



Social Media + Data: Patients Helping Patients

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Conflict of Interest Disclosure

Sally Okun is a paid employee of PatientsLikeMe, Inc. and owns stock options in the company.

PatientsLikeMe works with major pharmaceutical companies doing clinical and market research.

“A great wind is blowing and that gives you either imagination or a headache”

Catherine the Great



Empowered Patient



Molecular Medicine



Clinician Role



New Data Sources

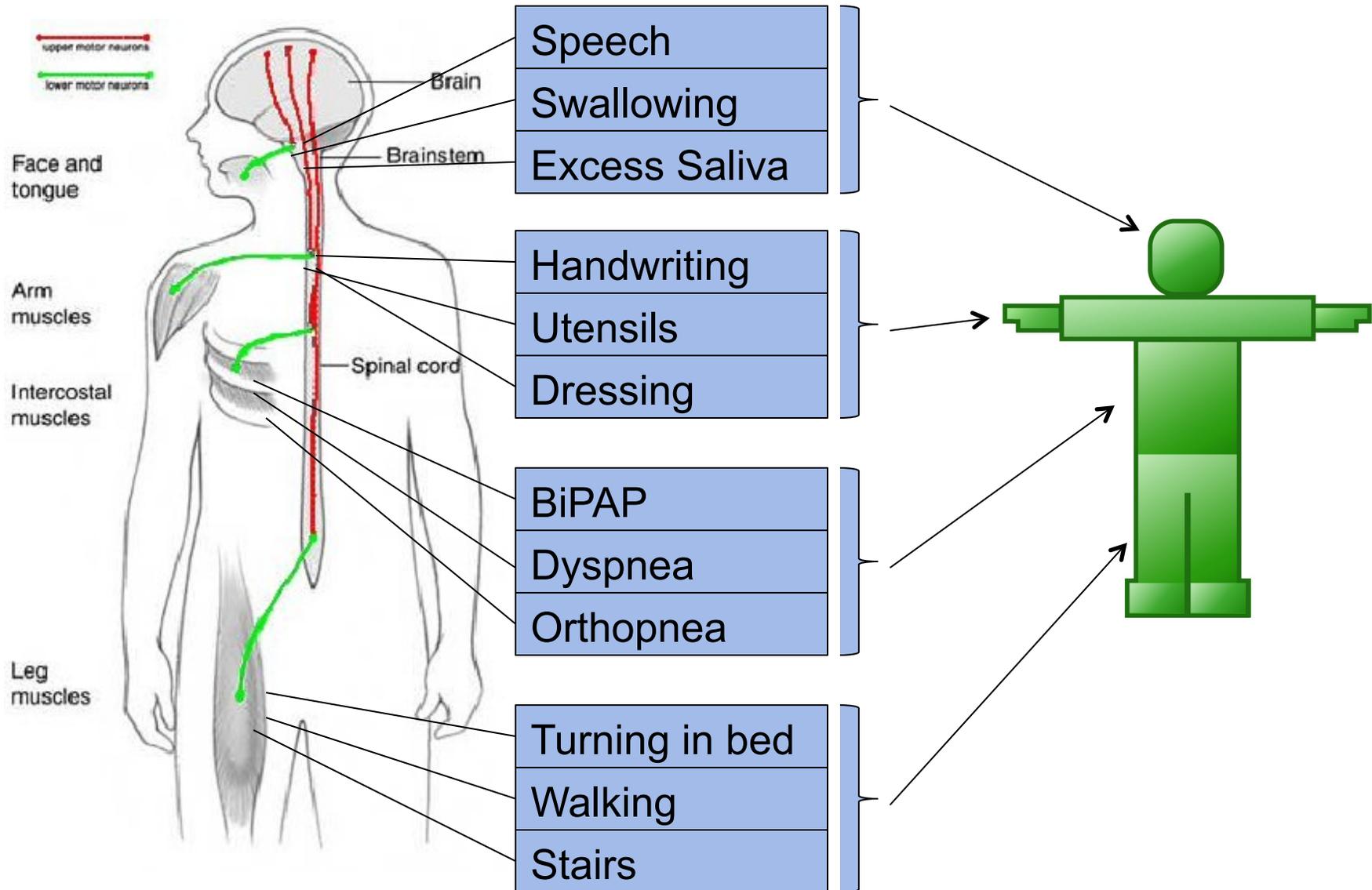


Payment Reform

“Given my status,
what is the best
outcome I can hope
to achieve, and how
do I get there?”



Amyotrophic Lateral Sclerosis (ALS)



What is my status?



