

# endParalysis foundation

## Annual Report 2017

March 2nd, 2018

# endParalysis foundation

## Introduction

- Non-profit organization registered in Eindhoven, The Netherlands, under kvk#59372087 and RSIN/fiscal number: 853446 313
-  The foundation has the ANBI status, enabling our donors to qualify for tax deduction in The Netherlands
- The foundation was officially launched on, and is operational since, June 27, 2014
- <sup>1</sup>
- The foundation's target is to accelerate research into curing chronic spinal cord injury, by:
  - (1) co-financing various goal-driven research projects with partners;
  - (2) promoting international collaboration and networking towards establishing a flexible roadmap to bridge the gap to cure.

More information to be found on our website: [www.endparalysis.org](http://www.endparalysis.org)

# Our achievements in 2017 (1/5)

## Research Funding & Information



### Fundraising and research funding:

We raised € 46,063 for research during the course of 2017 (coming on top of the >28,000 euro that were still available from previous years). Out of this amount:

- We have allocated €30,000- to the Chase-IT research project (on top of the €25,000- that we already allocated in 2015). The Chase-IT project is being implemented by Dr. Joost Verhaagen (NL) and Dr. Liz Bradbury (UK). See details about our donation as well as the aim and status of this project in Annex 1.
- The remaining amount will be allocated to another research project in the course of 2018. This second project is currently being selected.



### Informing patients about research progress:

We have again written an informative and well-underpinned report ([here](#)) on Progress & Prospects of SCI research in 2017 (Update June 2017- focus on Chronic SCI, translational research).

# Our achievements in 2017 (2/5)

## Advocating for cure research

### Science and Advocacy Symposium in the USA

We have actively participated (promoting an integral and targeted approach for research to cure Chronic SCI) during the [Working2Walk Science and Advocacy 2017 symposium](#). This symposium is a unique opportunity for patients to interact with researchers from the entire world and learn about the latest developments of SCI research.



### Disability and Advocacy congress in France

Thanks to her international profile, our foundation reaches out beyond borders. We participated in the French congress “Handicap, Garde ton cap” which was focusing on how to live and work with a handicap, and were happy to introduce the endParalysis foundation work. We defended the idea that accepting one’s handicap and making the best out of it can actually be coupled with fighting for a cure, if not for oneself, then for others.



# Our achievements in 2017 (3/5)

## Building cooperation with a new partner

### Nialls Foundation (thanks to fuelService.org)

We are very proud to introduce the Nialls Foundation as our new key funding partner starting as of 2017. The foundation was set up by Niall El-Assaad in the UK to support research into curing paralysis. It derives its funding from the profit generated by the social enterprise fuelService Ltd through commercializing the fuelService app in various countries of the world. The new app enables the drivers to locate a local petrol station to ensure that there will be an attendant able to help. The idea was the brainchild of Niall, who was fed up with struggling to refuel his car after being paralyzed in a cycling accident.



### More about the fuelService app:

The free fuelService app was recently introduced in a few countries around the world. Shell is the very first company to join the app in The Netherlands. Read more in Annex 2.

The endParalysis foundation thanks the Niall foundation for her very significant donation in 2017.



# Our achievements in 2017 (4/5)

## Event: raising funds & awareness

### Dancing for those who can't at Club Hifi Leiden – The Netherlands

In June 2017, [Club Hifi Leiden](#) organized an evening for the endParalysis foundation. All profits from the evening/night (€2,732) went to endParalysis and thus to research into curing chronic spinal cord injury. (Chase-IT research project as described in Annex 1). We are extremely happy with their choice and donation. This was also a great opportunity for endParalysis to raise awareness about the risk and consequences of spinal cord injury. We find it important that young people know how a spinal cord injury happens and how to prevent it by, for example, driving safely or not diving into shallow waters.



# Our achievements in 2017 (5/5)

## Visibility

- Our SEO (Search Engine Optimization) is progressing further to the top. The endParalysis foundation's website now systematically appears on the first page in Google search:

Language and Search key words	Ranking (Google search)
EN: "Spinal cord injury research"	Page 1 (middle)
EN: "Spinal cord injury research foundation"	Page 1 (middle)
EN: "Spinal cord injury cure"	Page 1 (second hit)
NL: "Dwarslaesie onderzoek (stichting)"	Page 1 (First and Second hit)
NL: "Dwarslaesie genezing/behandeling/herstel"	Page 1 (First, second and third hit)
NL: "Dwarslaesie stichting"	Page 1 (second , third and fourth hit)
FR: "Lesion medullaire fondation"	Page 1 (middle)

- [EndParalysis Facebook page](#) now has over **2000 Likes/followers**. Rating **4.8/5**
- [EndParalysis Twitter](#) now has **474 followers**
- [EndParalysis Youtube channel](#) now has over **6000 views**
- [Our latest endParalysis newsletter](#) was disseminated in December 2017, in 3 languages (EN-FR- NL). Subscribe [here](#)

