

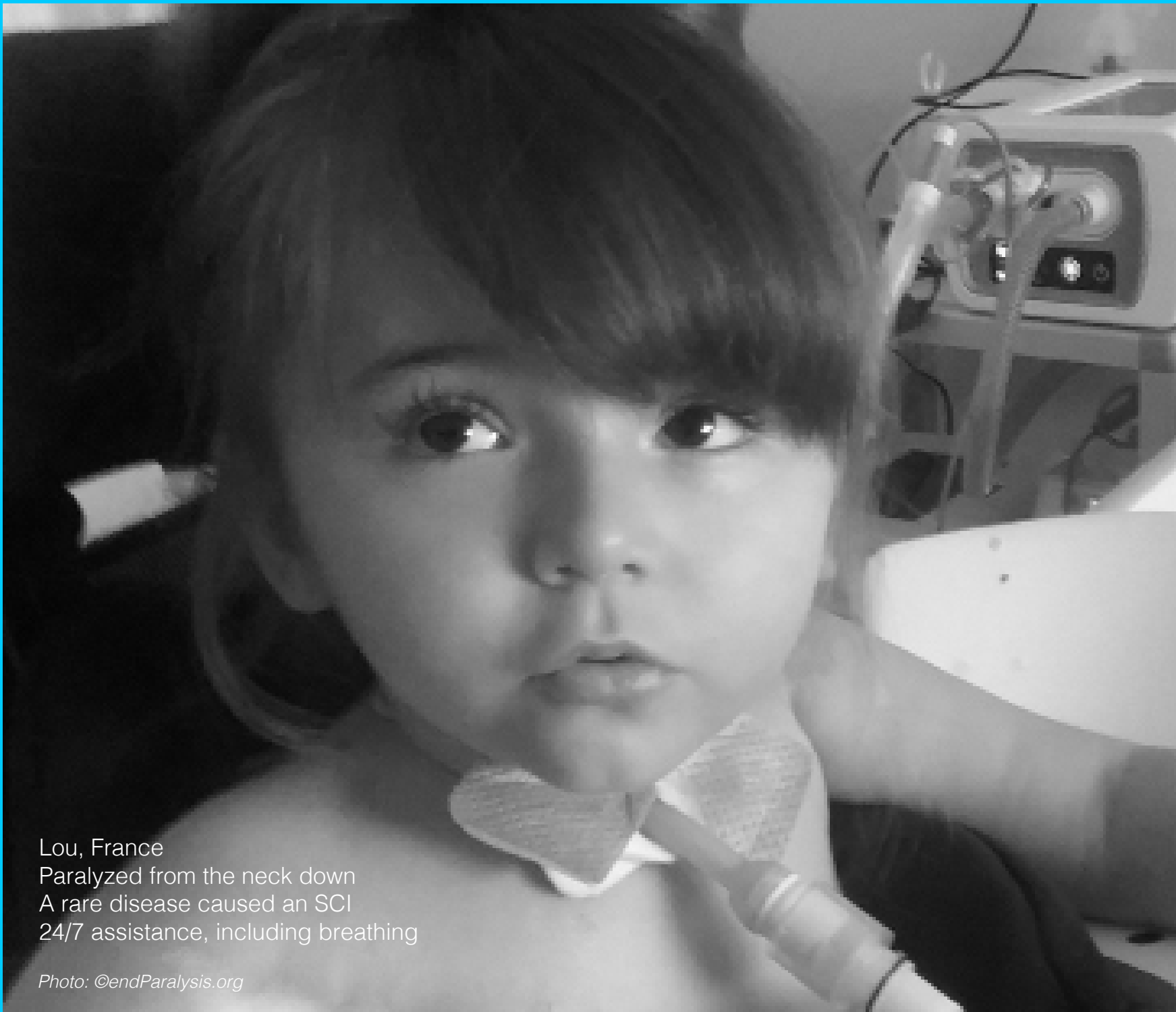
# 2021 Annual Report

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

# endParalysis: A COMPLEX BUT CONSTRUCTIVE 2021

2021 has been another challenging, but exciting year for spinal cord injury and endParalysis research. A few of our ongoing research studies have been slightly delayed by the COVID pandemic, but we will keep you informed as soon as possible via the Research pages of our website.

