James Heywood

Free the Data

- With open data the world will figure out effective ways to inform, protect and improve my health.

Think for Me

- It is complicated, just tell me what I need to know when I need to know it. Use my information to inform me.
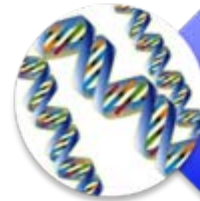
Open Safety Ecosystem

- Data from all sources should work together to deliver a personalized health and safety solution.

A great wind is blowing and that gives you either imagination or a headache.'

- *Catherine the Great*
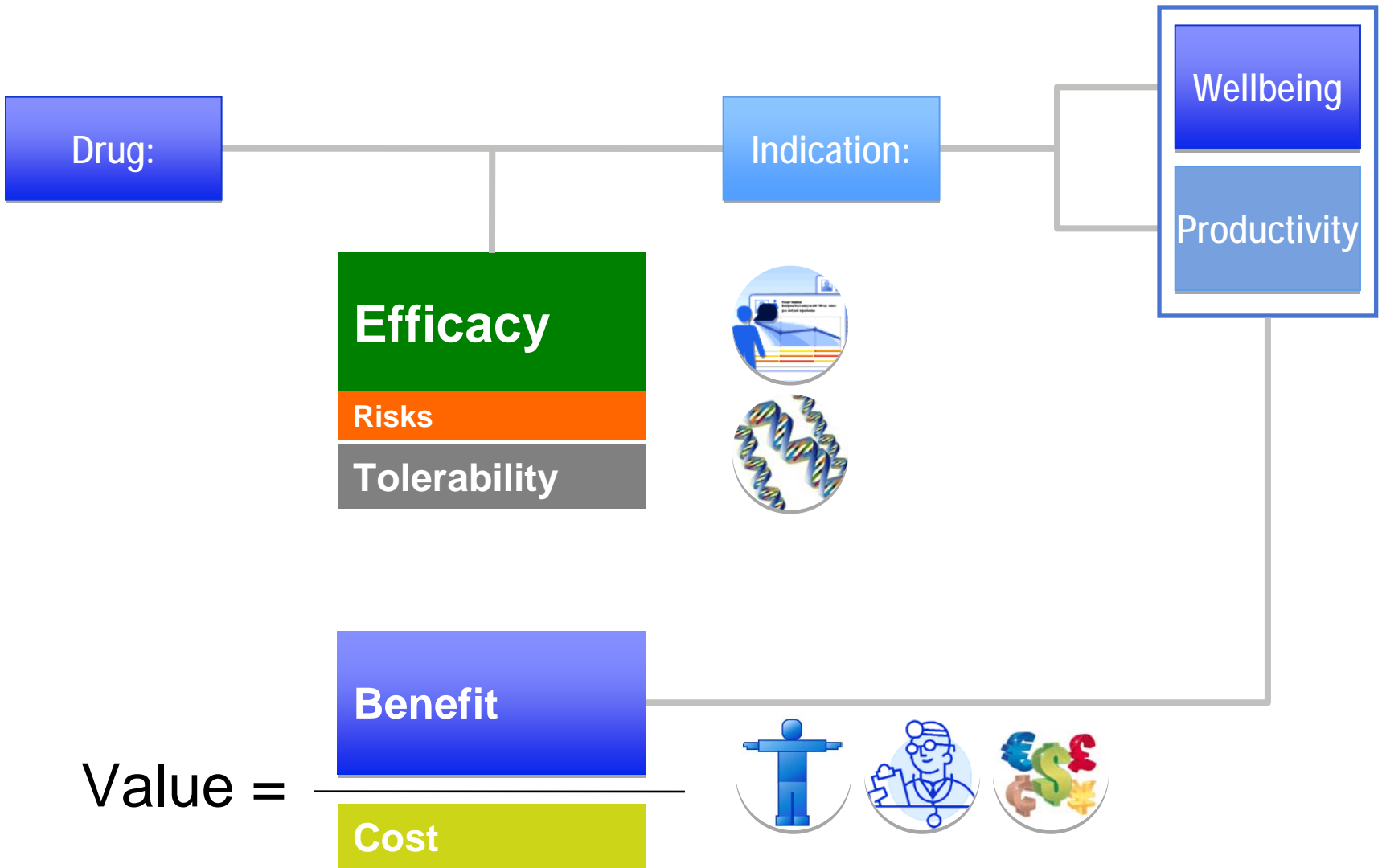

Empowered Patients

Molecular Medicine

Doctor Role

New Data Sources

Cost/Value

Drug:

