

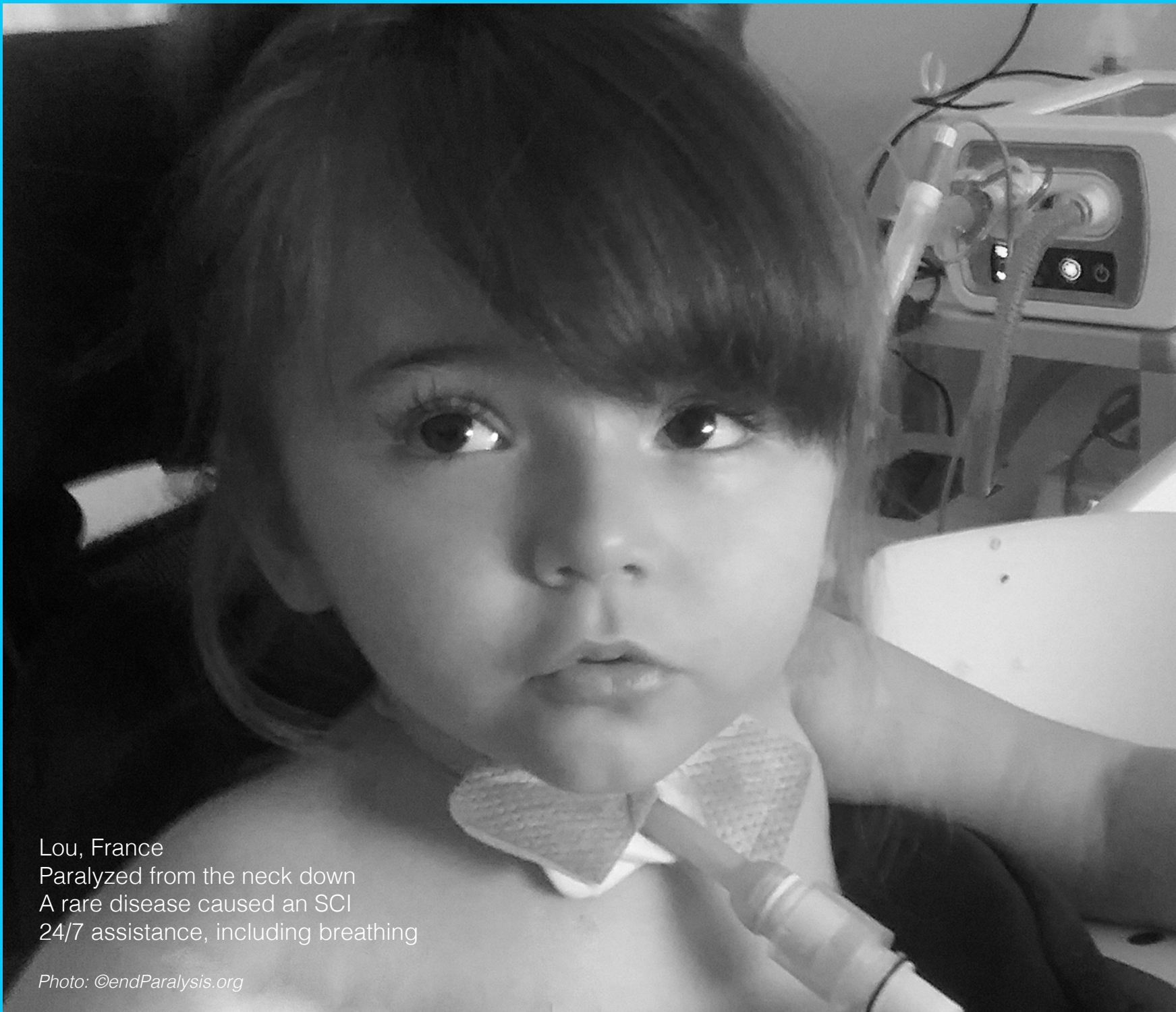
# 2019 Annual Report

endParalysis foundation



...  **be the  
change...  
be the cure!**  
[endParalysis.org](https://endParalysis.org)

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Lou, France  
Paralyzed from the neck down  
A rare disease caused an SCI  
24/7 assistance, including breathing

Photo: @endParalysis.org

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**be the  
change...  
be the cure!**  
**endParalysis.org**

# endParalysis: HOW WE STOOD OUT IN 2019

“Looking back on 2019, there are several achievements and activities that we are proud of. Firstly, we again allocated significant funding to co-finance the second CRP peptide study, a project that we already contributed to in 2018. That line of research is essential for chronic patients for it targets the scar that forms at the chronic stage of spinal cord injury. Furthermore, this therapy delivery is expected to be non-invasive, which will make clinical application easier. But funds are not everything. They have to be used smartly. On a strategic level, we participated in discussions regarding global research priorities and approaches. We promote goal-driven integrative approaches focusing on ambitious functional recovery goals and on global cooperation.