Walking



Breathing



Hands



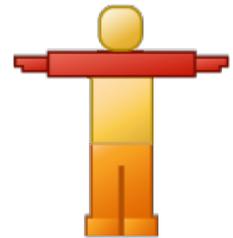
Speaking

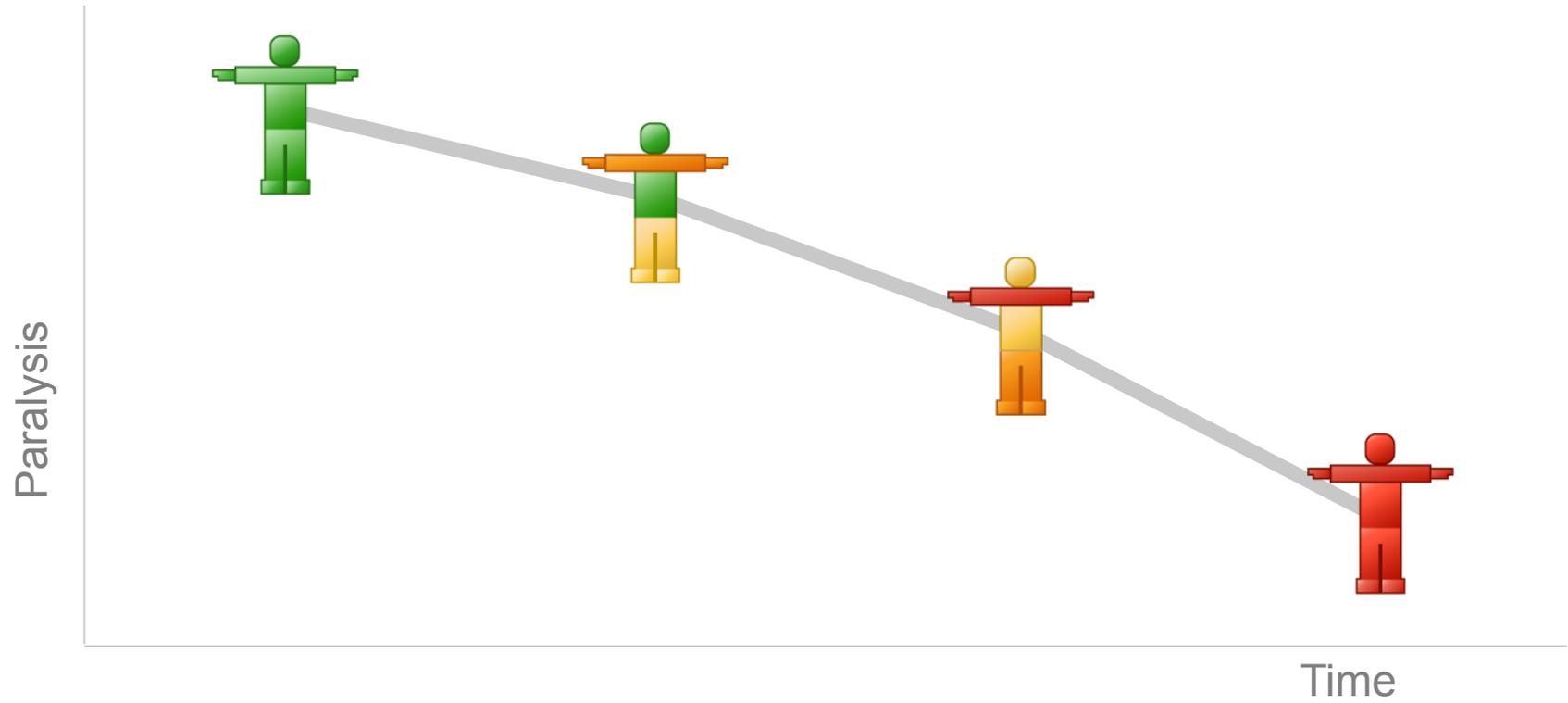


Wellbeing



Productivity





Stephen Heywood (alsking101)



alsking101
Male, 38 years
Newton, MA

ALS: 9 yrs

Diagnosis Summary
 Onset: Arms
 First symptom: Nov 1997
 Diagnosis: Jan 1998
 Deceased date: Nov 26, 2006

Updates
 Last updated: Oct 15, 2006

ALS Condition

FRS: 0
 (latest: 10/01/06)

Progression rate percentile

- 5-10th (rapid)
- 10-25th
- 25-75th (average)
- 75-90th
- 90-95th (slow)



FVC: 5%
 (latest: 02/06/06)

Warning Levels

- warning
- severe

Treatments

Prescription

Reasons Taken

- slow my ALS progress
- general health
- specific symptom
- other

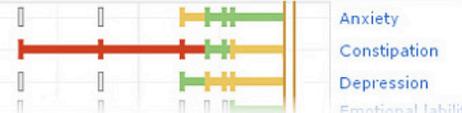


Symptoms

Primary Symptoms

Severity of Symptoms

- none
- mild



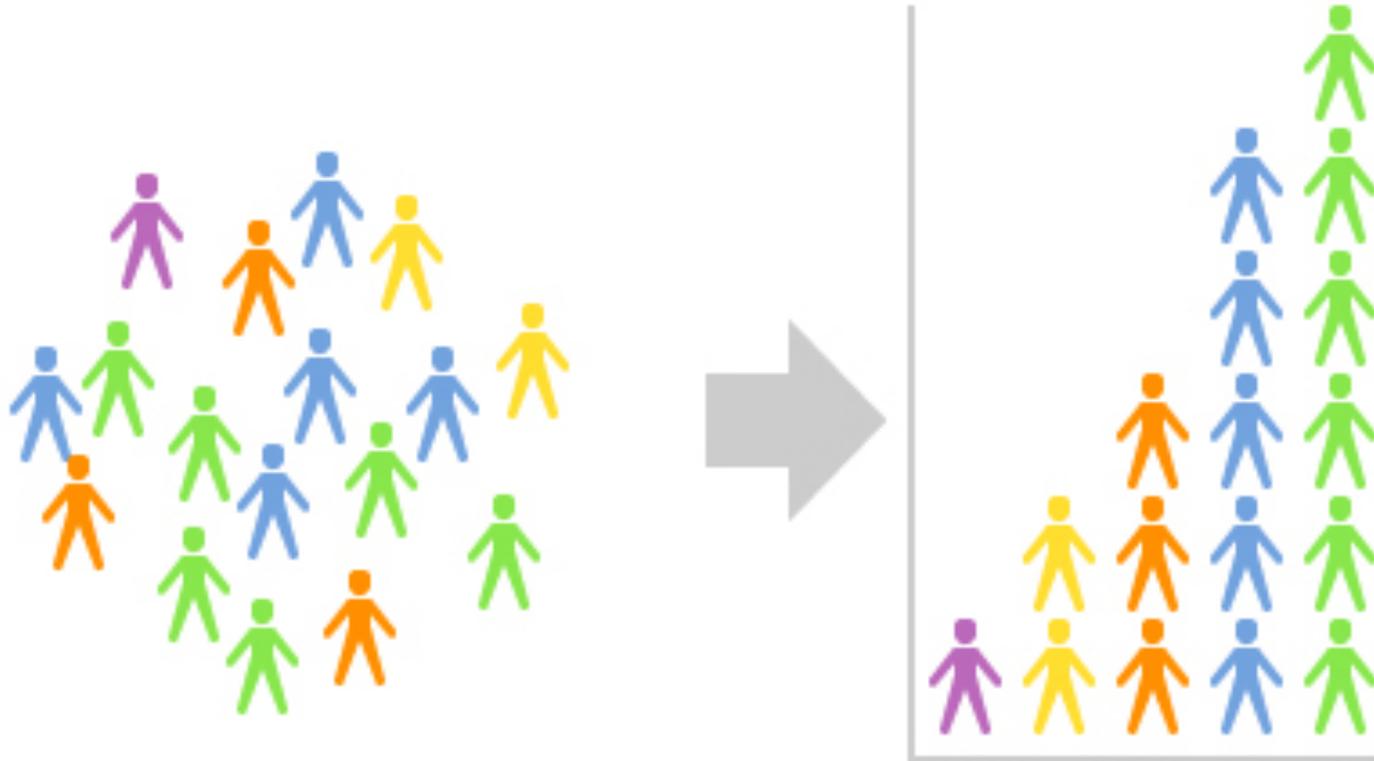
“Knowledge is power. Information is liberating. Education is the premise of progress, in every society, in every family.”

