



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Project MinE: an international ALS whole
genome sequencing initiative**

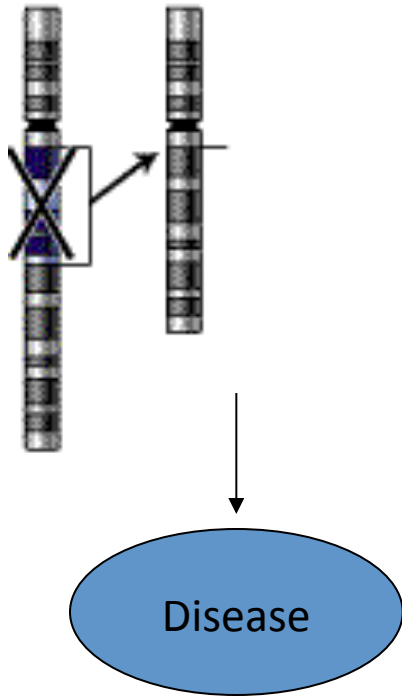
Leonard H van den Berg
UMC Utrecht, The Netherlands

Aim

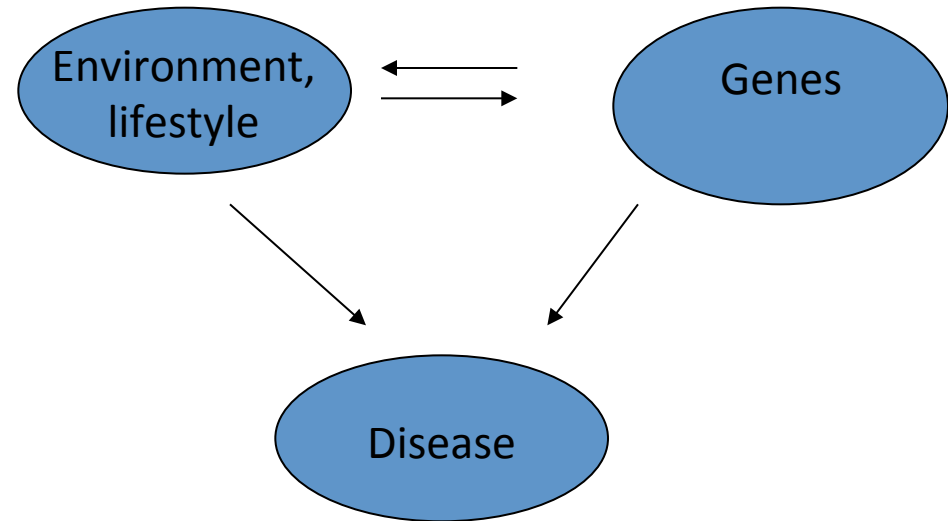
- To find an effective treatment and cure for ALS patients
- ALS one disease, one treatment
- ALS multiple diseases, multiple treatments
- Genetics: subgroups, stratification, disease mechanisms, biomarkers, disease models, etc

ALS

- Familial (Mendelian)