Our uniqueness? We are focused on adding value and are growing in that role, in a sustainable way without the overheads of paid staff and marketing cost. We have great supporters and volunteers that help us on a regular basis, sharing their time, professionalism, knowledge and fundraising network. The same applies to our partners. While always staying true to our own particular goals / priorities (e.g. focusing on chronic injuries and on repair), we co-operate with larger organizations and build further on their knowledge, capabilities and network, thereby adding value and moving research one step closer towards curing paralysis.

Lastly, and deserving our deepest thanks, we have a major sponsor, the non-profit fuelService.org. Not only do they help us through their significant financial support, their relentless determination to change the status-quo serves as daily encouragement to continue the fight.

We hope this annual reports inspires you to join our movement towards curing paralysis. You may donate, work with us, run / swim for us, reinvent your life with us. The choice is yours. The rewards will be huge. Think of the day when the kids portrayed in this report will suddenly be able to breathe or move on their own! Let's make this day happen together. “



**Corinne Jeanmaire**

Founder and President  
of [endParalysis.org](https://endParalysis.org)



# A CRITICAL & CHRONIC NEED

## 2.5 - 3 MILLION

people in the world live with  
spinal cord injury (SCI)

The consequences of SCI are not limited to the inability to WALK AND STAND. For many people, it also means debilitating chronic pain and most importantly:

## NO or IMPAIRED

- breathing function\*
- hand and arm function\*
- bladder, bowel function
- sexual control
- sensation below injury



Mattie, Ireland,  
Paralyzed from the neck down  
Cause: meningitis  
Photo: ©endParalysis.org

\* for high SCI (Cervical level)



## OUR GOAL & MISSION

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**Our goal is to help accelerate research into curing chronic spinal cord injury (SCI) by:**

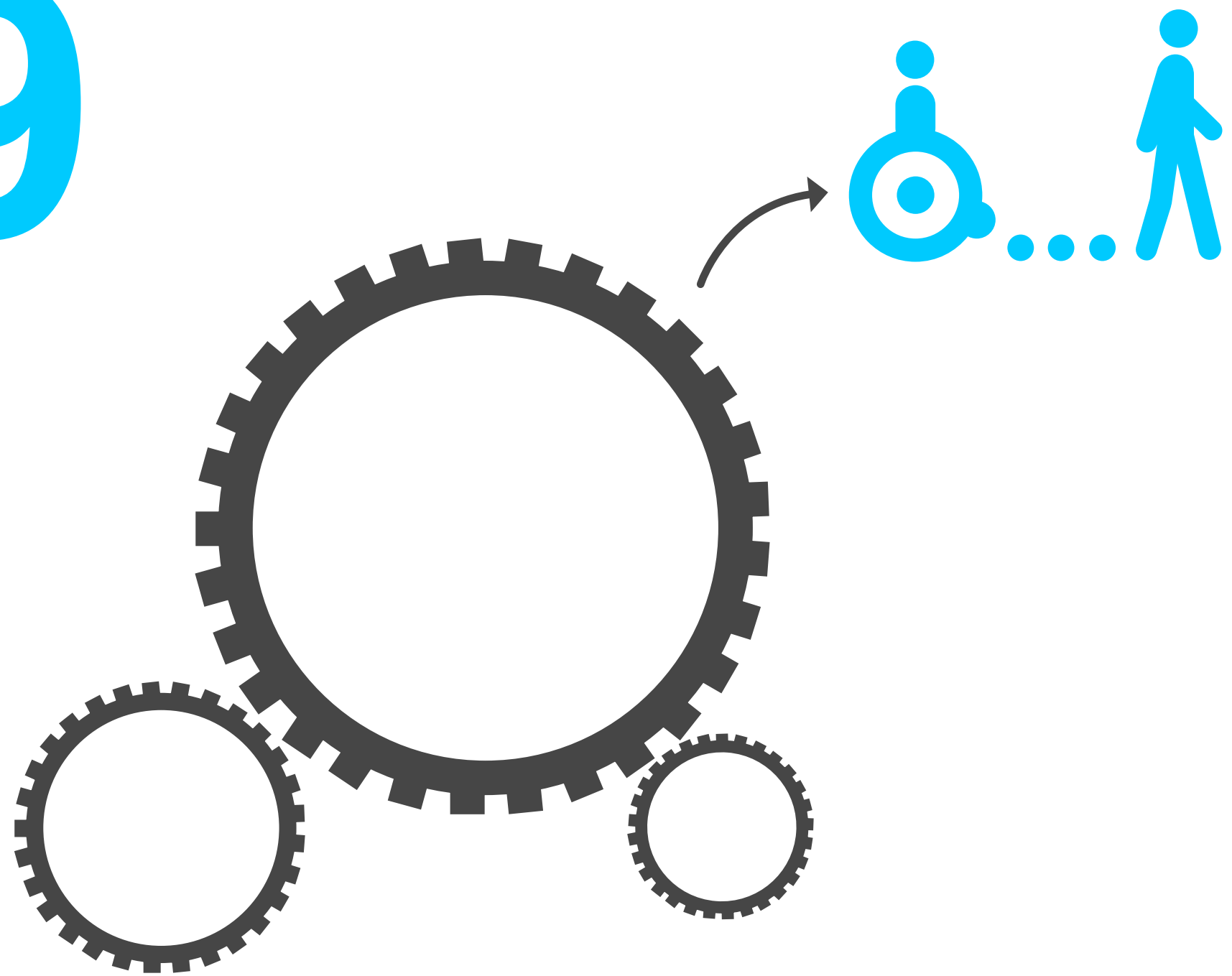
- **co-funding clinically-relevant and groundbreaking research projects**
- **promoting an integrative, collaborative, and goal-driven approach to SCI research**

