



Kind Beter

Business Plan Stichting Kind Beter (Foundation Child Well)

In cooperation with:



Kind Beter (Child Well)

Business plan to take on the
rare disease FoxP1 syndrome.



**Because every child deserves a
chance to get well!**

If only...

for Fenn



Inhoud

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Introduction

This document consists of a plan to finance the research for the cause and a possible cure for the rare disease FoxP1 syndrome as a starting point.

This is an initiative of the parents of Fenn Kloosterman.

The Hague,

Esther Kloosterman

André de Koning



Background

In 2012 our Fenn was born. At first he appeared to be a normal little guy, but soon we discovered that he was suffering from a rare genetic disease.

The genetic disorder on the FoxP1 gene has only been discovered a few years ago and there hasn't been any fundamental research at the cause or probable solutions.

Approximately 100 children around the world have been diagnosed with a variant of the FoxP1 syndrome. The severity of the symptoms are different and vary for each child.

Together with the medical university of Leiden (LUMC) a research programm has been defined. Funds need to be raised for this programm.

The Stichting Kind Beter (Foundation Child Well) has been brought to life to raise these funds.



Objective

Belief

A healthy and happy life for everyone.

Rare diseases are seen as an economical problem by institutes. Therefor any efforts made in working towards a cure for rare diseases, depend mainly on private initiatives.

Vision

We believe that, with the right effort, we can convince people to contribute to a solution for rare diseases.

Ambition

A solution for FoxP1 syndrome within five years.



Objective

First:

Raising funds for the research programm to the cause and possible cure to the rare disease FoxP1 syndrome

and

Financing possible medical treatment/medication for the cure of FoxP1 syndrome.

Second:

Screening possible simular disease which can be adressed for further analysis by this reseach.

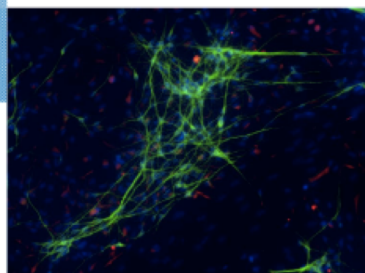
General:

Generating and maintaining relevant relations to accomplish these objectives.



Molecular mechanisms and gene targeting therapies for the Foxp1 syndrome

Ziektemechanismen en gentherapie voor het Foxp1 syndroom



Willeke M.C Van Roon-Mom, Department
Of Human Genetics, LUMC, 05-04-2018



2.3 Aims of this project

1. To create induced pluripotent stem cell lines carrying the FOXP1 p.R514H variant and a FOXP1 knock out cell line using CRISPR/Cas9.
2. Determine the role of FOXP1 protein during brain development using cerebral organoids from induced pluripotent stem cells.
3. Study the disease mechanism of the Foxp1 p.R514H variant in early brain development using cerebral organoids from induced pluripotent stem cells (See Figure 1).
4. Explore the potential of programmable adenine base editors (ABEs) to correct the G to A conversion in FOXP1 in genomic DNA.

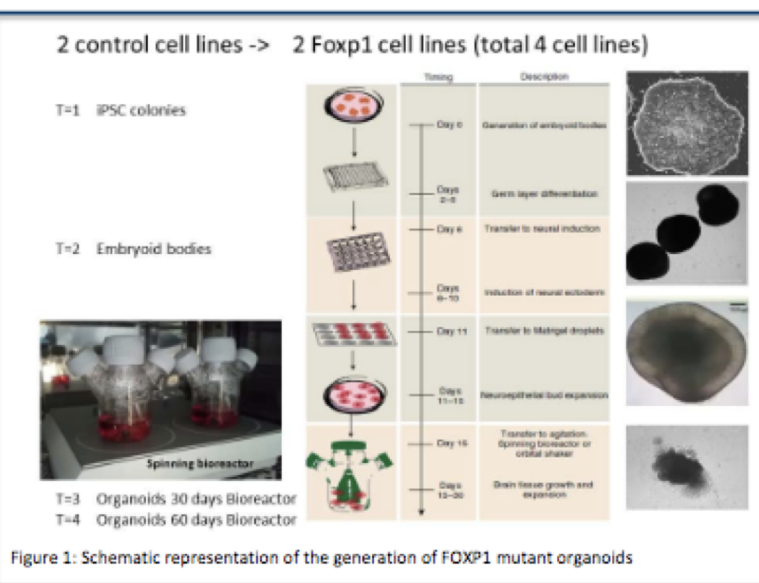


Figure 1: Schematic representation of the generation of FOXP1 mutant organoids

Organisation

To be able to have an independent and transparent process a Foundation has been brought to life. *The application of the ANBI (= Public Benefit Organization) status for our foundation, is in progress at this moment.*

