

# Social Media + Data: Patients Helping Patients

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April 29, 2011

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# Conflict of Interest Disclosure

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

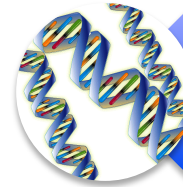
PatientsLikeMe works with major pharmaceutical companies doing clinical and market research.

“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**



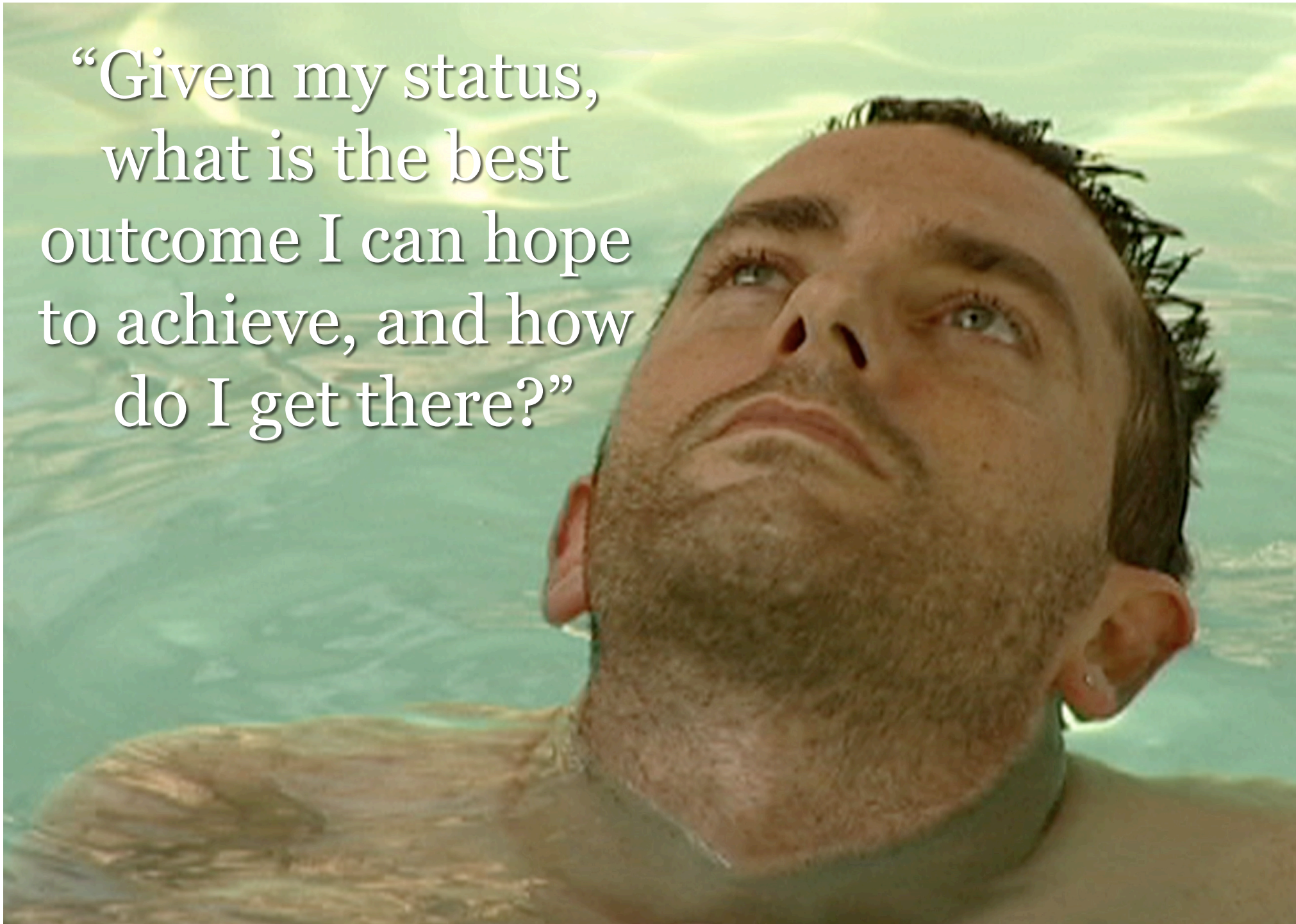
**Payment  
Reform**

# Imagine: Transforming Patient Stories into Data

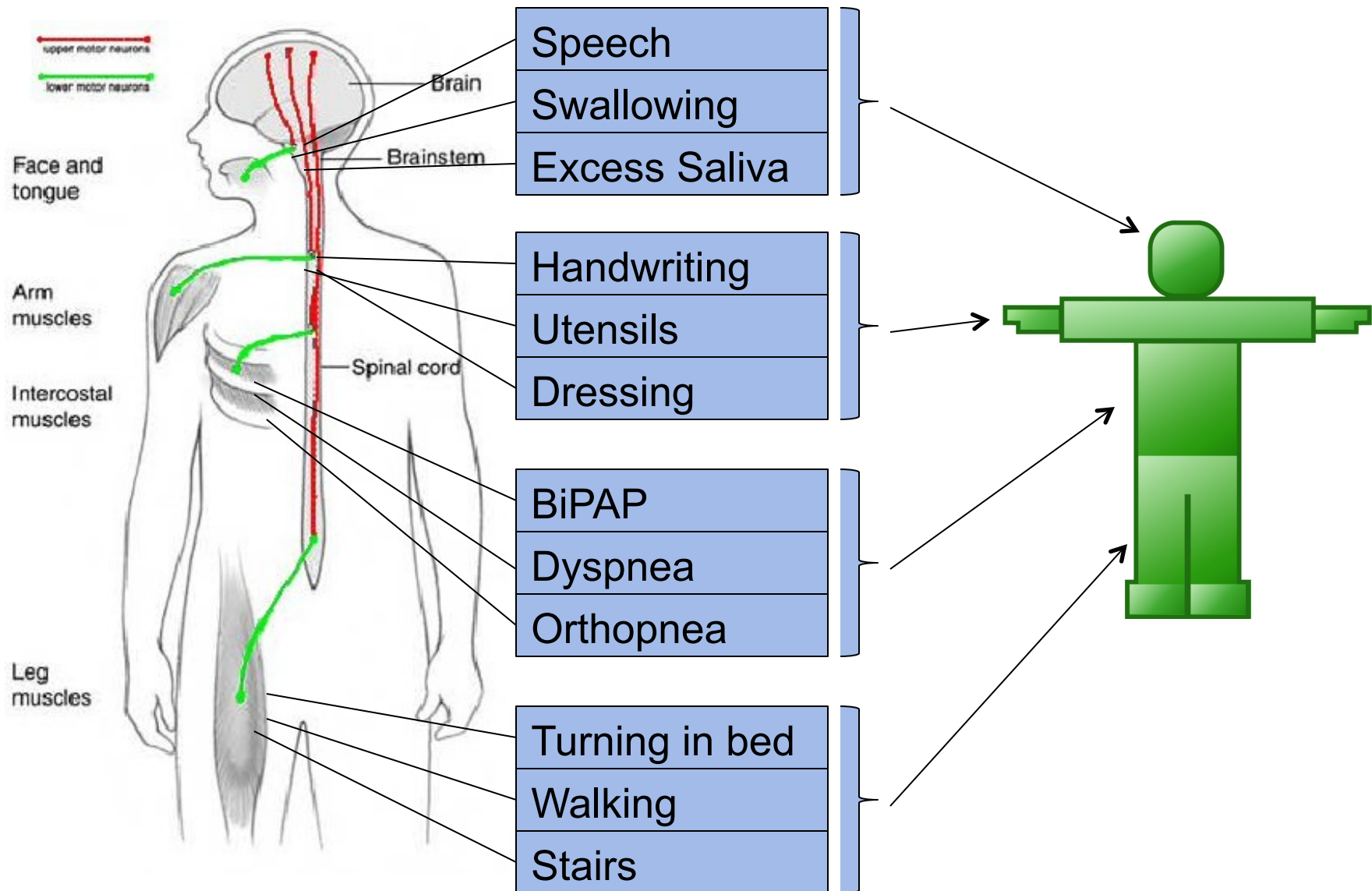




“Given my status,  
what is the best  
outcome I can hope  
to achieve, and how  
do I get there?”