In the clinical arena, the media has reported some exciting advances, including e-stim/neuro-stimulation, which will soon allow people to improve their physical rehabilitation outcomes and recover as much as neuro-plasticity allows. This, while welcome, does not amount to repair and therefore leads to limited functional and sensory return for patients currently living with a “complete” SCI (with no motor or sensory function below their lesion). We, on the other hand, have continued to focus on developing therapies that target true functional and sensory return for people living with chronic SCI. We managed to raise about 80K€ during this year, our highest annual income on far. A portion of the funds has been dedicated to studies aimed at promoting nerve regrowth as well as reconnection. More details are provided in the Research pages of this report. The remaining funds were allocated to an animal study that will begin in 2022. This will be a continuation of our previous funding of CRP (a peptide developed by the Lee lab in Cleveland that reduces the scar preventing nerve regrowth). Following the very positive results of the 2019-2021 dosing study (available on our website), we will continue developing this promising therapy through testing the combination of the peptide with electrical stimulation, to see if recovery can be further improved.

You’ve read a lot about preclinical/animal studies and may be wondering why we keep testing therapies on animals for so long and when humans will finally get a chance? Don’t worry, our goal is to treat humans. There are a number of steps that need to be taken before we can bring a treatment to people, but our plan is definitely to bring the most effective therapies to the clinics, so that patients currently living with SCI can benefit.

Thank you for all the support you have given us so far and please continue to help us so that together we can cure paralysis!

**Corinne Jeanmaire**

Founder & President of endParalysis.org



Corinne is paraplegic (T10-T12) since 2001 (car accident) and launched endParalysis foundation in June 2014



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# A CRITICAL & CHRONIC NEED



Mattie, Ireland,  
Paralyzed from the neck down  
Cause: meningitis

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)