Indication:

Wellbeing

Productivity

Efficacy

Risks

Tolerability

Benefit

Value = $\dfrac{\text{Benefit}}{\text{Cost}}$

Cost

ALS: 9 yrs

alsking101
Male, 37 years
Newton, MA

Condition History
Onset: **Arms**
First symptom: 11/97
Diagnosis: 12/98
Genetics: Non-SOD1 ALS
Deceased: 11/26/06

My Care Team

Profile Activity
45752 Views
29 Comments

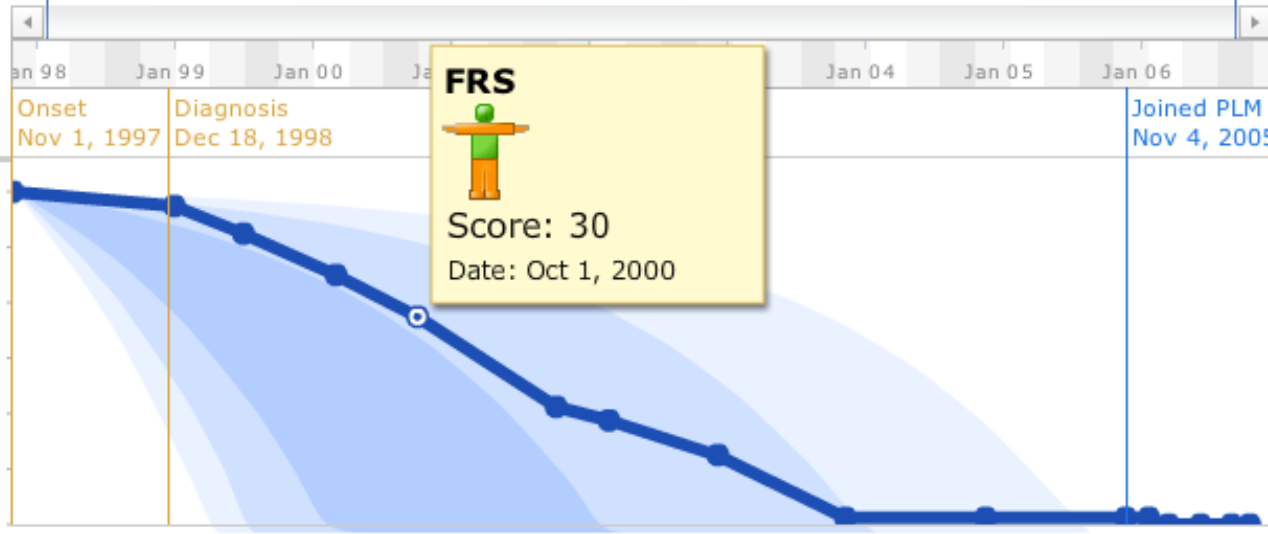**Forum Activity**
5 posts
3 helpful marks
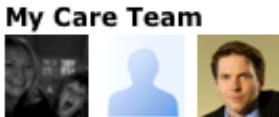
About Me
Stephen Heywood passed away at Thanksgiving of 2006. His wonderful wife and amazing son still live in Newton, MA. Stephen is the inspiration for PatientsLikeME and his story is profiled in the documentary SO MUCH SO FAST. You can donate to the Stephen Heywood Fund. at ALS TDI ▼ More...

| **Profile** | Feeds | Comments (29) |

1 mo | 3 mo | 6 mo   + −   ◄► Nov 1, 1997   Drag the arrows or use the tools on the left to change the view of th... Nov 26, 2006 ◄►
1 yr | 2 yr | **All**

Jan 98   Jan 99   Jan 00   Ja   Jan 04   Jan 05   Jan 06

Onset   Diagnosis   Joined PLM   Deceased
Nov 1, 1997   Dec 18, 1998   Nov 4, 2005 Nov 26, 2006

FRS

Score: 30
Date: Oct 1, 2000

▼ **FRS**
Progression rate
percentile

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

48
40
32
24
16
8
0

0
Last score

Last update:
Oct 1, 2006

patientslikeme™

Pregabalin Treatment Report

Category: Prescription Drugs

Most Popular Brands: Lyrica

Generic Name: Pregabalin

Overview | Individual Patient Evaluations

What is Pregabalin?