# Amyotrophic Lateral Sclerosis (ALS)



# What is my status?



Walking



Breathing



Hands



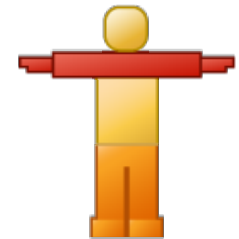
Speaking

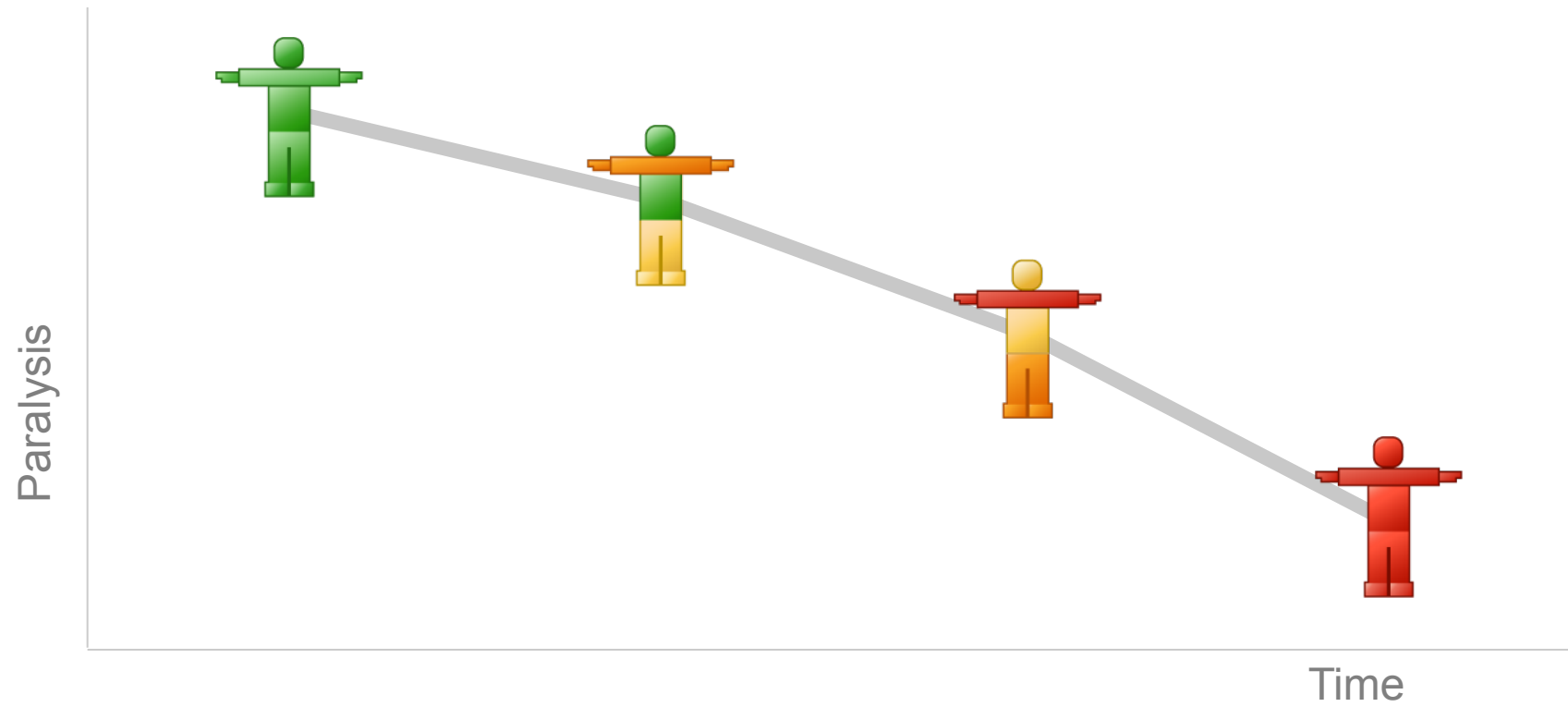


Wellbeing



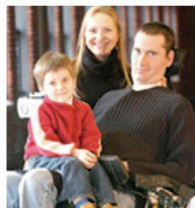
Productivity







# Stephen Heywood (alsking101)



**alsking101**  
Male, 38 years  
Newton, MA



## 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)

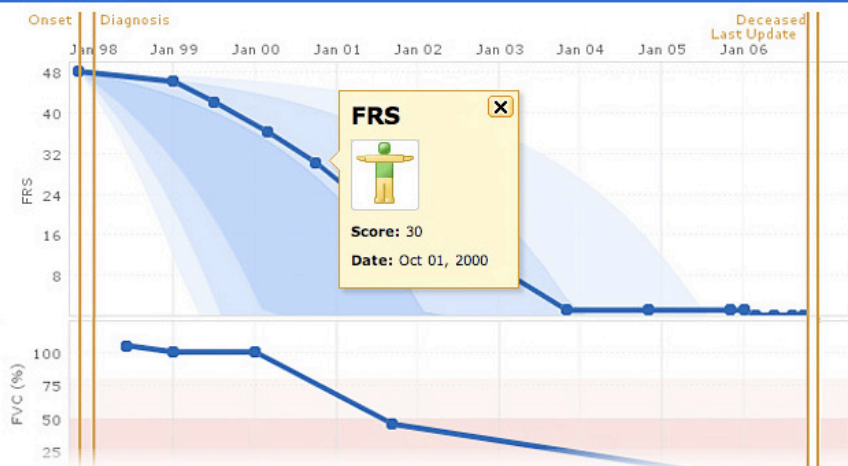
Progression rate  
percentile

