adding personal data to pharmaceutical data: leverage from the commons
@wilbanks
3/31/14
Converting Anecdotes Into Signals

Stephen Friend at TED 2014

Sage Bionetworks CEO spoke from the main stage yesterday at TED 2014 in Vancouver. He announced the Research and Mt Sinai that is looking for healthy individuals... Read more
every age has its own lever.
ours is cheap data.
cheap data changes how we justify our opinions.
OPS = AB(H + BB + HBP) + TB(AB + BB + SF + HBP) / AB(AB + BB + SF + HBP)
cheap data is changing our politics.
PRISM Collection Details

Current Providers

- Microsoft (Hotmail, etc.)
- Google
- Yahoo!
- Facebook
- PalTalk
- YouTube
- Skype
- AOL
- Apple

What Will You Receive in Collection (Surveillance and Stored Comms)?

It varies by provider. In general:

- E-mail
- Chat – video, voice
- Videos
- Photos
- Stored data
- VoIP
- File transfers
- Video Conferencing
- Notifications of target activity – logins, etc.
- Online Social Networking details
- Special Requests

Complete list and details on PRISM web page:
Go PRISMFAA
cheap data is going to change our health.
1. research data v. cheap consumer data
# Disease Risk

23andWe Discoveries were made possible by 23andMe members who took surveys.

## Elevated Risk

<table>
<thead>
<tr>
<th>Name</th>
<th>Confidence</th>
<th>Your Risk</th>
<th>Avg. Risk</th>
<th>Compared to Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate Cancer</td>
<td>🟢🟢🟢</td>
<td>31.9%</td>
<td>17.8%</td>
<td>1.79x</td>
</tr>
<tr>
<td>Psoriasis</td>
<td>🟢🟢🟢</td>
<td>22.4%</td>
<td>11.4%</td>
<td>1.98x</td>
</tr>
<tr>
<td>Alzheimer's Disease</td>
<td>🟢🟢🟢</td>
<td>14.2%</td>
<td>7.2%</td>
<td>1.98x</td>
</tr>
<tr>
<td>Ankylosing Spondylitis</td>
<td>🟢🟢🟢</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>🟢🟢🟢</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bipolar Disorder: Preliminary Research</td>
<td>🟢🟢🟢</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic Lymphocytic Leukemia</td>
<td>🟢🟢🟢</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follicular Lymphoma</td>
<td>🟢🟢🟢</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Blood Pressure (Hypertension)</td>
<td>🟢🟢🟢</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Need to Know: Update for Blue Button Partners

The rollout of the upgraded Blue Button on September 29 and October 9 means enhancements for our Veterans who download their health care data from VA’s electronic health records. For our industry partners it means enhancements and improvements for their supporting software’s functionality.

Based on Veteran user feedback, the minor enhancements in this rollout will make the output more readable and user friendly. There is also a new set of data for ‘VA Immunizations,’ enhancements to the online user interface and improved data from the Military Service Information (MSI) section. We have provided these instructions on our Resources page along with updated sample files.

One Million Blue Button Users - Veterans Talk to Markle
The Scientific Services Marketplace

The easiest way to get experiments conducted by researchers in top core facilities and institutions.

Featured RNA microarray Providers

Science Exchange has 63 verified RNA microarray providers including the following featured providers.

RNA microarray
$107.50 per Sample

DNA Sequencing
$2.50 per Sample

Real Time qPCR
$3.50 per Sample

Mass Spectrometry
$10.00 per Sample

Immunohistochemistry
$10.00 per Sample

Bioinformatics
$50.00 per Hour

Virginia Bioinformatics Institute
Virginia Polytechnic Institute and State University | Blacksburg, VA, United States

The Core Laboratory Facility (CLF) at VBI functions as a multi-user resource dedicated to the development and application of various high-throughput technologies to aid in the discovery of biological macromolecules.