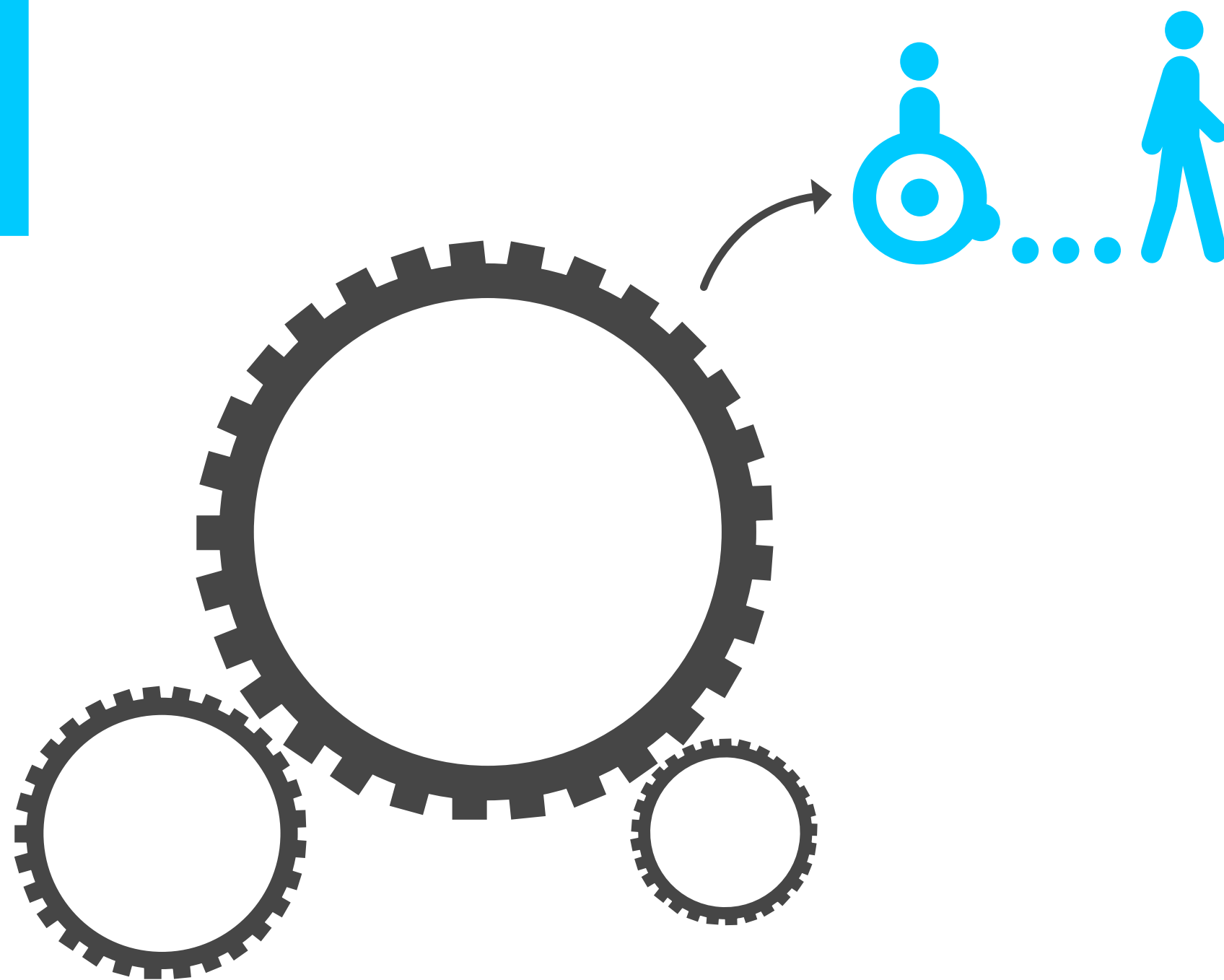
## OUR GOAL & MISSION

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 2021





# RESEARCH PROJECT FUNDING

## 2021: FOCUS ON NERVE REGROWTH + RECONNECTION

In 2021, we continued to address the second pillar of our research strategy, namely axon (nerve) regeneration and reconnection to enable recovery. The first two projects funded this year involve therapies that have been successfully applied to rodents with acute (very recent) SCI. We needed to test whether they could also promote recovery in rats with an older lesion, i.e. at a chronic stage. We spent €28,103 to co-fund the MicroCures/USU\* FL2 study and a final payment of €5,345 for the KN-Combined therapy to the Blackmore and Perlmutter Labs. See the details of these projects below.

As a reminder, the first pillar of our research strategy concerns the reduction of glial scars in chronic injuries. The CRP and PNNi studies, funded in 2019, have yielded very positive results (see detailed results to date on our website, [here](#)) and are being followed very closely, with our ultimate goal being to select a therapy and bring it to the clinics.

# 1

**FL2-MicroCures / USU\* (USA):** The over-expression of FL2 (an inhibitory protein) after spinal cord injury results in inhibition to axon growth. Preclinical research suggests that siFi2 (a drug developed by the US biotechnology company MicroCures) can silence FL2 activity and thus trigger regeneration and reattachment of axons at the site of injury. This therapy is based on gene lock-down and enhances the body's intrinsic healing processes. Following the promising functional improvement observed in previous acute trials, we have asked MicroCures and USU\* to test the siFi2 therapy in rats with chronic injuries. For the latest updates/results, visit our website, [here](#).


