

Breaking Down Barriers



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The Sylvia Adams Charitable Trust



Alström Syndrome UK
Strength for today, hope for the future

Project Background:

The **GENE**ius Programme

- GENEius - launched Nov 2016
- Trigger – Community Screening (with NHS, 9 severe, recessive JGDs)
 - **1 in 5** people of AJ origin a carrier
 - **3 carrier couples**
- Effective but need to increase reach / maximise impact

Project Overview:

- **What ...** Education & screening programme - young Jewish adults.
- **Aim ...** To prevent new cases of severe, recessive JGDs and improve management of hereditary cancers.
- **How ...** Focus 3 groups:
 - Year 12 in Jewish Secondary Schools
 - Jewish students at universities
 - Engaged couples - synagogue movement.

→ To change the culture so screening standard practise

Areas of Success

Schools programme – focus in 2017

- Endorsement - religious/community leadership
- Developed effective model
- Embraced by all 8 target schools
- Collaborative relationship with Dor Yeshorim

University programme

- Research and drafting of Uni model

Pre-marriage

- Integration into United Synagogue

PR and fundraising

Educational Video – Who is a carrier

Challenges

- Parent engagement – education and funding support
- University student engagement
- BRCA integration
- Resource management – HR; Database; GDPR
- Panel review / expansion
- **Funding**

Questions



Thank You



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