Kofi Annan

Individual Stories



Collective Wisdom



Responsibly engaging patients is challenging

Honor Patients' Trust

Our patients trust us with their most valued health information. We honor that trust, and we are dedicated to advancing the knowledge in the disease with the information they share.

Openness

Per our Openness Philosophy, we believe that sharing health information is good. Why? Because sharing will drive massive change in healthcare.

PATIENTS FIRST

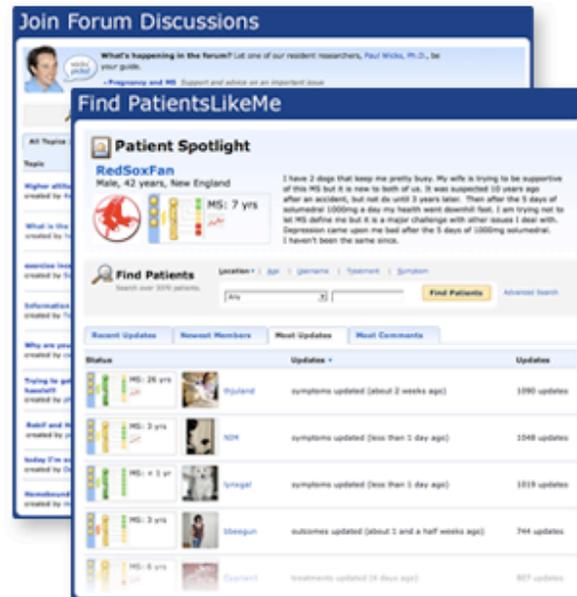
No surprises. Our members shouldn't be surprised by anything we do. Our goal is to disclose what we do with members' information, how we make money, as well as all of our partnerships on the site.

Transparency

When people see our site, we want them to think, "Wow!" Achieving our vision takes flawless execution and a deep understanding of patient needs.

Create WOW!

Core patientslikeme™ Platform



SHARE

Patients **sharing detailed health data** is what makes our communities unique. This information is the basis of the PatientsLikeMe network and validates each individual.

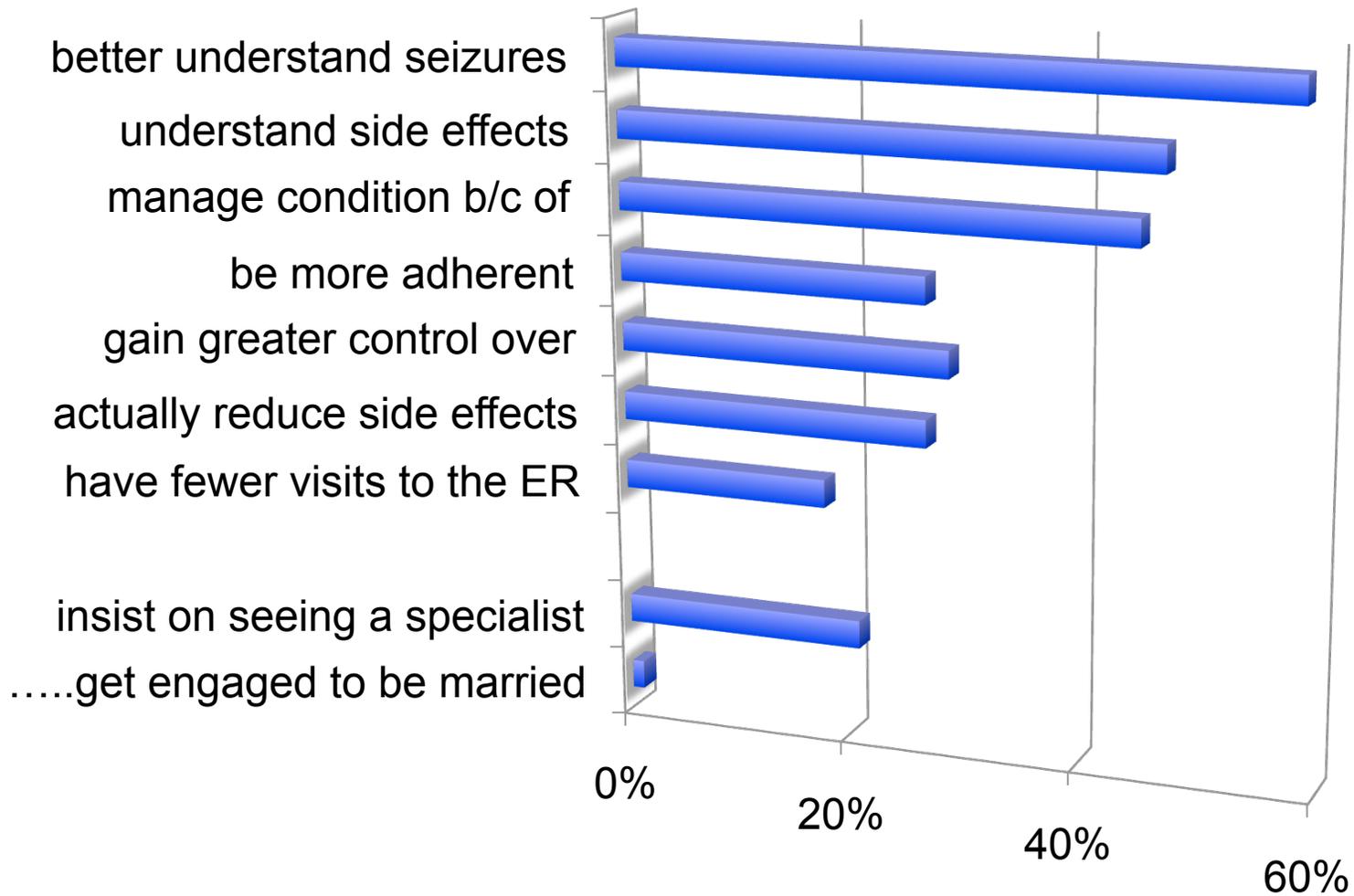
FIND

Patients **find other patients like them**. They discover what options are available for treatment and if their experience with their disease is normal. They can reach out to others like them for advice and insight.