- 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

100 mg daily  
80 mg  
1200 mg daily  
CoQ10  
Feeding Tube

Rilutek (riluzole)  
Elavil (amitriptyline)  
CoQ10  
Feeding Tube

## Symptoms

### Primary Symptoms

Severity of Symptoms

- none
- mild

Anxiety  
Constipation  
Depression  
Emotional lability





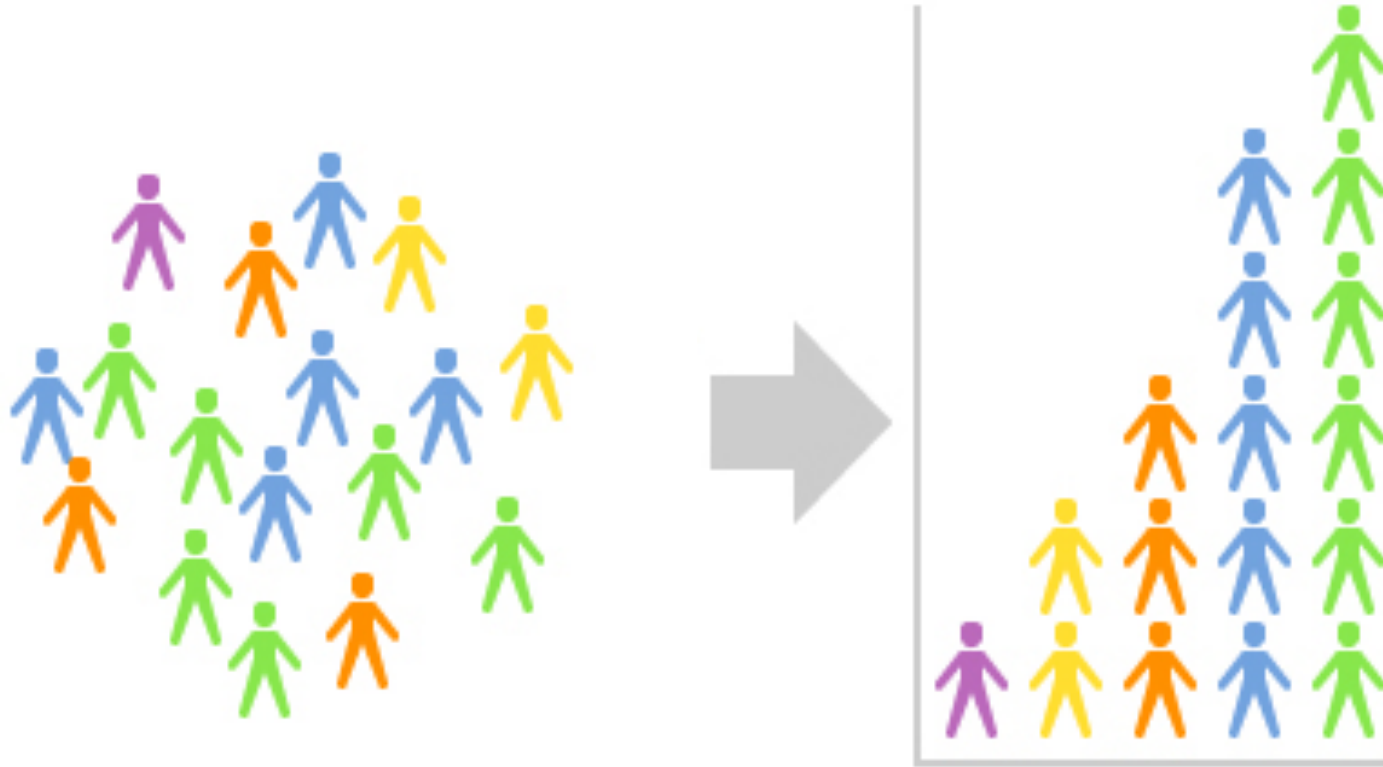
*“Knowledge is power. Information is liberating. Education is the premise of progress, in every society, in every family.”*