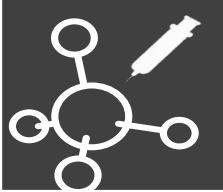


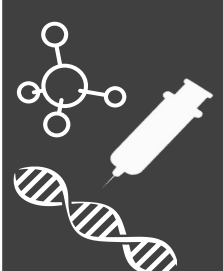
# 2

**KN-combined gene therapy - Blackmore and Perlmutter labs:** The animal study, funded by us in 2020- 2021, aims to advance a promising new gene therapy approach to improve axon growth after CHRONIC spinal cord injury. It is based on a recent discovery from Dr. Blackmore's lab that a combination of two transcription factors, Klf6 and Nr5a2 (KN), stimulates robust and highly reliable growth of corticospinal tract (CST) axons. The goal here is to enable the translation of this therapy by determining whether KN is also effective in a more chronic and clinically relevant model of spinal contusion. For the latest updates and results, visit the Research pages of our website, [here](#).

(\*) USU: Uniformed Services University of the health sciences



# 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	<b>Scar reduction</b> (enabling nerves regrowth at chronic SCI stage) + <b>plasticity</b> enhancement (creating new neural pathways and connections)
3 - 4	CRP peptide		Subcutaneous delivery (→ non invasive)	Dr Lee – Cleveland Clinic, USA	
5	PNNi oral drug		Off-the-shelf 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	Switching off growth inhibitors to enable <b>intrinsic axonal re- growth</b>
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	Trigger successful axon <b>regeneration</b> + <b>reattachment</b> at the site of injury

# 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

## 2021 RESEARCH LAY OVERVIEW

(chronic SCI pre-clinical & clinical research)

**New improved template!**



Spinal Cord Injury  
TRIALS

# FIND SCI TRIALS

WWW.SCITRIALS.ORG



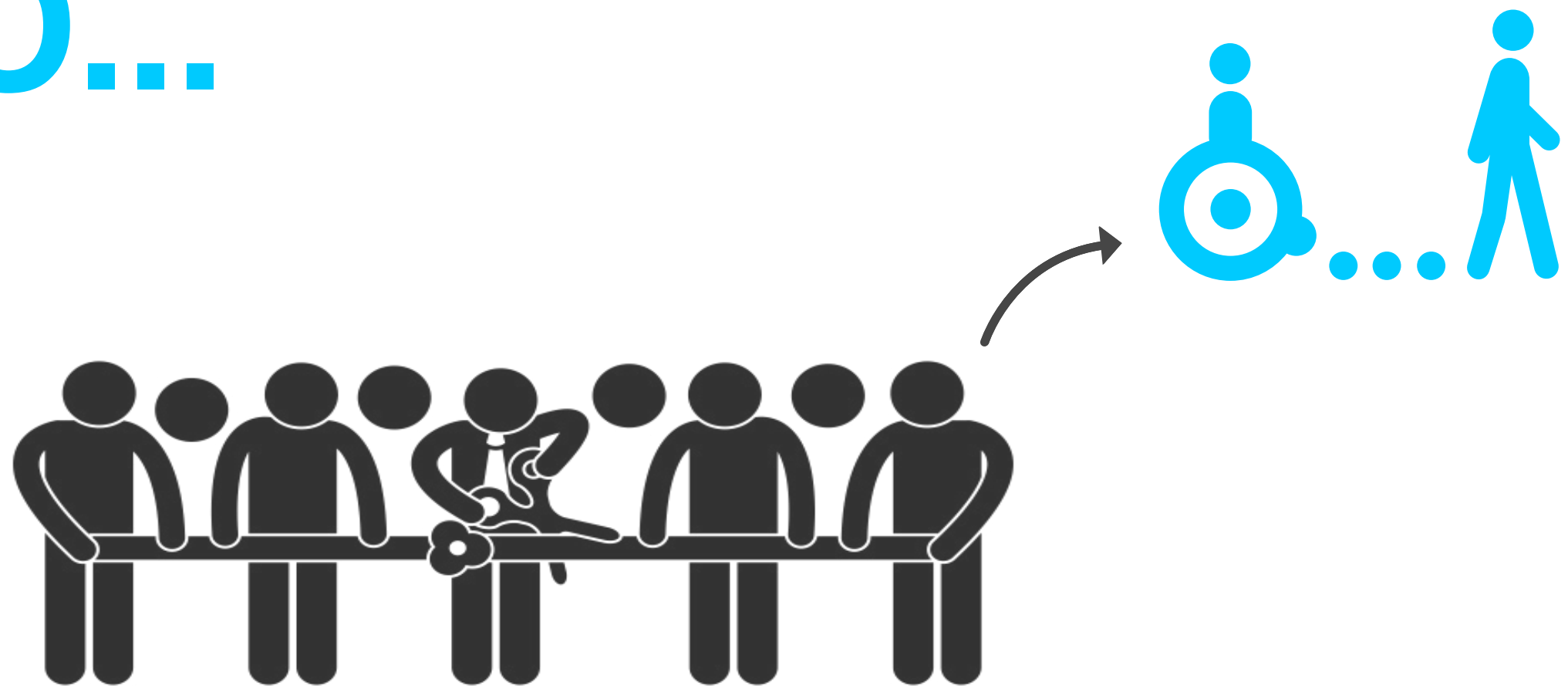
North American  
Spinal Cord Injury  
— Consortium —