LEARN

The information shared creates a **new knowledge** about the real-world **treatments**, **symptoms**, and reality of living with illness. Patients learn about their disease and themselves in context of the community.

Epilepsy users reported that PatientsLikeMe helped them....



 **Dirty Butter**
shared a forum post



100,232 patients
500+ conditions

Who's like you?



Share your experience.

The more you share, the easier it will be to find patients like you. Start by adding a condition, symptom or treatment.



I have



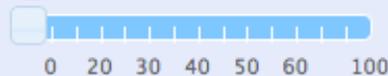
I take



I am



My Age



Join Now! (It's free)

The graphic features a large green speech bubble containing a white question mark and various medical icons (pill, stethoscope, flask, bandage). Below it, a row of blue human icons is shown, with the first one labeled 'YOU'. A large green arrow points from the 'YOU' icon towards the right, where a blue human icon is labeled 'your profile' next to a line graph showing an upward trend. The text 'patientslikeme®' is prominently displayed in the center.

Get your health in order. Join PatientsLikeMe.

[Find Patients Like You](#)[Explore our Treatment Reports](#)[Learn about Symptoms](#)[Review our Research](#)[Check for your Conditions](#)[Patient Testimonials](#)

"I don't think all the money in the world could replace what I've learned here."

—PatientsLikeMe member

About PatientsLikeMe

[Read about the company](#)[How we make money](#)[Be part of our team](#)[Contact Us](#)[Information for Industry Partners](#)

Capture Subjective Data

- **Subjective Measures**
 - About Me
 - Instant Me
 - Condition Specific Primary Outcomes
 - FRS, MSRS, Mood Map, PDRS, PFRS, Seizure Meter, NMORS, QoL
 - Symptom and Side Effect Reports
 - Treatment Evaluations
 - Forum Discussions

Collect Objective Data

- Demographics
 - Age, Gender, Ethnicity, Location
- Genetic Markers
- Weight
- Condition Specific Labs and Metrics
 - BP, HbA1c, Creatinine, GFR, FVC, Ejection Fraction, AST, Total Bilirubin
- Hospitalizations
- Treatments

Nugget

The screenshot shows a patient profile for Neissy, a 54-year-old female from MI, United States. Her primary condition is Epilepsy, with a first symptom in 04/78 and a diagnosis in 04/78. She has 4 more conditions. Her care team includes a photo of a man and a woman. A table lists seizure types: Atonic (0), Atypical absence (0), Complex Partial (0), Myoclonic (0), and Simple partial (0). A note from April 24, 2011, describes her as "bad" and "Very foggy, & in lots of pain..very cranked up for past 48 hours..not good". She has completed PRO 3 and has 3 stars.

Neissy
Female, 54 years
MI, United States

Condition History
Primary Condition: Epilepsy
First symptom: 04/78
Diagnosis: 04/78
▼ 4 More Conditions

My CareTeam

Seizures Last update: Apr 17, 2011	<ul style="list-style-type: none">Atonic 0Atypical absence 0Complex Partial 0Myoclonic 0Simple partial 0
I am: Last update: Apr 24, 2011	bad "Very foggy, & in lots of pain..very cranked up for past 48 hours..not good"
Surgery	None reported
PRO	Has completed PRO 3
Stars	This patient has 3 stars

Instant Me

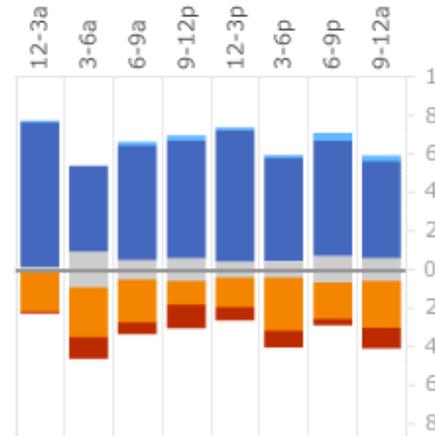
InstantMe History

Showing 10 InstantMe entries, from Apr 11, 2011 to Apr 24, 2011

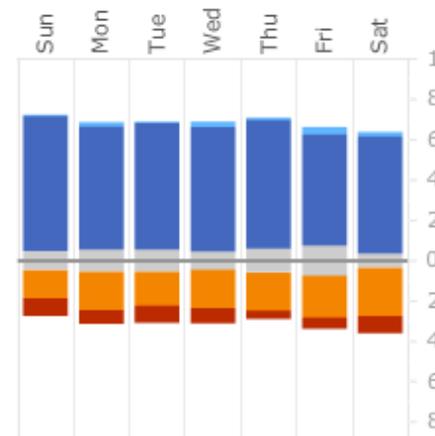
Date/Time	Status	Why?
Apr 22, 2011 10:46 AM	Good	
Apr 21, 2011 3:46 PM	Bad	
Apr 20, 2011 9:22 PM	Good	
Apr 19, 2011 5:30 PM	Good	
Apr 18, 2011 1:35 PM	Good	
Apr 16, 2011 6:08 PM	Good	
Apr 15, 2011 9:26 PM	Bad	
Apr 14, 2011 9:17 PM	Good	
Apr 13, 2011 7:22 PM	Good	

InstantMe Trends

By Time of Day



By Day of Week



Sort This Profile



InstantMe

- Very Good
- Good
- Neutral
- Bad
- Very Bad

Apr 11

■ Good

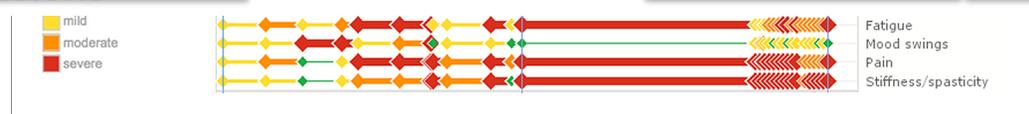
Apr 22, 2011 10:46 AM

[More](#)