Pregabalin is an analgesic and anti-convulsant drug that is used to manage pain associated with diabetic peripheral neuropathy, postherpetic (shingles) neuralgia, as an adjunctive treatment for partial-onset seizure disorder in adults and for the management of fibromyalgia.

Reasons taken & Efficacy

Reasons taken	# of patients	Efficacy	Major	Moderate	Slight	None	Can't tell	# of patients evaluated by
Fibromyalgia	1190							435
Pain	524							143
Nerve pain	374							114
Numbness and Tingling with Pins and Needles	91							24
Other	90							19
Muscle pain	81							25

See all **129 reasons taken** ▼

See all **2271 patients** currently taking Pregabalin

Mouse over the table for more information

Side Effects

Side effects **as an overall problem**

Severe	200
Moderate	219
Mild	200
None	140

Most commonly reported side effects

Weight gain	196
Brain fog	113
Dizziness	108
Daytime sleepiness	108
Lack of concentration	95
Blurry vision	94

■ Mild ■ Moderate ■ Severe

See all **249 reported side effects** ▼

Patient Evaluations

See all **759 patient evaluations**
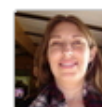
Brensui
150 mg daily
since Dec 09, 2008

Efficacy   **Side Effects**
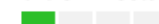
for Fibromyalgia

Advice/Tips
Start out at a low dose and work your way up. Try to stay on the lowest dose possible that will help control your pain. If you need to use during the day, us... See full evaluation

envyjoy
150 mg daily
since Jun 01, 2010

Efficacy   **Side Effects**

for Fibromyalgia
See full evaluation

lilybet
since Sep 09, 2008

Efficacy   **Side Effects**

for Other

Advice/Tips
Overall, a very good medication, with multiple uses. See full evaluation

The Missing Voice of Pat

Ethan Basch, M.D.

A patient wants to know
may have from a prescr
Consulting the label's "Ad
she finds a wealth of data.

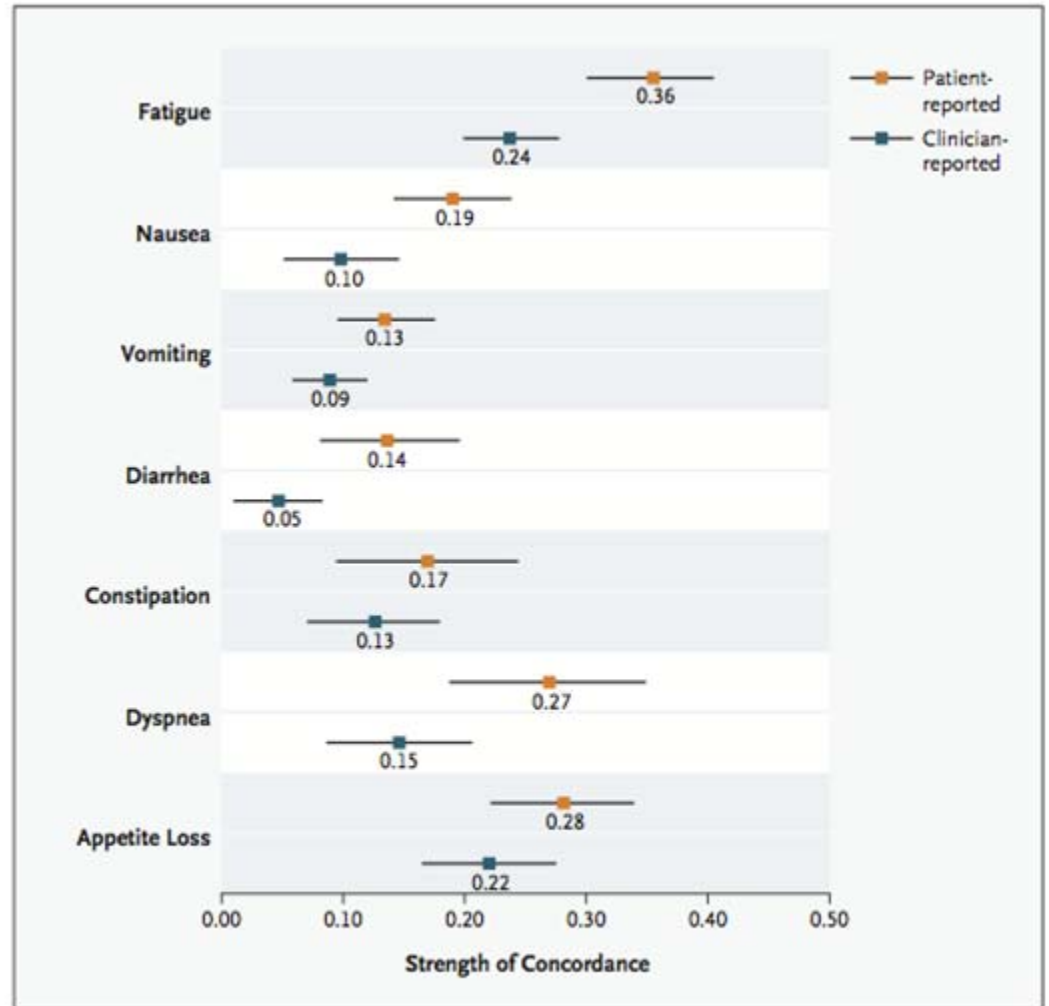this information, largely collected
during clinical trials, is based
almost entirely on clinicians' im-
pressions of patients' symptoms
— not on patients' own firsthand
reports of their experiences with
the drug.

