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
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)

- Speech
- Swallowing
- Excess Saliva
- Handwriting
- Utensils
- Dressing
- BiPAP
- Dyspnea
- Orthopnea
- Turning in bed
- Walking
- Stairs

Cedarbaum et al. (1999), JNeurolSci 169(1):13-21
<table>
<thead>
<tr>
<th>Status</th>
<th>Walking</th>
<th>Breathing</th>
<th>Hands</th>
<th>Speaking</th>
<th>Wellbeing</th>
<th>Productivity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
"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.

### Transparency

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.

### Create WOW!

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

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

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.

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....

- better understand seizures
- understand side effects
- manage condition b/c of
- be more adherent
- gain greater control over
- actually reduce side effects
- have fewer visits to the ER
- insist on seeing a specialist
- .....get engaged to be married
100,232 patients
500+ conditions

Get your health in order.
Join PatientsLikeMe.

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
Type at least 3 letters of a condition

I take
Type at least 3 letters of a treatment

I am Male | Female

My Age
0 20 30 40 50 60 100

Join Now! (It’s free)
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

Neissy
Female, 54 years
MI, United States

Condition History
Primary Condition: Epilepsy
First symptom: 04/78
Diagnosis: 04/78

My CareTeam

Seizures
Last update: Apr 17, 2011

- Atonic: 0
- Atypical absence: 0
- Complex Partial: 0
- Myoclonic: 0
- Simple 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

patientslikeme™
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 12, 2011 7:23 PM   Good

InstantMe Trends

By Time of Day

By Day of Week

patientslikeme™
Primary Outcome Measure: MSRS

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

<table>
<thead>
<tr>
<th>(0 Points)</th>
<th>(1 Point)</th>
<th>(2 Points)</th>
<th>(3 Points)</th>
<th>(4 Points)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Symptoms</td>
<td>None</td>
<td>Mild</td>
<td>Moderate</td>
<td>Total Disability</td>
</tr>
<tr>
<td>Walking</td>
<td>No Symptoms</td>
<td>None</td>
<td>✔️ Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Upper Limb Function</td>
<td>No Symptoms</td>
<td>✔️ None</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Vision</td>
<td>No Symptoms</td>
<td>✔️ None</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Speech</td>
<td>No Symptoms</td>
<td>✔️ None</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Swallowing</td>
<td>No Symptoms</td>
<td>✔️ None</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Thinking / Memory / Cognition</td>
<td>No Symptoms</td>
<td>None</td>
<td>✔️ Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Sensation / Burning / Pain</td>
<td>No Symptoms</td>
<td>✔️ None</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

Active Legends

- Light yellow: mild
- Light orange: moderate
- Red: severe

Fatigue
Mood swings
Pain
Stiffness/spasticity
Primary Outcome Measure: Mood Map

![Mood Map Chart]

Last update: Apr 24, 2011

- **Mood Map**
- **Mood Function**
  - High
  - Low
- **Distress**
  - High
  - Low
- **Distress Components**
  - Depression
  - Mania
  - Emotional Control
  - Anxiety
  - Compulsion
- **Mood External Stress**
  - Overwhelming
  - Severe
  - Moderate
  - Low
  - None
  - Low
- **Life Essentials**
  - Sleep
  - Energy
  - Appetite
  - Sex Drive

(patientslikeme™)
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

**Brain fog**

Created Apr 24, 2007 by Moonwolf
Symptom Report
18969 patients
693 side effect reports
8 hospitalizations
Associated Conditions: Neuromeiteis Optica, MS (Multiple Sclerosis), and Fibromyalgia

**ICD code**
F06.7 Mild cognitive disorder

**ICF code**
b140 Attention functions

**Meddra LLT code**
Foggy feeling in head (10016876)
(Edil) (Clear) (See related meddrea 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.
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:
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

- Severe: 2877
- Moderate: 6312
- Mild: 7803
- None: 3736

What Patients Take For The Purpose of Treating Brain fog

- Modafinil: 61
- Amphetamine-Dextroamphetamine: 29
- Methylphenidate: 27
- Omega 3 Fish Oil: 26
- Ginkgo Biloba: 33
- 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

- NS: 9 yrs
  - First Symptom: 04/02
  - Dx: 07/07

- CFS: 7y
  - PM: 2y Dx
  - F46y
  - First Symptom: 12/08
  - Dx: 07/09

- bremiliva
  - NS: 20 yrs
  - 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 Torronjo, Kevin Telbot, 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, Patrizia Longone, Luisa Cafaro, Olga Kastsiuchenchka, Michela Ferrucci, Maria Laura Manca, Gloria Lazzari, Alda Spalloni, Natascia Bellio, Paola Lanzi, Nicola Medugno, Gabriele Siciliano, Gino Isidori, Luigi Murni, Stefano Ruggieri, and Antonio Paparelli

Department of Human Morphology and Applied Biology, University of Rome Tor Vergata, Rome, Italy; Santa Lucia Foundation, Rome, Italy; and Department of Neurosciences, Catholic University of Health Sciences, University of Rome, Rome, Italy.

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 placebo.

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 consistent 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 characteristic of 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.

**ALSFRS-R (raw data)**

![Graph showing ALSFRS-R scores over time for treated and control patients.](image)

- **Results**
  - Effects of Lithium on Disease Duration
    - G93A male mice were treated daily with lithium in the 8- to 18-month-old age range.
    - Starting at 75 days after birth, the mean survival time was increased by 14 days (48 ± 3 days) compared to saline-treated animals (34 ± 2 days).
    - The survival benefit of lithium was statistically significant (P < 0.001).

- **Effects of Lithium on the Development of Disease
  - Lithium treatment was started at 12 weeks of age (120 days).
    - Lithium treatment led to a 30% increase in survival compared to controls,
      - starting at 26 weeks of age (9 months).

- **Effects of Lithium Treatment on Motor Neurons
  - Neuropathy was assessed using the ALSFRS-R (raw data).
    - Treated patients showed a significant improvement in the ALSFRS-R scores compared to controls.

**Conclusion**

Lithium treatment delays disease progression in human patients and animal models of ALS, providing a potential therapeutic strategy for this debilitating disease.
humberto-from-brazil
Male, 42 years
Brasilia, Distrito Federal

ALS Condition

FRS: 25
latest update: 25 Dec 2007

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

FRS: <1yr
Onset: Arms
First symptom: 09/06
Diagnosis: 03/07
Genetics: Non-SOD1 ALS

Member since: 02/08
Last updated: 12/25/07
Last login: 01/02/08

ALS Public Registry
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