

EndParalysis foundation Annual and Financial Report Year 2015

Established by Jaap Pipping, Treasurer,
January 30, 2016

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 get 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 some 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 2015 (1/6)

Research

- Co-financing of the Chase-IT Research Project, **at the level of 25,000 Euro** (see information on the project and progress in Annexes 1 and 2).



Picture: April 2015 - Professor Joost Verhaagen (NIN- Amsterdam), receives, on behalf of the CHASE-IT project consortium, a 25,000 euro cheque from endParalysis president Corinne Jeanmaire.

Our achievements in 2015 (2/6)

Research and Advocacy

- An informative and well-underpinned report ([here](#)) on Progress & Prospects of SCI research in 2015 (focus on Chronic SCI, translational research)
- Active participation (promoting an integral approach for research to cure Chronic SCI) in various top-level international scientific meetings/symposia: [ISRT network meeting](#) - [W2W symposium](#) – [ISCORE](#)
- Close co-operation with Dr J. Verhaagen leading to our selection in the Dutch “Medical Inspiration” competition. We reached 2nd place out of 12 pre-selected candidates
- Our Video describing the cooperation project: 80,000 views and almost 6000 Likes on Facebook. Here is a [Youtube short version](#)
- C. Jeanmaire, endParalysis Founder and President, received the “Cure Advocate Award” from U2fP during the Washington Working2Walk Scientific symposium. Read [more](#)

Our achievements in 2015 (3/6)

Increasing Visibility

- Largely improved SEO (Search Engine Optimization). EndParalysis foundation's website now appears on the first or second page in Google search in many cases:

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

- [EndParalysis facebook page](#) now has over **1600 Likes/followers**.
- [Our first endParalysis newsletter](#) was sent in June 2015. Subscribe [here](#)

Our achievements in 2015 (4/6)

Media and Events

- EndParalysis in the spotlight (media):
 - NL: [Groot Eindhoven - Omroep Brabant- ED.nl](#)
 - FR: [La Voix du Nord – L'Observateur du Cambresis](#)
- EndParalysis participated in the following events (with a booth, a presentation/a pitch...):
 - Open2Share Seats2Meet Strijp S (booth and lottery event)
 - Eindhoven Start-up Summit Conference (booth and pitch)
 - Business Borrel Eindhoven (pitch)
 - Spinal Cord Injury Community Reunion day in Haren (booth)
 - Spinal Cord Injury Dutch Association Day in Ede (booth)
 - Club 51 International Cambrai (France – presentation)
 - Seats2meet Jubileum (booth and donation box)
 - Roll-on and Multi-adapt open door (booth and lottery)

Our achievements in 2015 (5/6)

Donors and Sponsors

We thank our donors and sponsors for their financial and networking support in 2015:

- [Van Hooff Intertransport](#)
- [SMART group](#)
- [DASIO consulting](#)
- [Ernstmedia.nl](#)
- [Senserius.com](#)
- [Rotary Club Uden](#)
- [E-bullition.com \(agence print et web\)](#)
- [Serenagravili.com](#)
- [Fifty-one International Club \(Nord de la France\)](#)
- [Seats2Meet Strijp S – Eindhoven](#)
- [Multi-Adapt](#)
- [Lika Skincare](#)
- [Ribotas](#)

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

Our achievements in 2015 (6/6)

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 2015): In alphabetical order: **Amina Abed – Elise Adriaanse - Dr Mark Bacon - Jo Baltus - Jos Dekkers - Dr Elly Hol - Jane Horsewell - Dr v. Kuppeveld - Jaap Pipping – Chris Powell - Ruth Purves –Thierry Schmitter.- Dr Jerry Silver – Dr Joost Verhaagen- Jos Vd Wouw***

We also want to give a big thanks to the many volunteers and supporters who have helped us tremendously during this year in various fields: graphic design, communication, marketing, video making, translations. In alphabetic order: **Jan Willem Alphenaar, Jamie Becker family, William vd Berg (senserius.nl), Jan Bommerez, Thierry Delrieu, Marianne Driessen, Damien Fournier, Serena Gravili (serenagravili.com) - Ernst ter Horst (Enstmedia.nl), Ameli Icli family, Mattie's family, Dick Janssen (www.ideeenlab.nl), Jasmin Koskiranta, Desiree Van Lieshout, Marc Rencksen, Emre Sahare (Sahareimaging.nl), Beverley Saunders, Helma Schellen, Dennis Tesolat, Liesbeth Tillemans, Mymza Wever, Joop Wenstedt, Esther Wensveen.**

Last but not least we thank our partner organizations: **Spinal Research (UK), DON (NL) , U2FP (USA), ALARME (France), ESCIF (Europe)** and other friend organizations who have supported our efforts during this year and have greatly contributed to our success, such as **CureGirls , GUSU4cure.org, Pushingboundaries.org...**

**We are sorry to announce that one of our board members, Mr Jos vd Wouw, our secretary, lawyer by profession passed away in 2015. He was involved from the very onset of the foundation and was extremely enthusiastic about it but was soon prevented by health issues. Jos has not yet been replaced. More info about our organization [here](#).*

2015 Financial Report (1/2)

Income

Income from donations:

- External donations: Euro 22,362.05
- Internal donations (*) covering costs: Euro 4,484.04

Total Income from donations: Euro 26,846.09

Other income: Euro 0.00

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Total income: Euro 26,846.09

() 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.*

2015 Financial Report (2/2)

Bank Account Data

Bank account saldo on December 31st, 2015:

• Current account:	Euro 1,766.41
• Savings account:	Euro 6,401.22
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Total:	Euro 8,176.63

Annex 1 – CHASE-IT Research Project Progress

- **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 is working together with other labs in the UK to develop a vector (a carrier) that will enable a very precise and controlled delivery.

- **Progress so far (status January 2016) :**

Professor Verhaagen's lab has now produced a viral vector that expresses Chondroitinase in a regulated way (it can be switched on and off when needed so that the timing and quantity of the enzyme can be controlled to the spinal cord in the most optimal way). The gene vector is based on the AAV (adeno-associated viral) vector, which is already used clinically, reducing many safety concerns.

The vector is now being tested in Professor Liz Bradbury's lab (Kings College, UK) on rats with clinically relevant spinal cord injuries, to check the treatment's effectiveness *in vivo*. The next step will be to test the therapeutic gene vector in injured rats at chronic time points to confirm potential benefits for patients with long-standing injuries and establish the best therapeutic window for the treatment.

More info on the project [Here](#)

Annex 2 – Our financial contribution

International Spinal Research Trust
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SPINAL RESEARCH OFFICIAL RECEIPT

I being the Trust Manager of the International Spinal Research Trust acknowledge to have received a donation to the value of €25,000 from the EndParalysis Foundation and confirm that this donation will be restricted to co-financing the CHASE-IT project and specifically Professor Joost Verhaagen at the Nederlands Herseninstituut.

Spinal Research is a registered charity, charity number 1151015

Signature: _____

A handwritten signature in black ink, appearing to read "James Clark", written over a horizontal line.

James Clark (Trust Manager)

Dated: 15/04/2015

Chairman John Hick BA
Honorary Treasurer & Scientific Director Ian Curtis
Dr Mark Bacon
Chairman Strategic Advisory Committee
Dr Mark Bacon

Chairman Grant Advisory Committee
Prof Sue Barnett BSc, PhD FSB
Honorary Scientific Advisors
Prof Frank Walsh PhD
Dr Ruth McKernan CBE

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