ALS Initiatives Overview

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

Leonard van den Berg
Ronald Krabben

**Cause**
Find the cause of ALS on a genetic level by mapping and analyzing whole DNA’s of 15,000 ALS patients

Jan Veldink
Michael Teichmann

**Cure**
Build a company to bring ALS drugs to market

Inez de Greef
Edwin van der Stam

**Care**
Project ... Enabling the ALS individual

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

T.b.a
Marc Dijks

* ALS Initiatives Overview

* Connect

* Cause

* Cure

* Care

* Capital

* Project Xavier

<name>
Introduction

Accenture colleagues join Garmt van Soest in finding and funding a cure for ALS – Full story

Garmt, 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 Garmt. He and Netherlands leadership quickly shifted into project mode. This wasn’t just Garmt’s disease to battle alone; they were all thinking big in their quest for a cure.

Garmt joined two other ALS patients, Robbert Jan and Bernard to fight the battle head-on. The three, Garmt’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, Garmt 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”

Capital

External Team

<table>
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<tr>
<th>External Partner</th>
<th>Team members</th>
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| Yet to be assigned! | Bernard Muller  
|                  | Robbert Jan Stuit  
|                  | Inez de Greef  
|                  | Ronald van der Geest  
|                  | Bas Nagtzaam  

Fund Manager

Accenture Team

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<tr>
<th>Accenture Sponsor</th>
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|                  | Garmt van Soest  
|                  | Mark Jonker  
|                  | Jeroen Mulder  
|                  | Yorgos Roussakis  

Marc Dijks

External Partner

Team members

Yet to be assigned!

Fund Manager

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

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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”

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

External Team
- External Partner: Inez de Greef
- Team members: Robbert Jan Stuit, Bernard Muller, Ronald van der Geest, Arjan Blaak

Accenture Team
- Accenture Sponsor: Garmt van Soest, Michael Little
- Team members: Edwin van der Stam

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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”

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

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

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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”

Connect

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)

External Team

External Partner
Leonard van den Berg

Team members
Dr. Sanne Piepers
Barbara Thuss

Accenture Team

Accenture Sponsor
Ronald Krabben

Team members
Alexander Assink
Yasser Mdaghri
Tinke Wesseling
Murat Celik
Pim Herlaar

Bas van der Sommen

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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.”

Care

Project Xavier

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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

- <>

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Engage the local community to raise funds for ALS

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

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

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<td>Berend de Jong</td>
<td>Last year 40+ colleagues joined the city swim!</td>
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Contact
Berend.de.Jong@accenture.com

External Partner
N/A

Team members
N/A

Accenture Sponsor
Berend de Jong

Team members
Last year 40+ colleagues joined the city swim!
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