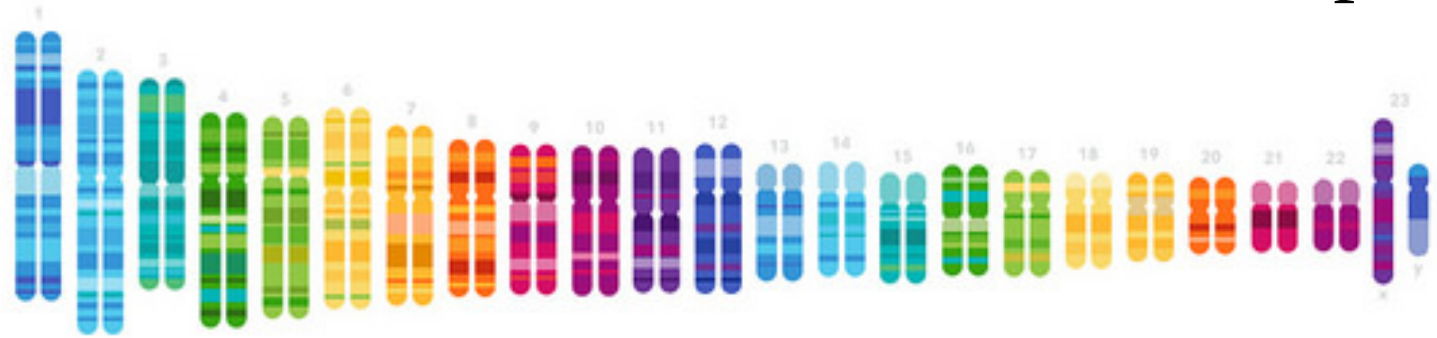
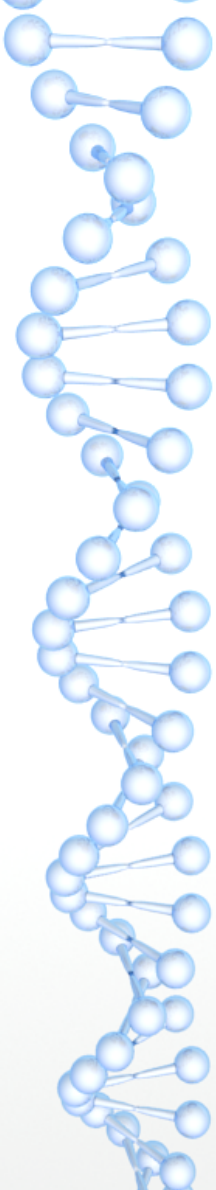
23andMe: Discover Your Genetic Blueprint



Presentation for the Potomac Area Technology and Computer Society
by Geof Goodrum
16 September 2017



Outline

- What is 23andMe?
- What do I get in the Genetic Tests?
- Reports
- Order Processing
- What's in the kit?
- Why would I want this?
- Some Caveats
- Some Terms and Conditions
- Privacy
- Security
- Summary

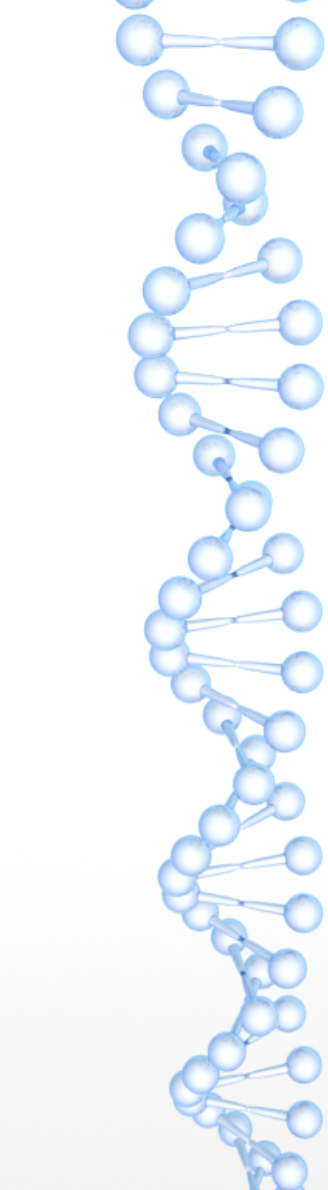
What is 23andMe?

