



Preventing Genetic Disorders in the British Jewish Community

Jewish Community and Genetic Disorders

JGD Screening: A brief history

Jnetics and GENEius

**Conservative Muslim Forum
House of Lords - 11.03.19**

**Katrina Sarig
Executive Director**

About the British Jewish Community

History:

- **Arrival** - 1070 (William) → 1656 (Oliver)
- **'Large' influx** - 1880 (Russian Empire) → World War II (Germany, Poland)

Demographics:

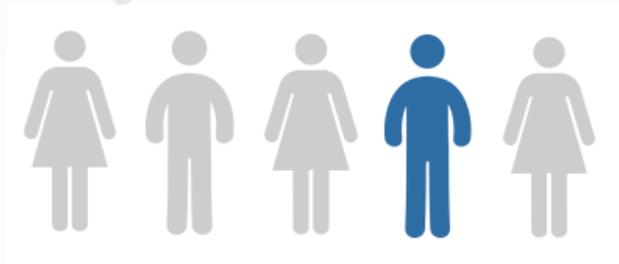
- 263,346 'Jewish' (2011 census) ... 300,000 (approx. 0.5% UK total)
- Ashkenazi (80%); Sephardi/Middle Eastern (5%); rest mixed
- Religiousness: 40% Orthodox; 20% Progressive; 40% unaffiliated
- Location – London, Manchester

Jewish Genetic Disorders (JGDs)

Genetic conditions that are more common in people of Jewish ancestry relative to the general population

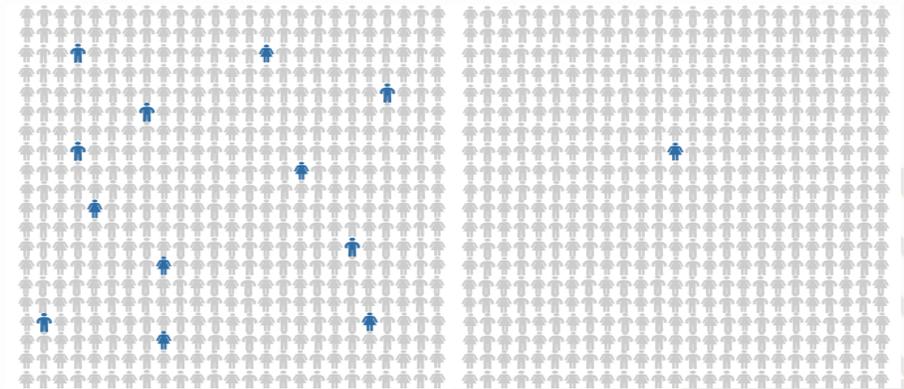
RECESSIVE

It's Not Just Tay-Sachs



1 in 5 Ashkenazi Jews is a carrier of at least one severe recessive JGD

DOMINANT



1 in 40 Ashkenazi Jews is BRCA positive relative to 1 in 500 in general population

Severe Recessive JGDs: Carrier Frequency

Disorder	Carrier Frequency in AJ
Tay-Sachs Disease	1 in 25
Cystic Fibrosis	1 in 25-29
Familial Dysautonomia	1 in 30
Canavan Disease	1 in 40-57
Glycogen Storage Disease (type 1a)	1 in 71
Fanconi Anaemia (type C)	1 in 89
Niemann-Pick Disease (type A)	1 in 90
Bloom Syndrome	1 in 100
Mucopolysaccharidosis IV	1 in 100-125

JGD Screening in the UK: A brief history

Tay-Sachs Disease

- Dor Yeshorim - Rabbi Eckstein
- NHS Individual/Community → Guy's Hospital
- National Screening Committee - 2013



JEWISH CARE

Other JGDs

- NHS - Diagnostic and Cascade
- Australia, USA, Canada, Israel → TSD - 8/16/48 -100+ (pan-ethnic)
- Private options – costly; limited GC

 THE DOCTORS
LABORATORY

 23andMe



Jnetics - Addressing a Need

- Registered charity - established 2010
- Only organisation in UK dedicated to improving management and prevention of JGDs
- Activities – awareness-raising; signposting ... facilitating access to responsible screening services
- 2014 – **partnership with NHS**
- Community Screening for **9 severe, recessive JGDs**
- 18 community events – **500 people; 1 in 5; 3 carrier couples**

