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

by

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member of

DEMENTIA ALLIANCE INTERNATIONAL

Support & advocacy of, by & for people with dementia
Thank you,

ALZHEIMER’S DISEASE INTERNATIONAL

&

DEMENTIA ALLIANCE INTERNATIONAL
My Research in Educational Settings
Some Early Diagnoses

1999
“normal”
“depresion”
“normal white matter changes”
“anxiety”

2005
“multiple sclerosis”
“infection”

2014
“vasculitis”
“age-associated memory impairment” (at age 55)

2015
“Normal, but angry”
“suspected CADASIL”
“rushed out of the hospital”

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
Dr. Smigrodzki:
“leukodystrophy”

2015
“rushed out of the hospital”

DementAlliance International
The global voice of dementia
I have dementia.
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!
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.*

*now, some on me!
TESTS & PROCEDURES
First NIH Clinical Trial

MRIs
Peg tests
Memory tests
Number games
Evoked potentials
Nerve conduction studies
First Clinical Trial

Strength tests
Coordination
Walk on heels
Stair climbing
Touch your nose
Balance & reflex tests
First Clinical Trial

Blood tests
Hearing tests
Drawing shapes
Lumbar puncture
### My second clinical trial...

<table>
<thead>
<tr>
<th>Trial Month</th>
<th>My Activity</th>
<th>Trial Month</th>
<th>My Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-1</td>
<td>Applied in person, phone calls, emails.</td>
<td>10</td>
<td>I emailed, begging for test results.</td>
</tr>
<tr>
<td>1</td>
<td>NIH 1-day test. Told: wait weeks/months.</td>
<td>11</td>
<td>Depressed, I asked for test results.</td>
</tr>
<tr>
<td>2</td>
<td>Waited for results.</td>
<td>12</td>
<td>Appointment: results inconclusive.</td>
</tr>
<tr>
<td>3</td>
<td>Waited some, then requested results.</td>
<td>13</td>
<td>Emails. Wait to get a test to confirm.</td>
</tr>
<tr>
<td>4</td>
<td>Told to wait. Waited for results.</td>
<td>14</td>
<td>Emails. Wait to get a test to confirm.</td>
</tr>
<tr>
<td>5</td>
<td>Waited for results.</td>
<td>15</td>
<td>Emails. Wait to get a test to confirm.</td>
</tr>
<tr>
<td>6</td>
<td>Waited for results.</td>
<td>16</td>
<td>Wait to get a test to confirm.</td>
</tr>
<tr>
<td>7</td>
<td>Waited for results.</td>
<td>17</td>
<td>Wait to get a test to confirm.</td>
</tr>
<tr>
<td>8</td>
<td>Appointment for results… cancelled.</td>
<td>18</td>
<td>Waiting… ADI conference</td>
</tr>
<tr>
<td>9</td>
<td>Appointment for results… cancelled.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
"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). I have not yet had confirmation from our billing department but I think we will be able to do this. However, considering that I do not have confirmation yet I would prefer to schedule you for another visit so that you will not get a large bill. Will this be acceptable for you? I will try to keep you posted - our next two clinic dates are October 31 and November 12 and I am sure that we may find time
Communicating with Researchers

“I’d rather deal with administrative hassles... In fact, I’d rather have a root canal without anesthesia than have any more delays in trying to find out what’s happening!”

- Mary
Communicating with Me

“WE CAN ONLY TELL YOU WHEN WE FIND SOMETHING RELATED TO YOUR SYMPTOMS OR WHICH WILL AFFECT YOUR HEALTH. I WISH WE COULD REPORT NEGATIVE FINDINGS BUT WE’RE LIMITED LEGALLY (& UNFORTUNATELY DO NOT HAVE ENOUGH STAFF TO DO THIS..)”
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

“We do plan to get you into clinic. I am sorry our scheduling issues have been so difficult. Please be a bit more patient. Hopefully we’ll have these settled by the end of the week.”
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…”
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.”
Pushme-Pulleyou Dilemmas

My hopes vs. reality

I need medical care

Feeling useful vs. feeling used
Emotional Investment – noun

1. **cathexis**
   
Pronunciation: /kəˈθɛksɪs/
   
   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.
I BELIEVE...

Clinical trials should inform volunteers about the risks of emotional investment and strategies to help deal with 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!”

and should

We can conduct 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
People With Dementia
Conducting Valuable Research on Ourselves

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 be Valued 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?
Clinical trials yield new knowledge.

DSI – Diffusion Spectral Imaging (variant of MRI). Radio waves from H2O molecules, energized by a magnetic field, map the water in neuron fibers, revealing a unique wiring diagram.

DSI of human brain white matter, by Alfred Pasieka.
I’ll also build qualitative models to show actual & changing cognitive abilities.
This is just the beginning.

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