- Sporadic

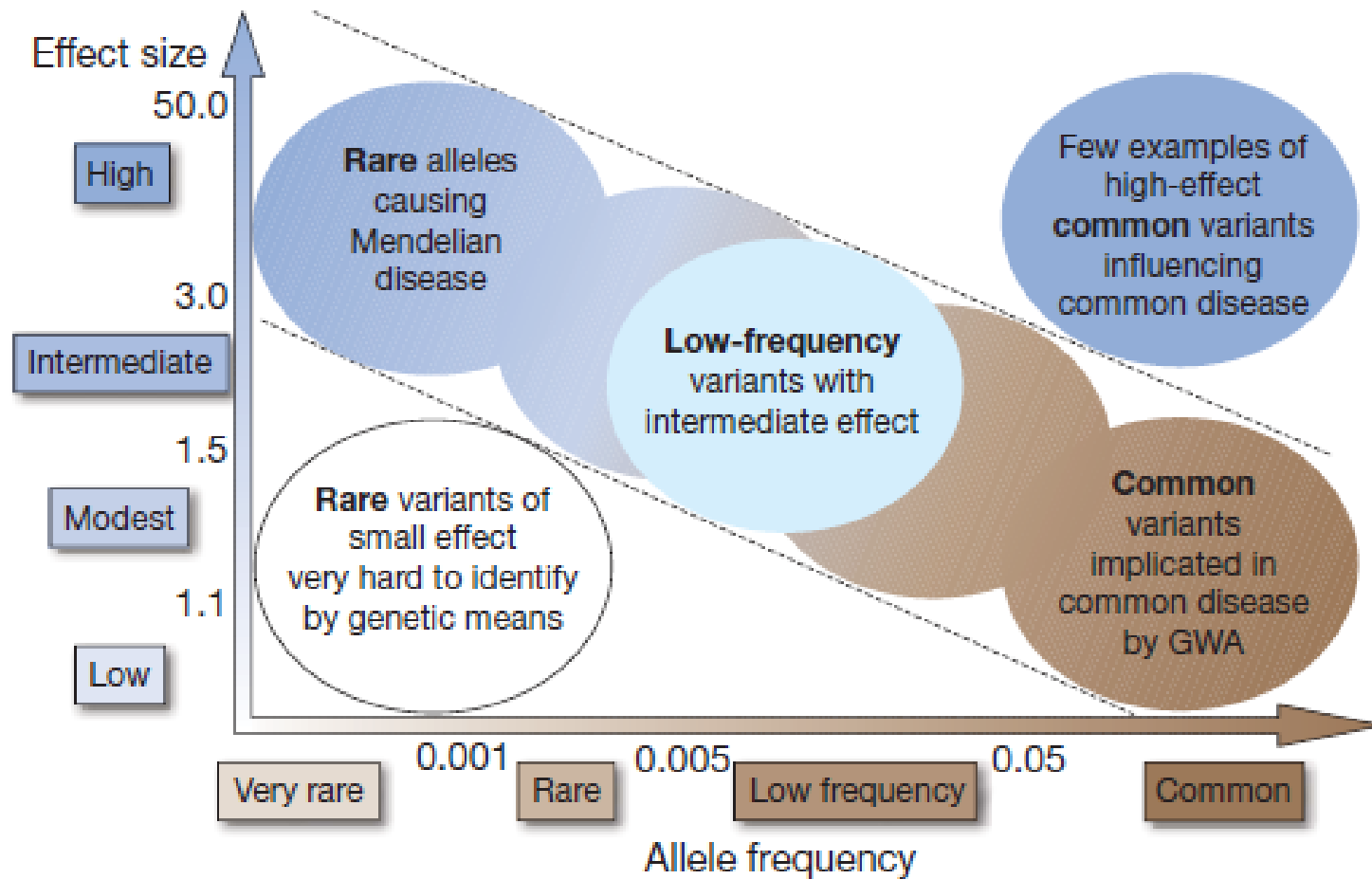


Twin studies: 61% heritability

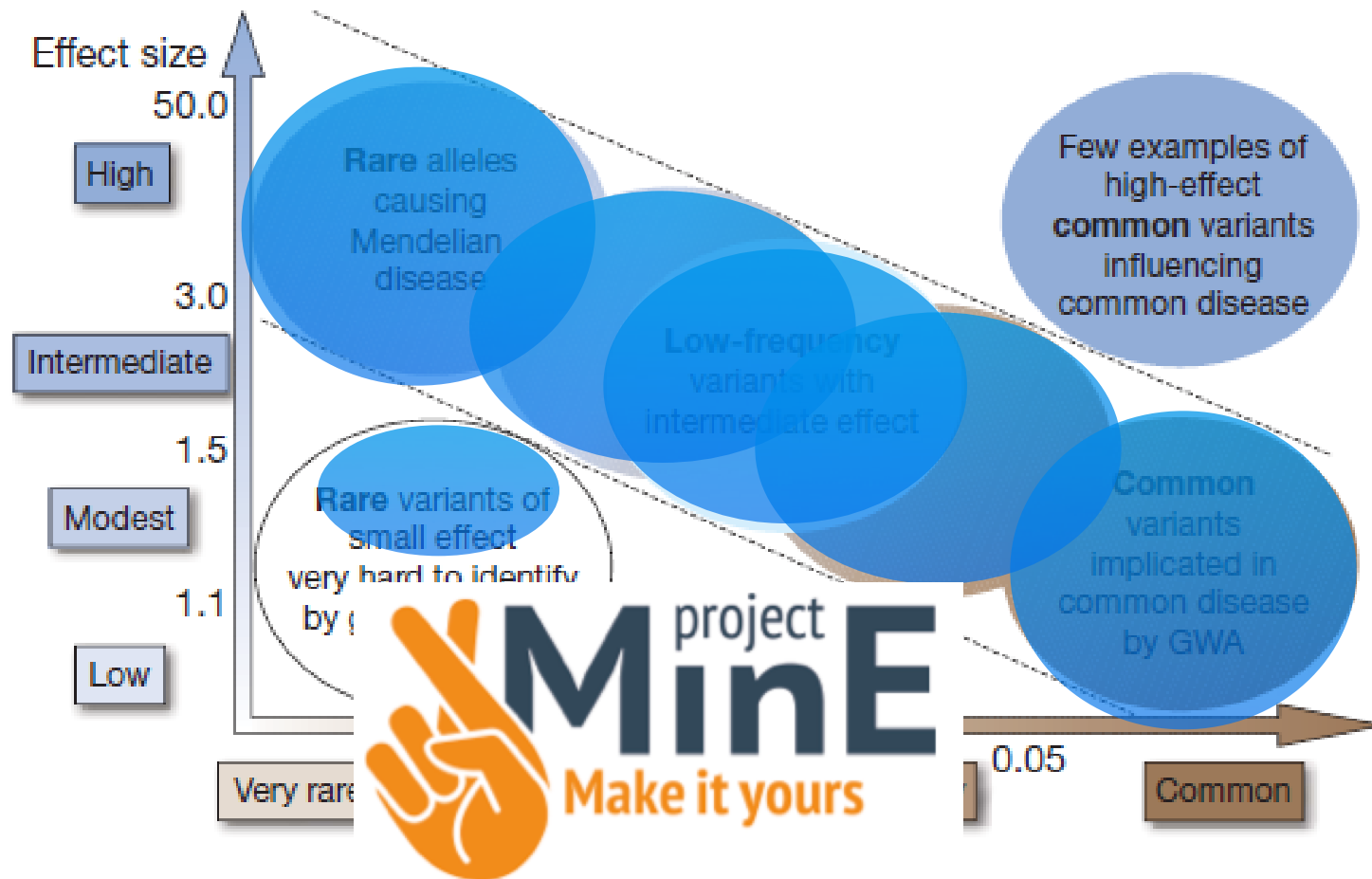
Aim Project MinE

- 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



International groundbreaking genetic ALS research

ALS patients have a life expectancy of 3 to 5 years. To understand the genetic basis of ALS and to ultimately find a cure for this devastating disease, we want to map the DNA profiles of at least 15,000 ALS patients and 7,500 controls.

goal
15,000 DNA profiles

14% raised
SEARCHING

collected so far
2,083.13 DNA profiles

We want to map the DNA profiles of 15,000 ALS patients.

Will you help us raise the funds to reach our goal?

Make it yours. 20088.000

Make a donation today

100 percent of all donations to Project Mine will go directly towards the mapping and analysis of DNA profiles.

 <p>Choose your own amount</p> <p>Donate €</p>	 <p>One chromosome</p> <p>Donate €75</p>	 <p>Four chromosomes</p> <p>Donate €300</p>	 <p>1/2 DNA profile</p> <p>Donate €975</p>	 <p>Full DNA profile</p> <p>Donate €1950</p>
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News

What is happening right now?

