

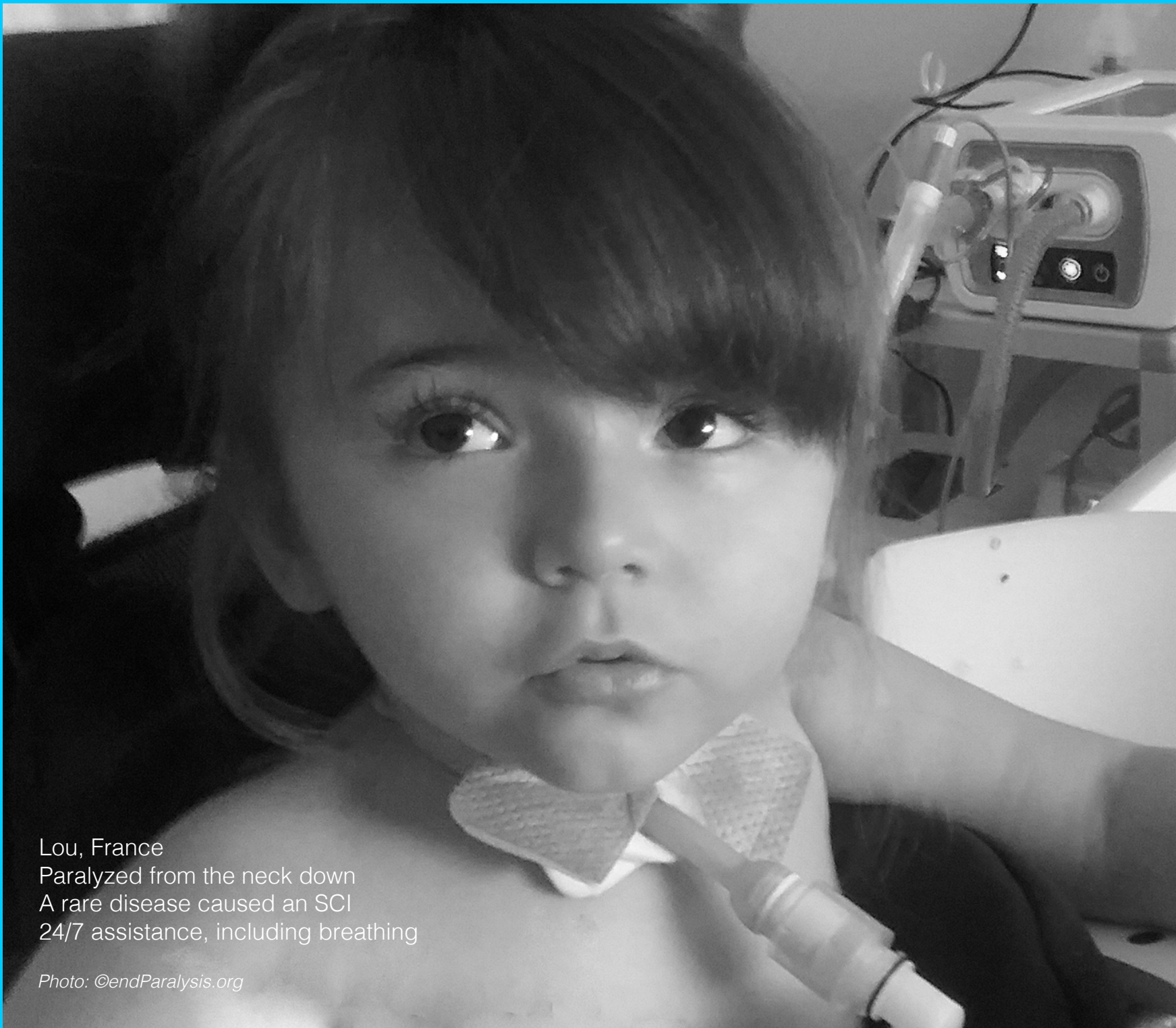
# 2020 Annual report

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 cure!**  
**endParalysis.org**



# endParalysis: UP TO THE CHALLENGE IN 2020 AND BEYOND

Many non-profit organisations experienced hard times during a strange and rather challenging 2020. So did our foundation. However, we stayed on track and performed well. We even took the opportunity to refine our strategy and invest in the future, sticking to our target more than ever: accelerating research to cure chronic spinal cord injury (SCI).

