosis**
- **Symptoms**

Timeline:
- **Birth**
- **50**
- **100**

Pre-diagnosis Period
We need more treatment options

We currently have only two FDA-approved classes of drugs to treat AD:
• Cholinesterase inhibitors
• NMDA receptor blocker
We need better support for caregivers

- Educational programs
- Respite care
So how do we, as a community, achieve these goals?
Give researchers greater opportunities to “leave no stone unturned”
What’s new in AD research

• Head injury may increase risk for AD
• Falling (i.e., balance and gait issues) may be early indicators of Alzheimer’s disease
• Reducing the numbers of “lifestyle-based” chronic diseases by 25% (diabetes, mid-life hypertension, etc.) could significantly reduce the number of AD cases
New research (cont’d)

• Characteristics of blood vessels in the back of the eye may serve as a “window” to AD diagnosis

• Survey of people in France, Germany, Poland, Spain and the U.S. about AD
  – people fear AD second only to cancer
    • Anecdotal evidence suggests that some fear AD more than cancer
  – many of the respondents believe there is now a reliable test for AD and effective medical treatment to slow the progression of AD – Not true
New research (cont’d)

• A cancer drug might be a candidate for treating amyloid “burden” in Alzheimer’s disease
  – Bexarotene (tradename: Targretin)
    • Used to treat a type of skin cancer (cutaneous T-cell cell lymphoma)
New research (cont’d)

• “Alzheimer’s disease seems to spread like an infection….”
  – This process of disease progression may be relevant to Parkinson’s disease as well
  – Abnormal tau protein was transmitted from nerve cell to nerve cell
  – Question remains as to whether cell vulnerability drives the progression of pathology, or whether, there truly is a communication of pathology from one cell to the next.
New research - Diagnostic advances

• Brain imaging advancements
  – PIB (Pittsburgh imaging compound B)
    • PET analysis with PIB to detect amyloid levels in the brain
  – Florbetapir
    • 2nd generation of Amyloid imaging compound
  – Use of Luminescent Conjugated Oligothiophenes (LCO)
    • Stick to amyloid and emit different colors depending on the shape and forms of the protein
New research - diagnostics

- The future diagnostic criteria will take advantage of new discoveries in the field of imaging and “biomarkers”
- Biomarkers
  - Measuring a specific group of proteins in blood
    - TARCC study
  - TOMM40
    - The “high risk” version of this gene is associated with learning and memory impairments, and less “gray matter volume”
  - Cerebrospinal fluid proteins
    - By measuring both amyloid beta (1-42) and phosphorylated tau (181P), researchers identified a subset of patients in which this measure was 100% predictive!!!
The REACH program

(Resource for Enhancing Alzheimer’s Caregivers Health)

• Evidence-based program that provides counseling and skills training to dementia caregivers over a 6 month period
  – Alzheimer’s Association awarded to be partner in the United Way’s Healthy Aging and Independent Living Initiative
  – Collaboration with the Area Agency on Aging, Easter Seals, University of North Texas Health Science Center (UNTHSC) and Community Living Program (CLP)

• Staffed by Dementia Care Specialists
The impact of the REACH program

- Decrease caregiver repeat hospitalization and early demise
- Prevent premature long-term care placement of the person with dementia
Problem: Limited Funding for Research

- The NIH annual budget for research into the causes, diagnosis, treatment and prevention of Alzheimer’s disease is estimated to be about $480 million.

- The estimated costs of care for Alzheimer’s disease currently is approximately $200 billion.  
  - By 2050: $1.1 trillion

We spend only $1 on research for every $280 spent on care!!!
What can we, as individuals, do?

• Educate our friends, colleagues, as well as our local, regional and federal politicians
  – Dispel fact from fiction
    • Sign petitions to enhance funding for research, care and service
    • Call/write letters to your local representatives

• Become active participants in the fight
  – Enroll in TrialMatch
  – Become an advocate
  – Take charge of our own health
So how do we convince local, state and federal groups/agencies to invest more?

Teach them the facts......
The facts

• Currently, ~5.4 million people suffer from Alzheimer’s disease
• Estimated that a new case of Alzheimer’s disease emerges every 69 seconds!
  – Estimates suggest that by 2050, a new case of AD will emerge every 33 seconds!!!!
• Huge emotional/psychosocial impact
• Financial burden
  – $200 billion dollars annually
    • ~$1.1 TRILLION dollars by 2050
While AD is the 6th leading cause of death, unlike other major diseases, the risk for AD is increasing dramatically.