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

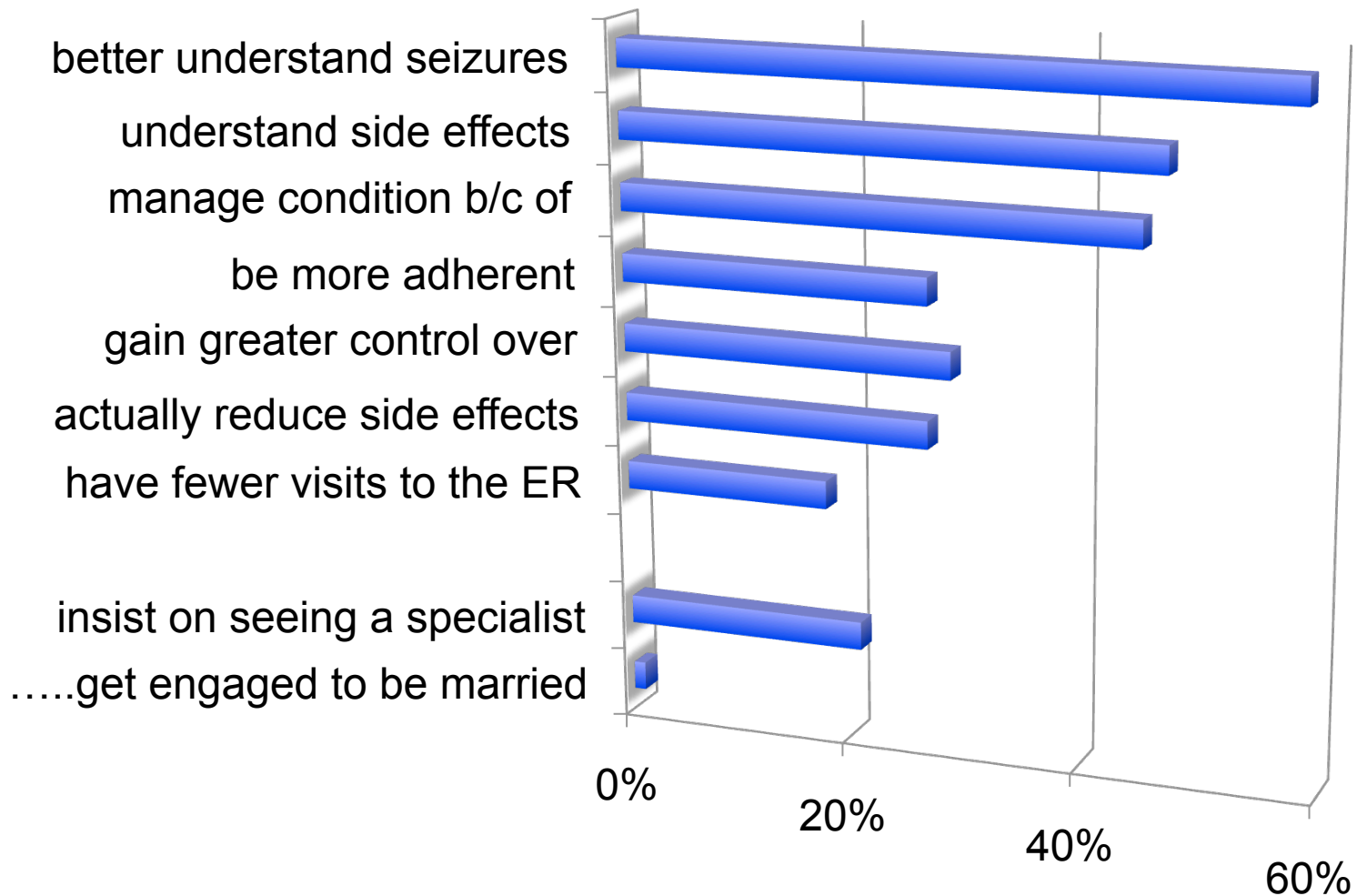
Patients **find other patients like them**. They discover what options are available for treatment and if their experience with their disease is normal. They can reach out to others like them for advice and insight.



## LEARN

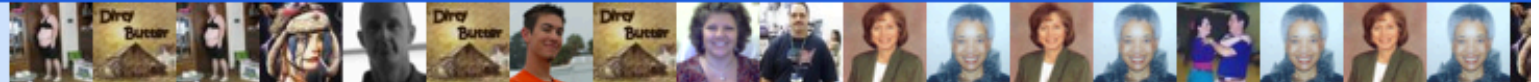
The information shared creates a **new knowledge** about the real-world **treatments**, **symptoms**, and reality of living with illness. Patients learn about their disease and themselves in context of the community.