Anita, Nepal  
Paralyzed from the waist down  
Fell from a tree  
Can't go to school anymore

Photo: @endParalysis.org



# OUR ACHIEVEMENTS & ACTIVITIES IN 2019



# RESEARCH PROJECT FUNDING

## A FEW ESSENTIAL STEPS

In 2015 and 2017, we allocated €55,000 to the Chase-IT project (1). In 2018, we gave €40,000 to the first study concerning the CRP Peptide (2) and we supported the follow-up study of the latter project with a €34,000 grant earmarked for Dr. Lee's lab at the Cleveland Clinic in 2019 (2).

What do those projects have in common? They are likely to provide a big accelerator in chronic SCI repair. Both projects are indeed focusing on tackling the scar that forms at the level of the spinal cord a few days/weeks after a lesion. That scar, exclusively concerns CHRONIC SCI, hampers axonal regrowth. Its neutralization is therefore an essential and sine qua non step towards recovery after chronic SCI.

# 1

**Ch'ase IT:** the application of a bacterial enzyme/ protein called Chondroitinase (Ch'ase), has repeatedly been proven to degrade the above-mentioned 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 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. See our [latest update here](#).

# 2

**CRP Peptide:** The small peptide (i.e. an organic compound) called CSPG\* Reduction Peptide (CRP) was designed by Dr. Yu Shang Lee's lab (Cleveland Clinic). The first study has shown that CRP has therapeutic effects on chronic SCI in rats. The non-invasive character of the CRP (it can be administered by subcutaneous injection) is of great interest. If proven effective, the treatment will, in principle, be easily applied to human patients. The second study funded by endParalysis mainly aims to test the effect of dosage on therapeutics results in chronic rats. For the latest update (results so far and next steps), please visit our website: [here](#).

(\*) Chondroitin sulfate proteoglycans (CSPGs) are the major components of the scar.





## SCI 2020 RESEARCH PRIORITIES?

Our feedback to the  
National Health  
Institute (USA)

[Read here](#)

# DISRUPT

## SCI RESEARCH DISRUPTION?

Our interview with U2FP

[Read here](#)

# INFORMING ABOUT RESEARCH & TRIALS

Again this year, we provided a lay research overview to inform people living with a chronic SCI about

SCIENTIFIC PROGRESS

In October 2019, together with our partners, we officially launched the new website about

WORLDWIDE CLINICAL RESEARCH/ TRIALS

## 2019 LAY OVERVIEW

(chronic pre-clinical & clinical research)

Click [here](#)