The GENEius Programme

Liverpool Women's 
NHS Foundation Trust


London North West
University Healthcare
NHS Trust

- **Launched** – 2017; NHS partnership
- **What** - Comprehensive education and screening programme targeting young Jewish adults in UK → **designed to change mindset.**
- **Aim** - eliminate new cases of severe, recessive JGDs and improve the management of hereditary cancers
- **3 core groups** – Year 12; university students; ‘pre-marriage’
- **Greatest reach** ‘pre-family planning’ given available resources
- **Endorsed** – religious movements and community leadership

The logo for the GENEius programme, featuring the word "GENEius" in a bold, blue, sans-serif font. The "E" is stylized with a blue circle around it. The logo is set against a background of faint, light blue DNA double helix structures.

Jewish Perspectives on Screening

Past:

- Early resistance due to ethical issues – some flexibility (case-by-case)

Present:

- Changing factors – increased understanding and options (PGD)
- Screening endorsed /encouraged across the entire religious spectrum

‘It is a fulfilment of the mitzvah of *‘you shall surely take care of your health’* to undertake those measures that can prevent illness in our lives and thereby enhance the health of our community’.

London Beth Din

Schools Programme

- **Who:** Year 12 students
- **Where:** 8 largest mainstream Jewish secondary schools
Approx. 870 across 8 schools
- **What:** Parent info → student education → optional screening (subsidised by funding from the Jewish community)
- **Reach:** EDUCATED - 1324 Year 12 students (13 cohorts)
SCREENED - 1043 Year 12 students – 60-75% 'eligible'
- **Feedback:** Positive from schools and student ... **Effective model**



University Programme

- 75% of students at 9 UK Universities (6,300)
- Different challenge – different delivery model based on research
- Birmingham Pilot – March 2019 → 140 students (community subsidised)
- Evaluate → 3 x 3 years

Pre-marriage/Community Programme

- All synagogue couples – for engaged couples+
- Integrating screening info via multiple channels
- Screening via Barnet Clinic – Nov 17; 2x month; £190 part subsidy; 300+

Summary and Going Forward

We have developed effective models for JGD prevention that are accepted, needed and wanted by the community (on-going evaluation).

Going forward – challenges and opportunities

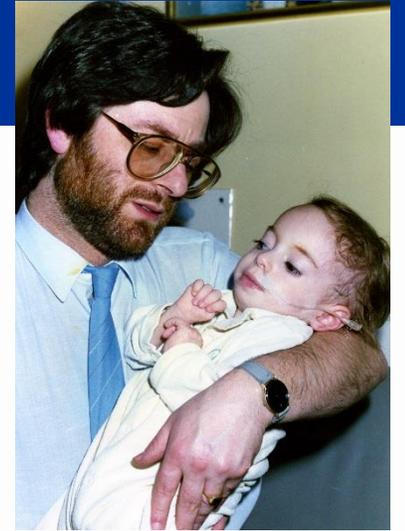
- Increasing reach (2,500 year) – need for on-going promotion
- Service expansion – international best practice (recessive/BRCA)
- Need for commissioning – community to NHS (cost-effective review)
 - Screening costs → £190 pp (£250 all-in real cost)
 - Lack of NHS commissioning for carrier screening for ‘at-increased risk’ groups

Issue for all ethnic groups - opportunity for dialogue/collaboration

Thank You

‘The pain of losing a child is unimaginable. I don’t want any other couple to go through the suffering we did now that screening is available. Don’t let us compound the inevitable heartache that a family will go through by knowing they could have done something but chose not to get tested. Knowledge is everything’

Brian Rose, whose son David passed way from TSD



‘Our child was diagnosed with a severe genetic disorder that has a specific Jewish risk. A simple blood test could have identified our risk and helped prevent so much suffering – how could we not have known?’

Jane & Ian Pearl, with Chanochi who has FD

www.jnetics.org

Any Questions?

info@jnetics.org