## 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**



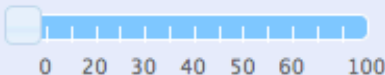
**I am**

[Male](#)

[Female](#)



**My Age**



**Join Now!** (It's free)



[Search](#)


**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

★

★

★



At

AAb


CP

Mv

SP

F54

OPES



**Neissy**

Female, 54 years

MI, United States

**Condition History**

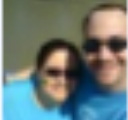
Primary Condition: Epilepsy

First symptom: 04/78

Diagnosis: 04/78

▼ 4 More Conditions

**My CareTeam**



had r

possi

neur

**Seizures**

Last update: Apr 17, 2011

★ Atonic

★ Atypical absence

★ Complex Partial

★ Myoclonic

★ Simple partial

0

0

0

0

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

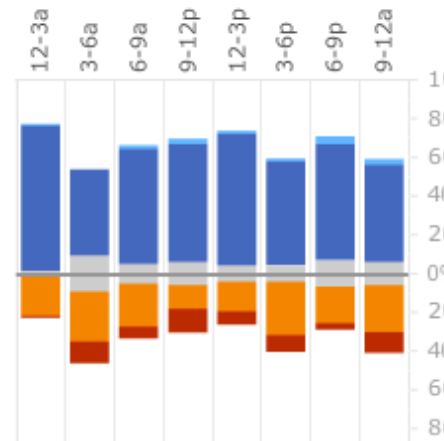
## InstantMe History

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

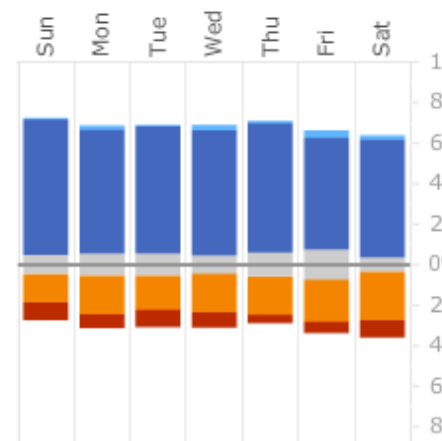
Date/Time	Status	Why?
Apr 22, 2011 10:46 AM	Good	
Apr 21, 2011 3:46 PM	Bad	
Apr 20, 2011 9:22 PM	Good	
Apr 19, 2011 5:30 PM	Good	
Apr 18, 2011 1:35 PM	Good	
Apr 16, 2011 6:08 PM	Good	
Apr 15, 2011 9:26 PM	Bad	
Apr 14, 2011 9:17 PM	Good	
Apr 13, 2011 7:22 PM	Good	
Apr 12, 2011 10:46 AM	Good	

## InstantMe Trends

### By Time of Day



### By Day of Week



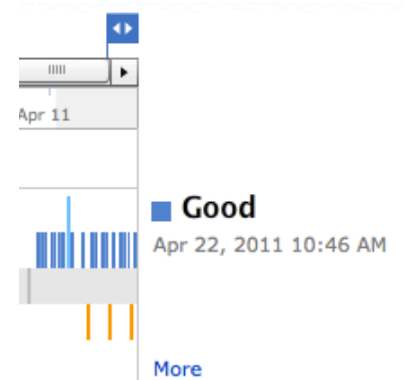
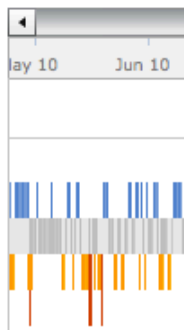
1 mo 3 mo 6 mo + -