Reflecting on 2020, our most visible achievement is the amount we invested in scientific research: over €46,000.

- Firstly, we funded a research project aiming at axons / nerves regrowth. Neural regeneration is indeed, next to scar alleviation, a critical challenge on the path of functional recovery after chronic spinal cord injury. The so-called “KN combined-gene therapy” was discovered by the Blackmore Lab (Marquette University). Dr Perlmutter (University of Washington) will be replicating the animal trial previously carried out just after the SCI to check if it can also unlock axonal growth in chronic settings.

- Secondly, we decided to support an alternative therapy to dissolve the scar: the PNNi, a drug that showed promising results when tested on rodents in the UK. Why add this potential therapy up to our portfolio? Mainly because it involves a drug which is already available off the shelf and is already used to treat people affected by a rare disease. Should it turn out to be safe and effective at the chronic stage of SCI, this repurposing strategy could definitely shorten the path to the clinic (thus to patients)!

EndParalysis has always been about co-operating and leveraging knowledge as well as resources. This philosophy also applies to the latter project since we partnered with two other foundations to finance the study. In that regard, we want to sincerely thank the Marina Romoli Onlus (Italy) and GUSU2Cure foundation (USA) who accepted our invitation to fund the PNNi study with us.

Last but not least, as hinted above, this year gave us the opportunity to think. How do we make a real difference? How do we accelerate the pace of translation of potential therapies? How do we make sure that at least one of the therapies that we believe is tested on patients as soon as possible and hopefully delivers positive results? We are currently taking steps in that direction, so watch the endParalysis space!



Follow us on:



@endParalysis



@endParalysis



@endParalysis



@endParalysis

and continue supporting us in any way you can to [BE THE CHANGE IN THIS WORLD!](#)

**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

---

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

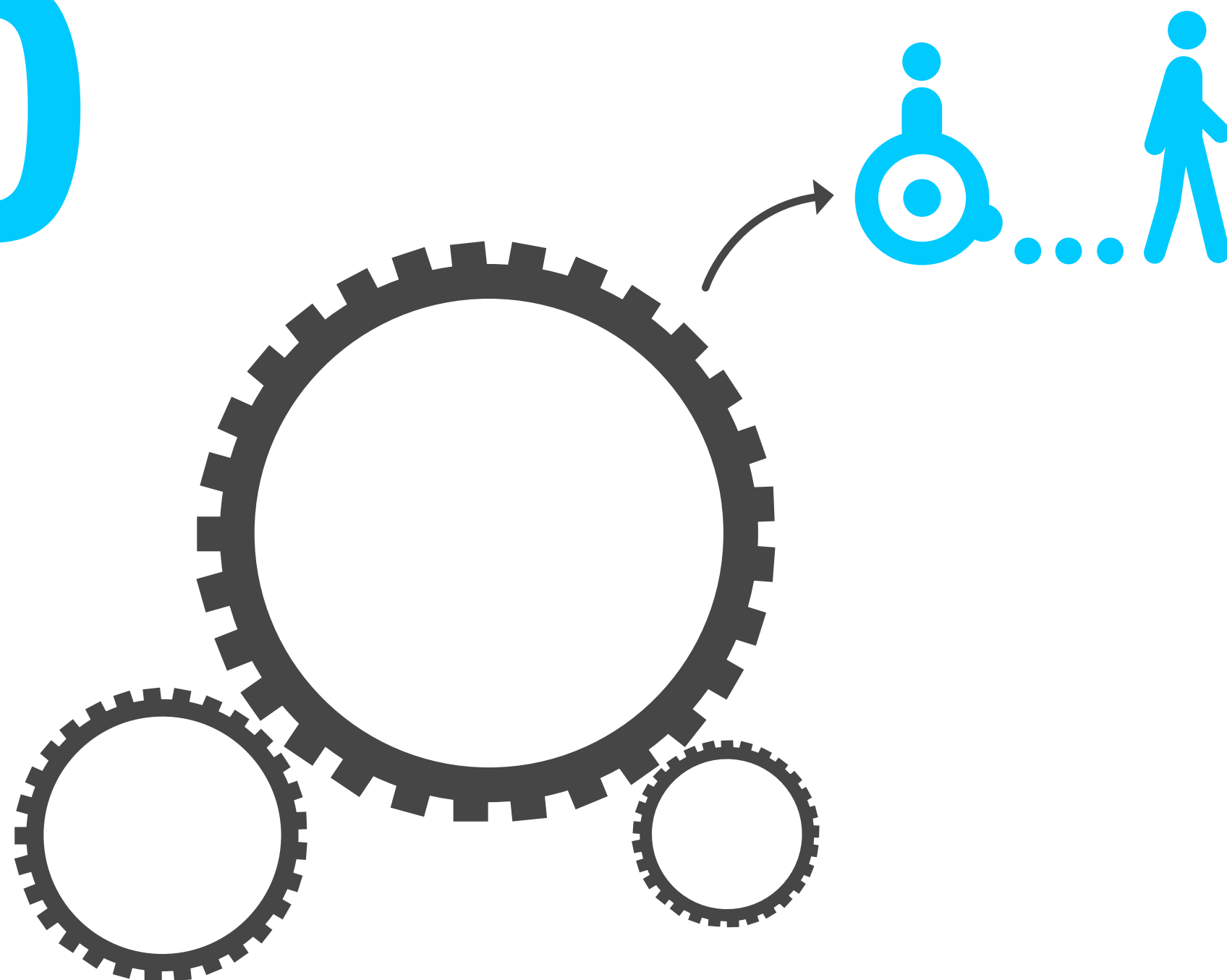
- co-funding clinically-relevant and groundbreaking research projects
- promoting an integrative, collaborative, and goal-driven approach to SCI research