$284.00 USD per Sample

https://www.scienceexchange.com
2.
increasing tensions.
Global Sales in 2012: US$ 856 billion (in constant USD)
Growth is slowing

Global Pharma Sales
(in constant US $)

Source: Reconstructed from IMS Health. May 2013 + history IMS April 2008
not just economic, but social tensions.
tension between anonymity and utility.
tension between expectation and reuse.
Original Investigation I August 19, 2013

Public Preferences About Secondary Uses of Electronic Health Information

David Grande, MD, MPA1,2; Nandita Mitra, PhD3; Anand Shah, MD, MSHP4; Fei Wan, MS3; David A. Asch, MD, MBA1,2,5

[+] Author Affiliations


Text Size: A A A A
tension between aggregate value and individual value.
How Much Are You Worth?

When you visit certain Web sites on the Internet, ad requests are sent to advertisers. They compete for a chance to serve ads to you. The bid prices they submitted to auctions are generally based on your information that advertisers possess, for example a profile inferred from your Web history, and your browsing context. The prices reflect how they evaluate your profile. We capture these prices to give you a quantification of your value from advertisers' perspective.

Results: We do not have any data associated with you. If you use Firefox or Chrome, please install the plugin and enable cookies. Note that our plugin does NOT work with Ad blocker extensions such as AdBlockPlus or any addons of these types. If you use Ad blockers, and still want to know how advertisers estimate your private data, you have three options:

- Deactivate Ab blockers, browse the Internet as usual, and reactivate your Ad blockers whenever enough prices are collected (i.e. our plugin starts showing you your average price and the number of prices is larger than 20–40). This could take a couple of days or just one day, depending on your browsing habits.
- Deactivate your Ad blockers, click on some (10 to 15, with e.g. several refreshes) of the links example from this list, and reactivate your Ad blockers later once you are done. This option is faster, but might somehow affect the results.
- For Firefox create a new Firefox profile and browse the Web as usual with our plugin installed. Of course do not use Ad Blockers. For Chrome, create a new browser user profile: see here or alternatively check this tutorial.

We show below some general highlights, if you do not use Firefox or Chrome, or do not wish to install the plugin.

The average price paid for user's private data (items in Web browsing history) for our users is:

$0.000564
if it can be sold, it will be sold at the lowest possible price.
tension between technology rate of change and policy rate of change.
our regulatory environment
that’s the setup.
3.

we need freedoms, not just free stuff, for data to change health for the better.
freedoms granted to small but coherent groups can create asymmetrically valuable resources.
Random Distribution

Power Law Distribution

$p(k)$ (number of nodes of size $k$)

$k$ (size of node)

small group sharing
proven to work in:
software
content
Cloud Computing, the EU, and Data Governance: A Sage Bionetworks White Paper

There is a lot of movement in regulatory regimes around the world to address issues of individual level data. Whether it’s from social networks, mobile networks, web traffic, or health data, gov... Read more »
let’s try a small but coherent group to share data and see if it works in breast cancer.
code sharing a prerequisite.
accuracy of model jumped three orders of magnitude in nine days.
76% accurate.
Biomolecular Events in Cancer Revealed by Attractor Metagenes
Wei-Yi Cheng, Tai-Hsien Ou Yang, Dimitris Anastassiou

21 February 2013

RESEARCH ARTICLE
COMPUTATIONAL MODELING
Development of a Prognostic Model for Breast Cancer Survival in an Open Challenge Environment
Wei-Yi Cheng, Tai-Hsien Ou Yang and Dimitris Anastassiou

17 April 2013

Multi-cancer molecular signatures and their interrelationships
Wei-Yi Cheng¹, Tai-Hsien Ou Yang¹, Hui Shen², Peter W. Laird², Dimitris Anastassiou¹ and the Cancer Genome Atlas Research Network

ongoing...
Multi-cancer molecular signatures and their interrelationships

Wei-Yi Cheng¹, Tai-Hsien Ou Yang¹, Hui Shen², Peter W. Laird², Dimitris Anastassiou¹ and the Cancer Genome Atlas Research Network

"Multi-cancer molecular signatures and their interrelationships"