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# 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

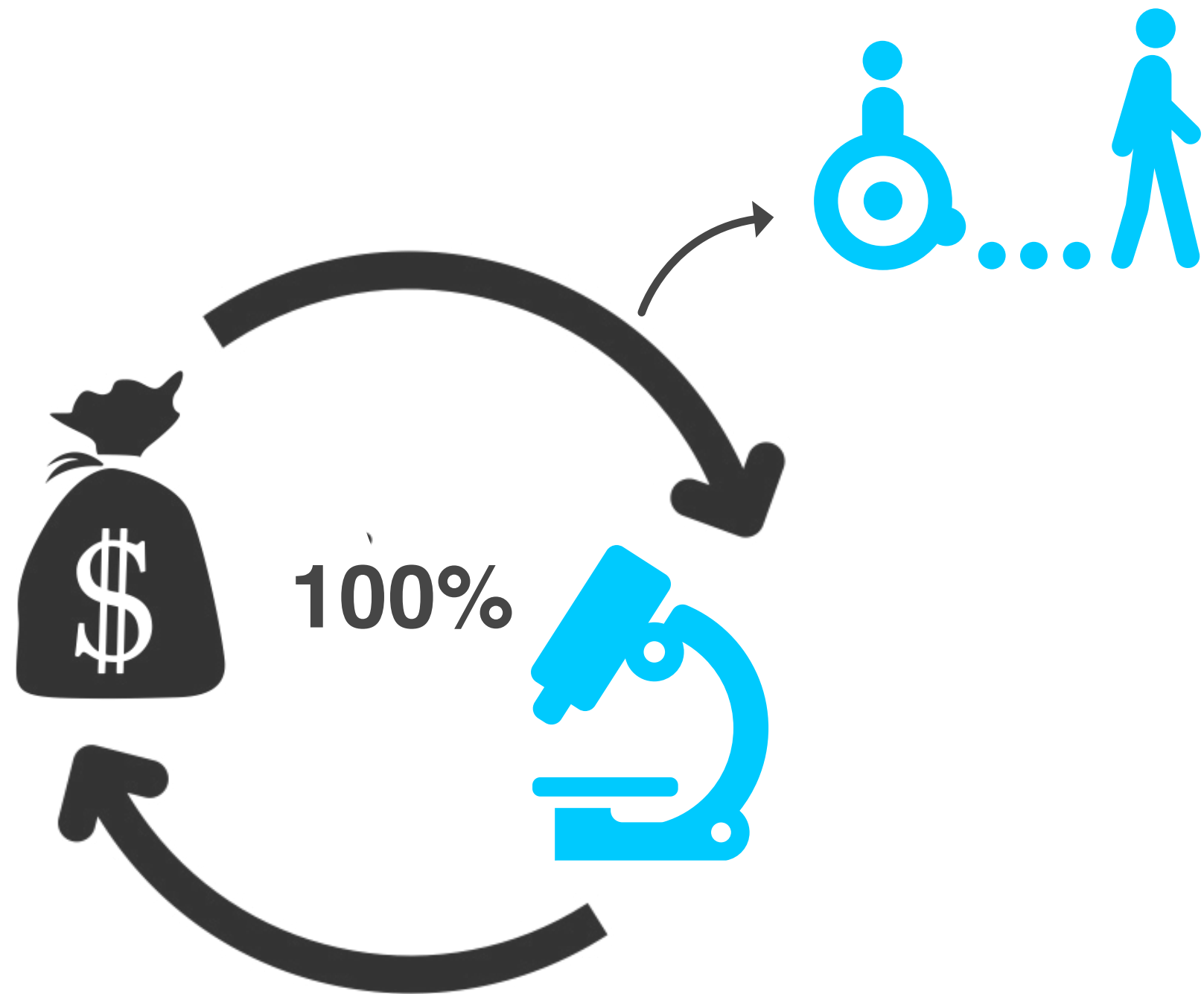
- Amina Abed
- Elise Adriaanse
- Dr. Mark Bacon
- Amit Chakraborty
- Jacob Zuurmond
- Dr. Elly Hol
- Corinne Jeanmaire
- Dr. Janneke Stolwijk
- Jaap Pipping
- Chris Powell
- Thierry Schmitter
- Dr. Jerry Silver
- Dr. Joost Verhaagen



