

# The Well-Educated Lab Rat: Clinical Research From Inside the Maze

by

Mary L. Radnofsky, Ph.D.

member of

DEMENTIA ALLIANCE INTERNATIONAL

Support & advocacy of, by & for people with dementia



**BUDAPEST 2016**  
**INTERNATIONAL CONFERENCE**  
**Alzheimer's Disease International**



*Thank you,*

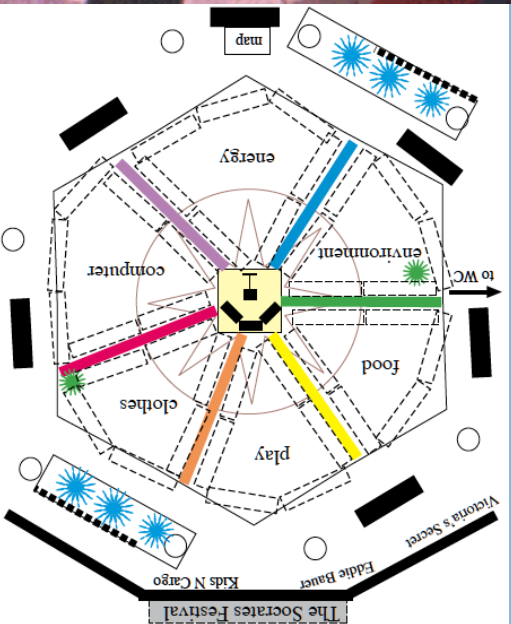
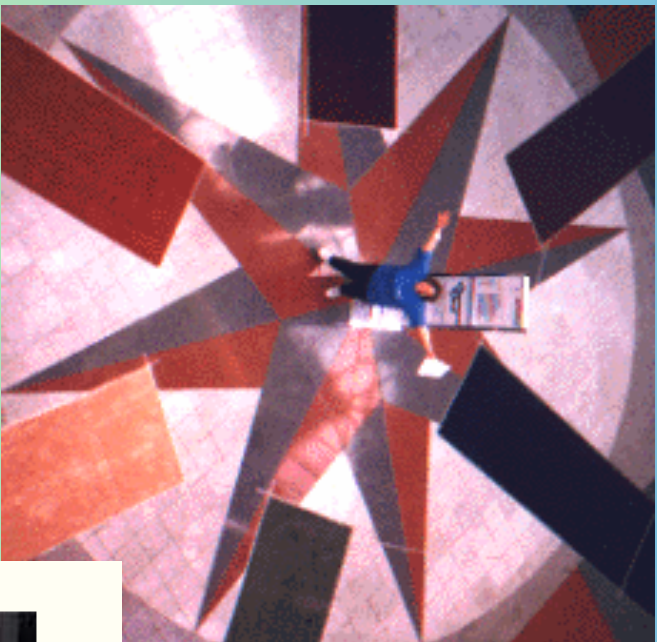
ALZHEIMER'S DISEASE  
INTERNATIONAL

&

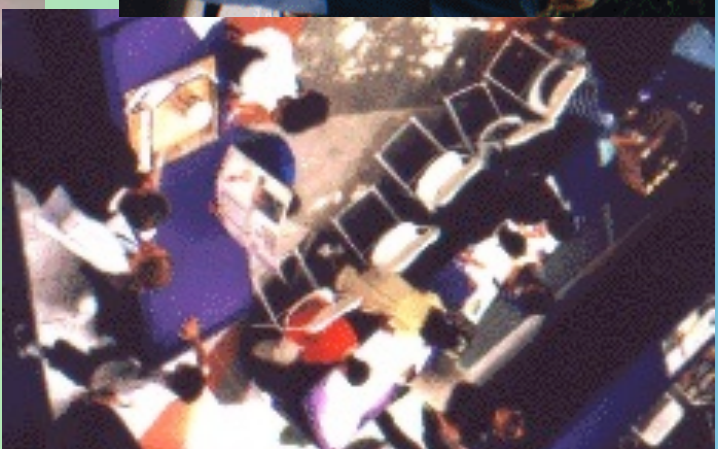
DEMEMENTIA ALLIANCE  
INTERNATIONAL



# My Research in Educational Settings



The Socrates Festival 1999 Landmark Mall



Official unveiling of the interdisciplinary mural: "Children's Visions of Alexandria: Past-Present-Future" on June 4, 1999.



