

The Learning Healthcare System in 2010 and  
Beyond:  
Investing patients in the research and  
continuous improvement enterprise

1 April 2010

Roundtable on Value and Science-Driven Health Care  
Institute of Medicine

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# Vision

A consumer initiated and/or driven learning system which aggregates and analyzes information over time to describe health and disease, enables discovery that leads to prevention strategies, diagnostics and treatments.

- The diagnosed
- The not-yet-diagnosed (public)
- Public health

## Find Patients Like You

You are not alone. Want to find patients just like you to see how they treat their disease? Now you can.



Select a community to **find people with your condition...**



As you share health data, we'll highlight people like you.



so you can **connect with people like you** to learn how they treat their disease.

## Start finding Patients Like You today

We currently have communities for the following conditions. **Pick one** to get started:

### Prevalent Diseases

[ALS/MND](#)

[Epilepsy](#)

[Fibromyalgia](#)

[Chronic Fatigue Syndrome/ME](#)

[HIV/AIDS](#)

### Mood Conditions

[Anxiety](#)

[Bipolar](#)

[Depression](#)

[OCD \(Obsessive-Compulsive Disorder\)](#)

[PTSD \(Post-Traumatic Stress Disorder\)](#)

### Rare Diseases

[CBD \(Corticobasal Degeneration\)](#)

[Devic's Neuromyelitis Optica](#)

[MSA \(Multiple System Atrophy\)](#)

[PLS \(Primary Lateral Sclerosis\)](#)

[PMA \(Progressive Muscular Atrophy\)](#)

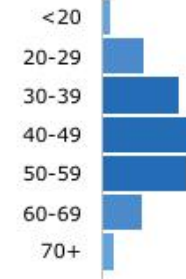
[PSP \(Progressive Supranuclear Palsy\)](#)

## About our Members

**60167** total patients  
**2078** patient updates this week  
**4537** new patients this month

73% female  27% male

### Age distribution






Data on  
1000  
people  
taking  
Riluzole.

Next  
practices.

### Side Effects

#### Side effects as an overall problem

Severe	10	8%	
Moderate	13	10%	
Mild	19	15%	
None	86	67%	



#### Most commonly reported side effects

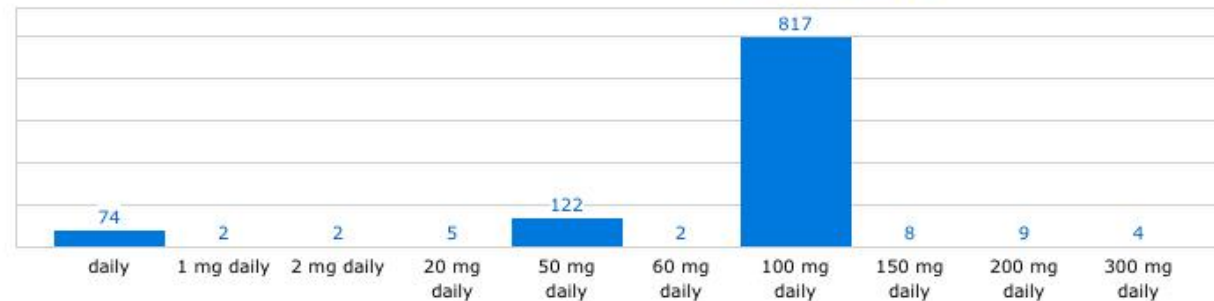
Fatigue	18	50%	
nausea, stomach and intestinal pain	8	22%	
weakness in lips	7	19%	
Muscle weakness	5	14%	
Sensation in tongue	5	14%	
cold feet and legs	3	8%	

 Mild  Moderate  Severe

[See all 21 reported side effects](#)

### Dosages

Top 10 dosages based on patients **currently taking Riluzole**. [See all 21 dosages](#)



### Stop Reasons

Why Patients Stopped Taking Riluzole (multiple reasons could be selected)

Side effects too severe	83	41%	
Did not seem to work	64	32%	
Expense	33	16%	
Other	26	13%	
Doctor's advice	25	12%	
Personal research	19	9%	
Not indicated	10	5%	
Course of treatment ended	3	1%	
Change in health plan coverage	1	0%	

[See all 201 patients](#) who've stopped taking Riluzole



# Genetic Alliance BioBank

<http://www.BioBank.org>

*5,000 member, Cross-disease,  
Trust Community*

Cooperative – extensible, interoperable, cost-sharing  
platform

Creates a Local (Global) Community

Trusted Agent

Tier consent, and recontact

*However, less than 5 percent of adults diagnosed with cancer each year will get treated through enrollment in a clinical trial.*

