

2022 Annual report

endParalysis foundation



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

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endParalysis: our progress in 2022

2022 was the year when things came back to almost normal and the beginning of the post-Covid era. We appreciated participating in face-to-face scientific meetings again, in order to network with researchers, scientists and representatives of other Spinal Cord Injury patients organizations, and gain deeper knowledge about global SCI research .

As many know, replicating a given research study from lab to lab, and combining various therapies do constitute a critical need and a serious challenge in SCI research. Therefore, our 2022 funding mainly aimed to combine the CRP peptide along with electrical neuro-stimulation to check if we can repeat but also improve the outcomes observed in the Yu-Shang Lee lab (Cleveland Clinic, USA) . This study takes place in the University of Leeds (Ronaldo Ichiyama's lab, UK) and will deliver its results in 2023.

Detailed results of the research studies we have funded so far can be found in the research page of this report, and in the research pages of our website. Please do visit our brand-new website, which was recently launched and includes clearer research overviews, for various therapies being developed in the word, focused on chronic spinal injuries, i.e. a few months or years after the initial injury.

You may continue to support our work by making a donation, 100% of which will be spent on curative research projects, or raise funds for that purpose, for example by taking your own personal challenge. You may create your own fundraising challenge page on our “Unfreeze” platform, or simply raise funds for endParalysis via social media. As always, we appreciate your support.

Corinne Jeanmaire

Founder & President of endParalysis.org



Corinne participating in the ISRT / Spinal Research scientific meeting (Sept. 2022, London, UK)



A CRITICAL & CHRONIC NEED



Mattie, Ireland,
Paralyzed from the neck down
Cause: meningitis
24/7 assistance needed, also for
breathing

Photo: @endParalysis.org

LATEST GLOBAL ESTIMATE (SOURCE [NCBI publication 2016](#)):

27 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

* for high SCI (Cervical level)

OUR GOAL & MISSION

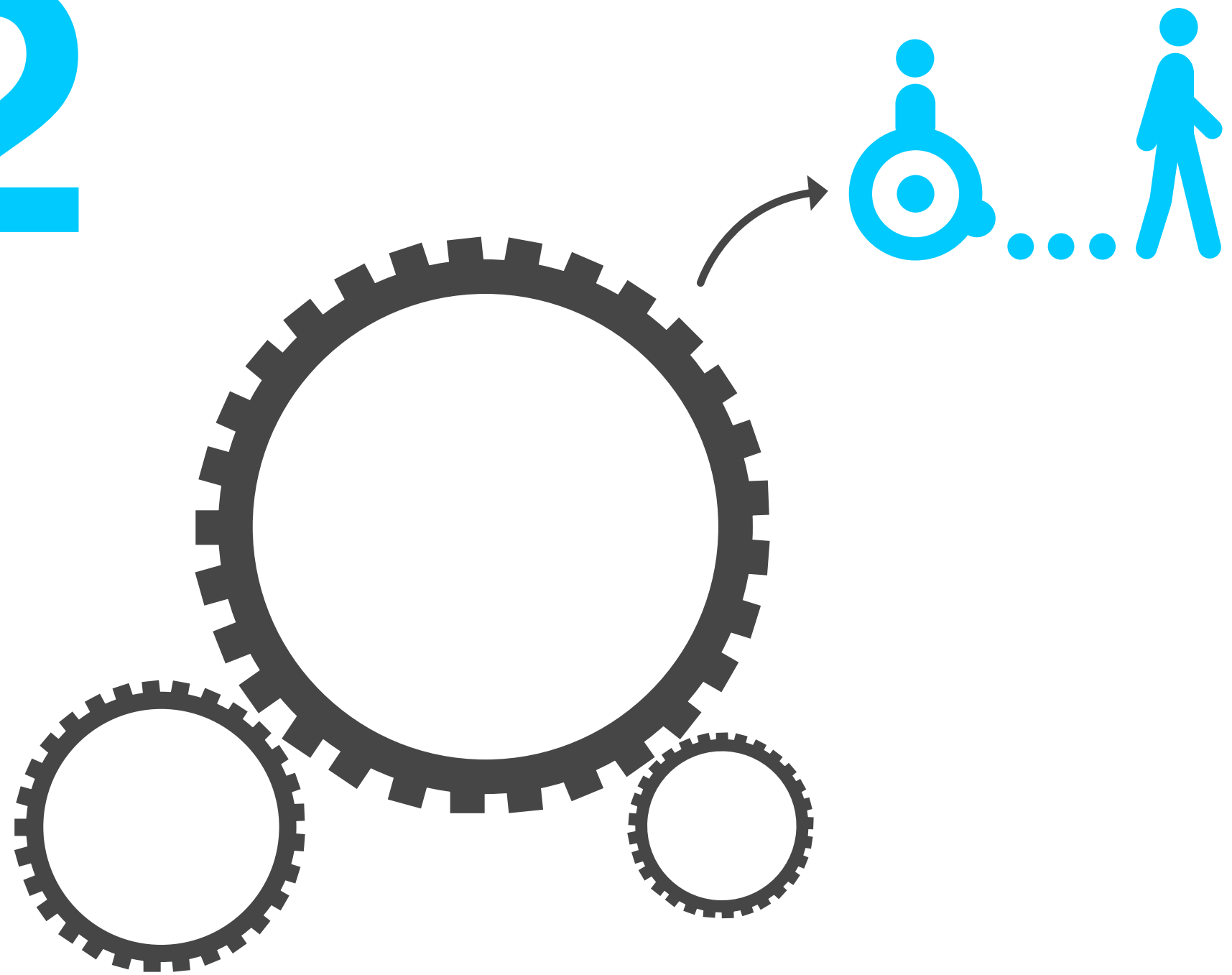
Our goal is to accelerate research into CURING chronic spinal cord injury by:

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

Sanne (25), The Netherlands
Paralysed from the shoulders down (Chronic cervical injury)
Car accident

Photo: ©SAN

OUR ACHIEVEMENTS & ACTIVITIES IN 2022



RESEARCH PROJECT FUNDING

2022: Combining therapies and checking efficacy vs dosage

The funding we provided in 2022 primarily concerns the first pillar of our research strategy, i.e. glial scar reduction and plasticity enhancement. It does also include a combinatory approach to possibly improve outcomes. Firstly, circa 40K€ were spent on an animal trial combining the CRP Peptide with e-stimulation. Secondly, a residual payment (circa 8K€) was made for the last stage of the PNNi dosing study started in 2019. For more detailed data about the projects we have funded so far, see our website, [here](#)).

1


CRP (*) Scar reduction peptide + e-stim (40K€- 2022): This animal study is carried out in Ronaldo Ichiyama 's lab (University of Leeds, UK). The CRP* peptide has already shown very encouraging results in various experiments led by Yu Shang Lee's lab in Cleveland Clinic, USA. It is shown to help dissolve the glial scar appearing a few weeks after the spinal cord injury, and therewith enables nerves to regrow. The combination trial is meant to check whether the behavioral improvements seen by the animals treated with CRP (significant recovery of the walking ability as well as a better bladder control), could be enhanced by the electric stimulation of the cord. E-stim through an implanted stimulator has repeatedly been shown to (slightly or significantly) improve behavioral outcomes in a number of human subjects by "awakening" the spinal cord neural connections that had become "dormant" as a consequence of the injury. The results of this combination study will be known in 2023.

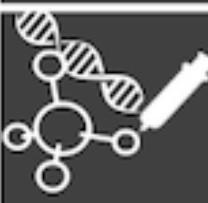
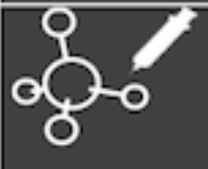
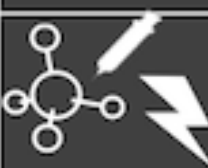


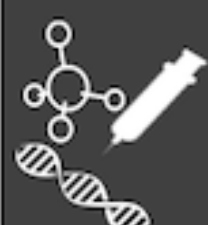
2

PNNi (*) for chronic SCI: efficacy + dosing study: The study funded by endParalysis + Marina Romoli Onlus (Italy) + Gusu (USA) revealed its final results in 2022. The purpose of the study by Jessica Kwok's lab (Leeds, UK) was to check the efficacy of the treatment at the chronic stage of SCI, and to determine the minimum dosage needed to reach a significant level of functional recovery. The study has proven that the molecule does indeed enable a clear functional recovery level in rats, even long after their initial injury, which is a very good outcome. PNNi molecule is used to treat people with a rare-disease and is thus suitable for clinical use. However, the latest study also showed that the dosage needed to achieve significant functional recovery in rats is higher than the one currently authorized on the market. Before going to human trial for use in spinal cord injury, it is necessary to finetune the treatment, either by increasing its efficacy so that it can be made effective at the authorized dosage or by addressing concerns of potential side effects and gaining regulatory approval for use at higher doses.