# Thanks to our Donors and Sponsors

We thank our donors and sponsors for their financial and professional support this year:

[FuelService via the Nialls Foundation](#)

[Club Hifi Leiden](#)

[Multi-Adapt](#)

[SMART group](#)

[Bas Hoogendoorn](#)

[Fifty-one International Club \(Nord France\)](#)

[Seats2Meet Strijp S – Eindhoven](#)

[Sahare.nl](#)

[Senserius.com](#)

[Serenagravili.com](#)

[Ernstmedia.nl](#)

fuelService

SMART  
GROUP

MULTI ADAPT



SEATS2MEET  
STRIJP-S EINDHOVEN

SAHARE  
STUDIOS

senserius



SERENA GRAVILI  
*designer and investor*



ErnstMedia.nl

We also thank all the individual donors who have proven their confidence through their generous private donations.

# Tribute to Bas

Bas Hoogendoorn, a friendly, sociable 15-year old had an accident during school gymnastics. The teenager fell out of the rings and suffered a high (C4/C5) spinal cord injury. The additional complication of a scarred trachea required placement of a trachea cannula. For Bas, this was the start of a life filled with pain and constant medical care.

He tried to build a new life; even learned new skills and was working towards obtaining a Bachelor in Communication and Multi Media Design. Bas fought and held on for 10 long years but it eventually became too much for him to handle. Bas passed away on February 1<sup>st</sup>, 2017.



During his memorial funeral service, almost €1,700 were collected from donations. It was Bas and his family's decision to collect funds for spinal cord injury research instead of receiving flowers. **"Because it can happen to anybody, anytime!"**

The donations were handed over to endParalysis and were exclusively used to fund research into curing spinal cord injury (see annex 1). We sincerely thank Bas and his family for their trust in our foundation and their support to end paralysis.

# Our team, volunteers & partners

We thank all our team members for their active co-operation and support in making endParalysis a small but successful and impactful foundation. In alphabetical order: [Amina Abed](#) – [Elise Adriaanse](#) – [Dr. Mark Bacon](#) - [Jo Baltus](#) - [Jos Dekkers](#) – [Dr. Elly Hol](#) - [Jane Horsewell](#) – [Corinne Jeanmaire](#) – [Dr. v. Kuppevelt](#) - [Jaap Pipping](#) – [Chris Powell](#) –[Thierry Schmitter](#).- [Dr. Jerry Silver](#) – [Dr. Joost Verhaagen](#).

Also, a big “thank you” to our volunteers who work with us, on a regular basis, translating and enabling us to operate our website and communication in 3 languages, i.e. English, French, Dutch: [Eva Alexandra](#)- [Ron Kuijpers](#) - [Desiree Van Lieshout](#) - [Marc Renckens](#)- [Beverley Saunders](#) - [Fons Weijtens](#).

A special mention and thanks to our many supporters who have again helped us on ad hoc basis, in various fields: graphic design, communication, marketing, IT, video making, networking, translations , scientific research or simple but useful inspiration. In alphabetic order: [Jamie Becker's family](#), [William vd Berg](#), [Laure and Isabelle Beauquel](#), [Barbara Carlile](#), [AC D’Audigier](#), [Thierry Delrieu](#), [Serena Gravili](#), [Ali Hamzehei](#), [Ernst ter Horst](#), [Mohammed Kabbara](#).- [Sharon Mc Laughlin](#),, [Emre Sahare](#), [Harvey Sihota](#).

Last but not least, we thank our partner organizations: [Spinal Research \(UK\)](#), [DON \(NL\)](#), [U2FP \(USA\)](#), [ALARME \(France\)](#), [ESCIF \(Europe\)](#).

# 2017 Financial Report (1/3)

## Income

Income from donations:	2016	2017
• Donations from external donors, for research:	€ 20,631	€ 46,063
• Donations from internal donors (*) covering operational costs	€ 4,142	€ 3,556
	=====	=====
Total Income from donations:	€ 24,773	€ 49,619
Other income (interest from savings):	€ 37	€ 22
	=====	=====
Total Income:	€ 24,810	€ 49,641

(\*) The “internal donations” cover all the foundation operational costs, so that 100% of external donations go to research funding and none of the donors’ money is used for any other purpose than funding research.

In 2017, the “internal donations” originated from endParalysis Board Members as well as from the Maecenata Stiftung in Germany (€484 TGE gift).