- A privately held biotechnology company
- Named after 23 pairs of chromosomes in normal human cells
- Based in Mountain View, California
- Founded in April 2006
- Markets direct-to-consumer genetics testing service
  - Received FDA approval for genetic risk tests in April 2017
  - 2 million customers as of April 2017
- Performs medical research with consumer opt-in genetic database
- More information:
  - https://mediacenter.23andme.com/
  - https://en.wikipedia.org/wiki/23andMe

What do I get in the Genetic Tests?

	Ancestry Only	Ancestry + Health
Cost	$99	$199
Ancestry Reports	✔	✔
DNA Relative Finder	Opt In	Opt In
Genetic Health Risk Reports		✔
Carrier Status Reports		✔
Wellness Reports		✔
Traits Reports		✔
Raw Data	✔	✔
Share and Compare	Ancestry Only	Ancestry + Health

Add Health reports to Ancestry Only for $125
10% discount on additional kits
$20 referral gift (ask me!)

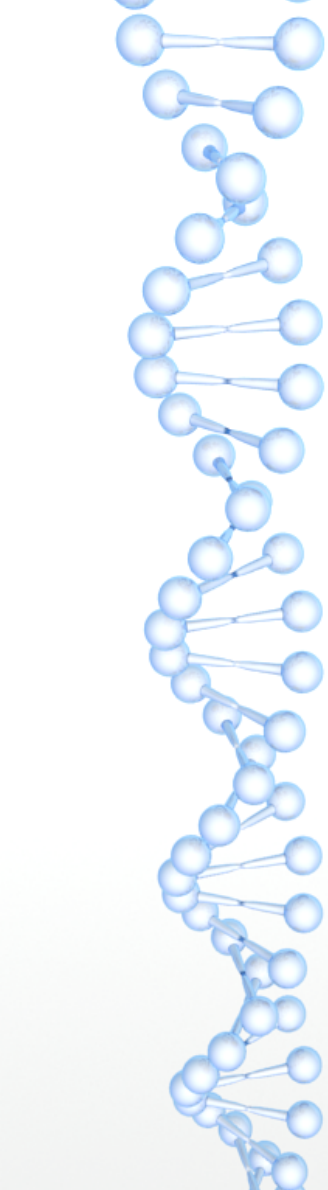


Ancestry Reports

- Ancestry Composition
- Maternal Haplogroup
- Paternal Haplogroup
- Neanderthal Ancestry
- Your DNA Family

Genetic Health Risk Reports

- Age-Related Macular Degeneration
- Alpha-1 Antitrypsin Deficiency
- Hereditary Hemochromatosis (HFE-Related)
- Hereditary Thrombophilia
- Late-Onset Alzheimer's Disease
- Parkinson's Disease

