“Given my status, what is the best outcome I can expect to achieve, and how do I get there?”
The PatientsLikeMe ALS/Motor Neuron Disease Community

ALS, or amyotrophic lateral sclerosis, is a neurodegenerative disease caused by the degeneration of motor neurons. Around 3,000 to 5,000 new cases of ALS are diagnosed every year in the United States alone. Imagine knowing what treatments work for people just like you — and having the ability to easily connect with those people. That's what makes PatientsLikeMe different. By sharing your symptoms, treatments and more, you can gain insight into what affects your condition while helping others learn from your experiences. Together, we can achieve more. Begin making a difference today!

Who Will You Find?

3,841 total patients
120 Profiles updated this week
76 New patients this month

What Are Patients Sharing?

Real-World Data

Top Treatments

Riluzole (Rilutek) 657 patients
CoQ10 (Coenzyme Q10) 523 patients
Wheelchair (powered) 475 patients
Vitamin E 467 patients

Real-World Experiences

Patient Forum

Stem Cell treatment shows early signs of improvement in ALS patient
634 new posts in the forum this week

PatientsLikeMe Blog: The Value of Openness

Find Patients Just Like You

Join Now! (It's free!)

Patient Spotlight

SmoothS
Male, 40 years, Chelsea (Boston), MA
My name is Steve, I am 40, and I was DX'd October 08. I think I am fairly atypical in that I move... See Profile...

What Can You Learn?

Your Health Profile

By creating and sharing your health profile with the community, you can learn more about how your condition affects you and help others learn from your experience.

Patient Learning in Action

The first thing that I thought might be your problem is malnutrition. Man, you're losing weight crazy fast. I think you better consider getting a tube if you desire. They are easy to care for and are literally a life saver. What are your thoughts on this?
- ALS Community Member
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: 02/05/06)
Warning Levels
- warning
- severe

FRS
Score: 30
Date: Oct 01, 2000

Treatments

Prescription
Reasons Taken
- slow my ALS progress
- general health
- specific symptom
- other

Symptoms

Primary Symptoms
Severity of Symptoms
- none
- mild
alsking101
Male, 38 years
Newton, MA

Diagnosis Summary
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- 25-75th (average)
- 75-90th
- 90-98th (slow)

FVC: 5%
(latest: 02/05/06)
Warning Levels
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- severe

FRS
Score: 30
Date: Oct 01, 2000

Treatments

Prescription
Reasons Taken
- slow my ALS progress
- general health
- specific symptom
- other

Symptoms

Primary Symptoms
Severity of Symptoms
- none
- mild

Fatigue
Fatigue is a feeling of being tired and having a lack of energy. People with fatigue may feel like they are working harder than usual to do the same amount of work. It can be a symptom of many different conditions, including sleep disorders, chronic illnesses, and mental health issues.

**Fatigue Symptom Severity**

- **mild**: 4150 patients (27%)
- **moderate**: 6186 patients (39%)
- **severe**: 3951 patients (25%)
- **none**: 1454 patients (9%)

**Treatments Patients Take For Fatigue**

- **Modafinil**: 581 (5%)
- **Handicapped parking permit**: 287 (2%)
- **Amantadine**: 185 (1%)
- **Naps**: 176 (1%)
- **Rest**: 132 (1%)
- **Vitamin B**: 97 (1%)
- **Methylphenidate**: 90 (1%)
- **Dextroamphetamine-Amphetamine**: 83 (1%)
- **Walking Stick/Cane**: 75 (1%)
- **Wheelchair (powered)**: 68 (0%)
- **Heat avoidance**: 60 (0%)
- **Wheelchair (manual)**: 60 (0%)
- **Vitamin B Complex**: 57 (0%)
- **Multivitamin**: 49 (0%)
- **Coffee**: 42 (0%)
- **Vitamin B12 Injection (cyanocobalamin)**: 33 (0%)
- **Coenzyme Q10 (CoQ10)**: 32 (0%)
- **Electric scooter/chair**: 30 (0%)
- **Walker**: 27 (0%)
- **BiPAP Humidifier**: 26 (0%)
- **Shower/Tub Chair**: 26 (0%)
- **Caffeine**: 23 (0%)
- **Sleep**: 23 (0%)
- **Vitamin D**: 20 (0%)
- **Water-water and more-water**: 19 (0%)

14336 patients currently experience Fatigue. See all...
<table>
<thead>
<tr>
<th>Name</th>
<th>Age/Status</th>
<th>Diagnosis</th>
<th>Symptoms/Outcomes Updated</th>
<th>Other Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>FM: 7 yrs</td>
<td></td>
<td>Definitive Dx</td>
<td>outcomes updated</td>
<td>other onset: 01/02 Dx: 01/07</td>
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<tr>
<td>MS: 21 yrs</td>
<td></td>
<td></td>
<td>outcomes updated</td>
<td>difficulty walking onset: 04/88 Dx: 06/89 Type: Relapsing-Remitting</td>
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<tr>
<td>FM: 16 yrs</td>
<td></td>
<td>Definitive Dx</td>
<td>treatments updated</td>
<td>other onset: 01/93 Dx: 01/93</td>
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<td></td>
<td>CFS-Ed</td>
<td>outcomes updated</td>
<td>Depression member since May 2008</td>
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<td></td>
<td></td>
<td>outcomes updated</td>
<td>Depression member since Mar 2008</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>symptoms updated</td>
<td>sensory changes onset: 05/00 Dx: 07/00 Type: Progressive Relapsing</td>
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<td></td>
<td>symptoms updated</td>
<td>Depression member since Apr 2008</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>treatments updated</td>
<td>sensory changes onset: 09/74 Dx: 02/75 Type: Progressive Relapsing</td>
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<td></td>
<td>outcomes updated</td>
<td>other onset: 06/00 Dx: 08/07</td>
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<tr>
<td>Drug (generic name)</td>
<td>Sexual side effect (in patients’ words)</td>
<td>% reporting on PatientsLikeMe</td>
<td>% reporting in clinical trial (as ‘libido decreased’)</td>
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<tr>
<td>Prozac N=141</td>
<td>Sexual side effects Sexual dysfunction</td>
<td>18%</td>
<td>4% N=2869</td>
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<tr>
<td>Lexapro N=123</td>
<td>Decreased sex drive</td>
<td>25%</td>
<td>3% N=715</td>
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<tr>
<td>Zoloft N=148</td>
<td>Loss of sex drive</td>
<td>26%</td>
<td>6% N=2799</td>
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<tr>
<td>Cymbalta N=207</td>
<td>Decreased sex drive</td>
<td>21%</td>
<td>3% N=1139</td>
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</table>
What outcome can I expect?

The diagram shows a graph with the x-axis representing time in years (0 to 10) and the y-axis representing FRS score. Two lines are drawn, one indicating the Onset and another indicating the Bulbar Onset. The Arms Onset is also marked on the graph.

The graph suggests that as time progresses, the FRS score decreases, indicating a possible decline in the condition being measured.
Can I change my outcome?
Can we know if treatments work in the real world?
Can we accelerate discovery?
Jamie Heywood