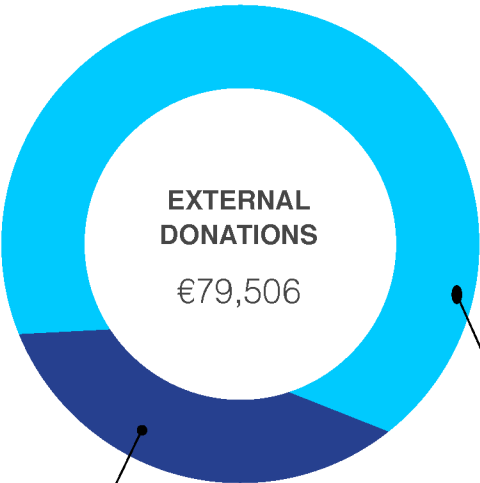
- Eva Alexandra
- Gianluca Ariello
- Serena Gravili
- Ernst ter Horst
- Mohammed Kabbara
- Ruwan vd Leeuwen
- Desirée Van Lieshout
- Ruth Purves
- Marc Renckens
- Andries Riedstra
- Emre Sahare
- Beverley Saunders
- Fons Weijtens

# FINANCIALS

# 2021



# FINANCIALS IN 2021



TOTAL INCOME	
External donations	€79,506
Internal donations*	€3,286
Interest from savings	-
<b>TOTAL 2021</b>	<b>€82,793</b>

## 2021 SIMPLIFIED BALANCE SHEET

ASSETS		LIABILITIES	
Current bank account ING	€6,940	Retained earnings	€55,317
Savings bank account ING	€5,180		
WISE GBP account (*)	€43,197		
<b>TOTAL ASSETS</b>	<b>€55,317</b>	<b>TOTAL LIABILITIES</b>	<b>€55,317</b>