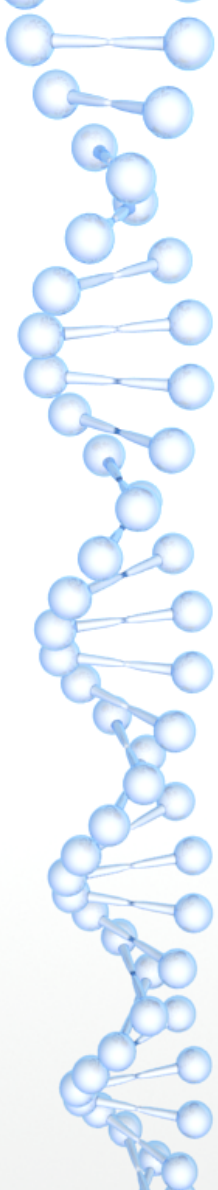


Carrier Status Reports

- ARSACS
- Agenesis of the Corpus Callosum with Peripheral Neuropathy
- Autosomal Recessive Polycystic Kidney Disease
- Beta Thalassemia and Related Hemoglobinopathies
- Bloom Syndrome
- Canavan Disease
- Congenital Disorder of Glycosylation Type 1a (PMM2-CDG)
- Cystic Fibrosis
- D-Bifunctional Protein Deficiency
- Dihydrolipoamide Dehydrogenase Deficiency
- Familial Dysautonomia
- Fanconi Anemia Group C
- GRACILE Syndrome
- Gaucher Disease Type 1
- Glycogen Storage Disease Type Ia
- Glycogen Storage Disease Type Ib
- Hereditary Fructose Intolerance
- Herlitz Junctional Epidermolysis Bullosa (LAMB3-related)
- Leigh Syndrome, French Canadian Type
- Limb-Girdle Muscular Dystrophy Type 2D
- Limb-Girdle Muscular Dystrophy Type 2E
- Limb-Girdle Muscular Dystrophy Type 2I
- MCAD Deficiency
- Maple Syrup Urine Disease Type 1B
- Mucolipidosis Type IV
- Neuronal Ceroid Lipofuscinosis (CLN5-Related)
- Neuronal Ceroid Lipofuscinosis (PPT1-Related)
- Niemann-Pick Disease Type A
- Nijmegen Breakage Syndrome
- Nonsyndromic Hearing Loss and Deafness, DFNB1 (GJB2-Related)
- Pendred Syndrome and DFNB4 Hearing Loss
- Phenylketonuria and Related Disorders
- Primary Hyperoxaluria Type 2
- Rhizomelic Chondrodysplasia Punctata Type 1
- Salla Disease
- Sickle Cell Anemia
- Sjögren-Larsson Syndrome
- Tay-Sachs Disease
- Tyrosinemia Type I
- Usher Syndrome Type 1F
- Usher Syndrome Type 3A
- Zellweger Syndrome Spectrum (PEX1-Related)

Wellness Reports

- Alcohol Flush Reaction
- Caffeine Consumption
- Deep Sleep
- Genetic Weight
- Lactose Intolerance
- Muscle Composition
- Saturated Fat and Weight
- Sleep Movement



Traits Reports

- Asparagus Odor Detection
- Back Hair (available for men only)
- Bald Spot (available for men only)
- Bitter Taste Perception
- Cheek Dimples
- Cleft Chin
- Earlobe Type
- Earwax Type
- Eye Color
- Finger Length Ratio
- Freckles
- Hair Curliness
- Light or Dark Hair
- Male Hair Loss (available for men only)
- Newborn Hair Amount
- Photic Sneeze Reflex
- Red Hair
- Skin Pigmentation
- Sweet Taste Preference
- Toe Length Ratio
- Unibrow
- Widow's Peak

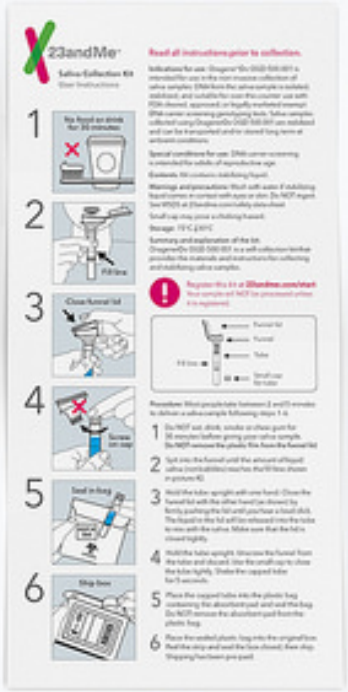
Order Processing

- Order kit online (https://www.23andme.com/)
- Receive kit (3-5 days)
- Create account and register kit on website
- Return kit with sample (within 12 months)
- Check account for test results (6-8 weeks)
- Getting Started Video: https://youtu.be/3oTaydRPm3w

What's in the kit?

saliva collection kit

specimen bag



step by step instructions

funnel lid

saliva collection tube

tube cap

tube container

Why Would I Want This?