The board contains of the parents of a FoxP1 child and an external advisor. *All members of the Stichting Kind Beter (Foundation Child Well) perform their activities without any payment.*

If a workforce would be installed, remuneration will be market conform.

*Stichting KindBeter (Foundation Child Well) will have the ANBI status (Public Benefit Organization). This means that Stichting Kind Beter is a non-profit organisation which has a 100% public interest objective. We do not receive state grants and are completely depending on donations and gifts of funds, private or business.

Organisation

Board members:

Esther Kloosterman

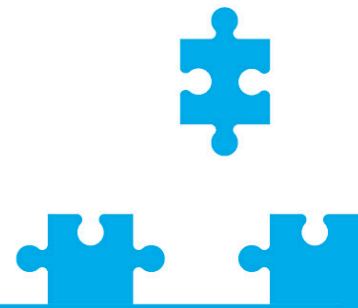
Secretary, mother Fenn

André de Koning

Chairmen, father Fenn

Wilko Korving

boardmember and controller



Budget LUMC

Research Costs LUMC	€ 245.000
Initial costs	no charge
Audit and account charges	no charge
Communication costs	no charges

Budgetplan:

2018 q2-2019 q4	€ 105.000
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Stichting Kind Beter (Foundation Child Well) is financially controlled by BWK administration in Zoetermeer, The Netherlands.

Budget LUMC

	Year 1				Year 2			
Tasks	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8
CRISPR/Cas cell line generation								
iPSC organoid culturing								
Immuno organoids								
RNAseq organoids								
Design ABEs								
Test ABEs in human cells								

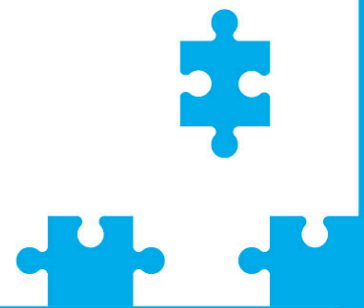
3.2 Budget

	Year 1	Year 2	Total
PostDoc salary (1.0 fte)			
Technician (0.2 fte)			
iPS cell culture			
scRNAseq			
Lab consumables			
Total cost			€245.000



Financial Policy

- Funds will not be invested or used for speculation.
- Financial control will be done by BWK administration in Zoetermeer, The Netherlands.



Fundraisingplan incl. planning

- | | | |
|-----|-------------------------------------------------------------------------------------------------------------------------------------|---------|
| 1. | Create own website with possibility to donate by Geef.nl | done |
| 2. | Create Facebook pagefor possible actions | done |
| 3. | Communicate with Funds like ZZF after approval of the ANBI status | Q2 2019 |
| 4. | Possible cooperation with Mount Sinai Hospital New York and the Seaver Institute New York (consult in juni during FoxP1 conference) | Q2 2019 |
| 5. | Start up Blog | Q3 2019 |
| 6. | crowd funding | Q3 2019 |
| 7. | PR research (no charge) | Q4 2019 |
| 8. | Link to a product/service– brand. | ? |
| 9. | Organizing of events. | ? |
| 10. | Link to an event. | ? |
| 11. | Look for an ambassador | ? |



Positioning

Kind Beter is a private initiative

Parents are the back bone

We want to address the disease with a light hearted and positive campagne

We don't push

Every contribution, no matter how small, is welcome



Contact and sources

Stichting Kind Beter (Foundation Child Well)

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Chamber of Commerce 71725261

RSIN/Fiscalnumber 858824693

<https://www.rareconnect.org/en/community/foxp1>





Kind Beter

Thanks for your attention!