The current drug-labeling prac-
tice for adverse events is based

Relative Strengths of Concordance of Patient-Reported versus Clinician-Reported Adverse Symptom Events with Overall Health Status.

proach that could add valuable   inherent limitations of preapprov-

Pregabalin (Lyrica) Package Insert:
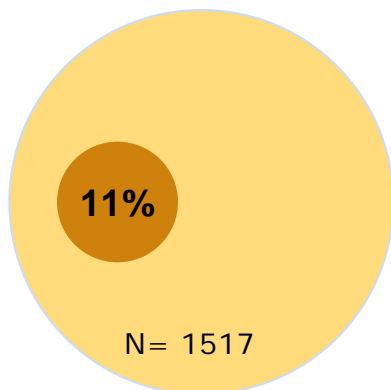
Weight Increase:

- What does this mean?
- How much weight?
- Over how long?
- Is it the same for:
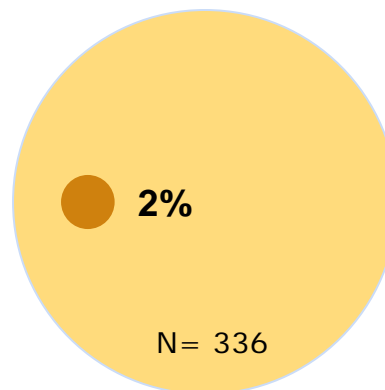 Men/Women?
  Overweight/Normal?
  Sicker/healthier?