Spinal Cord Injury  
TRIALS

# FIND SCI TRIALS

WWW.SCITRIALS.ORG



North American  
Spinal Cord Injury  
— Consortium —

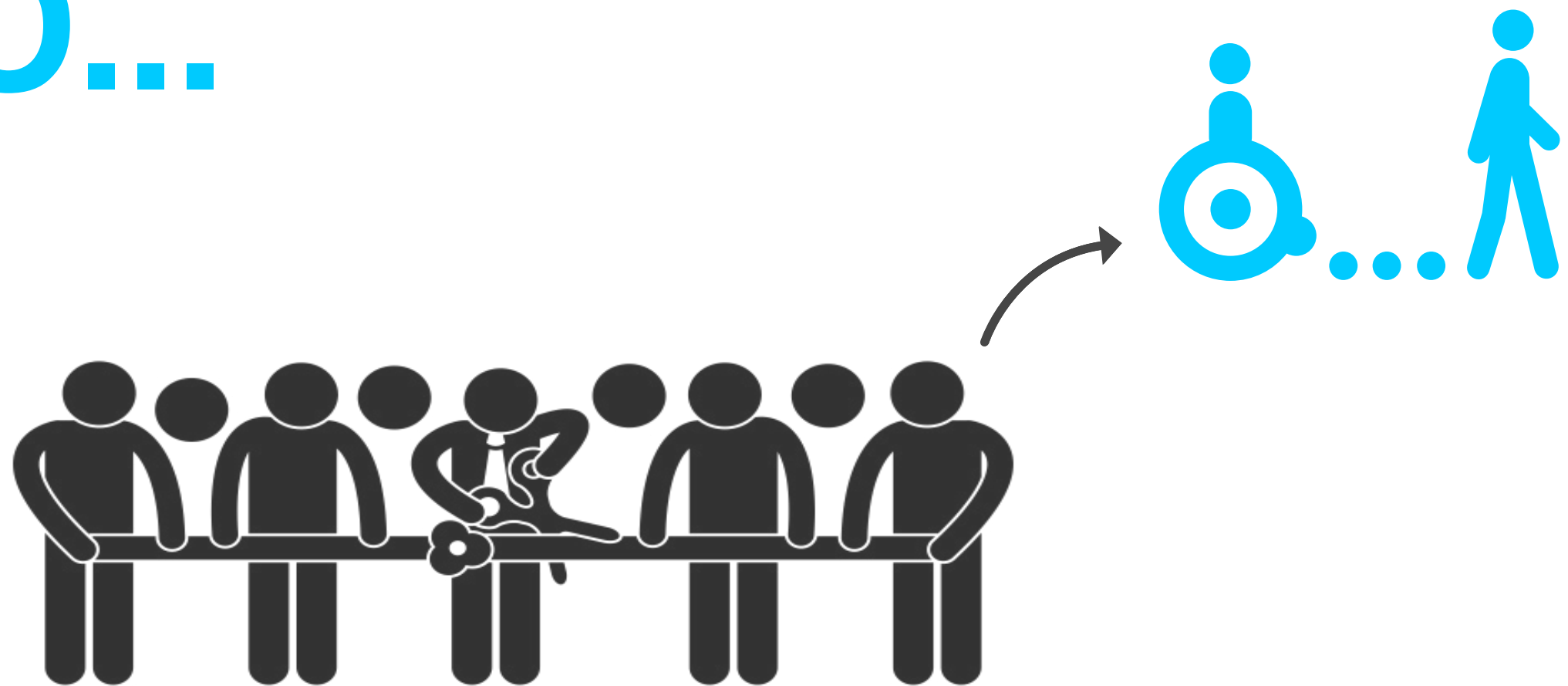


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be the cure!  
endParalysis.org



CSRO  
ASRO

# OUR THANKS GO TO...



## OUR DONORS, SPONSORS, AND SUPPORTERS

Our gratitude goes to all our generous donors/sponsors, private or institutional (fuelService, Smartgroup and Multiadapt) who trust us with their donations. Furthermore, we are surrounded and helped by a number of small enterprises granting us some of their time whenever we need professional advice or support, or a space to meet, work and connect. This is also priceless as it enables us to keep our endParalysis sharp, fresh, professional and connected. [Thanks to all of you!](#)

SMART  
GROUP



MULTI ADAPT



SAHARE  
STUDIOS





# GLOBAL PARTNER ORGANIZATIONS

We are very proud to co-operate with:

