

**endParalysis foundation**

**Annual Report  
2018**

**May 20, 2019**

# endParalysis foundation

## Introduction

- Non-profit organization registered in Eindhoven, The Netherlands, under kvk#59372087 and RSIN/fiscal number: 853446 313
- The foundation has the  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](http://www.endparalysis.org)

# Our achievements in 2018 (1/5)

## Research Funding & Information



### Research funding:

During 2018, we have contributed €40,000- to the CRP Research Project. See details about our donation as well as the aim and status of this Project in Annexes 1 and 2. Furthermore, we provide an update about the Ch'ase IT Research Project (for which we provided funding in 2015 and in 2017). See latest progress report in Annex 3.



### Informing patients about research progress:

We have again written an informative and well-underpinned report on Progress & Prospects of SCI research globally (See our latest update [here](#), with focus on Chronic SCI, translational research).

# Our achievements in 2018 (2/5)

## Global Advocacy for More / Better SCI research

### Europe: Interview by Health Europa Quarterly

In February 2018, the endParalysis foundation told *Health Europa Quarterly* why, despite the hurdles, she's optimistic that a cure will one day be found, and why it's vital that policymakers start paying more attention to SCI research. Read more in this [article](#).



### North America: Open Letter to the National Institute of Health

In December 2018, Corinne Jeanmaire sent [an open letter to Lyn Jakeman](#) of the NIH, in order to influence research priorities, which were going to be discussed during the meeting “SCI 2020: Launching a Decade for Disruption in Spinal Cord Injury.” The letter was widely spread in the social media and led to re-discussing the agenda of the meeting and the priorities of research, with a the need for more focus on repair/regeneration targets applied to chronic spinal cord injury. The discussion is continuing in 2019 and endParalysis continues to feed in the debate.



# Our achievements in 2018 (3/5)

## Contributing to [www.scitrials.org](http://www.scitrials.org)

**A website for patients to easily find and better understand SCI clinical trials**



There is no cure (as yet) or treatment to reverse spinal cord injury. However, more and more experimental therapies are ready for testing on patients. Scientifically-driven trials, unlike commercial therapies (for which patients have to pay), do contribute to progress towards finding effective treatments. Therefore, it is important that recruitment of patients for those clinical trials take place as smoothly as possible. It is also essential that all be informed of the risks and potentials linked to participating in any of those trials. The purpose of [scitrials.org](http://scitrials.org) is to inform patients, their family (and clinicians) about the current and upcoming trials on a global basis and to provide understandable information about each of them. The endParalysis foundation is happy and proud to be one of the organisations contributing to developing this new resource.

*Disclaimer: The website is purely informational. The endParalysis foundation does not endorse or recommend participating in any trial listed on the website.*

# Our achievements in 2018 (4/5)

## Raising funds & awareness

### Walking for those who can't – “Unfreeze!” Challenges

In 2018 we continued to help people raise funds (and awareness) for spinal cord injury research, through our fundraising platform, by which anyone can set up their own personal challenge, create and share their fundraising page. A great example of this is the Unfreeze your Body challenge of Elise and Steef. In September 2018, they decided to walk to Santiago de Compostela and raised over €4000 for endParalysis, all of which was allocated to SCI research.

Take a challenge!  
Unfreeze!

See [Elise & Steef](#) challenge: still open for [donations](#)

Do you want to see more challenges: [Get inspired](#)

Create your own fundraising challenge page: [here](#)





# Our achievements in 2018 (5/5)

## Visibility

- Our SEO (Search Engine Optimization) remains very good. The endParalysis foundation's website now systematically appears on the first page in Google search, in all three languages of our site:

Language and Search key words	Ranking (Google search)
EN: "Spinal cord injury research"	Page 1 (second half)
EN: "Spinal cord injury research foundation"	Page 1 (bottom)
EN: "Spinal cord injury cure"	Page 1 (second half)
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: "Recherche Lesion medullaire fondation"	Page 1 (second hit)