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

Photo: @endParalysis.org



# OUR ACHIEVEMENTS & ACTIVITIES IN 2020





# 2020 RESEARCH PROJECT FUNDING

## MORE KEY STEPS TOWARDS THE GOAL

As of 2015 we allocated significant funds to various studies (\*) aiming at tackling the scar that forms at the level of the spinal cord a few days/weeks after a lesion. That scar, mainly concerning CHRONIC spinal cord injury (SCI) hampers axonal regrowth. Its neutralization is therefore an essential step towards recovery after chronic SCI. But it is just as essential to actively promote the regrowth of axons after the lesion. Therefore, we have decided to extend our portfolio and to support a study in the latter area as well. In 2020 we spent a total of € 46,791 to enable two studies covering both complementary aspects.

# 1

**KN Combined gene therapy for axon regrowth (Blackmore's lab and Perlmutter's lab- USA):** This project will advance a promising new gene therapy approach for improving axon growth after 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 from corticospinal tract (CST) axons. The goal here is to push in the direction of translation by determining whether KN is similarly effective in a more chronic and clinically relevant model of spinal contusion in the laboratory of Steve Perlmutter at the University of Washington. For more info about the project and its selection, read [this blog post](#).

# 2

**PNN oral treatment (Dr Kwok- University of Leeds- UK):** PNNi refers to a molecule that is already on the market (used to treat a rare disease). In animal studies, the drug has shown promising results when used at the acute (i.e. very early) stage of SCI. The molecule seems to neutralize the PNN (PeriNeural Net) as well as the scar, which both prevent nerves regrowth. The goal of this new study is to test the treatment on rats with chronic SCI and to determine the most optimal doses. The main advantage of this therapy, if results are confirmed and the side effects are manageable, is obviously a shorter path to the clinics, since the drug is already approved! We thank the [Marina Romoli Onlus](#) (Italy) and by [Gusu2cure](#) (USA) for funding this project with us.

(\*) Consult the next page of this report and our website (research section) for more info about current & previous studies.