- Spinal Research (UK), U2FP (USA), Wings for Life (Austria, new partnership initiated end 2019) to share scientific expertise/network, and to co-fund goal-driven research projects
- The European SCI Federation ESCIF, Association Alarme, and DON, who respectively represent the SCI community in Europe, France and The Netherlands



# THANKS TO OUR TEAM

&

# OUR VOLUNTEERS

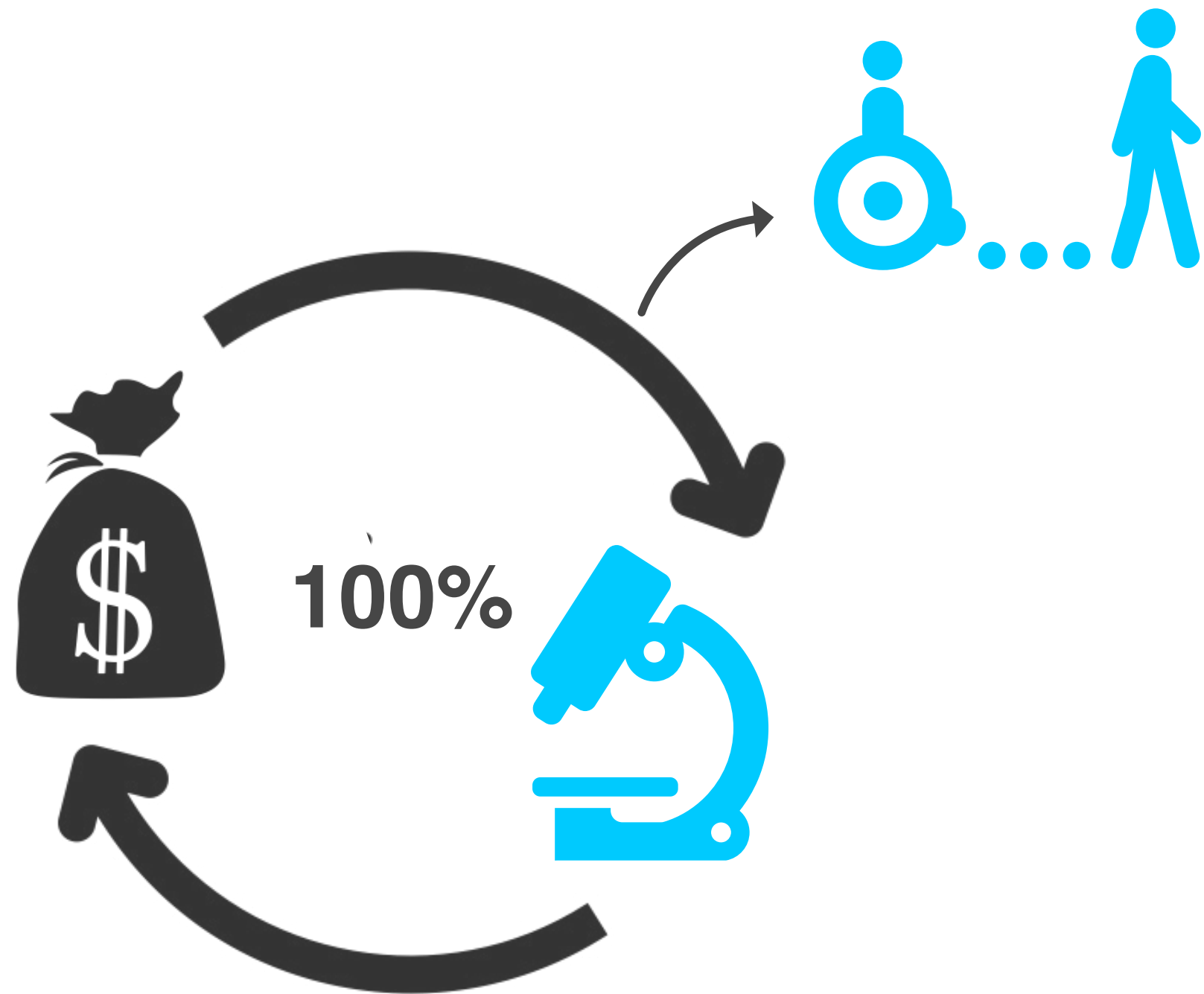
- Amina Abed
- Elise Adriaanse
- Dr. Mark Bacon
- Jo Baltus
- Jos Dekkers
- Dr. Elly Hol
- Corinne Jeanmaire
- Dr. Janneke Stolwijk
- Jaap Pipping
- Chris Powell
- Thierry Schmitter
- Dr. Jerry Silver
- Dr. Joost Verhaagen