# Some early [mis]diagnoses

“age-associated memory impairment” (at age 55)

2005

“MS”

“normal”

“depression”

2006

1999

“anxiety”

“infection”

“normal  
white matter  
changes”

“multiple sclerosis”

2014

“vasculitis”

*She left the office before I could schedule her for a 3rd neurology opinion and was upset that I did not feel she had a brain disorder.*

2013

2015

“dementia”

Dr. Smigrodzki:

“leukodystrophy”

“Normal,  
but  
angry”

“suspected  
CADASIL”

“ruled out demyelinating disorder”



# The Pushme-Pullyou Phenomenon



*(Dr. Doolittle, 1967)*



When you're being  
pushed in one direction  
and pulled in another...

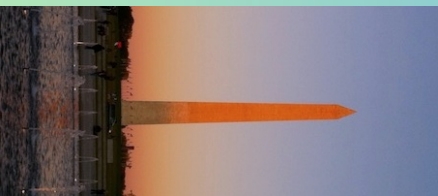


...you have to  
get creative if  
you want to  
dance!



*And I choose to  
dance!*

# My (Healthy) Neighbors



# Why I volunteer in medical research

1. I have no health insurance.

The lack of health insurance is the sixth leading cause of death in America, ahead of diabetes, respiratory disease, and AIDS.

*Critical Condition (2008)*



**DEMENTIA  
ALLIANCE  
INTERNATIONAL**  
The global voice of dementia



# Why I volunteer in medical research

1. I have no health insurance.
2. I trust science.
3. I was born to teach.
4. I'd like to matter to the world.
5. I need a little hope once in awhile.

NIH spends over \$32 billion per year on medical research. \*

[nih.gov](http://nih.gov)

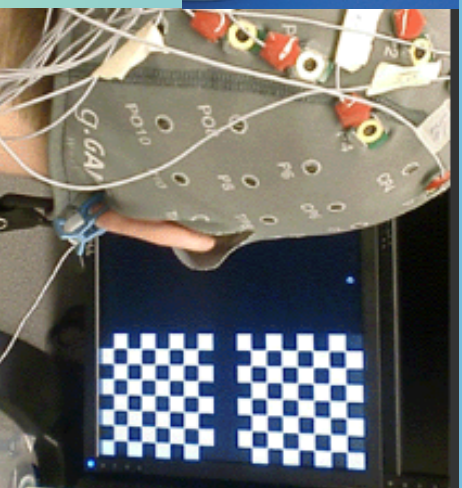


\*now, some on me!



# TESTS & PROCEDURES

## First NIH Clinical Trial (MS)



MRI's

Peg tests

Memory tests

Number games

Evoked potentials

Nerve conduction studies

# First Clinical Trial (MS)

Strength tests

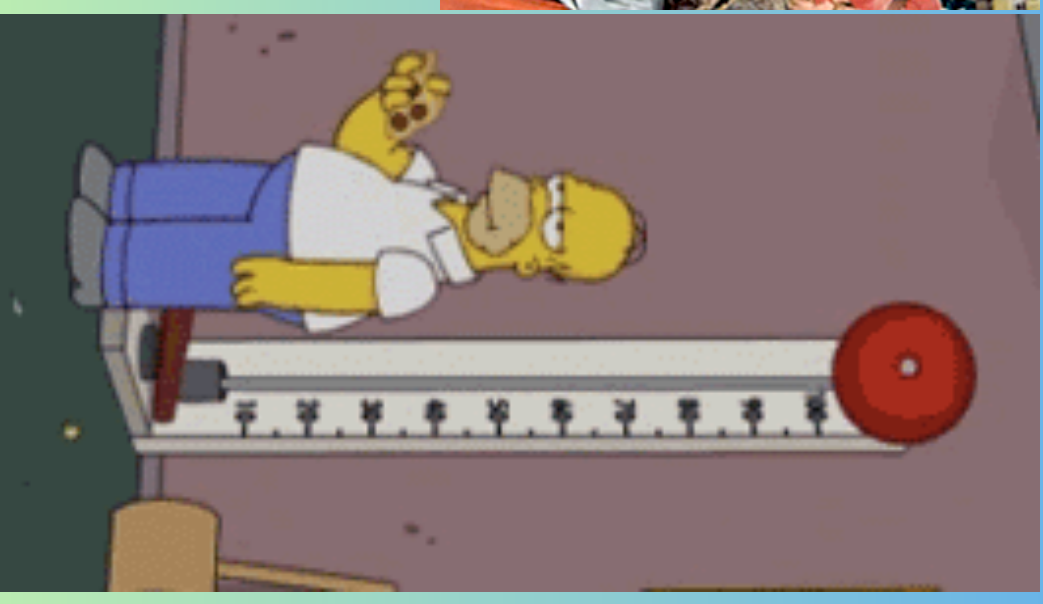
Coordination

Walk on heels

Stair climbing

Touch your nose

Balance & reflex tests



# First Clinical Trial (MS)



Blood tests

Hearing tests

Drawing shapes

Lumbar puncture



# Emotional Pushme-Pullyou



My  
hopes vs.  
reality



I  
need  
medical  
care



“Using  
humans”