11%
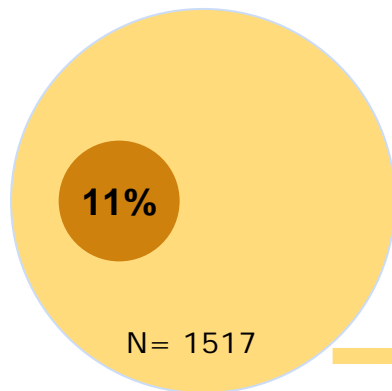
N= 1517

System Organ Class - Preferred term	150 mg/d [N=132] %	300 mg/d [N=502] %	450 mg/d [N=505] %	600 mg/d [N=378] %	All PGB* [N=1517] %	Placebo [N=505] %
Ear and Labyrinth Disorders						
Vertigo	2	2	2	1	2	0
Eye Disorders						
Vision blurred	8	7	7	12	8	1
Gastrointestinal Disorders						
Dry mouth	7	6	9	9	8	2
Constipation	4	4	7	10	7	2
Vomiting	2	3	3	2	3	2
Flatulence	1	1	2	2	2	1
Abdominal distension	2	2	2	2	2	1
General Disorders and Administrative Site Conditions						
Fatigue	5	7	6	8	7	4
Edema peripheral	5	5	6	9	6	2
Chest pain	2	1	1	2	2	1
Feeling abnormal	1	3	2	2	2	0
Edema	1	2	1	2	2	1
Feeling drunk	1	2	1	2	2	0
Infections and Infestations						
Sinusitis	4	5	7	5	5	4
Investigations						
Weight increased	8	10	10	14	11	2
Metabolism and Nutrition Disorders						
Increased appetite	4	3	5	7	5	1