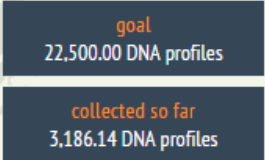
Project MineE: Make it yours!

Help us raise more funds by starting a campaign. Need inspiration? Check out [the current campaigns](#).

 Start your own campaign

Worldwide Project MinE

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



Sweden

18% of goal raised

293.40 RAISED

1,650.00 GOAL

[View country page](#)

Switzerland

4% of goal raised

21.32 RAISED

600.00 GOAL

[View country page](#)

Israel

3% of goal raised

6.67 RAISED

250.00 GOAL

[View country page](#)

United Kingdom

3% of goal raised

50.00 RAISED

1,800.00 GOAL

[View country page](#)

USA

39% of goal raised

384.73 RAISED

1,000.00 GOAL

[View country page](#)

Australia

4% of goal raised

35.95 RAISED

1,000.00 GOAL

[View country page](#)

Portugal

2% of goal raised

4.61 RAISED

400.00 GOAL

[View country page](#)

Ireland

1% of goal raised

0.37 RAISED

600.00 GOAL

[View country page](#)

Spain

2% of goal raised

11.64 RAISED

750.00 GOAL

[View country page](#)

Belgium

75% of goal raised

184.74 RAISED

750.00 GOAL

[View country page](#)

The Netherlands

74% of goal raised

2,192.71 RAISED

3,000.00 GOAL

[View country page](#)

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

- Project MinE Netherlands ALS Found Van den Berg, Veldink
- Project MinE UK MNDA Al-Chalabi, Shaw, Morrison
- Project MinE US ALSA Landers, Glass
- Project MinE Belgium ALS LIGA Robberecht, Van Damme
- Project MinE Ireland Irish ALS Hardiman
- Project MinE Australia MND Aus Blair, Kiernan
- Project MinE Switzerland Swiss ALS Weber
- Project MinE Israel Prize4life Gotkine
- Project MinE Spain FUNDELA Mora Pardina
- Project MinE Portugal APELA Carvalho
- Project MinE Sweden Neuroforb. Andersen
- Project MinE Italy ARISLA Chio, Silani
- Project MinE France ARSLA Corcia, Couratier
- Project MinE Germany Ger ALS Weishaupt
- Project MinE Turkey Turk. ALS Basak
- Project MinE

Where is Project MinE

- Consortium and datasharing agreement
- Core clinical dataset
- Environment/lifestyle questionnaire
- Legal issues
- Datastorage, computation power
- GWAS analyses ongoing
- 6000 genomes
- 16,500 to go.....