# Necessary Paws



# My second clinical trial...

## CLINICAL TRIAL TIMELINE

TRIAL MONTH	MY ACTIVITY	TRIAL MONTH	MY ACTIVITY
Pre-1	Applied in person, phone calls, emails.	10	I emailed, begging for test results.
1	NIH 1-day test. Told: wait weeks/months.	11	Depressed, I asked for test results.
2	Waited for results.	12	Appointment: results inconclusive.
3	Waited some, then requested results.	13	Emails. Wait to get a test to confirm.
4	Told to wait. Waited for results.	14	Emails. Wait to get a test to confirm.
5	Waited for results.	15	Emails. Wait to get a test to confirm.
6	Waited for results.	16	Wait to get a test to confirm.
7	Waited for results.	17	Wait to get a test to confirm.
8	Appointment for results... cancelled.	18	Waiting... ADI conference
9	Appointment for results... cancelled.		





# Communicating with Me

**“I apologize for the late response. We are trying to ensure that we could see you under the research (and therefore at no charge to you)...”**

# Communicating With Researchers

*“I’d rather have a root canal  
without anesthesia than any  
more delays in trying to find  
out what’s happening!”*

*- Mary*

# Communicating With Researchers

*“It's been 3 weeks since the scheduler cancelled my appointment... I no longer have any hope to see the doctor, so if you'd just find time to give me a few minutes to explain whatever gene/test results you have, I'd be satisfied. Thank you.”*

# Communicating with Me

**“You’ve not heard back because there is no update. We’re awaiting ethical approval. This is not a process which takes minutes, but rather involves a thorough review of the proposed research to ensure that it [is] appropriate for participants... I’ll let you know, but I do not update for every step.”**

# Communicating With Researchers

*“You still leave me in No-man’s land... I’ve been waiting nearly a year... just to get details on my condition so I could potentially pursue opportunities with other similarly-diagnosed patients, support groups... You know that timely intervention is key...”*

# Emotional Investment –

*noun*

1.

**cathexis**

Pronunciation: /kəˈtʰɛksəs/  

**NOUN**

*Psychoanalysis*

The concentration of mental energy on one particular person, idea, or object (especially to an **unhealthy** degree).

2. a topic *not* discussed in handbooks for volunteers in clinical trials.

# What Social Workers Offered for Psych Help

*“I could, like, just let you vent, or discuss communication problems.”*



# I BELIEVE...

Clinical trials should inform volunteers about the risks and strategies to help them deal with the emotional investment of being studied as human subjects.



# I ALSO BELIEVE...

Volunteers in clinical trials should be given easy and confidential access to psychologists or psychiatrists prior to, during, and for a brief time after the study.

...because instead of feeling  
like a human lab rat,



*We could feel like any  
other human on a  
research team.*

# Dementia Alliance International

*“Nothing about us without us!”*

We can ~~conduct~~ *and should* research on ourselves.

## Research Grant Application

Unveiling the Subculture of Adult Leukodystrophy: An Ethnography  
of the Human Experience With Cognitive Decline

October 14, 2014

Mary L. Radnofsky

Ph.D.

Director, The Socrates Institute



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# Conducting Research [on] Ourselves

## Research Plan

### 1. Hypothesis

What is the nature of the entire human experience in the leukodystrophy subculture? How does a patient perceive and respond to the world – physically, intellectually, psychologically, emotionally, aesthetically, socially, spiritually, gustatorily, spatially/geographically, technologically, environmentally, financially, and otherwise, as the condition progresses?

### 2. Specific Aims

- To illuminate hidden or invisible behaviors and perceptions, unspoken expectations and thought processes in a patient with adult-onset leukodystrophy and cognitive decline, so as to better inform doctors, caregivers, and future patients, thereby facilitating earlier diagnosis and treatment;
- To record daily observations, for one year, by a patient with adult-onset leukodystrophy, so as to chronicle her metacognitive insights related to physical and cognitive stressors perceived either as euphoric tension (i.e. pleasurable and stimulating) or dysphoric tension (i.e. disagreeable and discouraging), while medically documenting progression of the disease;

# Seeing the Value of Our Own Research

## *Unedited Comments of the Review Committee:*

### *Strengths:*

- I trust that the subjective experience of cognitive decline is an important one that can and should be addressed.
- The investigator is a committed individual to evaluating the experience and has presented a well worked out plan.
- This is a unique qualitative analysis of a leukodystrophy patient's subjective experience with the disease.
- The PI is highly experienced in the qualitative methodology proposed and is well qualified to collect and analyze the data.