# 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 injection (→ non invasive)	Dr Lee – Cleveland Clinic, USA	
⑤	PNNi oral drug		Off-the-shelve drug repurposing (→ short path to clinic)	Dr Kwok, University of Leeds- UK	
⑥	KN GENE therapy		Target intrinsic growth. Replicate prior study applying it to chronic	Dr Blackmore (Marquette)- Winsconsin + Dr Perlmutter (Washington) - USA	Switching off growth inhibitors to enable intrinsic axonal re-growth

# GLOBAL ADVOCACY: PARTICIPATION IN THE **WORKING 2 WALK SYMPOSIUM**



**FROM A MICRO-LEVEL  
TO A MACRO-PICTURE,  
FROM MINIMAL FUNCTIONAL  
RECOVERY TO CURE -**

**WHAT CAN WE DO?**

*A presentation by Corinne Jeanmaire  
endParalysis foundation*

ONLINE  
PRESENTATION

**Watch Here**

(as of 19.50'  
till 34.27')

# Working 2 Walk

**October 22-24, 2020**

**Virtual Symposium**



# INFORMING ABOUT SCI RESEARCH & TRIALS

We find it very important to help the SCI community locate and understand relevant information about

PROGRESS TOWARDS CURING CHRONIC SCI

## LAY OVERVIEW

(chronic pre-clinical & clinical research)

Click [here](#)



Are there any clinical trials that patients can participate in? With various global partners we offer a platform to easily search for