*National Cancer Institute*

## Vision **Private Access: Company Vision, Purpose and Strategy**



**PRIVACY  
ASSURED**  
with PrivateAccess

*Enabling use of the Internet to safely and securely share confidential health information with trusted parties*

## Purpose

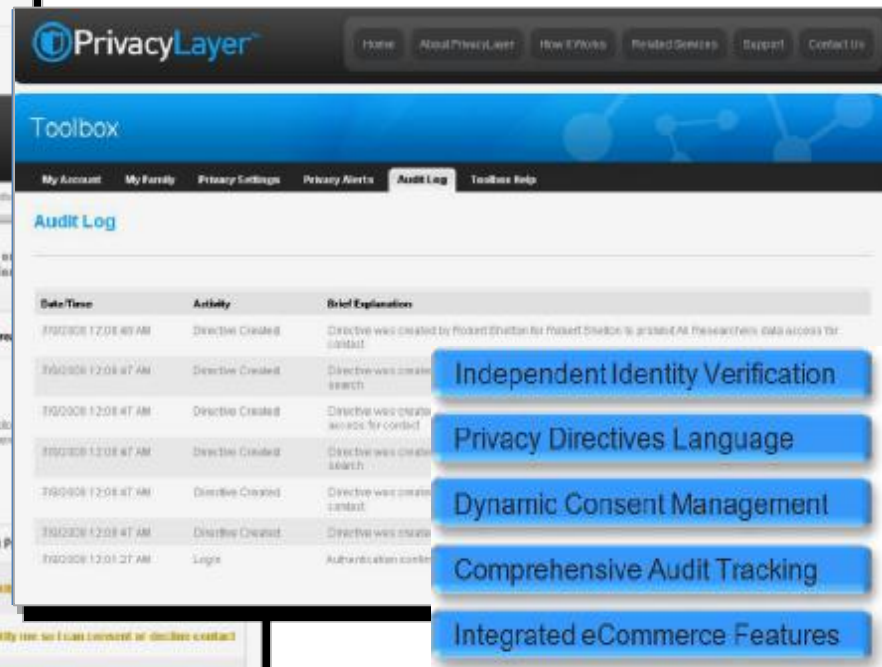
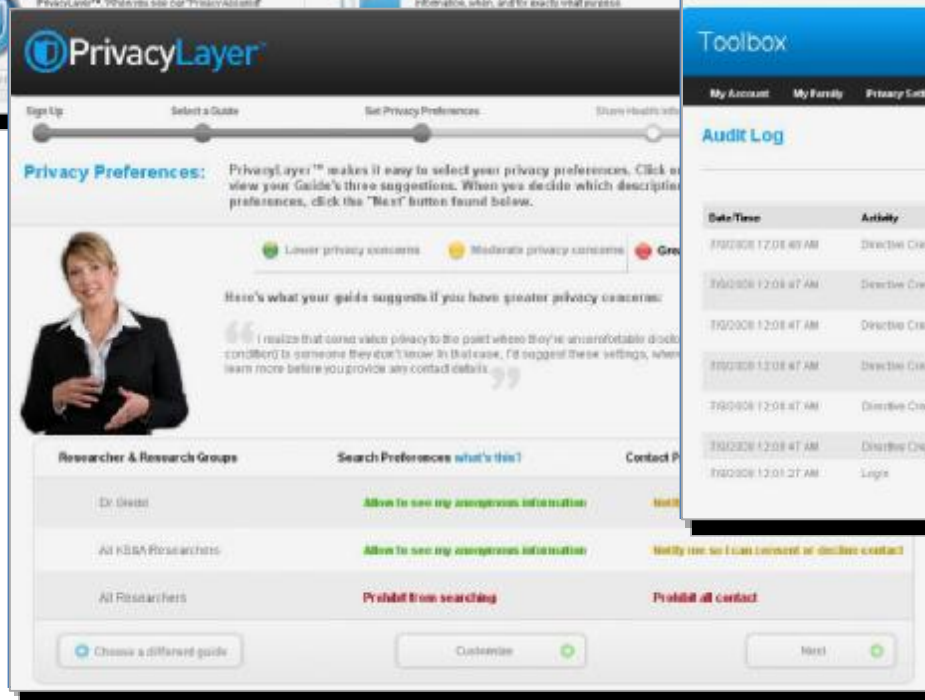
To protect the privacy of individuals' confidential health records while making it fast and easy for parties with proper authority to locate and use this vital information for medical research, diagnosis, treatment, and in other privacy-enabled applications.