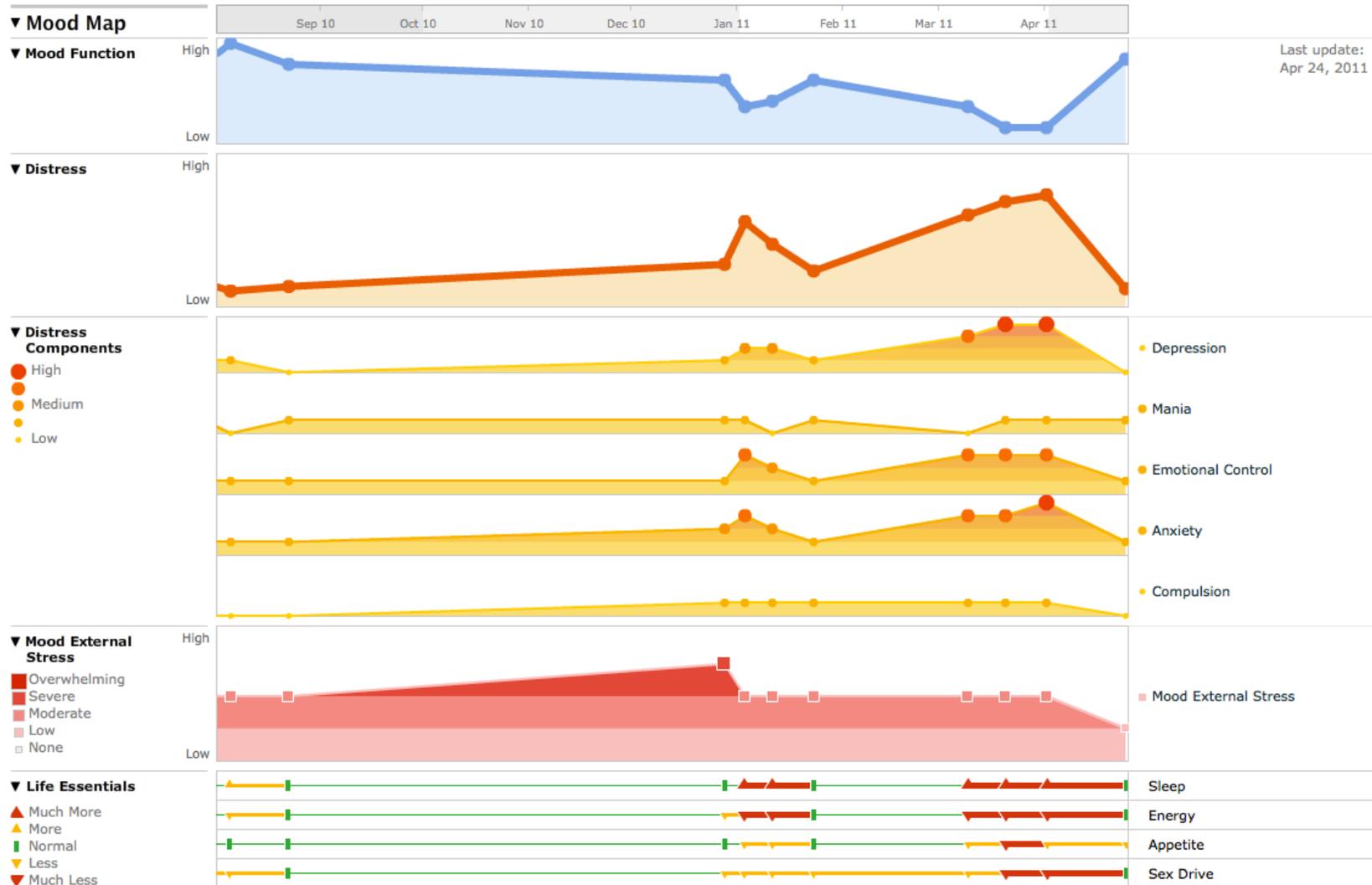
Primary Outcome Measure: MSRS

Select the level of disability that best represents your current condition...

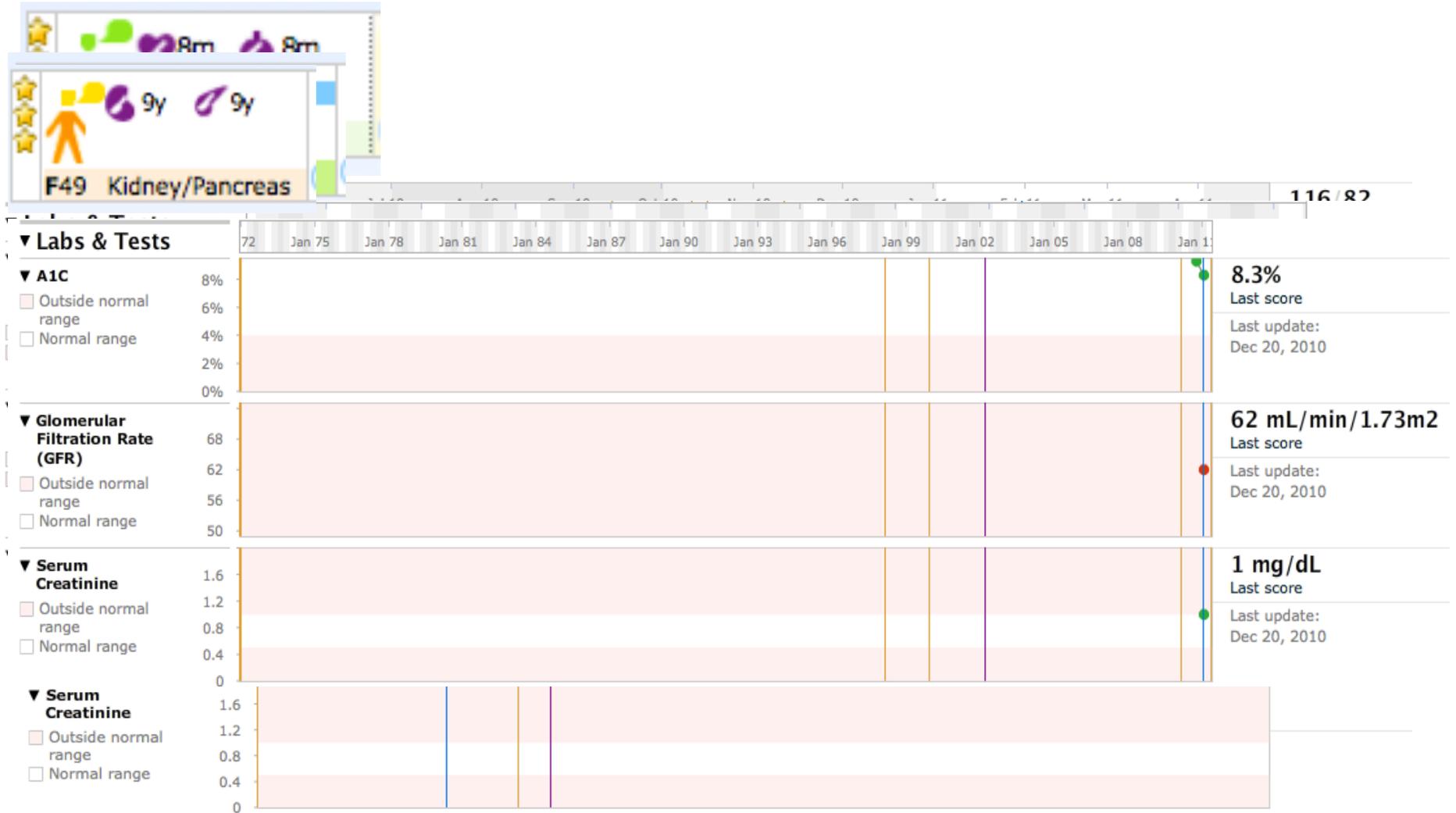
	(0 Points) No Symptoms No symptoms or disability in the specific area	(1 Point) None Aware of symptoms but no functional disability	(2 Points) Mild Mild disability but not requiring help from others	(3 Points) Moderate Moderate disability that requires some help from others	(4 Points) Total Disability Total disability and help always required
✓ Walking	No Symptoms	None	✓ Mild	Moderate	Total Disability
✓ Upper Limb Function	No Symptoms	✓ None	Mild	Moderate	Total Disability
✓ Vision	No Symptoms	✓ None	Mild	Moderate	Total Disability
✓ Speech	No Symptoms	✓ None	Mild	Moderate	Total Disability
✓ Swallowing	No Symptoms	✓ None	Mild	Moderate	Total Disability
✓ Thinking / Memory / Cognition	No Symptoms	None	✓ Mild	Moderate	Total Disability
✓ Sensation / Burning / Pain	No Symptoms	✓ None	Mild	Moderate	Total Disability