Weight Gain Side Effect (Comparing Across Drugs)
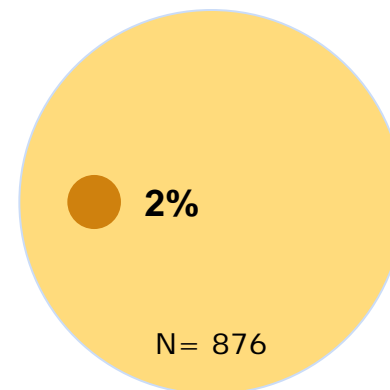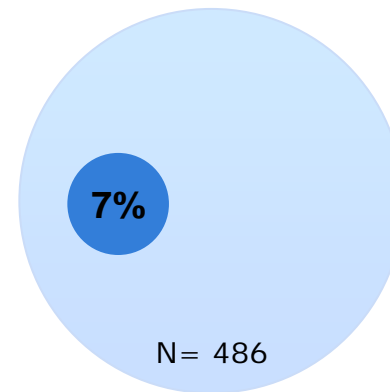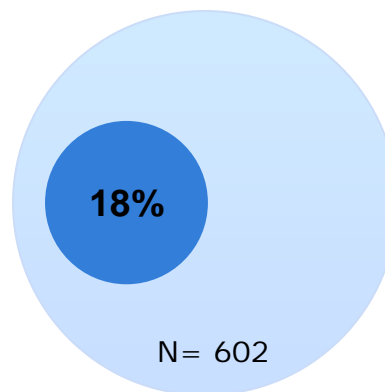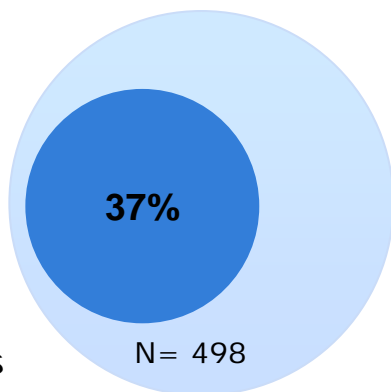
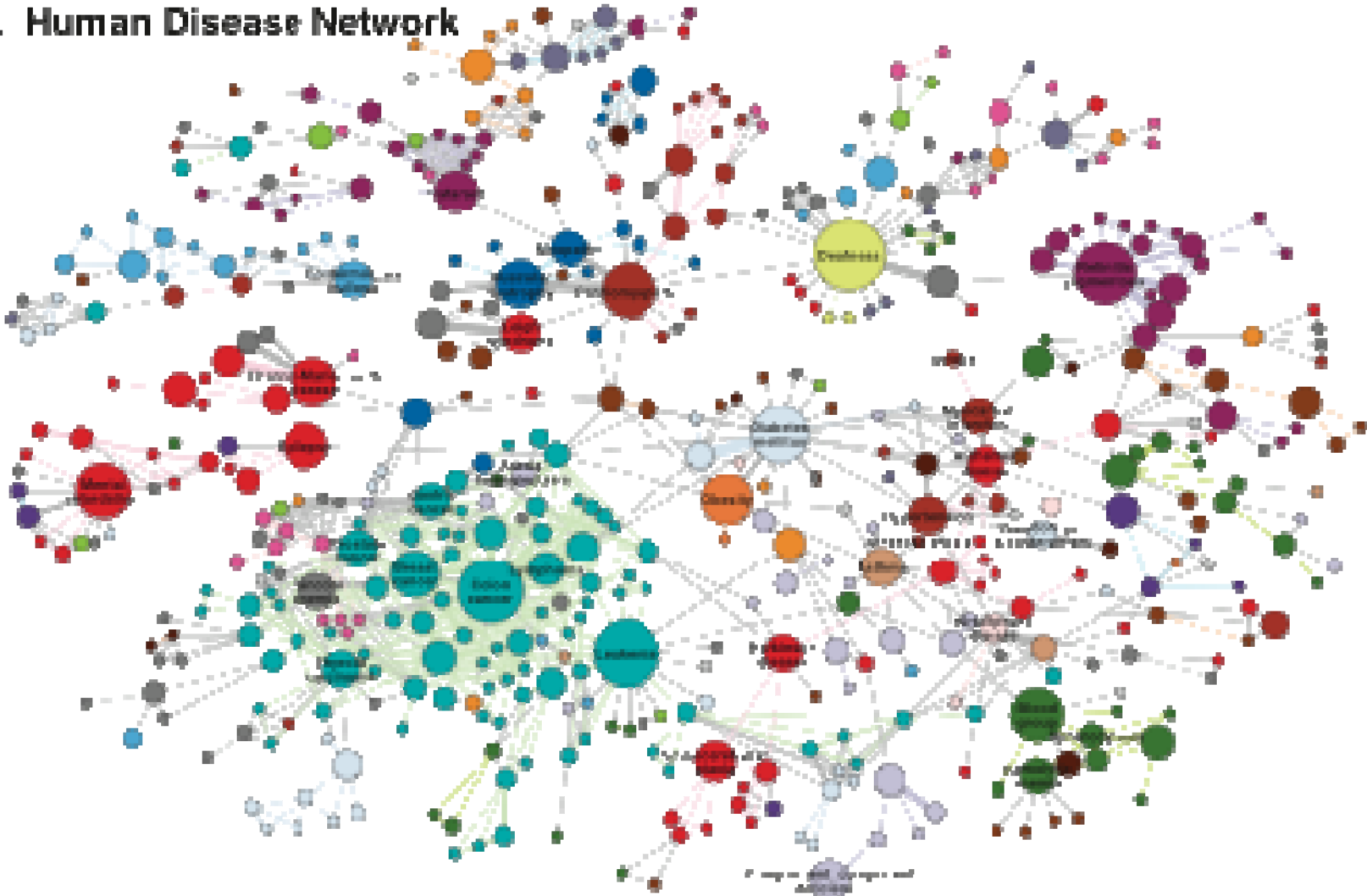# Observed