- [EndParalysis Facebook page](#) now has over **2100 Likes/followers**. Rating **4.8/5**
- [EndParalysis Twitter](#) now has **560 followers**
- [EndParalysis Instagram](#): New! (140 followers) Follow us [here](#)
- [EndParalysis Youtube channel](#) : over **6800 views** in total
- [Our latest endParalysis newsletter](#) was disseminated in July 2018, in 3 languages (EN-FR- NL). Subscribe [here](#)



# Thanks to our Donors & Sponsors

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

[FuelService via the Nialls Foundation](#)

**fuelService**

[Multi-Adapt](#)

**MULTI ADAPT**

[Seats2Meet Strijp S – Eindhoven](#)



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**senserius**



**SERENA GRAVILI**  
*designer and creator*

**SAHARE**  
**STUDIOS**



**ErnstMedia.nl**

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

# Tribute to Jane Horsewell



Jane Horsewell, President of ESCIF (European Spinal Research Federation) passed away in August 2018.

Jane, we at endParalysis are so thankful for your contribution. You made the cooperation between ESCIF and the endParalysis foundation possible when it was not a given. Much respect for your openness and for everything you fought for and accomplished. A lot of sadness for the loss of such a kind and compassionate spirit. You will be missed. Corinne Jeanmaire, president of [endParalysis.org](https://endParalysis.org)

# 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. Janneke Stolwijk - 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 - Desirée 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: William vd Berg, Laure and Isabelle Beauquel, Barbara Carlile, Thierry Delrieu, Serena Gravili, Ernst ter Horst, Mohammed Kabbara.- Emre Sahare, Harvey Sihota, Paolo Cipolla, The Cure Girls.

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

# 2018 Financial Report (1/3)

## Income

Income from donations:	2016	2017	2018
-Donations from external donors, for research:	€ 20,631	€ 46,063	16,031
-“Internal donations”(*) covering operational costs	€ 4,142	€ 3,556	1,502
	=====	=====	=====
Total Income from donations:	€ 24,773	€ 49,619	€ 17,533
Other income (interest from savings):	€ 37	€ 22	€ 29
	=====	=====	=====
Total Income:	€ 24,810	€ 49,641	€ 17,562

(\*) The “internal donations” cover all the foundation’s 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 2018 the “internal donations” originated from endParalysis Board Members as well as from the Maecenata Stiftung in Germany (€285 TGE gift in 2018)

Financial Report established by Jaap Pipping, Treasurer

# 2018 Financial Report (2/3)

## Expenditure

	2017	2018
• Funding of research projects (2018: see Annex 1 and 2)	€ 30,000	€ 40,000
• Operation costs (100% covered by “internal donations”)* Detail for 2018:	€ 3,556	€ 1,502
	=====	=====
Total expenditure	€ 33,556	€ 41,502

(\*) The “internal donations” cover all the foundation’s 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” covering operational costs originated from endParalysis Board Members as well as from the Maecenata Stiftung in Germany (€285 TGE gift in 2018).

# 2018 Financial Report (3/3)

## Balance sheet

### ASSETS

Current account ING*	€ 12,679
Savings account ING*	€ 5,170
PAYPAL account*	€ 3,242
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TOTAL ASSETS	€ 21,091

### LIABILITIES

Retained earnings	€ 21,091
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TOTAL LIABILITIES	€ 21,091

(\*) balance on December 31<sup>st</sup>, 2018





# Annex 1

## Co-funding the CRP project

Dr Yu-Shang Lee  
Cleveland Clinic  
Neurosciences department,  
Main Campus.  
9500 Euclid Avenue, Cleveland, Ohio 44195

16<sup>th</sup> May 2018

Dear Dr Lee

We are pleased to be able to inform you that the Boards of ISRT and endParalysis have approved the co-sponsorship of the study entitled "A translatable peptide reduces glial scar to repair chronic spinal cord injury".

It is intended that the study will start as soon as is practical, provided that all necessary administrative details (e.g. grant agreement) are finalised.

We very much look forward to working with you on this exciting project.