Primary Outcome Measure: Mood Map



Objective Measures



Health Data Integrity & Patient Safety

- Controlled vocabularies for coding data
 - Multum Cerner Drug Database
 - WHO ICD-10 and ICF
 - SNOMED-CT
 - MedDRA
 - ClinicalTrials.gov
 - LOINC
 - RxNorm
- Natural Language Processing
 - Multiple training sets developed

Symptom & Side Effect Admin Tools

Symptoms Admin

- Symptoms Admin**
- All
- Add
- Merge

- Meddra**
- Rules
- LLTs

Brain fog

Created Apr 24, 2007 by [Moonwolf](#)

Symptom Report

18989 patients

693 side effect reports

8 hospitalizations

Associated Conditions: [Neuromyelitis Optica](#), [MS \(Multiple Sclerosis\)](#), and [Fibromyalgia](#)

Admin

Administration Note

ICD code

Mild cognitive disorder

ICF code

Attention functions

Meddra LLT code

Foggy feeling in head (10016876)

[\(Edit\)](#) [\(Clear\)](#) [\(See related meddra symptoms\)](#)

Short Definition

Brain fog describes the feeling of impairment in cognitive functioning that may be caused by a physical or mental condition or related to specific medications or treatments. A person is often easily distracted, may have trouble concentrating, experience some confusion and/or forgetfulness.

Symptoms Admin
All
Add
Merge

Meddra
Rules
LLTs

Foggy feeling in head

Position(s) in Meddra Hierarchy

- SOC** General disorders and administration site conditions (10018065)
- HLGT** General system disorders NEC (10018073)
- HLT** Feelings and sensations NEC (10068759)
- PT** Feeling abnormal (10016322)

Linked Symptoms

- Brain fog
- Constant brain fog
- Fibro fog
- Cloudy thinking

Linked Side Effects

- Brain fog
- Constant brain fog
- Fibro fog
- Cloudy thinking

FDA Always Serious?

false

Always Serious Treatments

[]

Always Serious Manufacturers

[]

Expected Side Effect of:

Filter by: **All** **patients**

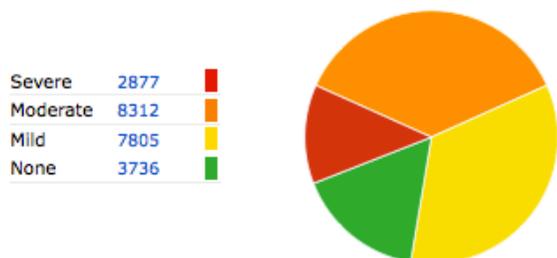
[Home](#) > [Symptoms and Side Effects Overview](#) > [Brain fog Report](#)

Brain fog Report

Brain fog describes the feeling of impairment in cognitive functioning that may be caused by a physical or mental condition or related to specific medications or treatments. A person is often easily distracted, may have trouble concentrating, experience some confusion and/or forgetfulness.

What we've learned from patients who report Brain fog

☰ Symptom Severities



☰ What Patients Take For The Purpose of Treating Brain fog

What Patients Take For The Purpose of Treating Brain fog

Modafinil	61	■
Amphetamine-Dextroamphetamine	29	■
Methylphenidate	27	■
Omega 3 Fish Oil	26	■
Ginkgo Biloba	22	■
Donepezil	20	■
CoQ10	17	■
Acetyl L-Carnitine	13	■
Naltrexone	13	■
Vitamin B	10	■
Armodafinil	8	■
Folic Acid	8	■
Memantine	8	■

See More Symptoms

See all 6850 symptoms in the PatientsLikeMe system shared by patients just like you.

Patients

Experiencing Brain fog

MS : 9 yrs

babybunny
First Symptom: 04/02
Dx: 07/07

CFS : 2y
FM : 2y Dx
F46y

Kaessa
First Symptom: 12/08
Dx: 07/09

MS : 20 yrs

tvermilye
First Symptom: 07/90
Dx: 07/95

See all 18986 patients currently experiencing Brain fog

Forum

What are people saying about Brain fog?