Coincident Weight Change
(lots of caveats)
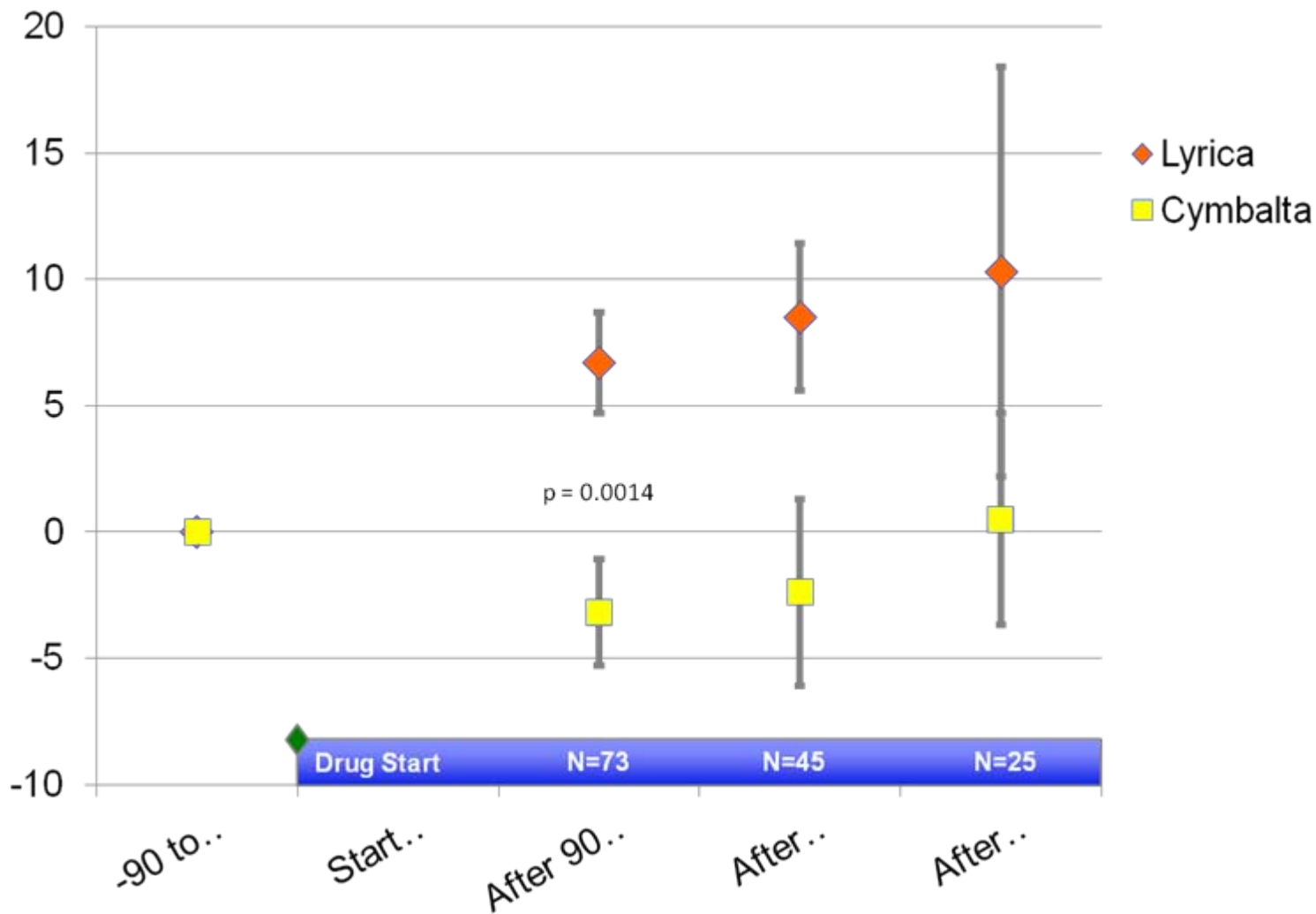
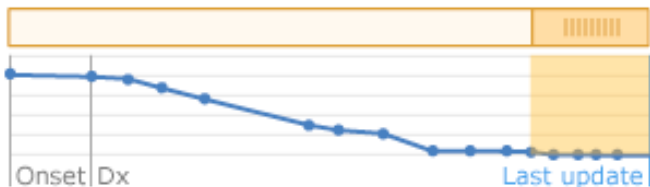# Projected Growth in Annual AE Reporting
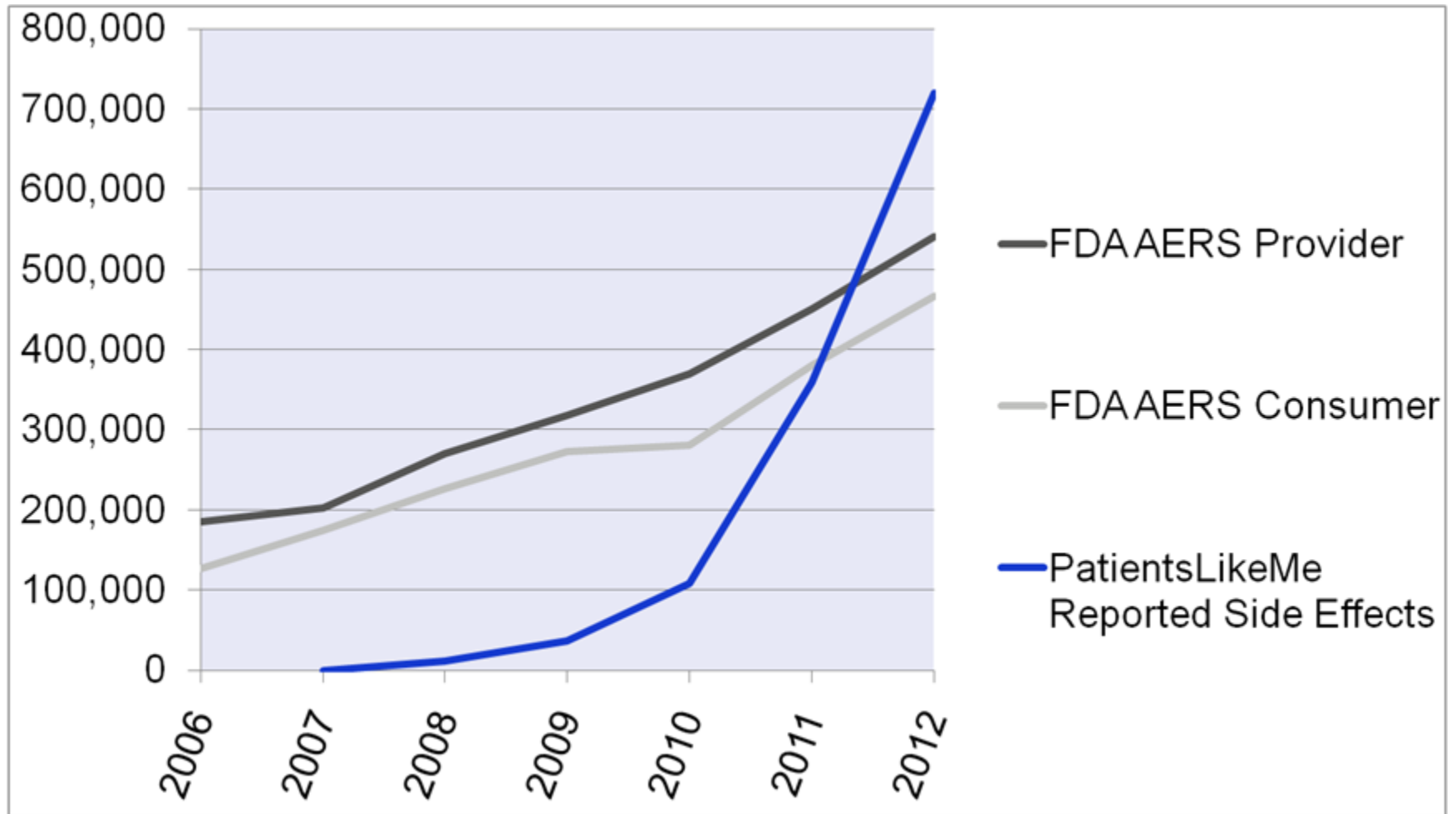
The human disease network