## Strategy

To build and operate the Private Access Bureau as an efficient, easy to use, and cost-effective service to protect, locate and share sensitive and/or confidential health information based on state and federal law, institutional policy, and personal privacy directives.

# Solutions So Far Directed to Registries and Biobanks

Technology that allows each person to grant “private access” to all or selected parts of their confidential personal information based on their particular needs and interests





**Demo Mode:** This account does not have a genetic profile and is showing the [Mendel family](#) as an example. Order your [Personal Genome Service](#) now.

🏠 [me](#)

- My Health and Traits
- Browse Raw Data
- My Profile

family & friends

- Compare Genes
- Family Inheritance

my ancestors

- Maternal Line
- Paternal Line
- Ancestry Painting
- Global Similarity

23andWe

- Introduction
- My Surveys (19)
- Featured Research

community

- 23andMe Community
- Parkinson's Disease
- Pregnancy

account

- Genome Sharing

Click 'My Health and Traits' to view your genetic data with regard to various diseases, conditions and traits.

New at 23andMe



Our **Pregnancy** Community:

- [Track your pregnancy.](#)
- [Compare notes in the community.](#)
- [See how your genes may affect your pregnancy.](#)

Explore your ancestry in different ways by clicking on the various links under "My Ancestors".



- [Variant Sensitivity](#)
- [BRCA Cancer Mutations \(selected\)](#)
- [Glycogen Storage Disease Type 1a](#)
- » [view all reports](#)

Participate in genetic research by taking our surveys.



- [An Introduction to 23andMe Labs](#)
- [Tree Mutation Mapper](#)

Recent Community Posts

[Health and Traits](#) | [Maternal Line](#) | [Paternal Line](#) | [Product Discussion](#)



[Any other I2a2a members out there?](#)

[View answers \(8\)](#) | Written by [s9arthur](#) | [Haplogroup I2](#)

Navigation

Click links in the left-hand column of any page to explore your genetic data.

next ▶

NO one is currently sharing their genetic data with you.

- [Share with friends and family.](#)
- [Search for other 23andMe members.](#)
- [Make yourself searchable.](#)

» [Edit sharing preferences](#)

Help/Contact Us

- [Download Getting Started Guide](#) 📄
- See our [Frequently Asked Questions](#). For other questions or feedback, please email [help@23andme.com](mailto:help@23andme.com).



Need more kits? [Visit the store.](#)

Show information for

Sharon Terry

assuming

European

ethnicity and an age range of

50-59

[Where's mine?](#)



### Sharon Terry

1.1 out of 100

women of European ethnicity who share Sharon Terry's genotype will get Restless Legs Syndrome between the ages of 50 and 59.



### Average

0.88 out of 100

women of European ethnicity will get Restless Legs Syndrome between the ages of 50 and 59.

### What does the Odds Calculator show me?

Use the ethnicity and age range selectors above to see the estimated incidence of Restless Legs Syndrome due to genetics for women with **Sharon Terry's** genotype. The 23andMe Odds Calculator assumes that a person is free of the condition at the lower age in the range. You can use the name selector above to see the estimated incidence of Restless Legs Syndrome for the genotypes of other people in your account.

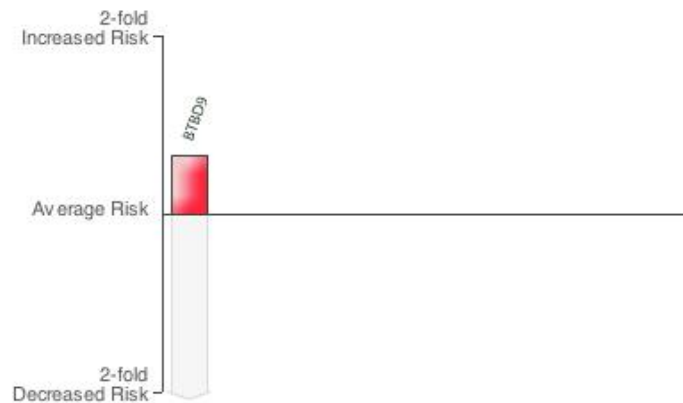
The 23andMe Odds Calculator only takes into account effects of markers with known associations that are also on our genotyping chip. Keep in mind that aside from genetics, environment and lifestyle may also contribute to one's chances of having Restless Legs Syndrome.

