

EndParalysis foundation

Annual Report 2016

January 30, 2017

EndParalysis foundation

Introduction

- Non-profit organization registered in Eindhoven, The Netherlands, under kvk#59372087 and RSIN/fiscal number: 853546 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**
- 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

Our achievements in 2016 (1/5)

Fundraising and Advocacy for Research

Fundraising and research:

- The Chase-IT research project that we co-financed in 2015 is progressing well. Additional animal testing have shown that a gene-delivery of the Chondroitinase enzyme to dissolve the scar tissue and enhance neuroplasticity at chronic stage remains a very strong and promising therapeutic strategy. Read more in annex.
- The amounts we raised (>28.000 euro available on Dec. 31st, 2016) will be entirely allocated to research towards curing chronic spinal cord injury during the course of 2017.



Information, education and advocacy:

- We have again written an informative and well-underpinned report ([here](#)) on Progress & Prospects of SCI research in 2016 (Update May 2016- focus on Chronic SCI, translational research)
- We have actively participated (promoting an integral and targeted approach for research to cure Chronic SCI) in various top-level international scientific meetings/ symposia: [ISRT 2016 meeting](#) - [W2W 2016 symposium](#)

Our achievements in 2016 (2/5)

Visibility

- Our SEO (Search Engine Optimization) remains very good. The endParalysis foundation's website appears on the first or second page in Google search in many cases:

Language and Search key words	Ranking (Google search)
EN: "Spinal cord injury research"	Page 1 (middle)
EN: "Spinal cord injury research foundation"	Page 2 (middle)
EN: "Spinal cord injury cure"	Page 2 (top)
NL: "Dwarslaesie onderzoek (stichting)"	Page 1 (Second hit)
NL: "Dwarslaesie genezing/behandeling/herstel"	Page 1 (First hit)
NL: "Dwarslaesie stichting"	Page 1 (second hit)
FR: "Lesion medullaire fondation"	Page 1 (second hit)

- [EndParalysis Facebook page](#) now has over **1800 Likes/followers**. Rating **4.8/5**
- [EndParalysis Twitter](#) now has **380 followers**
- [EndParalysis Youtube channel](#) now has **5693 views**
- [Our latest endParalysis newsletter](#) was disseminated in November 2016, in 3 languages (EN-FR- NL). Subscribe [here](#)

Our achievements in 2016 (3/5)

Launching our “Unfreeze!” program

We have built a peer-2-peer fundraising platform on our website enabling any supporter to create and share their own challenge/project page and to easily raise funds, for endParalysis (online and without any extra transaction cost from the platform).

Paralysis concerns us all. By participating in our Unfreeze! challenges, our supporters have the opportunity to improve their own life while helping the endParalysis foundation raise funds (of which 100% go to research towards curing spinal cord injury), The challenges are open to everyone whether able-bodied or not, around the themes “Unfreeze your body” or “Unfreeze your mind” . Various [inspiring examples](#) are now available on our website. See more about the program [here](#).

Our team and supporters have been able to raise over 17.000 euro in 2016, through our Unfreeze! program. We thank them for their involvement!

Unfreeze!



Photo: Sean Stephens

Our achievements in 2016 (4/5)

Donors and Sponsors

We thank our donors and sponsors for their financial and professional support in 2016:

[Multi-Adapt](#)
[SMART group](#)

[Fifty-one International Club \(Nord France\)](#)
[Seats2Meet Strijp S – Eindhoven](#)

[Sahare.nl](#)
[Senserius.com](#)
[Serenagravili.com](#)
[Eldesign.cz](#)
[Ernstmedia.nl](#)
[Osteopathie Smolders](#)
[Lika Skincare](#)
[Ribotas](#)

MULTI ADAPT

SMART
GROUP



SEATS2MEET
STRIJP-S EINDHOVEN

SAHARE
STUDIOS

senserius  eldesign

SERENA GRAVILI
Artisan and Designer

 ErnstMedia.nl



lika SKINCARE

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

Our achievements in 2015 (5/5)

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 2016- In alphabetical order: [Amina Abed](#) – [Elise Adriaanse](#) - [Dr Mark Bacon](#) - [Jo Baltus](#) - [Jos Dekkers](#) - [Dr Elly Hol](#) - [Jane Horsewell](#) – [Corinne Jeanmaire](#) - [Dr v. Kuppeveld](#) - [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: [Fons Weijtens](#) - [Desiree Van Lieshout](#) - [Beverley Saunders](#)

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: [Eva Alexandra](#), [Jamie Becker's family](#), [William vd Berg](#), [Laure and Isabelle Beauquel](#), [Jan Bommerez](#), [Barbara Carlile](#), [AC D'Audigier](#), [Thierry Delrieu](#), [Serena Gravili](#), [Ali Hamzehei](#), [Ernst ter Horst](#), [Dick Janssen](#), [Sharon Mc Laughlin](#), [Marc Rencksen](#), [Emre Sahare](#), [Harvey Sihota](#), [Eliska Slovakova](#), [Polett Villata](#). [Mymza Wever](#).

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

2016 Financial Report (1/2)

Income

Income from donations:

- External donations: Euro 20,631
- Internal donations (*) covering costs: Euro 4,142

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Total Income from donations: Euro 24,773

Other income (interest from savings): Euro 37

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Total Income: Euro 24,810

() The internal donations (made by foundation board members) cover the foundation 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.*

Financial Report established by Jaap Pipping, Treasurer

2016 Financial Report (2/2)

Bank Account Data

Bank account- balance on December 31st, 2016:

• ING Current account:	Euro 171
• ING Savings account:	Euro 28,619
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Total ING:	Euro 28,790
• PAYPAL account (balance on Jan 10th 2017)	Euro 157
• Grand Total:	Euro 28,947

*Financial Report established by Jaap Pipping,
Treasurer*

Annex – CHASE-IT Research Project

Progress (1/1)

- **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 (UK) 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.

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

Ch'ase delivery by gene therapy (using gene therapy vectors from Prof Joost Verhaagen and Dr. Liz Muir) has been shown to be effective in rats to promote functional recovery in both thoracic and cervical contusion injury paradigms. The latest animal studies (in 2016 by Liz Bradbury's group), showed that longer term administration of Ch'ase led to more significant motor control improvement (*).

- **Next steps:**

So far Ch'ase therapy has shown to be safe through the various pre-clinical trials. Nevertheless, more safety studies are necessary including toxicology before the therapy is ready for human trials. Given all of the results obtained so far with Ch'ase, including other pre-clinical studies (**), further therapy optimization and therapeutic window experiments, (such as the use in chronic injury and possible combination with other therapies) should also be planned.

(*) (**): see next page.

Annex – CHASE-IT Research Project Progress (2/2)

(*) Key details of the study (Regulateable Chondroitinase ABC gene therapy as a treatment for spinal cord injury):

- Injuries: rats with clinically-relevant contusion cervical injuries.
- Therapy: Ch'ase ABC 's administration through a lenti-virus vector switched-on at acute timing and alternatively switched off after 2.5 weeks or after 8 weeks.
- Results: especially the grasping capability of the rat was improved by a longer administration of Ch'ase).

(**) Other pre-clinical studies using Ch'ase:

- Ch'ase + Schwann cells: gene therapy in combination with Schwann Cells was also applied to two non-human primates (acute and sub-acute-14 days SCI) by the Miami Project, with very significant motor control improvement
- Dog clinical trial: Ch'ase direct delivery (without gene-therapy) was tested in a dog clinical trial (chronic SCI). That trial has shown that Ch'ase direct administration was safe. It also showed some functional recovery level, but maybe not significant enough for human trials.