(*) CRP: CSPG Reduction Peptide (CSPG stands for Chondroitin Sulfate ProteoGlycans . - PNN: PeriNeuralNet Both CSPG and PNN refer to the scar tissue that appears in and around the spinal cord after a lesion and forms a barrier against nerves regrowth.

OUR RESEARCH PORTFOLIO SO FAR



	ID	Type	Features	Research team	Research strategy
1-2	CH'ASE protein		Delivery through gene vector	Dr Verhaagen- Amsterdam- NIN- NL + Dr Bradburry- Kings College- UK	Scar reduction (enabling nerves regrowth at chronic SCI stage) + plasticity enhancement (creating new neural pathways and connections)
3-4	CRP peptide		Subcutaneous delivery (→ non invasive)	Dr Lee – Cleveland Clinic, USA	
4a	CRP peptide + e-stim		CRP peptide combined with e-stimulation	Dr Ichiyama, University of Leeds - UK	
5	PNNi oral drug		Off-the-shelve drug repurposing (→ shorter path to clinic)	Dr Kwok, University of Leeds- UK	
6	KN GENE therapy		Replicate prior study but applying it to chronic SCI	Dr Blackmore (Marquette)- Wisconsin + Dr Perlmutter (Washington) - USA	
7	siFi2 drug / FL2		Target intrinsic axonal growth but also rebinding. Replicate prior study but applying it to chronic SCI	Dr Byrnes (USUHS, Maryland, USA) - Dr Baker (MicroCures Inc.) - USA	

INFORMING THE SCI COMMUNITY ABOUT RESEARCH & CLINICAL TRIALS

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

RESEARCH PROGRESS

Together with our partners, we provide a website fully dedicated to

WORLDWIDE CLINICAL RESEARCH/ HUMAN TRIALS

2022 RESEARCH LAY OVERVIEW

(chronic SCI pre-clinical & clinical research)

New improved template!