AUTHORS: Wei-Yi Cheng, Tai-Hsien Ou Yang, Dimitris Anastassiou

ABSTRACT

Several molecular signatures, called attractor metagenes, present in multiple cancer types were recently identified and proved prolongation of survival. These signatures were found using an iterative data mining algorithm converging to the core of gene coexpression. The identification of additional multi-cancer molecular signatures resulting from analysis of data sets from twelve cancer types, including methylation and protein signatures and an angiogenesis-related signature.
We had previously found all three LYM, M+ and M- signatures from their association with the expression of miR-142. We have now confirmed in the pancan12 data sets, and we found that miR-150 and miR-155 are also strongly associated with the LYM signature. We had also previously presented the LYM signature as an attractor metagene3, and used it in the winning model of the Sage Bionetworks Breast Cancer Prognosis Challenge 2019, strongly associated with improved prognosis in ER-negative breast cancers, and this fact also provides an explanation for the relationship, as compared with other types of high-grade breast cancers.

Figure 2: Scatter plots connecting the LYM, M+ and M- meta-features in 12 cancer types. Each dot represents a cancer sample. The horizontal and vertical axes show the methylation values of the two methylation signatures, M- and M+, while the value of the expression of the LYM metagene is color-coded.
createFigure2 <- function(meta.pancan, x, y, z){

    fileName <- paste("scatter.", x, "x", y, "x", z, ".png", sep="")

    png(fileName, width=7.3, height=8, units="in", res=300, pointsize=12)
    par(mar = c(4,4,2,5), mfrow = c(4, 3), oma=c(0, 0, 0, 0), mgp=c(2, 1, 0))

    # find the features
    temp <- meta.pancan[[1]]
    idxx <- NULL
    idxy <- NULL
    idxz <- NULL
    for(d in names(temp)){
        if(x %in% rownames(temp[[d]])) idxx <- d
        if(y %in% rownames(temp[[d]])) idxy <- d
    }
}
let’s try a small but coherent group to share data and see if it works in “big science”.
The Cancer Genome Atlas Data Portal

Understanding genomics to improve cancer care

TCGA Data Portal Overview

We provide 3 ways to download data: The Cancer Genome Atlas (TCGA) Data Portal provides a platform for researchers to search, download, and analyze data sets generated by TCGA. It contains clinical information, genomic characterization data, and high-throughput sequencing analysis of the tumor genomes.

The TCGA Data Portal does not host lower levels of sequence data. NCI’s Cancer Genomics Hub (CGHub) is the new secure repository for storing, cataloging, and accessing BAM files and metadata for sequencing data. New users must still apply for authorized access through NCBI’s Database of Genotypes and Phenotypes (dbGaP).

Choose from three ways to download data

Download Data

Available Cancer Types

<table>
<thead>
<tr>
<th>Available Cancer Types</th>
<th># Cases Shipped by BCR</th>
<th># Cases with Data</th>
<th>Date Last Updated (mm/dd/yy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Myeloid Leukemia [LAML]</td>
<td>200</td>
<td>200</td>
<td>07/16/13</td>
</tr>
<tr>
<td>Adrenocortical carcinoma [ACC1]</td>
<td>80</td>
<td>80</td>
<td>07/22/13</td>
</tr>
</tbody>
</table>

Announcements

06/13/2013 - DCC Software Released

The software release scheduled for today is complete and the TCGA Data Portal has been returned to normal operation. As part of this release, a new version of the TCGA Archive Validator has been provided and we strongly suggest that data submitting centers download and use this new version. The TCGA Archive Validator can be found on the TCGA Wiki here.

A complete list of the items addressed in this release can be found on the TCGA Wiki here and for those with JIRA access the tickets covered in this release can be found on the wiki here.

If you have any questions or concerns about this release, contact tga-dcc-binf-l@list.nih.gov.