Kwang-Il Goh[*†§], Michael E. Cusick[†‡¶], David Valle[∥], Barton Childs[∥], Marc Vidal[†‡¶**], and Albert-László Barabási[*†‡**]

a Human Disease Network

Timeframe: Oct 27, 2006 — Nov 26, 2006

Onset | Dx | Last update

Legend:
- ✓ Treatment purpose
- + Positive side-effect
- − Negative side-effect

Treatments	Status	Botox	Provigil	Hydroxyurea	Hyoscyamine	Amitriptyline	Detrol	Allopurinol	Prozac	Rilutek	Prilosec	Mag Citrate	CoQ10
ALS			✓				✓		✓				
Primary ALS Symptoms													
▸ Stiffness/spasticity	◆ Moderate												
▸ Excess saliva	◆ Moderate	✓	+		✓	✓	+						
▸ Pain	◆ Moderate	−											
▸ Insomnia	◆ Mild		−		−	−		−	−				
▸ Fatigue	◆ Moderate		✓			−			−				
▸ Fasiculations	◆ None												
▸ Emotional lability	◆ Mild							−					
▸ Depression	◆ Moderate					+		−	✓				
▸ Constipation	◆ Moderate			−	−	−	−	+				✓	✓
▸ Anxiety	◆ Mild		−			−		−					
Secondary Symptoms													
Urinary urgency	◆ Moderate			−			✓						
Acid reflux	◆ Mild										✓		−
Other Conditions Update													
Asthma		−	−						−	−	−		

The best way to predict the future is to create it.

Peter Drucker