Spinal Cord Injury
TRIALS

FIND SCI TRIALS

WWW.SCITRIALS.ORG



North American
Spinal Cord Injury
— Consortium —

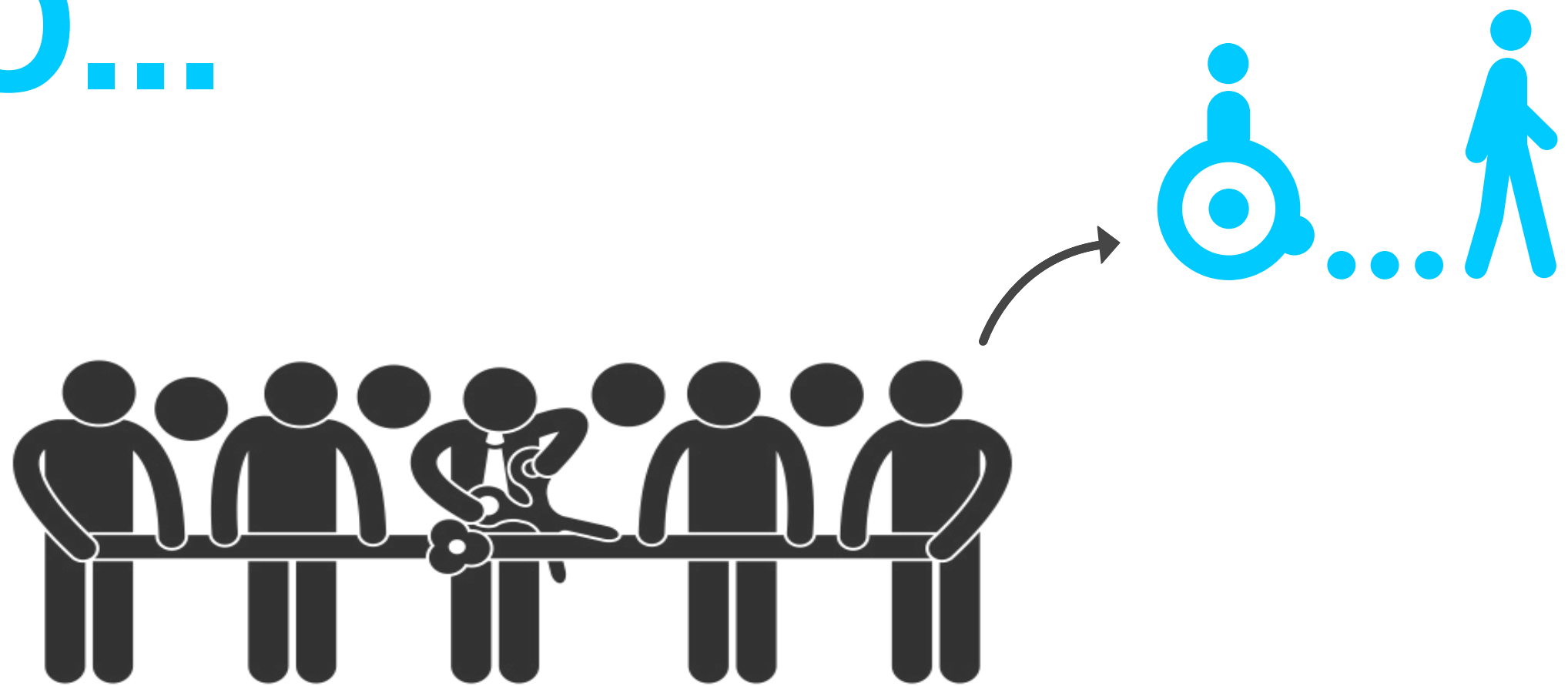


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CSRO
ASRO

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



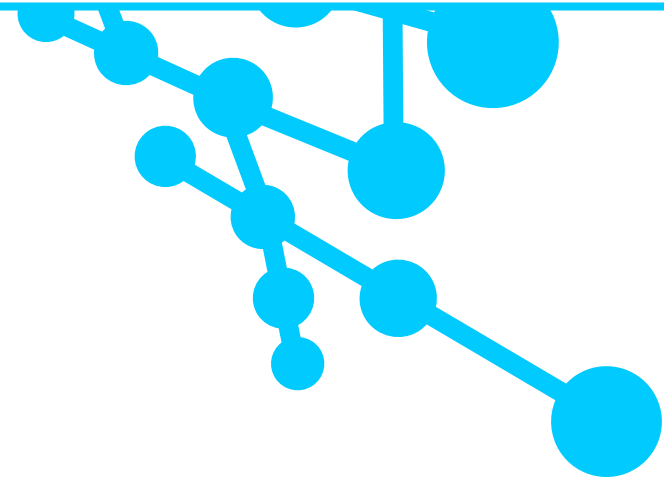
MULTI ADAPT



SAHARE
STUDIOS



GLOBAL PARTNER ORGANIZATIONS



We are very proud to co-operate with:

- Spinal Research (UK), U2FP (USA), Wings for Life (Austria), 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