Yours sincerely,

**Dr Mark Bacon**  
Executive & Scientific Director  
Spinal Research

**Corinne Jeanmaire**  
Founder and President  
The endParalysis Foundation

# Annex 2 – CRP Research Project

- **Background:** The formation of an enduring glial scar near the injured site leads to poor nerve regrowth capacity and poor functional outcomes in chronic stages after SCI. Chondroitin sulfate proteoglycans (CSPGs) are the major components of this glial scar. The small peptide called CSPG reduction peptide (CRP) was designed by Dr. Yu Shang Lee's lab to meet this need. The aim of the study is to replicate and hopefully confirm preliminary results which have shown that CRP has therapeutic effects on chronic SCI in rats. CRP can be applied non-invasively by subcutaneous injection. The non-invasive character of the CRP is of great interest as it would mean that the treatment, if proven effective, will, in principle, be easily applied to human patients. This could constitute a very valuable alternative to other therapies currently under development such as Ch'ase, that requires a specific and elaborate delivery method to safeguard its effectiveness as well as safety for the patient.
- **Latest update (April 2019):** Further to initial testing of the CRP on a small number rats in 2017, Dr. Yu Shang Lee's lab carried out additional studies on a larger number of rats (T8 chronic contusion SCI), as of August 2018. The project, co-funded by the endParalysis foundation, aimed to determine the efficacy of CRP alone and of CRP + ISP (ISP is another peptide, developed in Dr. Jerry Silver's lab, Case Western University). Starting two-month post-SCI, the treated animals received the various peptides by daily subcutaneous injection during three consecutive months.
- **Results/ study outcome:** The study shows an overall improvement in locomotor and bladder function in the treated animals. While there was a trend showing CRP+ISP works slightly better in improving BBB scores (testing stepping function) than CRP alone, there was, overall, no significant difference between the CRP+ISP and CRP groups. Importantly, both CRP and CRP+ISP groups demonstrated better hind limb / forelimb coordination).
- **Conclusion:** The study seems to show that CRP enhanced connectivity established across injury site and nerve sprouting below the injured site after treatment, as well as an improved both locomotion and bladder function (the CRP-treated groups show less hyperactivity, better void efficiency, and lower voiding pressures).
- **Next steps:** Dr. Lee indicates the following steps will include testing dose responses of CRP to see if higher dose can lead to an additional functional improvement, conducting Pharmacokinetics and Safety/toxicity tests of CRP and testing the efficacy of CRP in a large animal model with Dr. Brian Kwon using pigs T10 subacute stage injury model (two weeks post SCI) to test both locomotion and bladder function as well as in a cervical chronic SCI model (C4 hemisection) to test forelimb/hand function in collaboration with Dr. Jerry Silver's laboratory

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# Annex 3 – Ch’ase IT Research Project

- **Background:** The application of a bacterial enzyme called Chondroitinase, or Ch’ase, has repeatedly been proven to degrade the scar, to promote growth and to improve recovery in animal experiments. However, applying it to people is challenging. The goal of the project “CH’ASE-IT”, initiated by the International Spinal Research Trust (ISRT), is to make the Ch’ase therapy ready and safe for clinical application. It relies on an international collaboration between various researchers, among others in the UK and in The Netherlands. Recent experiments, using gene therapy models to deliver the enzyme, have moved the therapy closer to human application
- **Latest update (Dec. 2018):** Two alternative gene delivery therapies (The gene for Ch’ase is expressed in an active form in human cells and can be switched on and off to ensure an optimal and controlled delivery) have been developed/ are being tested:

a. The chondroitinase enzyme is delivered via a Lenti-virus vector (a harmless virus). The consortium demonstrated this therapy to give rise to improved walking and unprecedented upper limb function in rodent acute spinal cord injury models. See more information in [this article and video](#) and this [Brain](#) publication. The same treatment is currently being tested in a rodent chronic injury model (trial started in August 2018. Results will be shared in 2019). In parallel, work is carried out towards bringing this therapy to the clinics.

b. The Ch’ase enzyme is delivered via an Adeno-associated viral (AAV) vector which is already used in other human treatments and would therefore obtain easier access to clinical trials. Various AAV vectors were created by Verhaagen’s lab and tested but they need further adjustment to retain the same functional efficacy as the LV vector.

- **Next steps:**
  - The AAV vector, once optimized, will be tested in both acute and chronic SCI models (rodents).
  - Discussions are ongoing regarding testing the best version of the chondroitinase therapy on humans. This is, however, a long term goal.