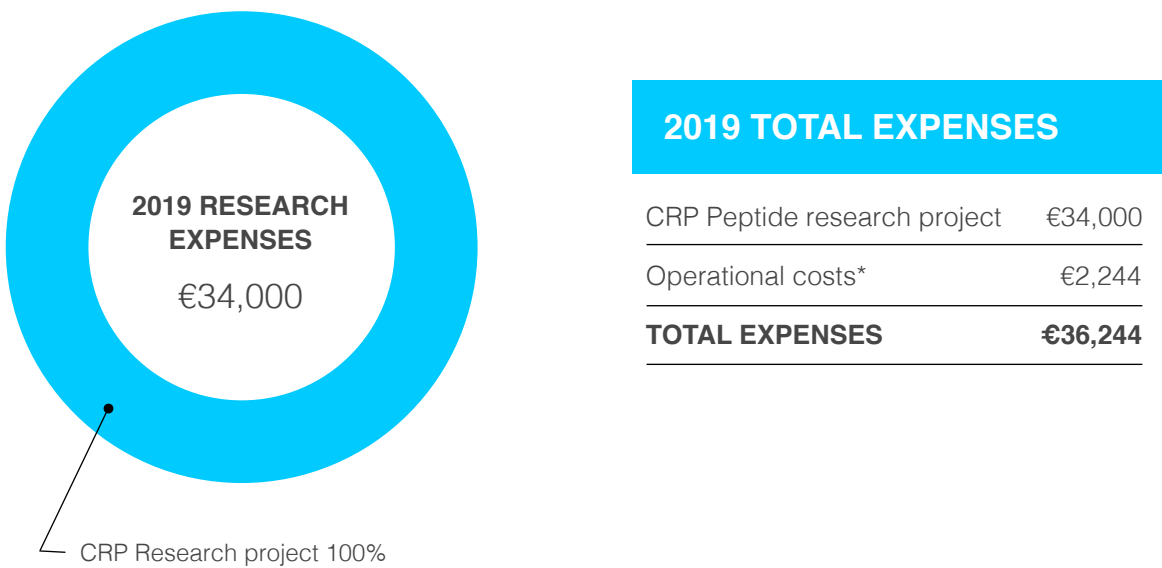
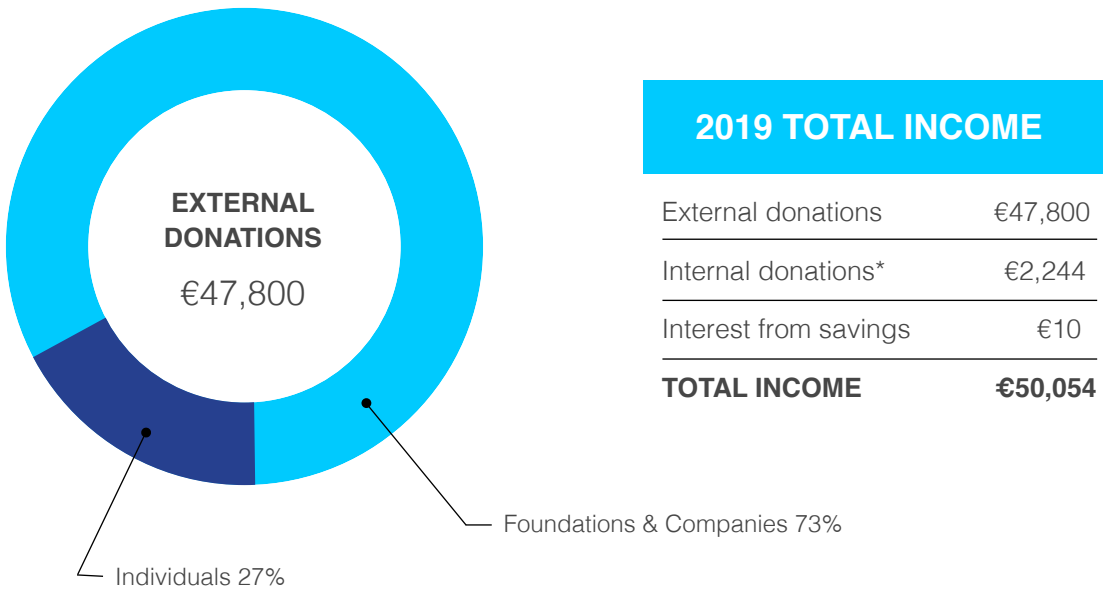
- Eva Alexandra
- Gianluca Ariello
- Serena Gravili
- Ernst ter Horst
- Mohammed Kabbara
- Ruwan vd Leeuwen
- Desirée Van Lieshout
- Ruth Purves
- Marc Renckens
- Andries Riedstra
- Emre Sahare
- Beverley Saunders
- Fons Weijtens