Elise Adriaanse

Dr. Mark Bacon

Amit Chakraborty

Jacob Zuurmond

Dr. Elly Hol

Corinne Jeanmaire

Dr. Janneke Stolwijk

Jaap Pipping

Sanne v Schaaik

Thierry Schmitter

Dr. Jerry Silver

Dr. Joost Verhaagen



Gianluca Ariello

Serena Gravili

Annemie Heselmans

Ernst ter Horst

Mohammed Kabbara

Ruwan vd Leeuwen

Desirée v. Lieshout

Ruth Purves

Marc Renckens

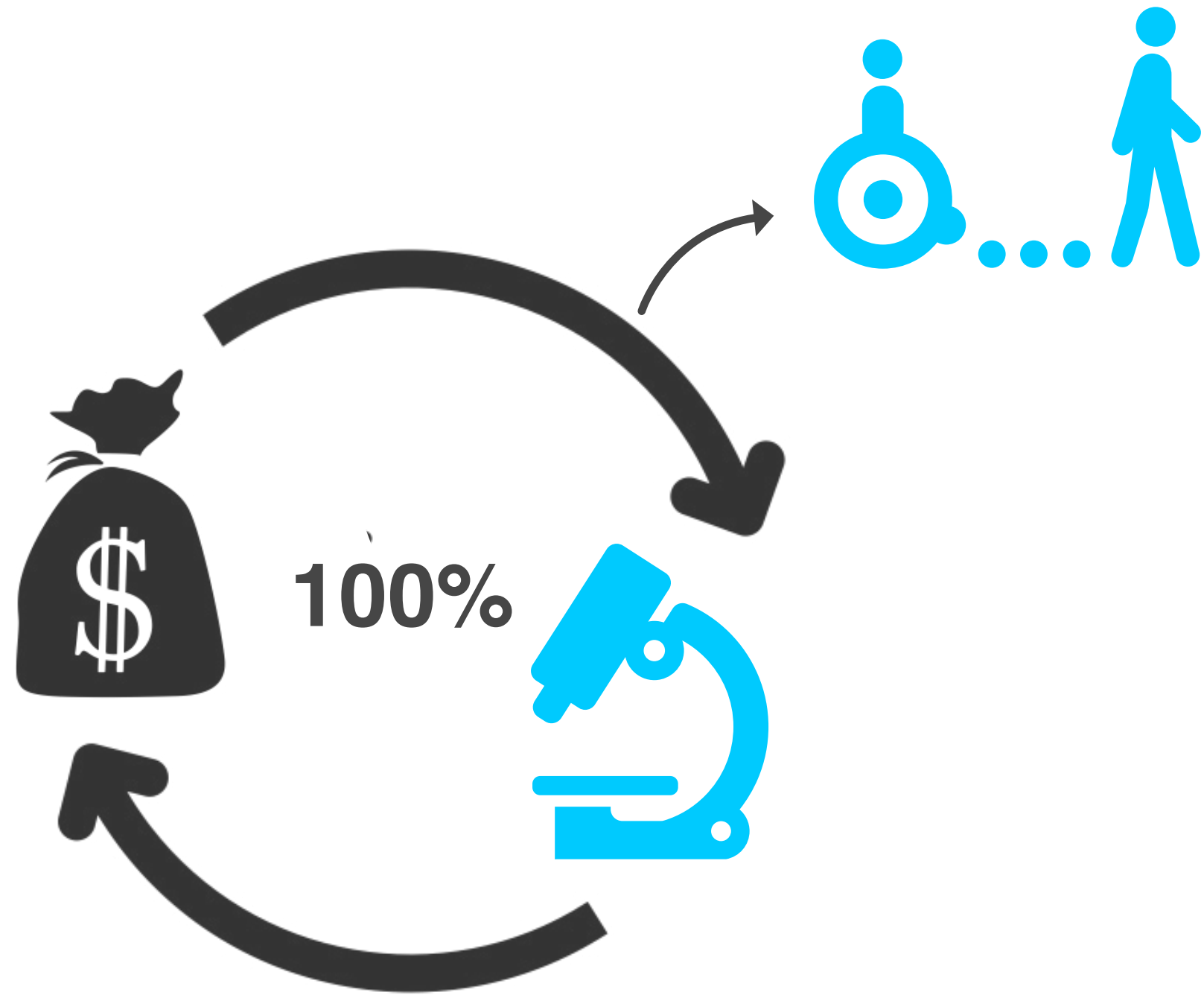
Andries Riedstra

Emre Sahare

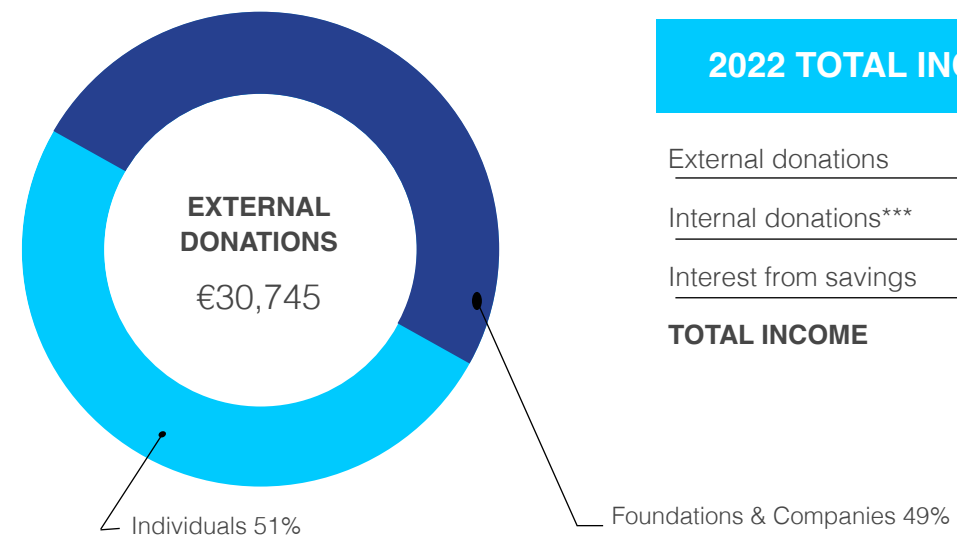