WORLDWIDE CLINICAL RESEARCH/ TRIALS



Spinal Cord Injury  
TRIALS

# FIND SCI TRIALS

WWW.SCITRIALS.ORG



North American  
Spinal Cord Injury  
— Consortium —

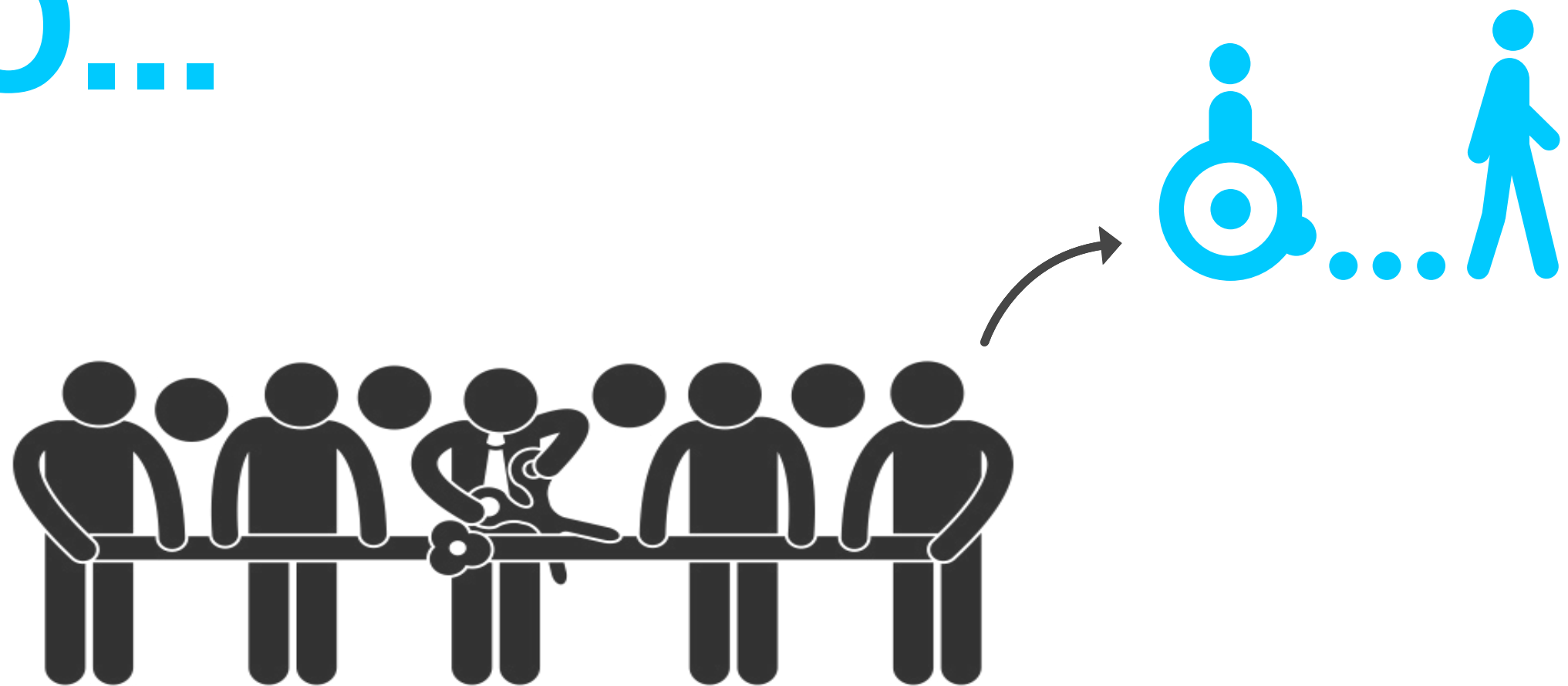


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CSRO  
ASRO

# 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, 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

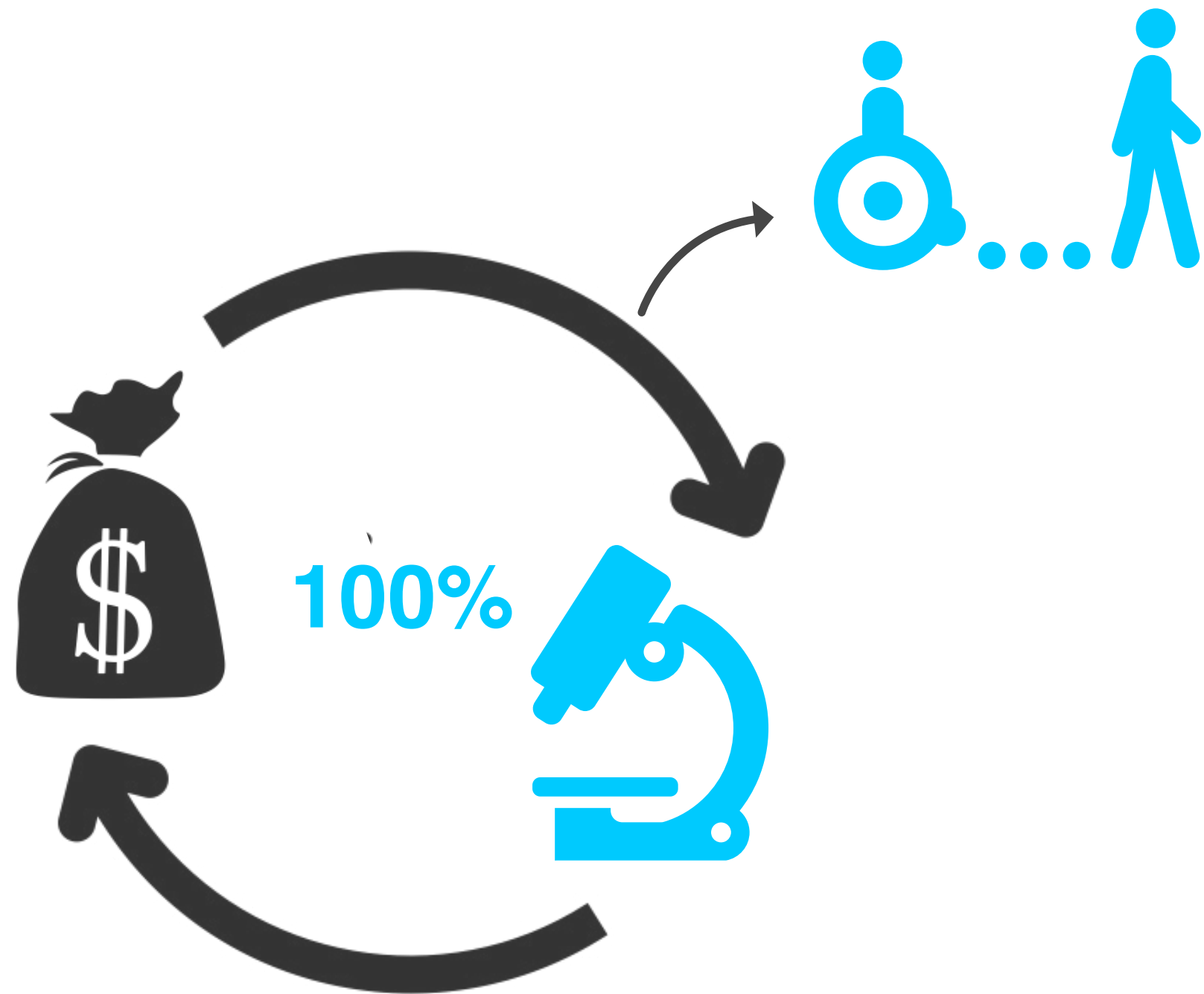
- Amina Abed
- Elise Adriaanse
- Dr. Mark Bacon
- Jo Baltus
- Jos Dekkers
- Dr. Elly Hol
- Corinne Jeanmaire
- Dr. Janneke Stolwijk
- Jaap Pipping
- Chris Powell
- Thierry Schmitter
- Dr. Jerry Silver
- Dr. Joost Verhaagen



