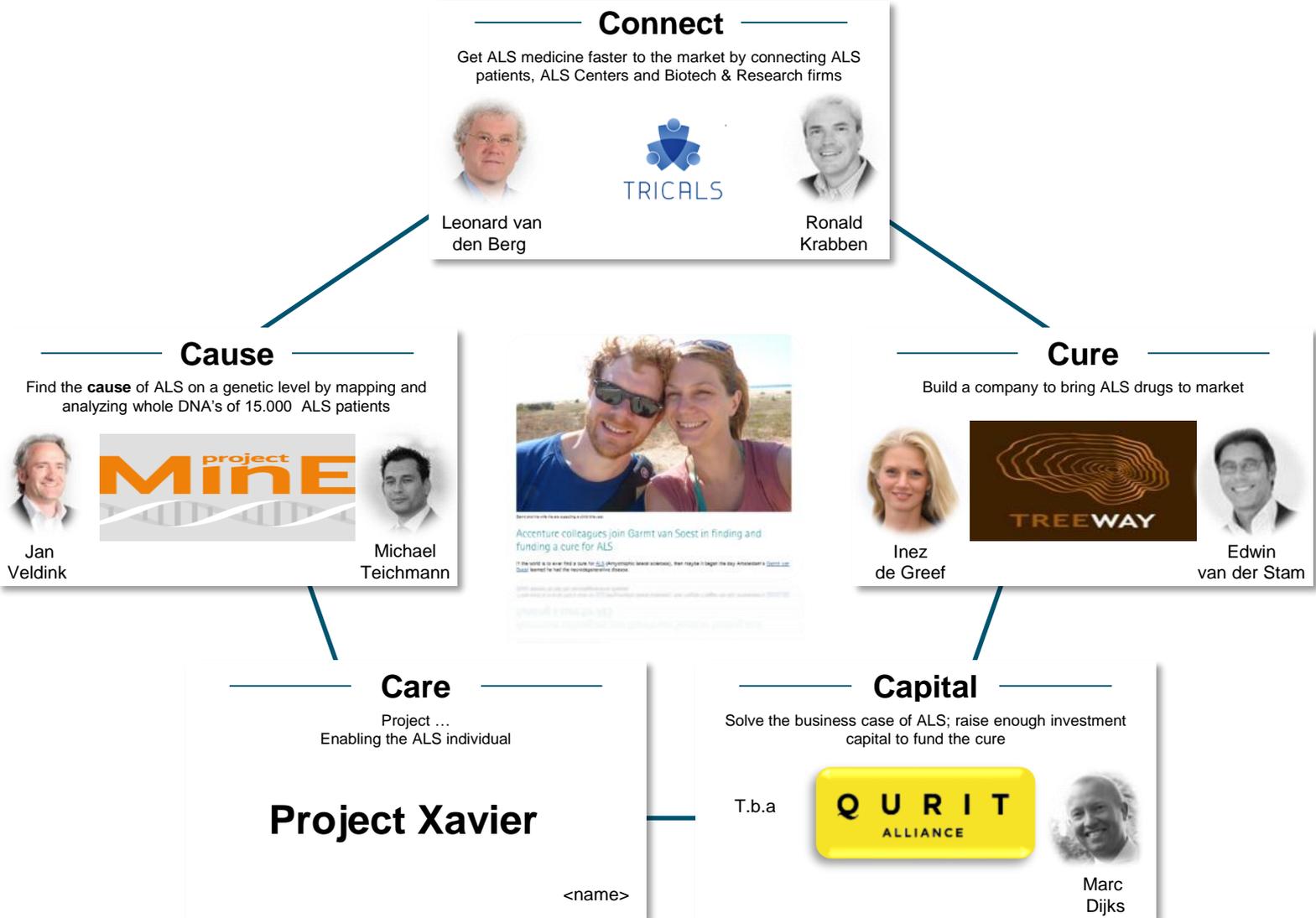


# ALS Initiatives Overview



# Introduction

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## Accenture colleagues join Garnt van Soest in finding and funding a cure for ALS – [Full story](#)

Garnt, an enterprise architect and application strategy senior manager in Accenture Strategy, was told in August 2013 he had ALS, also known as Lou Gehrig's disease or Motor Neuron Disease (MND).

It wasn't long before he made an impactful decision on how he would combat the fatal disease. As a matter of course, taking action in cooperation with his friends and colleagues in the Netherlands was a manifestation of Accenture on its best day.

Considering the reputation for scope and complexity of client engagements Accenture takes on, finding a solution to accelerate a cure for ALS seemed achievable to Garnt. He and Netherlands leadership quickly shifted into project mode. This wasn't just Garnt's disease to battle alone; they were all thinking big in their quest for a cure



Garnt joined two other ALS patients, Robbert Jan and Bernard to fight the battle head-on. The three, Garnt's colleagues, and two biotechnology industry experts, targeted the global investment/venture capital community to fund drug development that can generate up to US\$15 billion in returns. They collaborated on a strategy for an ALS investment fund, built a business case and operating model and wrote their "elevator" pitch.