Beverley Saunders

FINANCIALS

2022



FINANCIALS in 2022



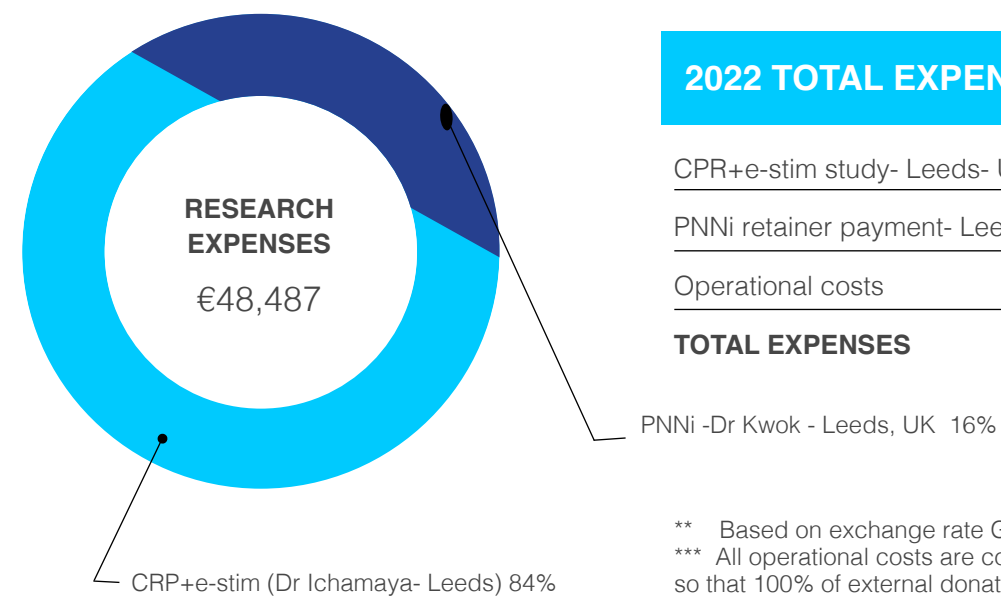
2022 TOTAL INCOME

External donations	€30,745
Internal donations***	€1,977
Interest from savings	-
TOTAL INCOME	€32,722

2022 SIMPLIFIED BALANCE SHEET

ASSETS		LIABILITIES	
Current bank account ING*	€22,127	Retained earnings	€35,034
Savings bank account ING*	€5,180		
WISE account**	€7,727		
TOTAL ASSETS	€35,034	TOTAL LIABILITIES	€35,034