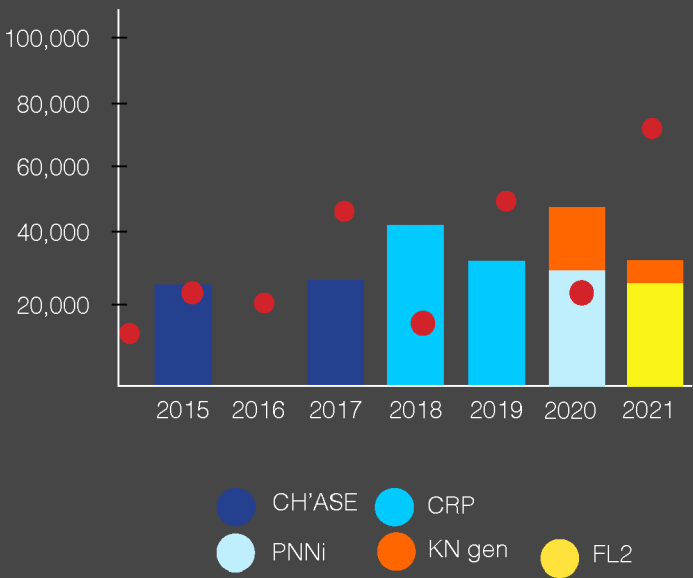
All balance figures on Dec 31, 2021. (\*) Based on exchange rate GBP/EURO Dec 31, 2021.



2021 TOTAL EXPENSES	
FL2 study - MicroCures-USU	€28,103
KN Combi gene research	€ 5,345
Operational costs*	€3,286
<b>TOTAL EXPENSES</b>	<b>€36,734</b>

# ... AND SINCE INCEPTION

## FUNDS RECEIVED AND DISTRIBUTED TO RESEARCH



Year	Research funding	External income (**)
2014	0	10,705
2015	25,000	22,562
2016	0	20,668
2017	30,000	46,085
2018	40,000	13,204
2019	34,000	47,607
2020	46,791	24,219
2021	33,448	79,506
<b>TOTAL</b>	<b>€209,239</b>	<b>€264,556</b>

Bank balance: € 55,317 (on December 31st, 2021)

\*\* All income excluding internal donations by endParalysis board members to cover operation costs.



(\*) The “internal donations” cover all the foundation’s operational costs, so that 100% of your gifts (i.e. “exter-nal 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 (at the level of €2906) and from the MAECENATA STIFTUNG (TGE GERMANY at the level of €380).