In addition, Garnt has added himself to the Project MinE initiative. Project MineE is studying the cause of ALS at the genetic level by mapping and analyzing the entire DNA structure of 15,000 ALS patients—the largest genetic research project in the world today.

On another front, Accenture volunteers are working with world renowned ALS researcher Dr. Leonard van den Berg on an initiative to reduce the duration of clinical trials and thereby get ALS medicine faster to market by connecting patients, ALS centers and biotechnology and research firms.

In addition to these initiatives and the impending investment fund, there's another encouraging project getting off the ground. Ray Pijpers, client executive – Communications, Media & Technology, is working on a thought-controlled communications and home control device designed specifically for ALS patients in later stages of the disease. The resulting Project Xavier is finalizing a partnership with one of the largest electronics companies in the world to bring the device to fruition.

# Solve the business case of ALS; raise enough investment capital to fund the cure

*“To create a patient-driven investment fund and an ALS Center of Business Excellence to combine and accelerate BioTech start-ups”*



**Contact**  
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## External Team

External Partner	Team members
<b>Yet to be assigned!</b>	Bernard Muller Robbert Jan Stuit Inez de Greef Ronald van der Geest Bas Nagtzaam
Fund Manager	

## Accenture Team

Accenture Sponsor	Team members
 Marc Dijks	Garmt van Soest      Maria Dourouka Mark Jonker          Joseph Kamara Jeroen Mulder        Lucas Fung Yorgos Roussakis

### What has been done

- Strategic direction setting
- Target Operating model design
- Define value proposition
- Initial feedback rounds from industry
- Engage industry experts as coaches
- Organized ALS Investors Day

### Current status

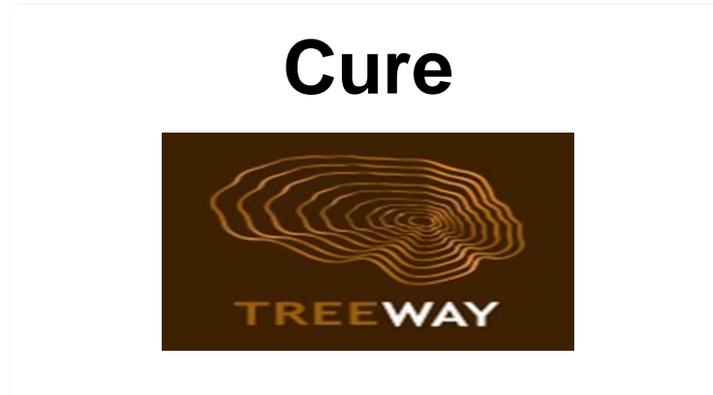
- Selection and recruitment of the fund manager by an industry expert
- Defining and creating the structure of the fund
- Defining the governance of the fund
- Developing business case

### What is needed

- Recruit Fund Manager
- Broaden online presence
- Increase media coverage

# Build a company to bring ALS drugs to market

*“Biotech company founded in 2012 by two ALS patients to accelerate ALS drug development. The goal is to move into clinical phase in 2014”*



**Contact**  
Edwin.van.der.stam@accenture.com

## External Team

### External Partner



Inez de Greef

### Team members

Robbert Jan Stuit  
Bernard Muller  
Ronald van der Geest  
Arjan Blaak

## Accenture Team

### Accenture Sponsor



Edwin van der Stam

### Team members

Garmt van Soest  
Michael Little

## What has been done

- Establish company
- Developed business plan
- Submitted grant request
- Initial market scan for potential compounds
- Initiated first clinical trial

## Current status

- Currently working on 4 promising compounds
  - Neuroprotection
  - Innate immune system
  - Co-development Adaptive immune system
  - Adaptive immune system

## What is needed

- TBD

# Find the cause of ALS on a genetic level by mapping and analyzing whole DNA's of 15.000 ALS patients

*“Project MinE – the largest genetics research project in the world today”*

## Cause



**Contact**  
Mike.van.Roon@accenture.com

### External Team

#### External Partner



Jan Veldink

#### Team members

Barbara Thuss  
Wouter van Rheenen  
Frank Diekstra  
Anne Visser

### Accenture Team

#### Accenture Sponsor



Michael Teichmann

#### Team members

Garnt van Soest  
Ron Evers  
Paul van der Linden  
Mike van Roon  
Myriam Kroll

### What has been done

- Requirement gathering for hardware needed to accelerating genome analysis
- Technical requirement gathering (incl. privacy & security)