Financial Report established by Jaap Pipping, Treasurer

# 2017 Financial Report (2/3)

## Expenditure

• Funding of Chase-IT translational research project (see Annex 1a- 1b)	€ 30,000
• Operation costs (100% covered by “internal donations”)*	€ 3,556
- Administrative costs :€798	
- Training and travelling costs €1059	
- Others: €1699	
	=====
Total expenditure	€ 33,556

*(\*) The “internal donations” cover all the foundation operational costs, so that 100% of external donations go to research funding and none of the donors’ money is used for any other purpose than funding research.*

*This year, the “internal donations” originated from endParalysis Board Members as well as from the Maecenata Stiftung in Germany (€484 TGE gift).*

# 2017 Financial Report (3/3)

## Balance sheet

### ASSETS

Current account ING	€ 505
Savings account ING	€ 44,141
PAYPAL account	€ 386

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TOTAL ASSETS	€ 45,032
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### LIABILITIES

Retained earnings	€ 45,032
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TOTAL LIABILITIES	€ 45,032
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# Annex 1a – CHASE-IT Research Project

- **What is the CHASE-IT Project:**

Laboratory studies have repeatedly shown that the Chondroitinase enzyme/protein can contribute to recovery after spinal injury. Among other effects, it helps dissolve the scar tissue that forms in the spinal cord after a lesion and promotes regeneration.

EndParalysis' partner Spinal Research (a UK charity) has initiated a program to ready the therapy for human trials. One of the challenges is administering the enzyme to the human spinal cord safely and effectively. The Netherlands Institute of Neuroscience has been working together with other labs in the UK to develop a vector (a carrier) that enables a very precise and controlled delivery. EndParalysis' contribution to the project so far: €25,000 in 2015 and €30,000 in 2017.

- **Progress so far (status December 2017):**

Since 2014, the CHASE-IT consortium has achieved several critical milestones by working on, and overcoming, many of the issues related to creating a safe gene therapy for chondroitinase:

- The gene for chondroitinase can now be expressed in an active form in human cells
- Expression of chondroitinase in the spinal cord can now be controlled, switching it on and off using an inducible switch responsive to the antibiotic doxycycline.
- Treatment gives rise to improved walking and unprecedented upper limb function in clinically-relevant spinal cord injury models.

- **Next translational steps:**

The results to date have relied on an experimental viral vector that has not been used clinically. This is one of the issues that will be addressed in the next stage of development, of which there are four parts.

- Demonstrate inducible chondroitinase gene therapy works in chronic injuries
- Transfer the inducible gene therapy machinery developed in the lentiviral vector to the more clinically-acceptable Adeno-associated viral (AAV) vector
- Eliminate any background expression of chondroitinase when system in the uninduced 'off' state
- Confirm chondroitinase-AAV retains comparable efficacy as chondroitinase-LV

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#### SPINAL RESEARCH OFFICIAL RECEIPT

I, being the Finance Manager of the International Spinal Research Trust, acknowledge to have received a donation to the value of €30,000 from the endParalysis foundation. I confirm that this donation will be restricted to the CHASE-IT project implemented by Dr Joost Verhaagen's lab in the Netherlands and Dr Liz Bradbury's lab in the UK.

Spinal Research is a registered charity, charity number 1151015

Signature: 

Katie Harvey (Finance Manager)

Dated: 4 December 2017

Chairman John Hick BA  
Honorary Treasurer Ian Curtis  
Executive and Scientific Director  
Dr Mark Bacon

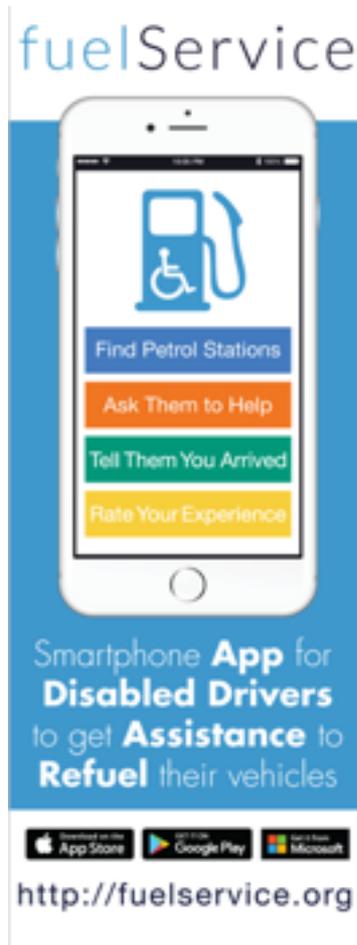
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# Annex 1.b Co-funding the CHASE-IT project

# Annex 2– fuelService app



The free fuelService app was recently introduced in a few countries around the world. Shell is the very first company to join the app in The Netherlands with 270 filling stations currently offering the service. With fuelService disabled drivers can:

- Find out which fuel-stations are likely to assist them,
- Enquire if the station can assist before driving there,
- Warn the staff as soon as they arrive at the pump,
- Rate the service offered by the station

The non-profit app is designed to help disabled people in many ways. It is free for all users but does nevertheless generate profit (from the annual license paid by the fuel stations / energy distributors). That profit is entirely redistributed, via the Nialls Foundation and its partners in various countries, to fund promising research project to cure paralysis, This allows companies like Shell to double their contribution to improve the lives of disabled persons. Read more over fuelService and **download the free app: [www.fuelService.org](http://www.fuelService.org)**