There are **3832** posts in our forum about Brain fog.

Publications from Our Team



Jan 27, 2011

Patient-reported Outcomes as a Source of Evidence in Off-Label Prescribing *Journal of Medical Internet Research*

By Jeana Frost, Sally Okun, Timothy Vaughan, James Heywood, Paul Wicks

When a drug is approved by the FDA, it is for a specific purpose or "indication". However, we noticed that many of our users said they had been prescribed drugs for purposes not included in the original approval, known as "off-label" usage. In this award-winning study, we sought to discover the experiences of patients taking two widely-used treatments for off-label purposes.



Jan 27, 2011

The Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ) *Journal of Medical Internet Research*

By Paul Wicks, Mike Massagli, Amit Kulkarni, Homa Dastani

For MS patients, taking their disease-modifying treatments on time can make the difference in terms of relapses, progression, and long-term function. Using the voice of our patients we constructed a scale that measures all the barriers that get in the way of our patients being adherent to their drugs, in the hope of improving their outcomes.



Jul 08, 2010

Concordance between site of onset and limb dominance in amyotrophic lateral sclerosis *Journal of Neurology, Neurosurgery, & Psychiatry*

By Martin Turner, Paul Wicks, Catherine Brownstein, Michael Massagli, Maria Toronjo, Kevin Talbot, Ammar Al-Chalabi

For this project we collaborated with the University of Oxford. In a survey of our ALS patients, we found that patients with an arm-onset were most likely to get the condition first in their "dominant" hand (i.e. right handers were more likely to get it in their right hand first); the same was not true for those with leg-onset ALS. This finding is consistent with the idea of a link between exercise and ALS.



Jun 15, 2010

Sharing Health Data for Better Outcomes on PatientsLikeMe *Journal of Medical Internet Research*

By Paul Wicks, Michael Massagli, Jeana Frost, Catherine Brownstein, Sally Okun, Timothy Vaughan, Richard Bradley, James Heywood

Results from our user survey suggest that our members perceive a variety of benefits from using PatientsLikeMe, including feeling better informed about their treatment decisions, better communication with their healthcare providers, and improved quality of life!



Oct 22, 2009

The power of social networking in medicine *Nature Biotechnology*

By Catherine Brownstein, John Brownstein, David S. Williams III, Paul Wicks, James Heywood

A summary of recent advances on the PatientsLikeMe site including the potential for our system to identify the potential for off-label uses of existing drugs.

Lithium delays progression of amyotrophic lateral sclerosis

Francesco Fornai^{1,2}, Patrizia Longone⁵, Luisa Cafaro¹, Olga Kastsiuchenka^{*}, Michela Ferrucci^{*}, Maria Laura Manca³, Gloria Lazzari^{*}, Alida Spalloni⁵, Natascia Bellio³, Paola Lenzi^{*}, Nicola Modugno¹, Gabriele Siciliano³, Ciro Isidoro³, Luigi Murri⁵, Stefano Ruggieri¹, and Antonio Paparelli^{*}

^{*}Department of Human Morphology and Applied Biology, and ²Department of Neuroscience, Clinical Neurology, University of Ferrara, 44100 Ferrara, Italy; ¹Istituto Neurologico Mediterraneo, Istituto Di Ricovero e Cura a Carattere Scientifico Neuromed, 86077 Pozzilli (IS), Italy; Santa Lucia Foundation, 00179 Rome, Italy; and ³Department of Medical Sciences, University of Novara, 28100 Novara, Italy

Edited by Thomas C. Südhof, University of Texas Southwestern Medical Center, Dallas, TX, and approved December 21, 2007 (received August 24, 2007)

ALS is a devastating neurodegenerative disorder with no effective treatment. In the present study, we found that daily doses of lithium, leading to plasma levels ranging from 0.4 to 0.8 mEq/liter, delay disease progression in human patients affected by ALS. None of the patients treated with lithium died during the 15 months of the follow-up, and disease progression was markedly attenuated when compared with age-, disease duration-, and sex-matched control patients treated with riluzole for the same amount of time. In a parallel study on a genetic ALS animal model, the G93A mouse, we found a marked neuroprotection by lithium, which delayed disease onset and duration and augmented the life span. These effects were concomitant with activation of autophagy and an increase in the number of the mitochondria in motor neurons and suppressed reactive astrogliosis. Again, lithium reduced the slow necrosis characterized by mitochondrial vacuolization and increased the number of neurons counted in lamina VII that were severely affected in saline-treated G93A mice. After lithium administration in G93A mice, the number of these neurons was higher even when compared with saline-treated WT. All these mechanisms may contribute to the effects of lithium, and these results offer a promising perspective for the treatment of human patients affected by ALS.

autophagy | clinical study | G93A mice | morphological analysis

ALS is a devastating neurodegenerative disorder with no effective treatment that usually leads to death within 3–5 years from diagnosis (11 months for the bulbar form) (1). ALS occurrence is primarily (90%) sporadic, while only 10% is

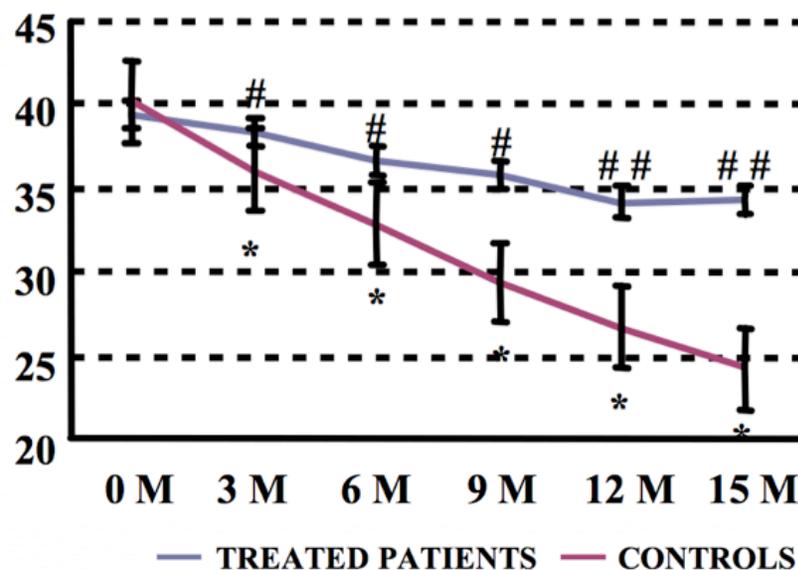
G93A ALS mouse model. Based on the results obtained in mice we quickly moved to human patients. At the end of its second year.