* Balance on Dec 31, 2022



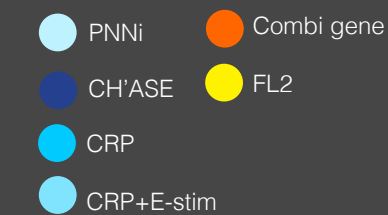
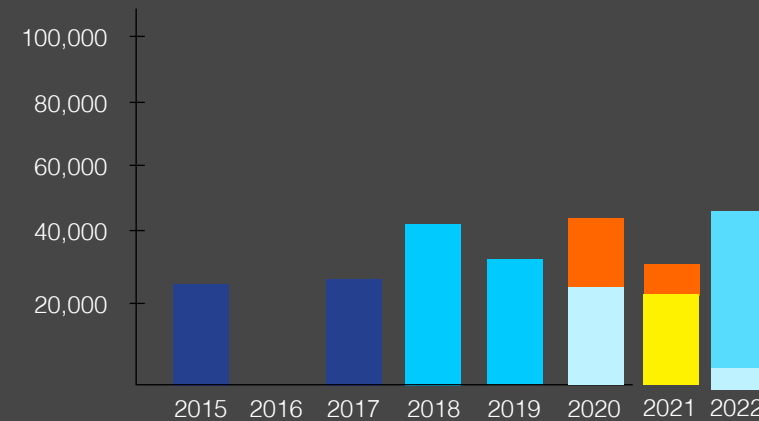
2022 TOTAL EXPENSES

CPR+e-stim study- Leeds- UK	€40,487 **
PNNi retainer payment- Leeds-UK	€ 7,831 **
Operational costs	€ 1,977 ***
TOTAL EXPENSES	€50,464

** Based on exchange rate GBP 1=€1.12 (31.12.2022)
*** All operational costs are covered with internal donations so that 100% of external donations go to scientific research

....AND SINCE INCEPTION

FUNDS DISTRIBUTED TO RESEARCH SINCE INCEPTION

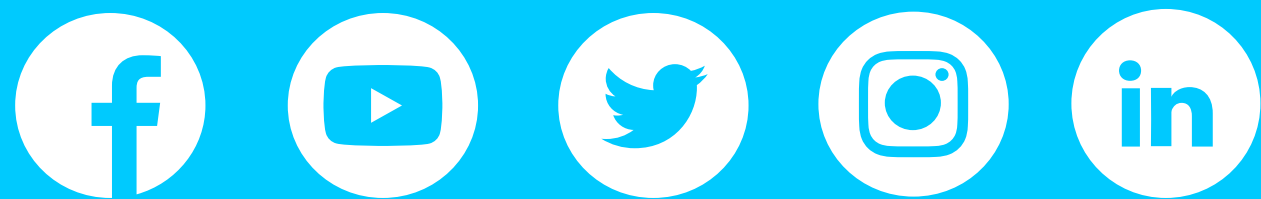


100%***
of your donation goes to
RESEARCH

*** All operational costs are covered with internal donations so that 100% of external donations go to scientific research.

This year, internal donations were respectively coming from endParalysis board-members at the level of €1,445 and from Maecenata Foundation (TGE Germany) at the level of €532.