05/21/2013 - DCC Software Released

OS/21/2013 · Dee Software Released
TCGA Pan-Cancer Consortium

**Analysis of:** 12 Tumor types, 6 molecular profiling platforms

**Focus series of:** 4 papers in *Nature Genetics*, with 14 more to follow in other NPG journals

---

Enabling transparent and collaborative computational analysis of 12 tumor types within The Cancer Genome Atlas

Larsson Omberg1, Kyle Elliott2, Yuan Yuan3,4, Cyriac Kandoth5, Chris Wong6, Stephen H Friend1, Josh Stuart1, Han Liang3,4 & Adam A Margolin1

The Cancer Genome Atlas Pan-Cancer Analysis Working Group collaborated through Synapse, a software platform, to share and evolve data, results and methodologies to perform integrative analysis of molecular profiling data from 12 tumor types. The group's work serves as a pilot case study that provides (i) a template for future large collaborative studies; (ii) a system to support collaborative projects; and (iii) a public resource of highly curated data, results and automated systems for the evaluation of community-developed models.

Omberg, et al. *Nature Genetics*
68 core projects
107 datasets
172

results

3
papers in press
let’s try a small but coherent group to share data and see if it works in health.
**Elevated Risk**

<table>
<thead>
<tr>
<th>Name</th>
<th>Confidence</th>
<th>Your Risk</th>
<th>Avg. Risk</th>
<th>Compared to Average</th>
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</thead>
<tbody>
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</tr>
<tr>
<td>Ankylosing Spondylitis</td>
<td>★★★</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>★★</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bipolar Disorder: Preliminary Research</td>
<td>★★</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic Lymphocytic Leukemia</td>
<td>★★</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follicular Lymphoma</td>
<td>★★</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Blood Pressure (Hypertension)</td>
<td>★★</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Table 1. Total Prostate-Specific Antigen for White Males

<table>
<thead>
<tr>
<th>Age Group</th>
<th>PSA Levels (ng/mL)</th>
<th>PSA Levels (μg/L)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men &lt;40 years</td>
<td>&lt;2 ng/mL</td>
<td>&lt;2 μg/L</td>
</tr>
<tr>
<td>Men 40–50 years</td>
<td>2–2.8 ng/mL</td>
<td>2–2.8 μg/L</td>
</tr>
<tr>
<td>Men 51–60 years</td>
<td>2.9–3.8 ng/mL</td>
<td>2.9–3.8 μg/L</td>
</tr>
<tr>
<td>Men 61–70 years</td>
<td>4–5.3 ng/mL</td>
<td>4–5.3 μg/L</td>
</tr>
<tr>
<td>Men &gt;70 years</td>
<td>5.6–7.2 ng/mL</td>
<td>5.6–7.2 μg/L</td>
</tr>
</tbody>
</table>

Overdiagnosis Due to Prostate-Specific Antigen Screening: Lessons From U.S. Prostate Cancer Incidence Trends

Ruth Etzioni, David F. Penson, Julie M. Legler, Dante di Tommaso, Rob Boer, Peter H. Gann and Eric J. Feuer

Correspondence to: Ruth Etzioni, Ph.D., Program in Biostatistics, Fred Hutchinson Cancer Research Center, 1100 Fairview Ave. North, MP-665, Seattle, WA 98109-1024 (e-mail: retzioni@fhcrc.org).

Received November 19, 2001. Revision received April 25, 2002. Accepted May 15, 2002.

Abstract

[Abstract]

Full Text (HTML)  Full Text (PDF)

Alert me when cited  Alert me if corrected
“eat less and exercise”
the experiment:
These are the rights you are granting to qualified researchers:

- [ ] Right to do research with my data
- [ ] Right to redistribute my data
- [ ] Right to publish the results of research from my data
- [ ] Right to commercialize products derived from research on my data

All boxes must be checked to move forward in the consent process.
Genotype- 23andme (syn1418166)

Added by: Xavier Schildwachter on: Mon Oct 01 18:59:24 GMT-700 2012
Modified by: Christine Suver on: Tue Oct 02 09:07:59 GMT-700 2012
Version: 0.0.0 [1] (show all versions)

Description

Genotype from individual 1418165, generated by 23andme using the Illumina OmniExpress Plus genotyping beadchip.