# ... But Failing to See Our Value as Expert Researchers.

## *Weaknesses:*

- n=1
- If one of the main objectives is to “facilitate future diagnoses”, I do not see how this project will contribute towards that aim.
- It is uncertain how one year’s worth of information of one individual is going to provide the insight into the broader issues of progression in the adult population.
- Original proposal but incomplete. I accept importance of personal ethnography and gathering of meta cognitive data but need methods for disseminating information. Suggest blog / social media component and closer comparison with existing descriptions of subcortical dementia. Feedback from other patients and closer networking encouraged. Survey generation?

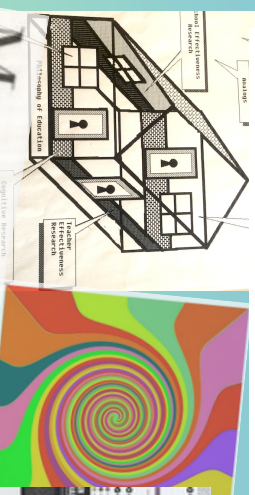


# ... But Failing to See Our Value as Expert Researchers.

- The study is short term (1 year) in a patient who may not demonstrate significant neurologic decline during the study interval. What is her current functional impairment and how much has it changed over the past year? What changes in MRI have occurred? If the PI does deteriorate quickly, she may be unable to complete the study.
- PI is the patient, which may cloud the objective investigation of the disease.
- No molecular diagnosis is known on this person. What leukodystrophy does she have? And how applicable is this study to other leukodystrophies?

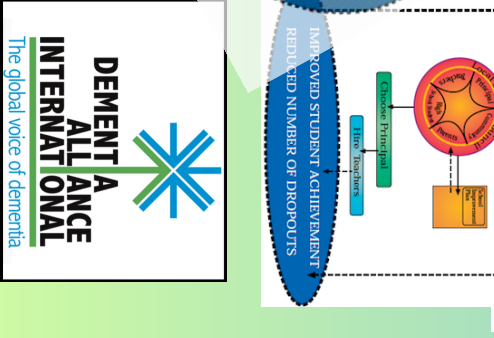
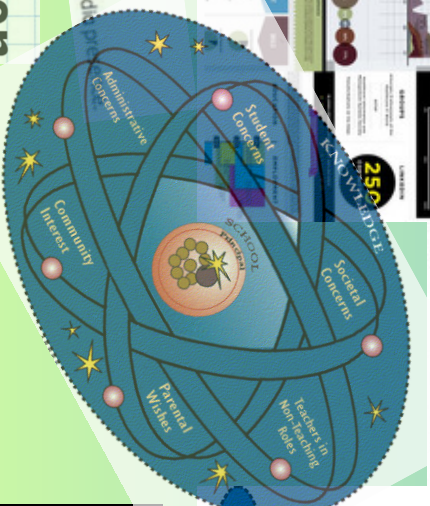
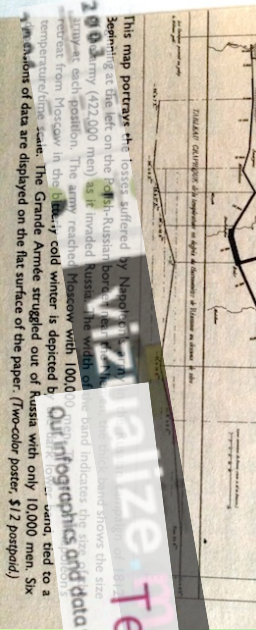
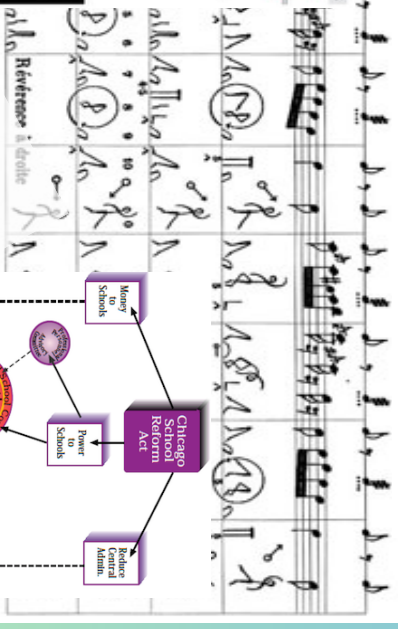
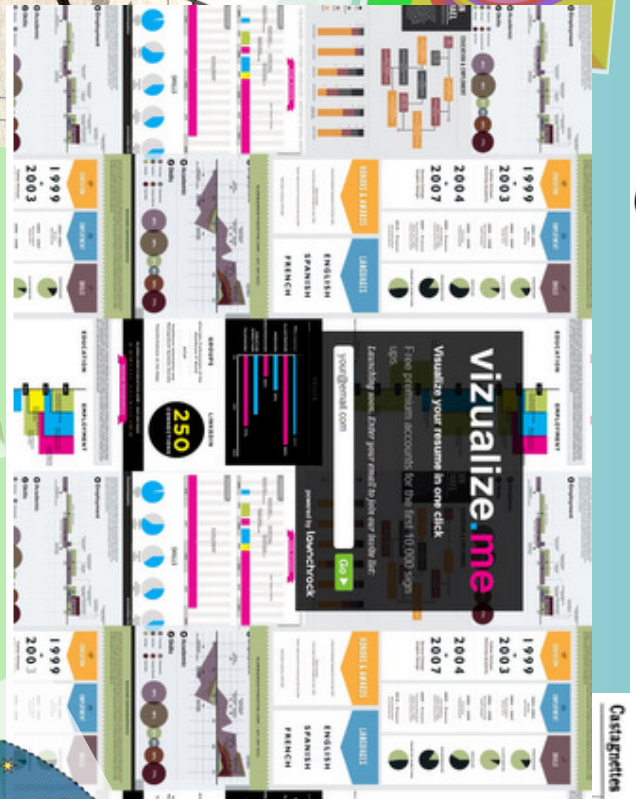


