patient ownership of clinical research data

@wilbanks
john.wilbanks@sagebase.org
1. what do you mean by clinical?
1. what do you mean by clinical? research?
1. what do you mean by clinical? research? data?
2. we’re not very patient.
John, welcome to you.

View Your Printable Genetic Health Summary

See your genetic results for all health topics with Established Research in one easy-to-read place! Print the summary for your records or share it with your health care provider.

View Report  Don't show again.

A new survey is available: The Empathy Quotient

2 days ago

Cilantro Love and Hate: Is it a Genetic Trait?

Why do some people love cilantro, while others hate it with every fiber of their being? With the help of customers like you, we’ve identified a genetic variant associated with disliking cilantro and thinking it tastes soapy.

» Read more
Self-Contributed Data for Common Genomics Research (syn1418121)

Added by: Xavier Schildwachter on: Mon Oct 01 10:16:10 GMT-700 2012

Description

Dataset of self-contributed health and Genomics data available for use in emerging genomics research. These data were donated through Portable Legal Consent (PLC) by individuals who wish to broadly share their personal information with the Synapse user community for research purposes. Portable legal Consent: http://weconsent.us/about

ProjectContents

- Individual 1418122
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's page

jtw has uploaded genotyping rawdata.

- Download this set (23andme)

Description
This user has not entered a description yet.

jtw's variations
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
Male Male.

rs5186(C;C)
- **7.3x increased risk of hypertension**...
- **Bad**: Repute 4, Magnitude 0.1575, GMAF 54, References 148459988 Position 20120810, Rs time
- **AGTR1**: Gene, Chromosome 3
- **High blood pressure, Pre-eclampsia**

rs6152(A;A)
- **won't go bald** This genotype seems to prevent baldness...
- **Good**: Repute 4, Magnitude 0.214587, GMAF 11, References 66765627 Position 20120812, Rs time
- **AR**: Gene, Chromosome X

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

'JTW'   'jw' '615' 23andMe Results Chromosomes 1-22 4 October 2012

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

---

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<th>Chromosomal Location</th>
<th>Genotype</th>
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<th>Minor Allele MAF</th>
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</table>
“Also there is no suggestion of consanguinity in your pedigree.”

http://www.ianlogan.co.uk/
The Scientific Services Marketplace

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

Search All Services

RNA microarray
- $107.50 per Sample

DNA Sequencing
- $2.50 per Sample

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Mass Spectrometry
- $10.00 per Sample

Immunohistochemistry
- $10.00 per Sample

Bioinformatics
- $50.00 per Hour

Featured RNA microarray Providers

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

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
3. principles for sharing.
honesty. reusability. portability.
http://synapse.sagebase.org
Consent to Research  Getting Consent

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.

GET INFORMED
- Welcome
- Researcher Terms of Use
- Grant Rights
- Watch Video
- Checkpoint
- Acknowledge Understanding

CONSENT TO RESEARCH
- Consent Form
- Generate ID

UPLOAD YOUR DATA
- User Profile
- Sign In
- Upload Data

Next

http://weconsent.us
Public Sage/DREAM Modeling Competition Leaderboard

8/28: We have re-run the evaluation due to a bug found in our exactConcordanceIndex calculation. We apologize for any inconvenience.

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</tbody>
</table>
WELCOME TO BRIDGE

We believe knowledge sharing is vital for new discoveries. With that in mind, we created Bridge as a platform to accelerate medical research through open-source collaboration.

Bridge is currently focused on

- Real Names
- Breast Cancer
- Fanconi Anemia

http://sagebridge.org
Get Involved

It will take the efforts of all of us working together in new ways to learn what happens when people affiliate their real names with their data and then have an active voice in determining what happens with that data. Link below to learn more about how you can best make a difference.

Get Connected

Patient advocate communities will serve as an important cornerstone for the success of the Real Names Discovery Pilot. Read more below and link to the sites of two such groups that have already stepped up to help launch Real Names Discovery Pilot.

PATIENTS LIKE ME

PatientsLikeMe is committed to putting patients first. We do this by providing a better, more effective way for you to share your real-world health experiences in order to help yourself, other patients like you and organizations that focus on your disease or Parkinson-like disorders (parkinsonisms). The networks are centered around one or more partnerships neurology of the regional hospitals.

PARKISONNET

The ParkinsonNet consists of regional networks of care providers in the Netherlands who specialize in treating and managing patients with Parkinson’s disease or Parkinson-like disorders (parkinsonisms).
if we scale...
honesty, reusability, and portability will change a clinical outcome.
TREATMENT
thank you