**1 yr** 2 yr All

Sort This Profile

## InstantMe

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

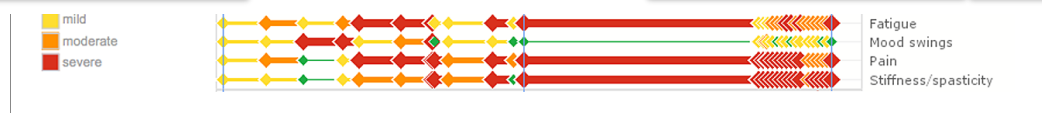




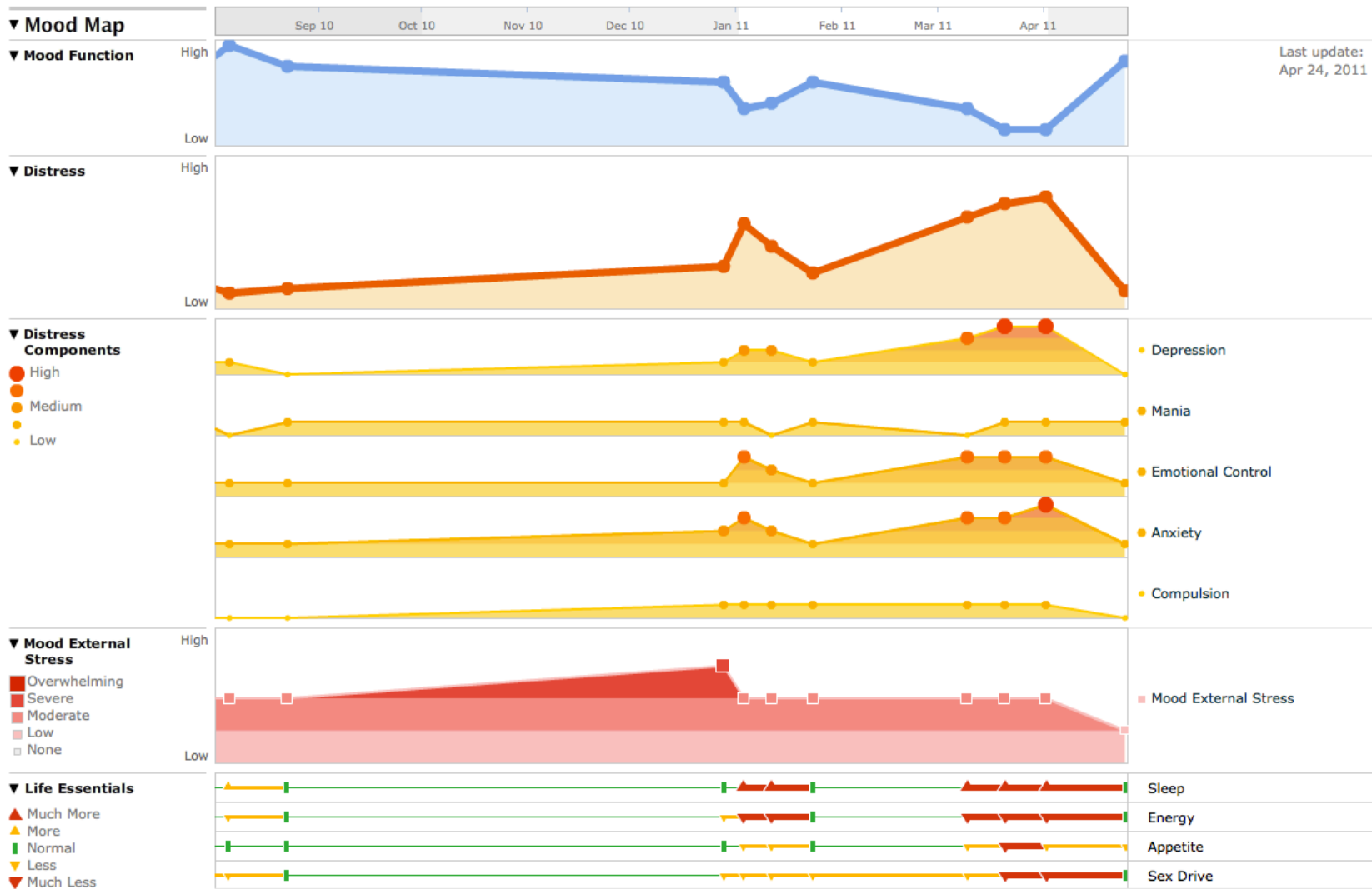
# Primary Outcome Measure: MSRS

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

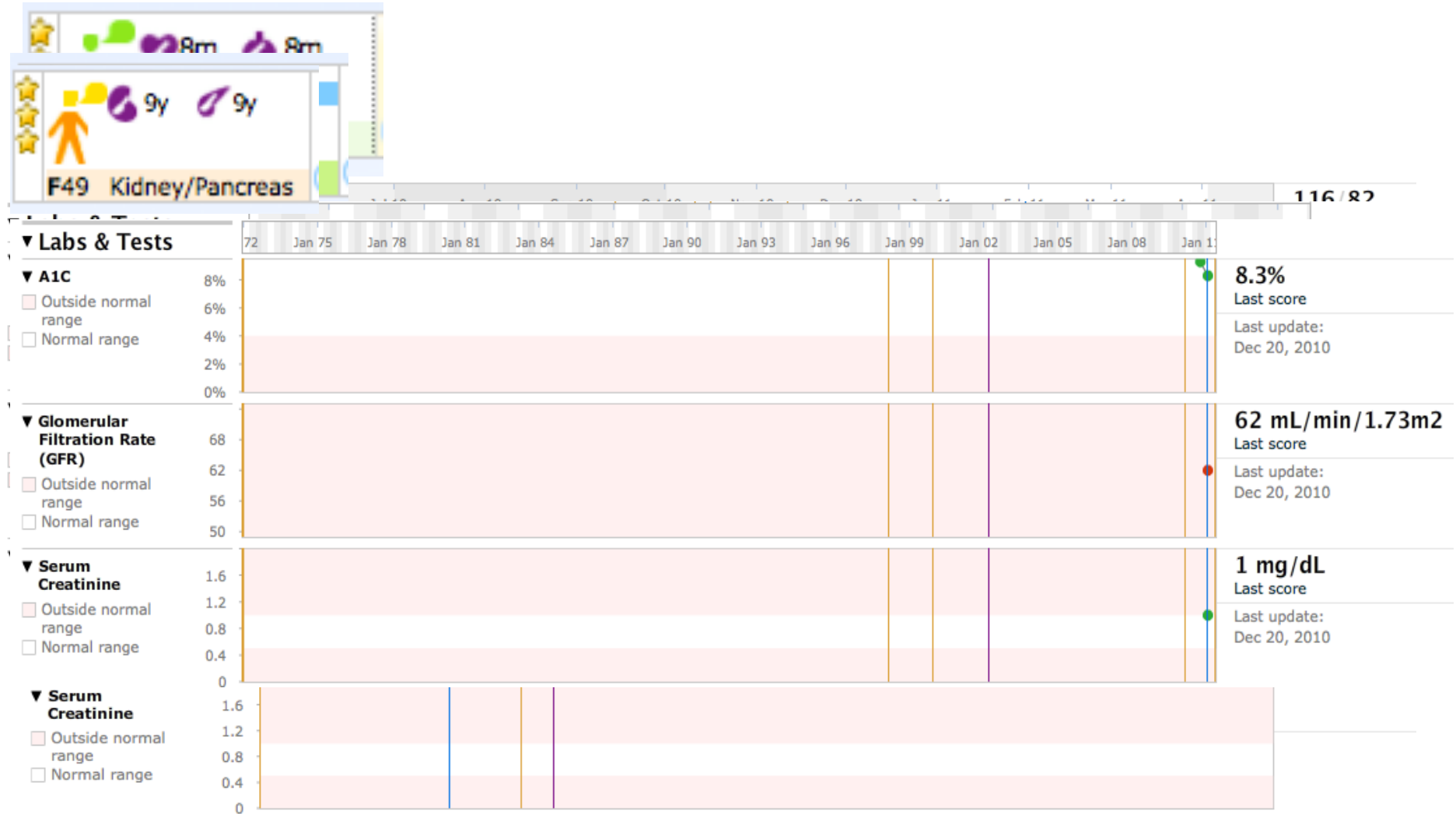
	(0 Points) <b>No Symptoms</b> No symptoms or disability in the specific area	(1 Point) <b>None</b> Aware of symptoms but no functional disability	(2 Points) <b>Mild</b> Mild disability but not requiring help from others	(3 Points) <b>Moderate</b> Moderate disability that requires some help from others	(4 Points) <b>Total Disability</b> 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