Video's



<http://www.youtube.com/watch?v=naxl74.JakQk&hd=1>



<http://vimeo.com/90307659>



<http://www.projectmine.com/country/belgium/>



https://www.youtube.com/watch?v=n9DEXVtsszI_-t=11

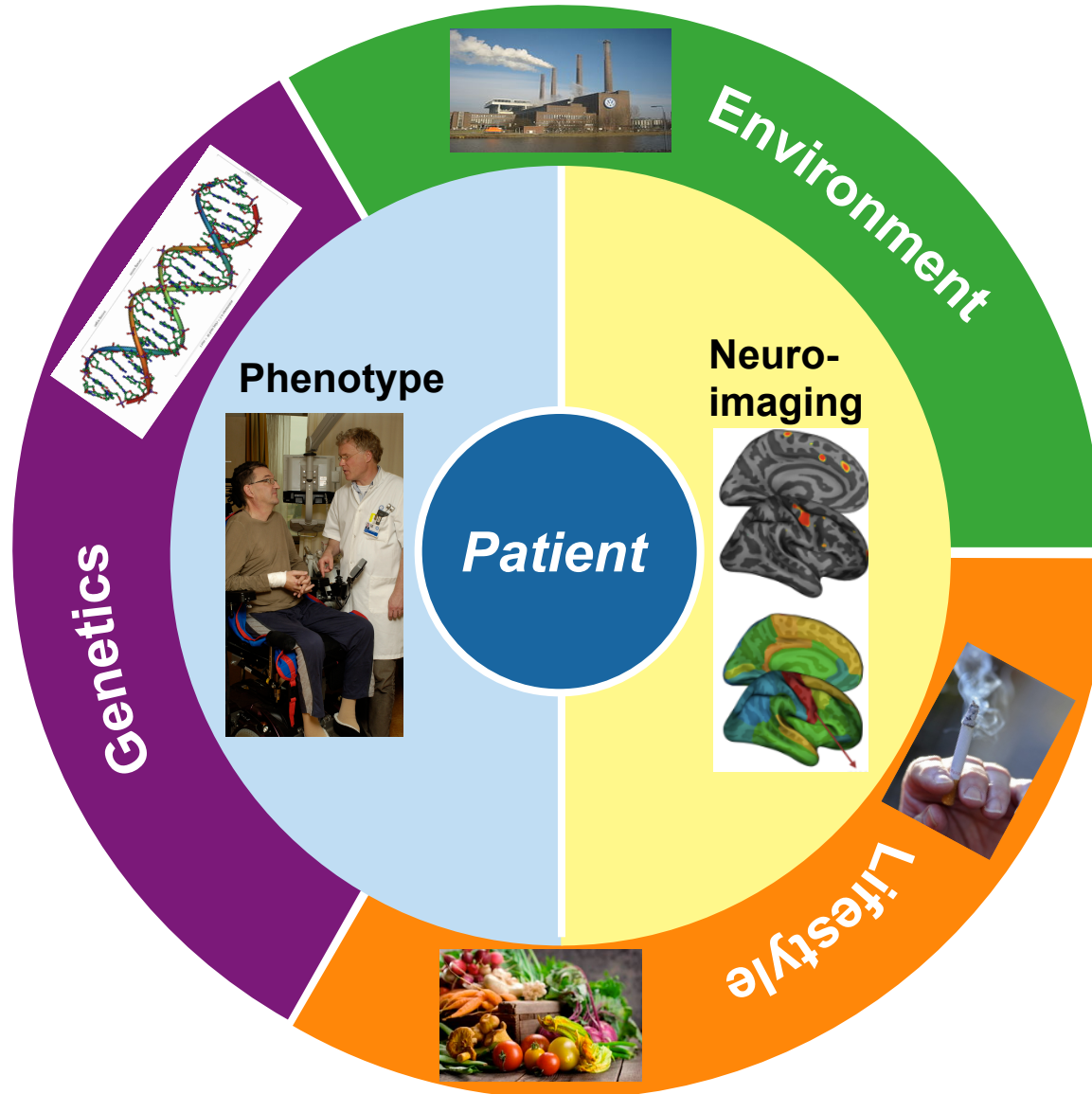


<http://pauwenwitteman.vara.nl/media/313165>



<https://www.youtube.com/watch?v=nJrMQ5Al4ro>

Unravel the complexity of ALS





TRICALS

Treatment Research Institute
for the Cure of ALS

ALS CENTERS

PEOPLE
WITH ALS

PHARMA &
BIOTECH



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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.