This is a PLC contributed dataset (http://weconsent.us/about)
jtw has uploaded genotyping rawdata.

- Download this set (23andme)

This user has not entered a description yet.

This user has not entered any phenotypes yet.

Contact openSNP: Blog | Twitter | Mail | Privacy Policy | openSNP in the press

The openSNP project is licensed under CC BY SA 3.0. The data is licensed under CC0 1.0. The hand drawn icons were created by one seventy seven and are licensed under CC BY 3.0, the CSS of openSNP is provided by Bootstrap, from Twitter and is licensed under the Apache License v2.0. Tiny white person in the navigational-bar from glyphicons.

http://opensnp.org/users/615
4 Magnitude

rs5168(C·C)

Baldness

AGTR1 Gene

3 Chromosome

148459988 Position

20120810 Rs time

Male Male.

7.3x increased risk of hypertension...more...

曝 won't go bald This genotype seems to prevent baldness...more...

http://files.snpedia.com/reports/promethease_data/genome_jtw_ui2.html
MINOR ALLELE PROGRAM REPORT

The program finds about 60 'rare/uncommon' SNPs from the 900,000+ tested by 23andMe.

There is just a single 'homozygous-recessive' result:

'AA'   rs11869580    Intergenic

but as this occurs in an Intergenic region it is unlikely to be of significance.

There are no SNPs of special note.

---

RESULTS

<table>
<thead>
<tr>
<th>SNP</th>
<th>Chromosome</th>
<th>Allele</th>
</tr>
</thead>
<tbody>
<tr>
<td>rs56367069</td>
<td>1:17326767</td>
<td>'CT'</td>
</tr>
<tr>
<td>rs4949212</td>
<td>1:31961711</td>
<td>'CT'</td>
</tr>
<tr>
<td>rs1181088</td>
<td>1:54563039</td>
<td>'CT'</td>
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<td>1:67862482</td>
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<td>1:98056007</td>
<td>'AG'</td>
</tr>
<tr>
<td>rs35669708</td>
<td>1:156851382</td>
<td>'AG'</td>
</tr>
<tr>
<td>rs35698797</td>
<td>1:229665958</td>
<td>'CT'</td>
</tr>
<tr>
<td>rs45471294</td>
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</tr>
<tr>
<td>rs1776702</td>
<td>2b:103317676</td>
<td>'AG'</td>
</tr>
<tr>
<td>rs17760364</td>
<td>2c:189631806</td>
<td>'AG'</td>
</tr>
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<td>rs279552</td>
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</tr>
<tr>
<td>rs460965</td>
<td>3a:10122927</td>
<td>'CT'</td>
</tr>
<tr>
<td>rs2067466</td>
<td>3a:11300780</td>
<td>'CG'</td>
</tr>
</tbody>
</table>
“Also there is no suggestion of consanguinity in your pedigree.”

http://www.ianlogan.co.uk/
(not so good)
requires coherence and scale - easier to enforce in closed systems...
4. someone’s going to achieve coherence and scale.
INTRODUCING UP AND THE NEW UP 3.0 APP

Connect wirelessly with real-time insights to turn intentions into actions.

image via http://jawbone.com/
Healthbook

Sync with Carlos' iWatch

Last sync: 12:21

Physical status: 79 kg, 1.86 m

Today (as of 12:21)
- 7 Laps (5.1 km) ran
- 1,023 Calories burnt
- 2,221 Calories eaten

Notes
1. Warm up 15 minutes before Crossfit tomorrow.
2. Bring one apple and one banana to the gym.
3. On Feb. 10, I completed 19 rounds of "Cindy".