# FINANCIALS

# 2019

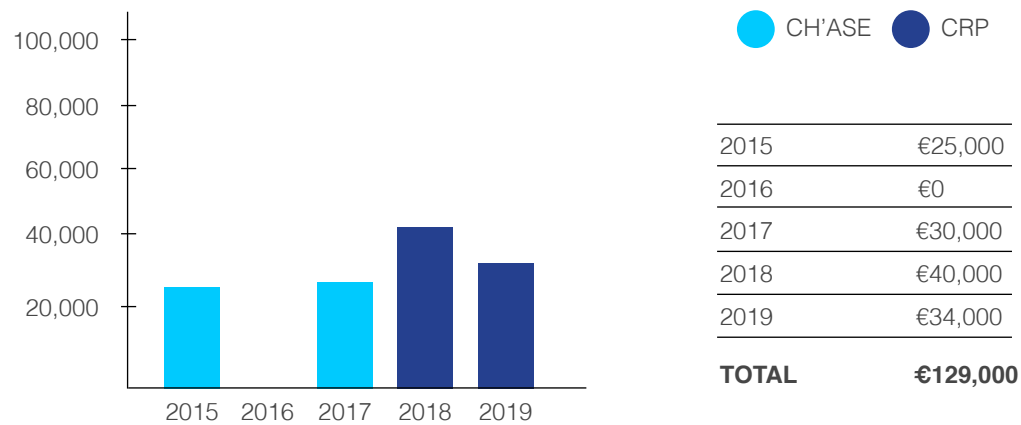


# 2019 FINANCIALS



2019 SIMPLIFIED BALANCE SHEET			
ASSETS		LIABILITIES	
Current bank account ING	€26,450	Retained earnings	€31,901
Savings bank account ING	€5,180		
PayPal account	€271		
<b>TOTAL ASSETS</b>	<b>€31,901</b>	<b>TOTAL LIABILITIES</b>	<b>€31,901</b>

## FUNDS DISTRIBUTED TO RESEARCH SINCE INCEPTION



**100%**  
OF YOUR DONATION  
GOES TO  
**RESEARCH!!!**  
\*

(\*) The “internal donations” cover all the foundation’s operational costs, so that 100% of your gifts (i.e. “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.