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Latest News

5/21/2014 [Teleurstellende resultaten Tirasemtiv](#)

5/21/2014 [Anti-epilepticum als mogelijke kandidaat-therapie voor ALS](#)

[More news...](#)

Homepage for patient



Treatment Research Institute
for the Cure of ALS

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Home

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!](#)

[TRICALS - User Manual Patients.pdf](#)

My Studies

[View Trial](#) 1 to 1 of 1

Trial Location	Trial Name	Trial Sponsor	Your Status ▲	Invitation date	Start date	Completion	Trial Status
ALS Centre UM	removepatient	Pharma 2	Terminated	1/27/2014			In Preparation

ALS-FRS-R



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ALS-FRS-R

Search

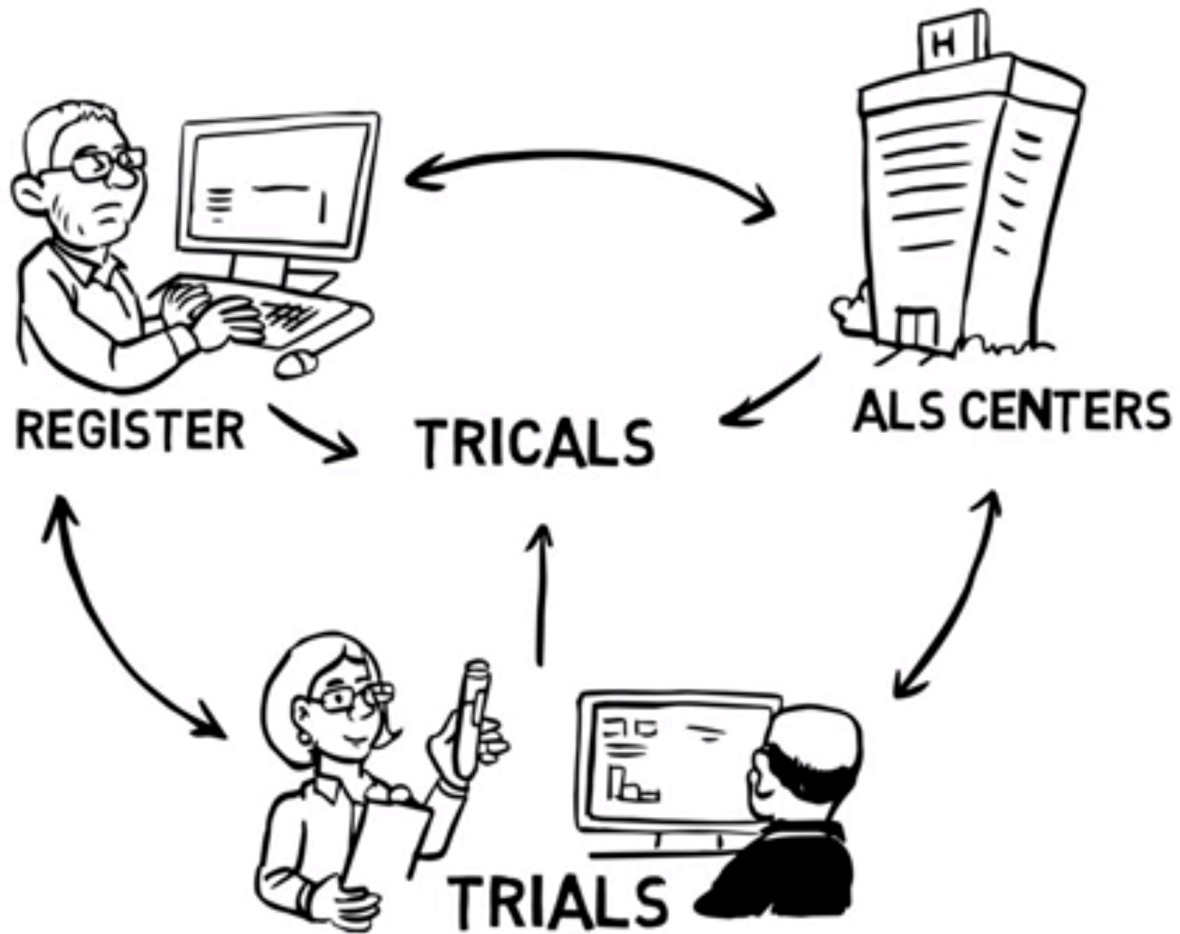


1 Speech

- 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



 www.projectmine.com

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 twitter.com/_MakeitYours