Source: Alzheimer’s Association 2011 Alzheimer’s Disease Facts and Figures.
We need to help our society come to make tackling Alzheimer’s disease a priority
How much do we spend on the Superbowl?

Source: http://blog.turbotax.intuit.com/2012/01/22/super-bowl-bound-how-much-is-spent-for-americas-biggest-game/
How much we spend on just snacks during the superbowl?

**FANS EAT, DRINK, AND BE MERRY FROM HOME**

Super Bowl viewers stock their at-home parties with nearly 177 million pounds of snacks.

**SUPER BOWL SNACK SALES, 2011:**

- Crackers: $189.7 M
- Potato Chips: $184.8 M
- Tortilla Chips: $145.7 M
- Nuts: $129.1 M
- Popcorn (Un-Popped): $39.2 M
- Pretzels: $40 M
- Puffed Cheese: $36.3 M
- Corn Chips: $22.4 M
- Popcorn (Popped): $9.5 M
- Rice Cakes: $11.8 M

Total spend on snacks: **$1.02 Billion**

*Sources: NRF.com, 2011 | Nielsen.com, 2011 | KantarMediana.com, 2012*
What must we do?

• Educate ourselves (and others)
  – The warning signs
  – What are the resources available to help us?
    • www.alz.org
    • The Alzheimer’s Disease Education & Referral Center
      (sponsored by the National Institute on Aging – a division of
      the NIH)
    • Local resources – UNT Health Science Center at Fort Worth

• Challenge our local, state and federal representatives to increase funding for
  Alzheimer’s disease – related research and programs

• The status quo is not enough
Now: ~340,000
2025: 470,000 *

Unpaid care:
2008 – cost: ~ 7 billion
2010 – cost: ~ 14.5 billion

*: reflects only the estimation of people over 65 with AD
What are some local resources?

• The North Central Texas Alzheimer’s Association Chapter
  – 24/7 Helpline
  – Case management
  – [www.alz.org/trialmatch](http://www.alz.org/trialmatch) • phone-based (800-272-3900)

• The University of North Texas Health Science Center
  – Institute for Aging and Alzheimer’s Disease Research
  – Multi-disciplinary approach that embraces the philosophy of “bench-to-bedside-to-community”
TrialMatch

• Lets you search clinical trials that are recruiting and helps you identify those for which there is a reasonable chance to be accepted for enrollment.
  – http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp

• The database of trials come from various sources
  – Clinicaltrials.gov
  – Other sponsored trials that have an approved IRB protocol, and have been “vetted” by the Alzheimer’s Association
How TrialMatch works

**Step 1**
Access the TrialMatch tool at the top of this page or call our toll-free number, 1-800-272-3900, 7 a.m.-7 p.m. CT, Monday–Friday.

**Step 2**
Complete a brief questionnaire about your diagnosis and current treatments, either online or over the phone, to create a profile for the potential clinical trial participant.

**Step 3**
Based on the specified eligibility criteria (i.e., diagnosis, treatment history, location), the Alzheimer's Association will compare your unique profile to its comprehensive, up-to-date clinical trial database.

**Step 4**
With your permission, an Alzheimer's Association Contact Center specialist will contact you to provide unbiased trial result options and trial site contact information. Specialists will not recommend any particular trial, but will help you identify trials that match your specific eligibility criteria.

Taken from: www.alz.org
What information you will need to help you identify a trial

- What is the clinical diagnosis?
  - Mild, moderate, severe AD?
  - MCI

- What tests were used to diagnose Alzheimer's disease or identify the stage of dementia?
  - Brain scan, neuropsychological “battery”

- What Alzheimer’s medications are currently being taken?
  - Aricept, Namenda, etc.

- Are there other diagnosed conditions?
  - Mood disorders, other neurological disease
Understanding and “managing risk” factors

- ApoE genotype (E2, E3, E4)
- Mild cognitive impairment
  - About 15% of MCI patients “convert” to dementia per year
- Cardiovascular disease risk factors
  - Diabetes, stroke Remember: “Healthy heart, healthy brain”
- Head trauma
  - “moderate” injury – 2 times more likely to develop AD
  - “severe” injury – 4.5 times more likely to develop AD
- Menopause
  - Potential for estrogen/hormone therapy?
We can make a difference!
Questions?