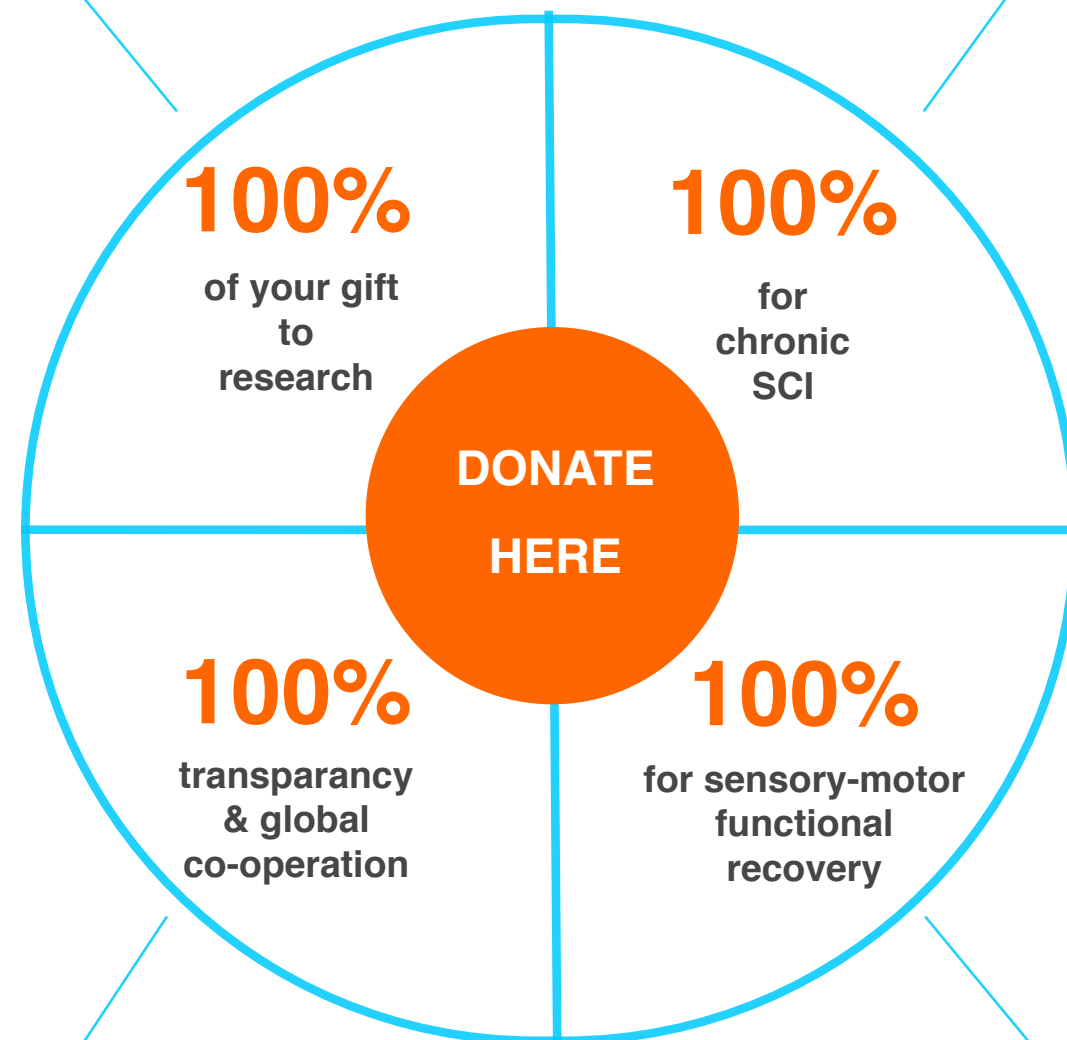
# GET INVOLVED



# WHY DONATE TO US?

We don't have paid staff and the limited foundation's operational costs are paid by our board

All SCI patients are "chronic after a few weeks. There for we only fund research applicable to chronic



+

We co-operate with larger foundations to leverage resources & knowledge. [yearly reports](#) online

We do not fund any project for "compensatory measures"/ equipment/ robotics. Biological regeneration is our focus.

**TAX RETURN IN EUROPE!**  
(Contact us)

# RAISE FUNDS OR HELP US!



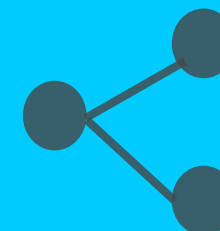
**Volunteer!**  
We can always use help



**Unfreeze Your Body/ Your mind**  
Take a fundraising challenge



**Donate for free!**  
Shop online with Sponsorkliks



**Like us & Share us!**



endParalysis



endParalysis



endParalysis



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## IN THE SPOTLIGHT:

## UNFREEZE YOUR MIND! CHALLENGE

by Serena



In 2019 Serena decided to travel alone for the first time therewith confronting her fear, demonstrating the empowerment of women with the purpose of raising funds to cure paralysis  
(€730 raised, all of which allocated to SCI research)



Photos: ©Arianna Fotografie



# Unfreeze Your Body!

Take an Unfreeze challenge!  
Visit our fundraising platform  
[Here](#)

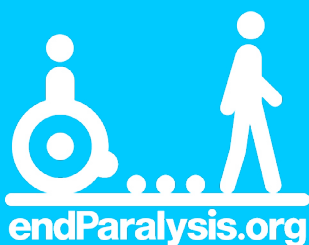


Photo: ©endParalysis.org





Photo: ©endParalysis.org



**endParalysis foundation**

Cederlaan 135  
5616SC EINDHOVEN  
The Netherlands

**Non-profit (ANBI)**

registered in  
Eindhoven, NL as:  
Stichting endParalysis.org  
Fiscal # (RSIN) : 853446313

**Contact us:**

info@endParalysis.org  
www.endParalysis.org  
Tel: +31 622 788798



@endParalysis



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@endParalysis

Bank account: NL05 INGB0006501452 (IBAN) - BIC (SWIFT) INGBNL2A -  
Account holder: Stichting endParalysis.org