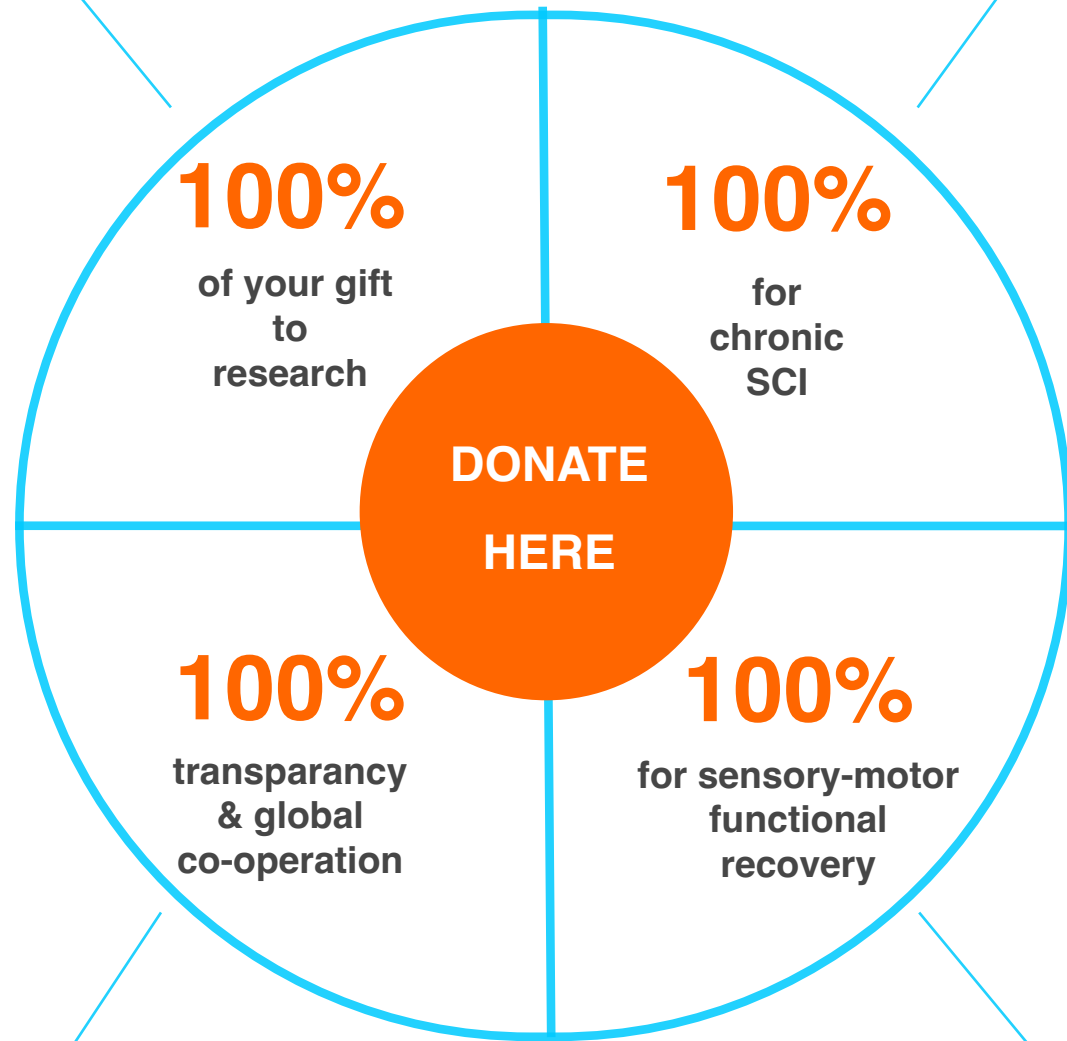
GET INVOLVED



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. Therefore, we only fund research applicable to chronic SCI



+

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!



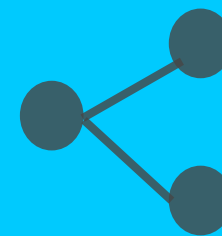
Volunteer!
We can always use help



Unfreeze Your Body/ Your mind
Take a fundraising challenge



Donate for free!
Shop online with Sponsorkliks



Like us & Share us!



2022 UNFREEZE! CHALLENGE IN THE SPOTLIGHT:



Picture:

Marion, the challenge initiator, heading the cheque to Jaap, endParalysis board member.

Video:

We thank Neil Sachse for Spinal Cord Research, and the South Australian Health & Medical Research Institute for allowing us to use their series of animations as a basis to compile this [video](#).

Finding a cure for spinal cord injury is critical. Prevention of SCI is just as important.

Therefore, this year, the Unfreeze Challenge in the spotlight informed young people about the risk and the consequences of meeting with such an injury. For that purpose a short video was made: [here](#).

The challenge was headed by Marion and deployed over a number of classes of pubers at the "school Scholengemeenschap Were Di in Valkenswaard"

It has enabled us to raise awareness of the young generation but also to raise €2,317 for research to cure paralysis.





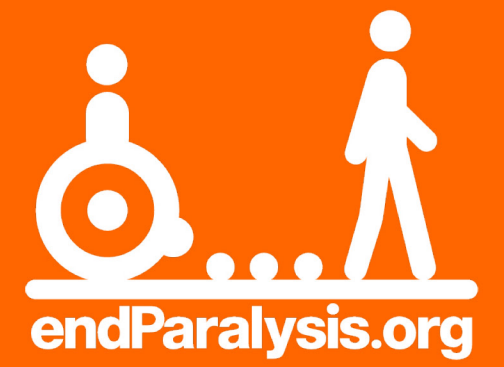
Photo: ©endParalysis.org

Unfreeze Your Body!

...and raise funds to CURE
spinal cord injury.

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





Non-profit (ANBI)
registered in
Eindhoven, NL as:
Stichting endParalysis.org
KvK#59372087

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Donate

Get involved