### Current status

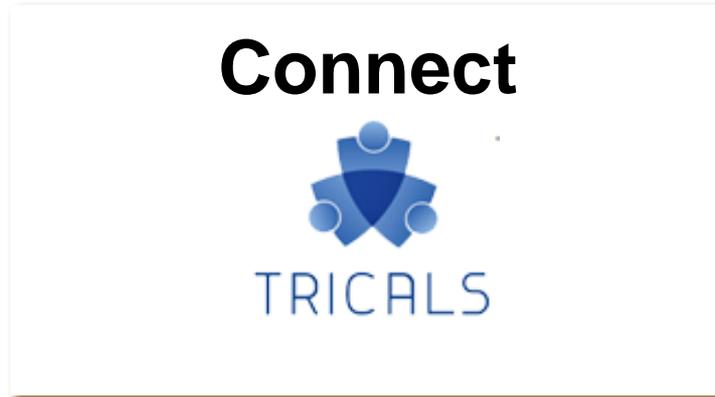
- Solution blueprinting with potential hardware vendors
- Vendor selection

### What is needed

- Agreement on objective for the initiative
- Agreement on requirements
- Project funding

# Get ALS medicine faster to the market by connecting ALS patients, ALS Centers and Biotech & Research firms

*“Setting up a digital platform to connect the ALS patients, ALS Centers and Biotech & Research firms to speed up the Clinical Trial process in order to get ALS medicine faster to the market”*



**Contact**  
Ronald.Krabben@accenture.com

## External Team

## Accenture Team

External Partner	Team members
 Leonard van den Berg	Dr. Sanne Piepers Barbara Thuss

Accenture Sponsor	Team members
 Ronald Krabben	Alexander Assink Bas van der Sommen Yasser Mdaghri Tinke Wesseling Murat Celik Pim Herlaar

### What has been done

- Digital platform value realization
- Build of the digital platform
- TRICALS platform tested and approved by the ALS Centre, Netherlands
- Telestration available used as communication asset to summarize the initiative

### Current status

- Testing by patients, ALS Centers in UK, Italy, Pharma & Biotech
- Creating brochures for patients
- Buy-in from Pharma & Biotech to participate
- Platform successfully tested by the stakeholders

### What is needed

- Set-up a foundation (TRICALS)

# Allow ALS patients to get back parts of their independence and improve quality of life

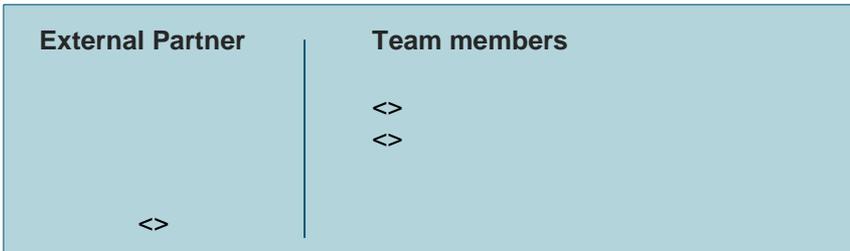
*“Project Xavier allows patients to get back parts of their independence and improve quality of life through the use of technology.”*



**Contact**  
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## External Team

## Accenture Team



### What has been done

- Initiation of project with external partner
- The Development Team and funds setup
  - Google Glass expertise
  - Android expertise

### Current status

- Developing prototypes into product
- License out access to technology/app
- Consortium of companies/spin off
- Open source the code and give it to the world

### What is needed

- <>

# Engage the local community to raise funds for ALS

*“Engage the local community to raise funds and awareness of ALS”*



**Contact**  
Berend.de.Jong@accenture.com

## External Team

External Partner	Team members
N/A	N/A

## Accenture Team

Accenture Sponsor	Team members
 Berend de Jong	Last year 40+ colleagues joined the city swim!

## What has been done

- Contact has been made with the organizers of the ACS
- Promotion for Accenture colleagues to join the swim is being developed and rolled out

## Current status

- Goal is to have over 100 people from Accenture join the Swim
- Accenture is looking into the possibilities of becoming an official sponsor

## What is needed

- A group of enthusiastic people, willing to swim in the Amsterdam canals to raise funds and increase ALS awareness

# Other Initiatives

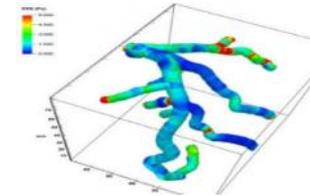
Understand how to best develop a Funding & Investment Strategy



Campaign to raise funds needed to sustain patient care services and support ALS research.



Improve collaboration on ALS theory by visualizing the disease in a 3d Model



Capture ALS news with an ALS Dashboard



Globalize the initiatives of ProjectMinE by expanding to new markets.



Universal collaboration of patients to join the fight against ALS. Rune Indrevoll (Managing Director of Accenture Norway) has also join the fight.



ALS – Wikipedia page



Linking patients to investigational medicines (potential cure) for ALS through ALS-ETF USA.



Developing the best eye-controlled keyboard at low cost