F06.7

Mild cognitive disorder

ICF code

b140

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**

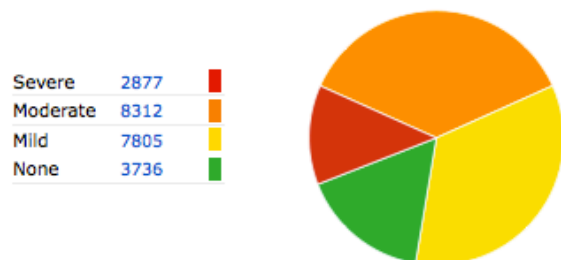
[Home](#) > [Symptoms and Side Effects Overview](#) > [Brain fog Report](#)

## 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

[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

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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<sup>1,2</sup>, Patrizia Longone<sup>3</sup>, Luisa Cafaro<sup>1</sup>, Olga Kastsiuchenka<sup>\*</sup>, Michela Ferrucci<sup>\*</sup>, Maria Laura Manca<sup>3</sup>, Gloria Lazzeri<sup>\*</sup>, Alida Spalloni<sup>3</sup>, Natascia Bellio<sup>3</sup>, Paola Lenzi<sup>\*</sup>, Nicola Modugno<sup>1</sup>, Gabriele Siciliano<sup>3</sup>, Ciro Isidoro<sup>3</sup>, Luigi Murri<sup>3</sup>, Stefano Ruggieri<sup>1</sup>, and Antonio Paparelli<sup>\*</sup>

<sup>\*</sup>Department of Human Morphology and Applied Biology, and <sup>2</sup>Department of Neuroscience, Clinical Neurology, University of Rome Tor Vergata, 00133 Rome, Italy; <sup>3</sup>Istituto Neurologico Mediterraneo, Istituto DI Ricovero e Cura a Carattere Scientifico Neuromed, 86077 Pozzilli (IS), Italy; Santa Lucia Foundation, 00179 Rome, Italy; and <sup>1</sup>Department 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 (first published 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

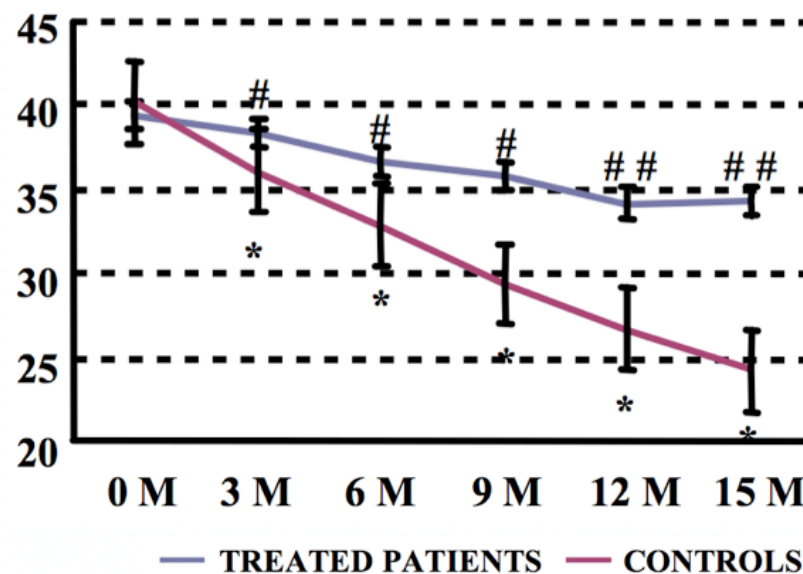
G93A ALS mouse model. Based on results obtained in mice we quickly moved to the study of human patients at the end of its second year.

## 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  $148 \pm 4.3$  (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 was observed (SI Fig. 6, s). In addition, we report in SI Fig. 6, s, the effects of lithium on the increase in disease duration was observed (SI Fig. 6, s).

**Effects of Lithium Treatment on Motor Neurons in Lumbar and Cervical Spinal Cord and on Astrocytes.** Effects were accompanied by a reduction in the number of reactive astrocytes (SI Fig. 7). However, the effects of lithium treatment were delayed compared with the effects of riluzole, which occurred later following lithium treatment (SI Fig. 7). Within lumbar lamina IX of the G93A mice, the number of motor neurons was comparable to that found in the control mice (SI Fig. 8). However, we detected a disease-modifying effect of lithium on the number of motor neurons in the G93A mice (SI Fig. 8).