- Learn about genetics
- Understand your ancestry
- Discover living relatives
  - Adoptees
- Participate in research
- Identify risk of genetic conditions

Some Caveats

- Reports are delivered via the web but are printable and downloadable
- Tests may not be reliable for Bone Marrow recipients
- Traits are statistical probabilities based upon customer samples (and things you already know about yourself)
- Health tests do not indicate that you have a genetic condition, only that you do or do not have a genetic variation associated with a condition that may increase risk of passing the condition to children or developing a condition
- 23andMe does not provide Medical advice nor Genetic Counseling services
- Before accessing genetic health reports, customers must agree to accept consequences of the knowledge, i.e., “Do you really want to know this?”
  - See https://customercare.23andme.com/hc/en-us/articles/202907980-What-unexpected-things-might-I-learn-from-23andMe-

Some Terms and Conditions

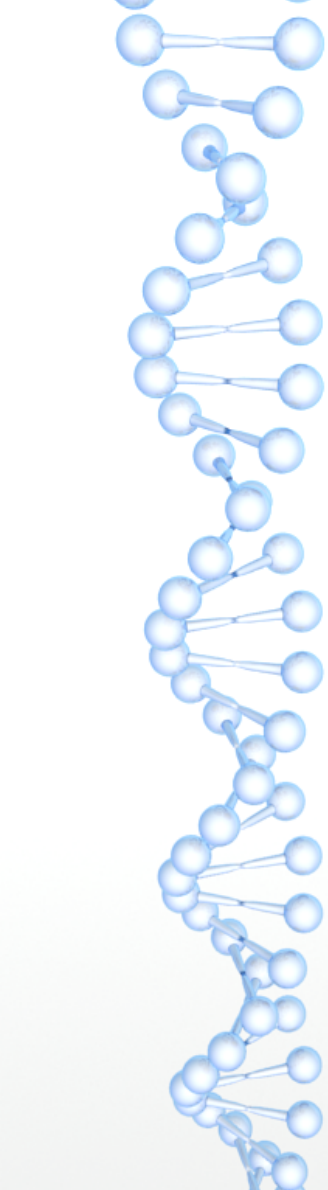
- Cancel order within 60 minutes to void charge
- Return unused kit within 30 days for full refund
- Kits not returned within 12 months or lost/damaged will be replaced at no additional charge
- If the first sample fails, 23andMe will provide a second sample kit at no additional charge.
  - A second failed sample results in refund less S&H, and no refunds on any future purchased kits
- "… you acquire no rights in any research or commercial products that may be developed by 23andMe or its collaborating partners."
- See https://www.23andme.com/about/tos/

Privacy

- You are responsible for information that you share
- Only anonymous, aggregated information is shared with third parties
- Submit Consent Document to participate in scientific research
  - Consent can be withdrawn with information removed within 30 days of request EXCEPT information already used in research
- Account can be closed with all information removed within 30 days of request EXCEPT information already used in research
- See https://www.23andme.com/about/privacy/

Security

- User ID (email)
- Password
- Security Question
- Trusted Website Certificate (https)
  - Rated ‘C’ by SSL Labs, accepts weak ciphers (RC4, 3DES)
- NO two factor authentication option



Summary

- Learn a lot about your genetic makeup
- Ancestry+Health service is a good deal
- Be careful what you share with social features
- Understand the implications of genetic health risk and carrier reports
- Privacy policy and service terms seem reasonable, but YOU must decide for yourself. REVIEW THEM!
- Website security could be improved