# GET INVOLVED



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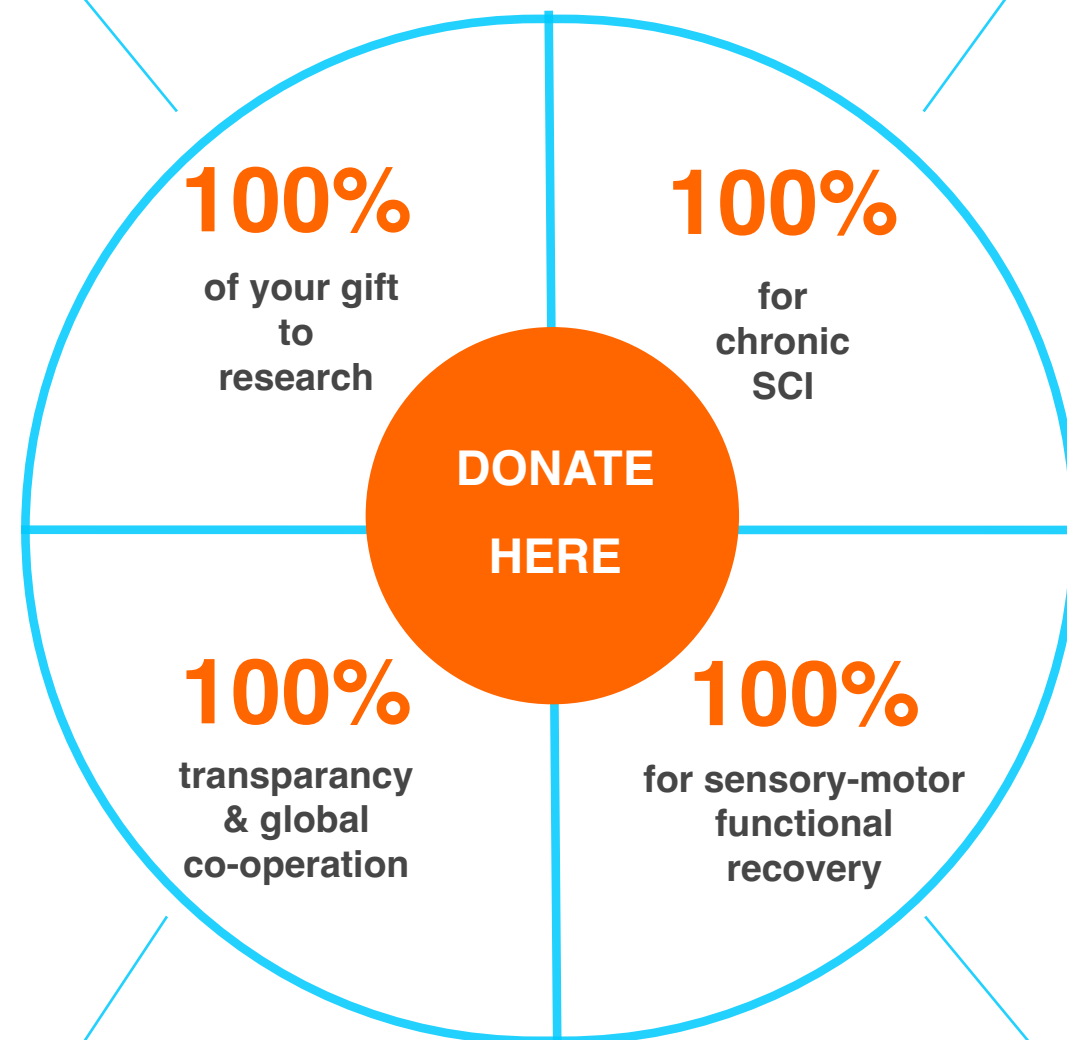
endParalysis



# 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!



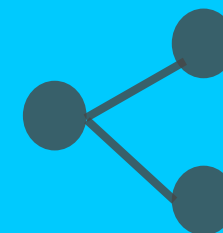
**Volunteer!**  
We can always use help



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



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



**Like us & Share us!**



endParalysis



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Photo: ©endParalysis.org

# Unfreeze Your Body!

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

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





## IN THE SPOTLIGHT:

In 2021, Marion chose to walk the Handelse Processie (NL). There were no big crowds to accompany her, as the procession was officially cancelled due to COVID. But she stood her ground and carried on, paying tribute to her father, with whom she used to do this walk every year.

Her father died of a spinal cord injury after only a minute of inattention on a ladder. That minute, she says, is “a minute I will never forget”. Aware that it really can happen to anyone, Marion decided to help research to cure paralysis by taking an Unfreeze challenge and raised over €800 for research. After the walk, she also told us how cathartic the experience had been for her.

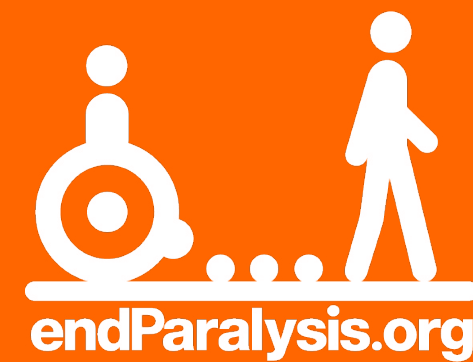
Thank you so much Marion!

More about Marion's challenge, click [here](#)



Picture: ©endParalysis





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

**Contact us:**  
info@endParalysis.org  
www.endParalysis.org  
Tel: +31 622 788798  
**endParalysis foundation**  
Cederlaan 135  
5616SC EINDHOVEN

**Donate**

**Get involved**