Diet
- Breakfast: 2 eggs, 1 glass of milk, 1 glass of orange juice, 2 slices of bread, 2 sausages, (Total calories: 2,221)

Health Status
- Blood Pressure: 100/70 (Type: A+)
- Hydration Level: 55%
- Heart Rate: 120 bpm

Medications
- Drink Protein
- Drink Nitric oxide

image via http://macrumors.com/
but will we be allowed to opt out?
thus we have to talk about the politics of data.
three choices for coherence and scale.
a. “just like now, but moreso”
c. an open system.
Rheumatoid Arthritis Responder DREAM Challenge

Programmatic Clients

Synapse is designed to easily integrate into your current work. That’s why we’ve created the following clients so that you can interact with all of Synapse's functionality programatically. Create provenance, download files, generate provenance, query, create wikis and more all from the comfort of your own code. Don’t see your language of choice here? Check out our full REST API documentation.

R Client

```r
source('http://depot.sagebase.org/CRA
pkgInstall(c("synapseClient"))
```

API Documentation & Example Code

Python Client

```python
# From Terminal Prompt:
pip install synapseclient
# or
easy_install synapseclient
```

Command Line Client

```bash
# From Terminal Prompt:
pip install synapseclient
# or
easy_install synapseclient
```

Java Client

```java
API Documentation & Example Code
```
Accelerating Medicines Partnership

The Accelerating Medicines Partnership (AMP) is a bold new venture between the National Institutes of Health (NIH), 10 biopharmaceutical companies and several non-profit organizations to transform the current model for developing new diagnostics and treatments by jointly identifying and validating promising biological targets of disease. AMP will begin with three to five year pilot projects in three disease areas: Alzheimer’s disease, type 2 diabetes, and the autoimmune disorders of rheumatoid arthritis and systemic lupus erythematosus (lupus).

For each pilot, scientists from NIH and industry have developed research plans aimed at characterizing effective molecular indicators of disease called biomarkers and distinguishing biological targets most likely to respond to new therapies. The ultimate goal is to increase the number of new diagnostics and therapies for patients and reduce the time and cost of developing them.

Through this cross-sector partnership, which will be managed through the Foundation for the NIH (FNIH), NIH and industry partners are sharing expertise and resources ~$230 million ~ in an integrated governance structure that enables the best informed contributions to science from all participants. A critical component of the partnership is that industry partners have agreed to make the
Open Source and Standards

Open Source and Standards in the Marketplace

Technology and the Internet revolution have made the world a smaller and “flatter” place. Global innovation continues to bring people around the world closer to one another, but we’re now starting to realize that just being connected isn’t enough.

Fortunately, a new revolution is beginning: one that holds significant potential. The planet is becoming smarter. Intelligence is being infused into the way the world literally works—into the systems, processes and infrastructure that enable physical goods to be developed, manufactured, bought and sold; that allow services to be delivered; that facilitate the movement of everything from money and oil to water and electrons. Ultimately, this will help to improve how billions of people work and live.

Open Source & Standards are key to making our planet smarter and improving the way we live and work.

Open Source:
Open source in IT is software whose source code is published and made available to the public, enabling anyone to copy, modify and redistribute the source code without paying royalties or fees.

Standards:
A standard is a specification that has been agreed upon by a community, through usage or declaration. Once established, any number of duplicates or variants can be made, while keeping the basic structure or function intact.

IBM is driving reforms for IP, Open Source & Standards
IBM is an industry leader helping governments move toward greater openness and innovation.
Welcome to Project Data Sphere... a simple idea for transforming innovation in cancer treatment research.

Project Data Sphere enables researchers across industry and academia to share oncology clinical trial data through a single online platform. Sharing data will speed our understanding of the disease and drive efficiencies in the development of new drugs and treatment approaches.

Project Data Sphere represents the collaborative effort of industry, academia, and patient advocacy organizations united in their fight against cancer. **Read More >>**

**What data sharing means for COMPANIES and INSTITUTIONS**

**Why data sharing promotes innovation by RESEARCHERS**

**How data sharing honors PATIENTS**
c. the cartel.
Facebook helps you connect and share with the people in your life.

Sign Up
It's free and anyone can create an account.

Full Name: 
Your Email: 
New Password: 
Select Sex: 
Month: ___ Day: ___ Year: ___

Why do I need to provide this information?

Sign Up

To create a page for a celebrity, but...
thank you

@wilbanks
john.wilbanks@sagebase.org