## ALSFRS-R (raw data)



patientslikeme™

Welcome | Inbox | Account | Display options ▼ | Logout

Home | My Profile



Patients

Forum

Treatments

Symptoms

Research

Search

Help | Crisis



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

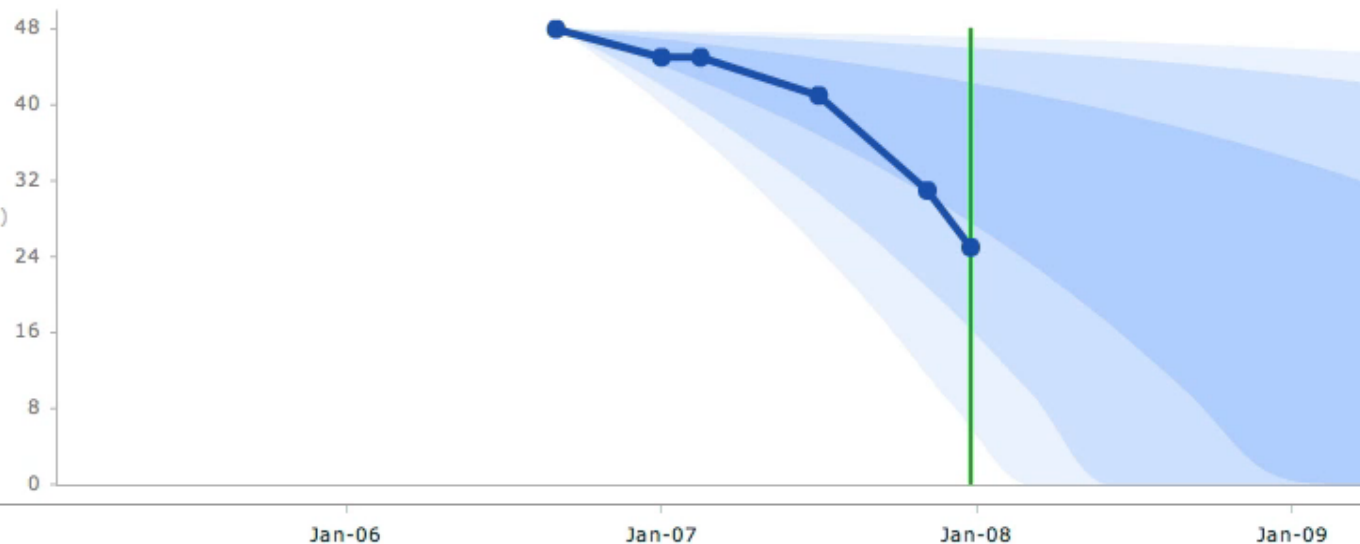
ALS Public Registry

**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



The logo for the journal Nature, featuring the word "nature" in a white, lowercase, serif font on a dark green background.

**THE WALL STREET JOURNAL.**

WSJ.com

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.

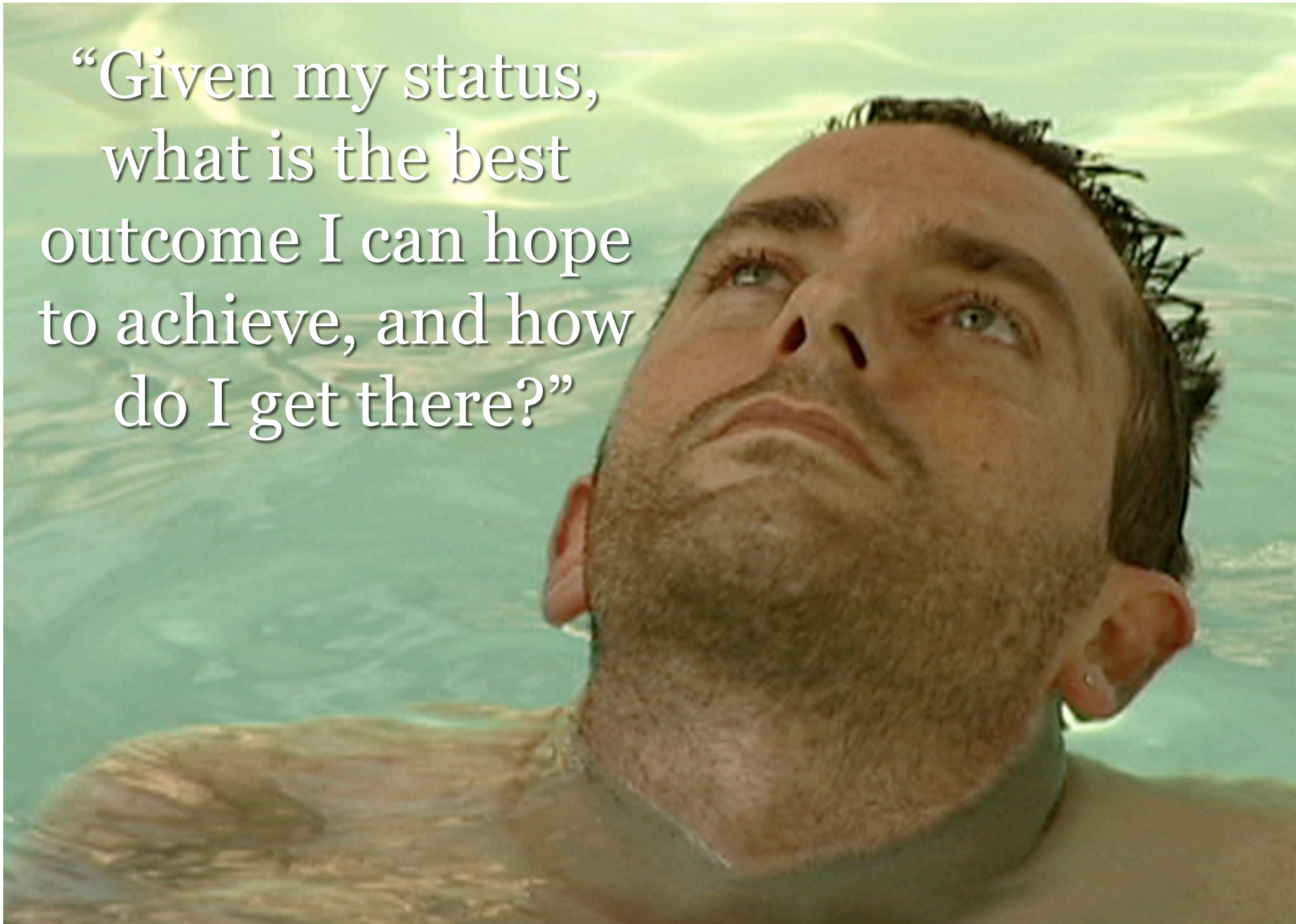
"The approach has tremendous potential," said Lee Hartwell, a Nobel Prize-winning scientist now at Arizona State University, and formerly president of the Fred Hutchinson Cancer Research Center. Standard clinical trials play a central role in the research enterprise of both of those institutions.

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.

patientslikeme™

“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*