Results

Effects of Lithium on Disease Duration in G93A Mice. G93A male mice were treated daily with lithium (100 mg/kg, i.p.), starting at 75 days of age. This treatment prolonged the mean survival time to 148 ± 4.3 (n = 20, ~36% of the control; $P < 0.001$) and, most important, delayed the onset of disease (from a mean of 9 days to >38 days compared with the G93A mice treated with saline; $P < 0.001$). More specifically, lithium treatment was started at the time of the increase in disease duration (shown). More specifically, lithium treatment delayed the increase in disease duration (shown). More specifically, lithium treatment delayed the increase in disease duration (shown). More specifically, lithium treatment delayed the increase in disease duration (shown).

Effects of Lithium Treatment on Motor Neurons in Lumbar and Cervical Spinal Cord and on Disease Progression. Effects were accompanied by a reduction in the number of motor neurons (SI Fig. 7). However, lithium treatment delayed the disease progression, occurred later following lithium treatment within lumbar lamina IX of the G93A mice was comparable to that found in the control mice (SI Fig. 8). How lithium treatment delayed the disease progression (SI Fig. 8). How lithium treatment delayed the disease progression (SI Fig. 8). How lithium treatment delayed the disease progression (SI Fig. 8).

ALSFRS-R (raw data)





ALS: <1yr

humberto-from-brazil

Male, 42 years
 Brasília, Distrito Federal

Diagnosis
 Onset: Arms
 First symptom: 09/06
 Diagnosis: 03/07
 X Genetics: Non-SOD1 ALS

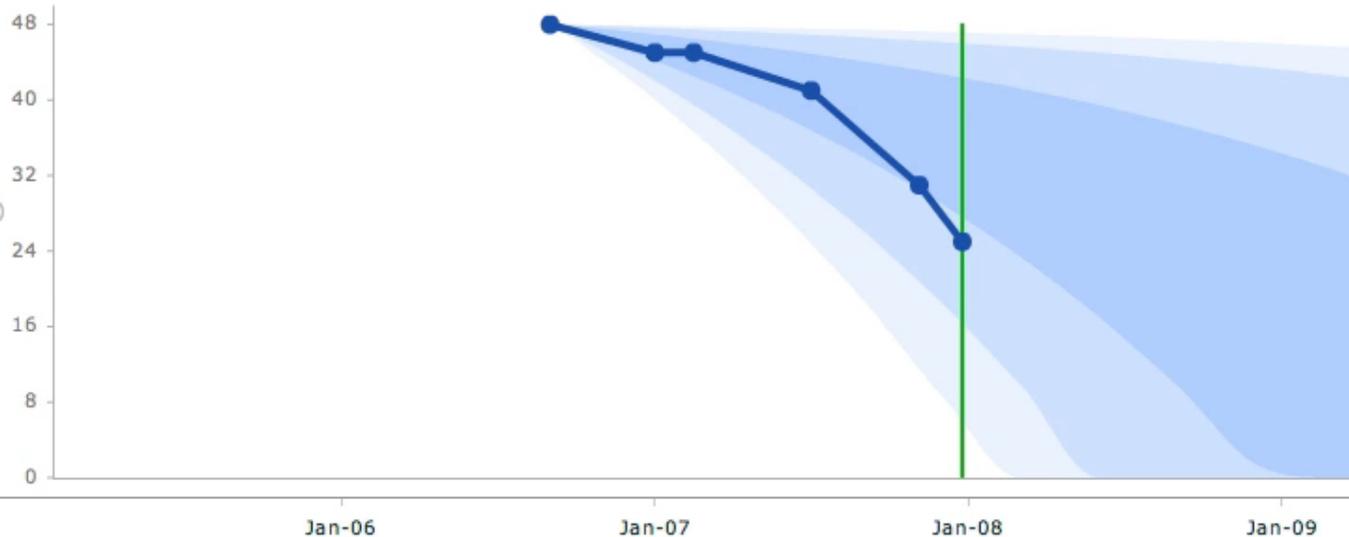
Member since: 02/08
 Last updated: 12/25/07
 Last login: 01/02/08
[ALS Public Registry](#)

ALS Condition

▼ **FRS**

Progression rate percentile

- 5-10th (rapid)
- 10-25th
- 75-90th
- 25-75th (average)
- 90-95th (slow)



FRS: 25
 latest update:
 25 Dec 2007

1 Feb 2005

1 Apr 2009

HEALTH INDUSTRY | APRIL 24, 2011, 6:45 P.M. ET

ALS Study Shows Promise of Social Media

By AMY DOCKSER MARCUS

A new clinical trial found that lithium didn't slow the progression of Lou Gehrig's disease, but the findings released Sunday also showed that the use of a social network to enroll patients and report and collect data may deliver dividends for future studies.

The study was based on data contributed by 596 patients with the disease, formally called amyotrophic lateral sclerosis or ALS. By showing that the drug didn't have any effect on progression of the condition, it contradicted a small study three years ago that suggested such a benefit was possible.

The new study, published online in the journal *Nature Biotechnology*, represents an early example of how social networking could play a role in clinical trials, an area of medical science with strict procedures that many would consider especially difficult to apply in the online world.

"The approach has tremendous potential," said Lee Hartwell, a Nobel Prize-winning scientist now at Arizona State University, and formerly president of the Fred Hutchinson Cancer Research Center. Standard clinical trials play a central role in the research enterprise of both of those institutions.

Dr. Hartwell, who wasn't involved in the study, said social-network trials aren't likely to replace conventional randomized, double-blinded, placebo-controlled trials, the gold-standard for generating medical evidence. But such trials have become so complicated and time-consuming that new models are needed, he said.

Paul Wicks, a co-author of the paper, said social network-run studies may be most useful for testing efficacy of so-called off-label or off-patent compounds that patients are using but are unlikely to ever attract pharmaceutical company interest.

“Given my status,
what is the best
outcome I can hope
to achieve, and how
do I get there?”



...the future of Nursing and Informatics

*“The best way to predict
the future is to create it.”*

Peter Drucker