### Genes vs. Environment

54 %  
Attributable to  
Genetics

The **heritability** of restless legs syndrome is estimated to be 54%. This means that genetic and **environmental factors** contribute nearly equally to differences in risk for this condition. Genetic factors that play a role in restless legs syndrome include both unknown factors and known factors such as the SNPs we describe here. Environmental factors include pregnancy. Low iron levels, dialysis for end-stage renal disease, and damage to the nerves of the hands and feet tend to worsen the condition. ([sources](#))

### Marker Effects

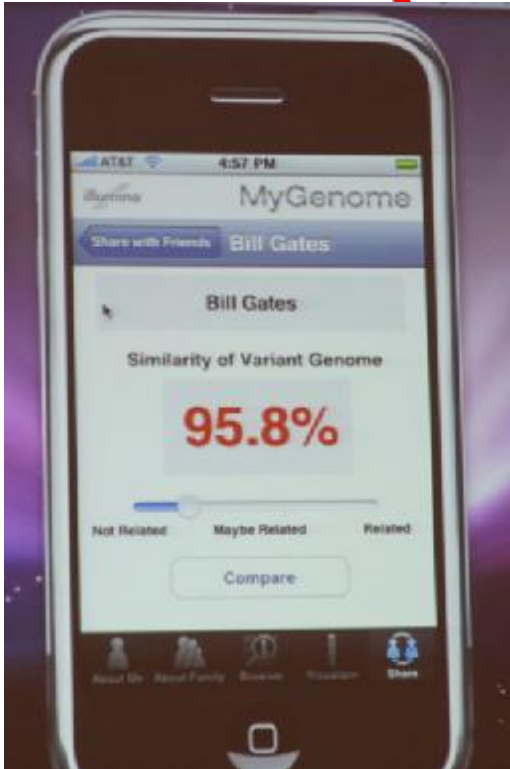


### What does this chart show?

The chart shows the approximate effects of the selected person's genotype at the 1 reported marker. Higher, **red bars** indicate **increased risk** from the average, while lower, **green bars** indicate **decreased risk** from the average. The light gray bars show the maximum possible effects for the possible genotypes at the marker.

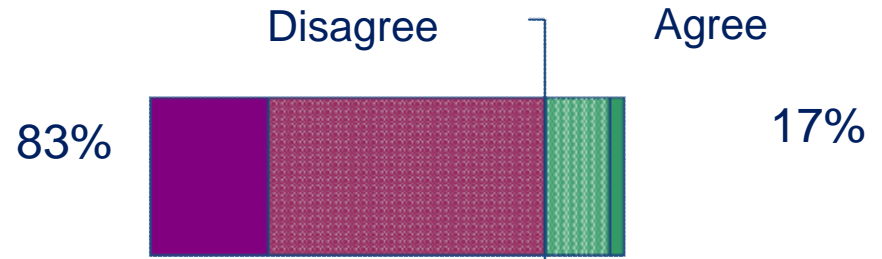
health

About 1.2 Million Results

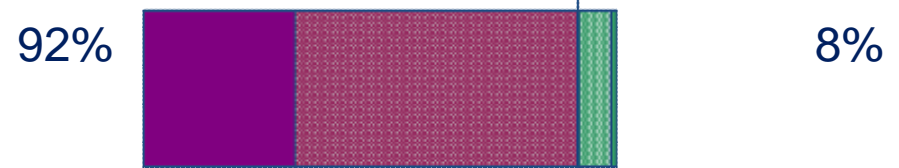


# "I would not want to get research results because:"

"It would worry me."



"It would be too much information."



"I am not that interested."



100 80 60 40 20

Strongly Disagree Disagree Agree Strongly Agree

# Genetics and Public Policy Center Survey for Large Cohort Study

If individual research results were not returned to participants, would you be more or less likely to participate?

- 75% less likely
- 4% more likely
- 22% it would not make a difference

# Public Health

Newborn Screening System – consent use and storage of bloodspots, with EMR, and PHR

<http://www.nbsclearinghouse.org>

GEDDI - Genetics for Early Disease Detection and Intervention to Improve Health Outcomes

<http://www.geneticalliance.org/geddi>

Family Health History – Genetic Alliance/HRSA Consumer Centered Tool

<http://www.doesitruninthefamily.org>

# Conclusion

- Long distance to overcome perceived paternalism in the system, and low medical/scientific literacy
- Wide adoption of integrated EMR, with one click PHR, and easy privacy protections
- Transparency and connect the dot for benefit – open access
- Clear articulation of value: what motivates – curiosity, benefit, family
- Community/affinity group support

**“You never change things by fighting existing reality. To change something, build a new model that makes the existing model obsolete.”**

**Bucky Fuller**