# I'll also build qualitative & quantitative models to show actual & changing cognitive abilities.



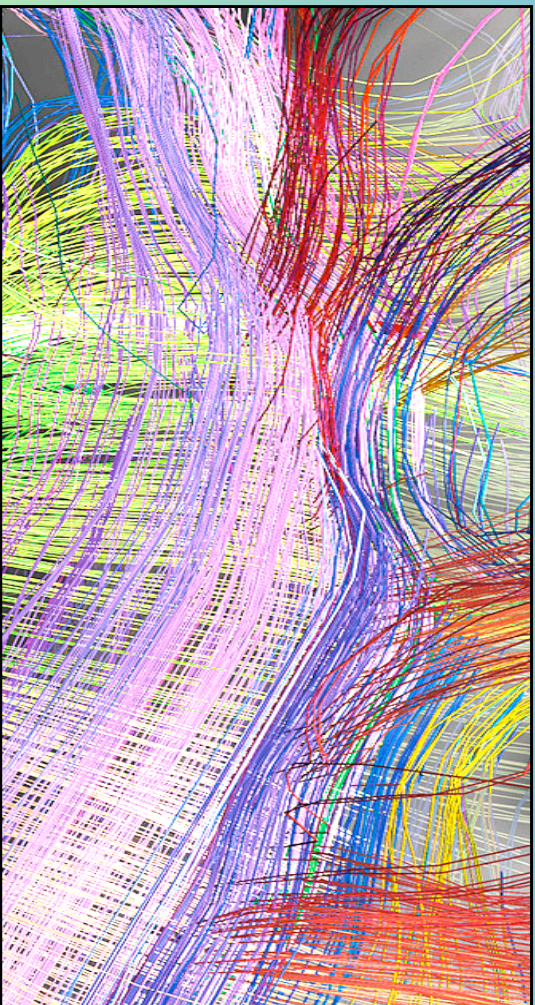
**Mapping Time**  
 Figure 1. The map shows the...  
 CHARACTERISTICS BY INDICATING A MAP OF...  
 (Caption text is partially obscured and difficult to read)

**THE VISUAL DISPLAY OF QUANTITATIVE INFORMATION**





# Clinical trials yield <sup>cool</sup> new knowledge.



Brain neuronal connections - DSI MRI

**DSI of human brain white matter, by Alfred Pasieka.**

**DSI – Diffusion Spectral Imaging (variant of MRI).**

Radio waves from H<sub>2</sub>O molecules, energized by a magnetic field, map the water in neuron fibers, revealing a unique wiring diagram.

So, yes, you're welcome to explore my unique brain...



*With me — all of me.*

**This is just the  
beginning.**



**[info@infodai.org](mailto:info@infodai.org)**