Project MinE: an international ALS whole genome sequencing initiative

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Aim

• To find an effective treatment and cure for ALS patients
• ALS one disease, one treatment
• ALS multiple diseases, multiple treatments
• Genetics: subgroups, stratification, disease mechanisms, biomarkers, disease models, etc
ALS

- **Familial (Mendelian)**

- **Sporadic**

  Twin studies: 61% heritability
Aim Project MinE

• Elucidate the genetic basis of ALS: a ‘human genome project’ for ALS
• Identify common as well as rare genetic risk factors with high, intermediate and low risk for ALS
• Establish a database of genetic variants from various backgrounds benefitting ALS research for years
Spectrum of genetic variants
Common variants with small effect: GWAS
Aim

• Whole genome sequencing: 15,000 ALS patients and 7,500 controls (+ imputation)
Patient-driven
• Initiated by 2 patients
• Started with fundraising in The Netherlands
International approach

• Consortium of researchers
• Consortium of fundraisers, charities
International approach Project MinE

• Worldwide collaboration between ALS centers and foundations
• Groundbreaking scale
• Only a multinational approach in various populations will generate significant results
• Combination of ALS biobanks/patient databases worldwide: unique opportunity for already established databases/biobanks.
• Reduction of whole genome sequencing costs by combining efforts (tiered pricing model)
International approach Project MinE

• International campaign for funding (‘sponsor a genome’) has proven to be successful: raised awareness, raised funding for Project MinE, raised funding for ALS in general
• Decentralized organizational structure: researchers/charity in each country remain in charge of their own data, funding, campaigns, etc
• For example: Belgium sponsors for Project MinE donate to ALS Liga
• Discovery of ALS genes will help to identify disease pathways necessary to develop treatment for patients
• Raising hope for ALS patients
Website for collaboration & fundraising: www.projectmine.com
Worldwide Project MinE

Together these countries already reached 10% of our goal! More and more countries will join Project MinE in the coming months.

View country page

View country page

View country page

View country page

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What can you do?

• Make a donation at www.projectmine.com/donate

• Start a campaign to raise funds on www.projectmine.com/campaigns, for example run 5 km/10 km/a marathon, cycle, swim and get sponsoring, sell cookies and donate the profit, organise an evening with bands/music and donate the profits, etc.

• Involve your employer and raise funds by for example not sending Christmas cards to business contacts this year but instead donate to Project MinE, organise a charity volleyball tournament with your company, organise a charity auction, etc.

Edwin ran a marathon for Project MinE
Ineke convinced her employer to support Project MinE
# Project MinE: an international ALS whole genome sequencing initiative

<table>
<thead>
<tr>
<th>Project</th>
<th>Country</th>
<th>Initiative</th>
<th>Lead Investigator(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project MinE Netherlands</td>
<td>Netherlands</td>
<td>ALS Found</td>
<td>Van den Berg, Veldink</td>
</tr>
<tr>
<td>Project MinE UK</td>
<td>UK</td>
<td>MNDA</td>
<td>Al-Chalabi, Shaw, Morrison</td>
</tr>
<tr>
<td>Project MinE US</td>
<td>US</td>
<td>ALSA</td>
<td>Landers, Glass</td>
</tr>
<tr>
<td>Project MinE Belgium</td>
<td>Belgium</td>
<td>ALS LIGA</td>
<td>Robberecht, Van Damme</td>
</tr>
<tr>
<td>Project MinE Ireland</td>
<td>Ireland</td>
<td>Irish ALS</td>
<td>Hardiman</td>
</tr>
<tr>
<td>Project MinE Australia</td>
<td>Australia</td>
<td>MND Aus</td>
<td>Blair, Kiernan</td>
</tr>
<tr>
<td>Project MinE Switzerland</td>
<td>Switzerland</td>
<td>Swiss ALS</td>
<td>Weber</td>
</tr>
<tr>
<td>Project MinE Israel</td>
<td>Israel</td>
<td>Prize4life</td>
<td>Gotkine</td>
</tr>
<tr>
<td>Project MinE Spain</td>
<td>Spain</td>
<td>FUNDELA</td>
<td>Mora Pardina</td>
</tr>
<tr>
<td>Project MinE Portugal</td>
<td>Portugal</td>
<td>APELA</td>
<td>Carvalho</td>
</tr>
<tr>
<td>Project MinE Sweden</td>
<td>Sweden</td>
<td>Neuroforb.</td>
<td>Andersen</td>
</tr>
<tr>
<td>Project MinE Italy</td>
<td>Italy</td>
<td>ARISLA</td>
<td>Chio, Silani</td>
</tr>
<tr>
<td>Project MinE France</td>
<td>France</td>
<td>ARSLA</td>
<td>Corcia, Couratier</td>
</tr>
<tr>
<td>Project MinE Germany</td>
<td>Germany</td>
<td>Ger ALS</td>
<td>Weishaupt</td>
</tr>
<tr>
<td>Project MinE Turkey</td>
<td>Turkey</td>
<td>Turk. ALS</td>
<td>Basak</td>
</tr>
<tr>
<td>Project MinE</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Where is Project MinE

- Consortium and data sharing agreement
- Core clinical dataset
- Environment/lifestyle questionnaire
- Legal issues
- Data storage, computation power
- GWAS analyses ongoing
- 6000 genomes
- 16,500 to go.....
Videos

1. https://www.youtube.com/watch?v=naxl74JokQk&hd=1
2. http://pauwenwitteman.vara.nl/media/313165
3. https://www.youtube.com/watch?v=n9DEXVtsszl - t=11
5. https://www.youtube.com/watch?v=nJrMQ5Al4ro
Unravel the complexity of ALS

Patient

Genetics

Environment

Phenotype

Neuro-imaging

Lifestyle
Create a world without ALS
Unite to fight!

For ALS Centres
Register with TRICALS for easy access to new clinical trials and our supporting services on clinical trial development.
Read more...

For People with ALS
Register with TRICALS and participate in research that can advance better treatment for people with ALS.
Read more...

For Pharma / Biotech
Register with TRICALS and take advantage of our network of experienced ALS centres, an international patient registry and our clinical trial support.
Read more...

Latest News

5/21/2014  Teleurstellende resultaten Tirasemitiv
5/21/2014  Anti-epilepticum als mogelijke kandidaat-therapie voor ALS

More news...
Welcome Oralie Nettie

TRICALS is the international, online platform for people with ALS. Together with ALS centres and the pharmaceutical industry, people with ALS will stand together to find a better treatment for this devastating disease.

Download our user manual!


My Studies

Trial Location | Trial Name | Trial Sponsor | Your Status | Invitation date | Start date | Completion
---|---|---|---|---|---|---
ALS Centre UK | removepatient | Pharma 2 | Terminated | 1/27/2014 | | In Preparation
ALS-FRS-R

1. Speech
   - Normal speech processes
   - Detectable speech disturbance
   - Intelligible with repeating
   - Speech combined with nonvocal communication
   - Loss of useful speech

2. Salivation
   - Normal
   - Slight but definite excess of saliva in mouth; may have nighttime drooling
   - Moderately excessive saliva; may have minimal drooling
   - Marked excess of saliva with some drooling
• www.tricals.com

• A platform for patient-oriented research