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

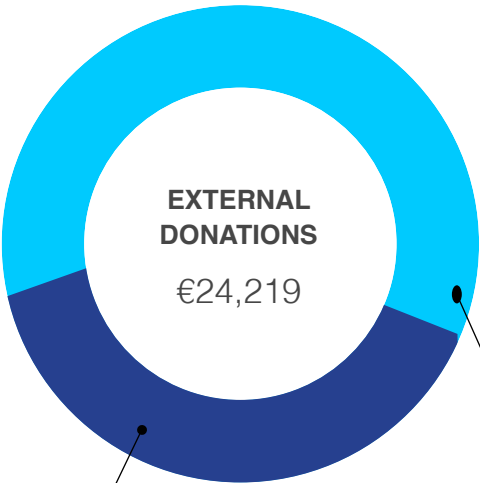
# FINANCIALS

# 2020





# FINANCIALS IN 2020



Foundations and companies 57%  
Individuals 43%

## TOTAL INCOME

External donations	€24,219
Internal donations*	€1,014
Interest from savings	-
<b>TOTAL 2020</b>	<b>€25,233</b>

## 2020 SIMPLIFIED BALANCE SHEET

ASSETS		LIABILITIES	
Current bank account ING	€4,100	Retained earnings	€9,280
Savings bank account ING	€5,180		
PayPal account	€0		
<b>TOTAL ASSETS</b>	<b>€9,280</b>	<b>TOTAL LIABILITIES</b>	<b>€9,280</b>

All balance figures on Dec 31, 2020



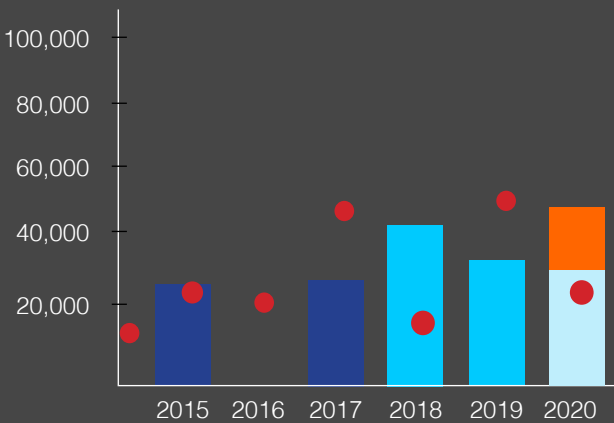
PNNi molecule therapy: 66%  
KN: Combi-gene therapy: 34%

## 2020 TOTAL EXPENSES

PNNi research project	€30,835
KN Combi gene research	€15,956
Operational costs*	€1,014
<b>TOTAL EXPENSES</b>	<b>€48,005</b>

# ... AND SINCE INCEPTION

## FUNDS RECEIVED AND DISTRIBUTED TO RESEARCH



CH'ASE CRP  
PNNi KN gen

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
<b>TOTAL</b>	<b>€175,791</b>	<b>€185,272</b>

Bank balance: € 9,260 (on December 31st, 2020)

● External income \*\*

\*\* 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. “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 (€729) and from the MAECENATA STIFTUNG (TGE GERMANY : €285€).

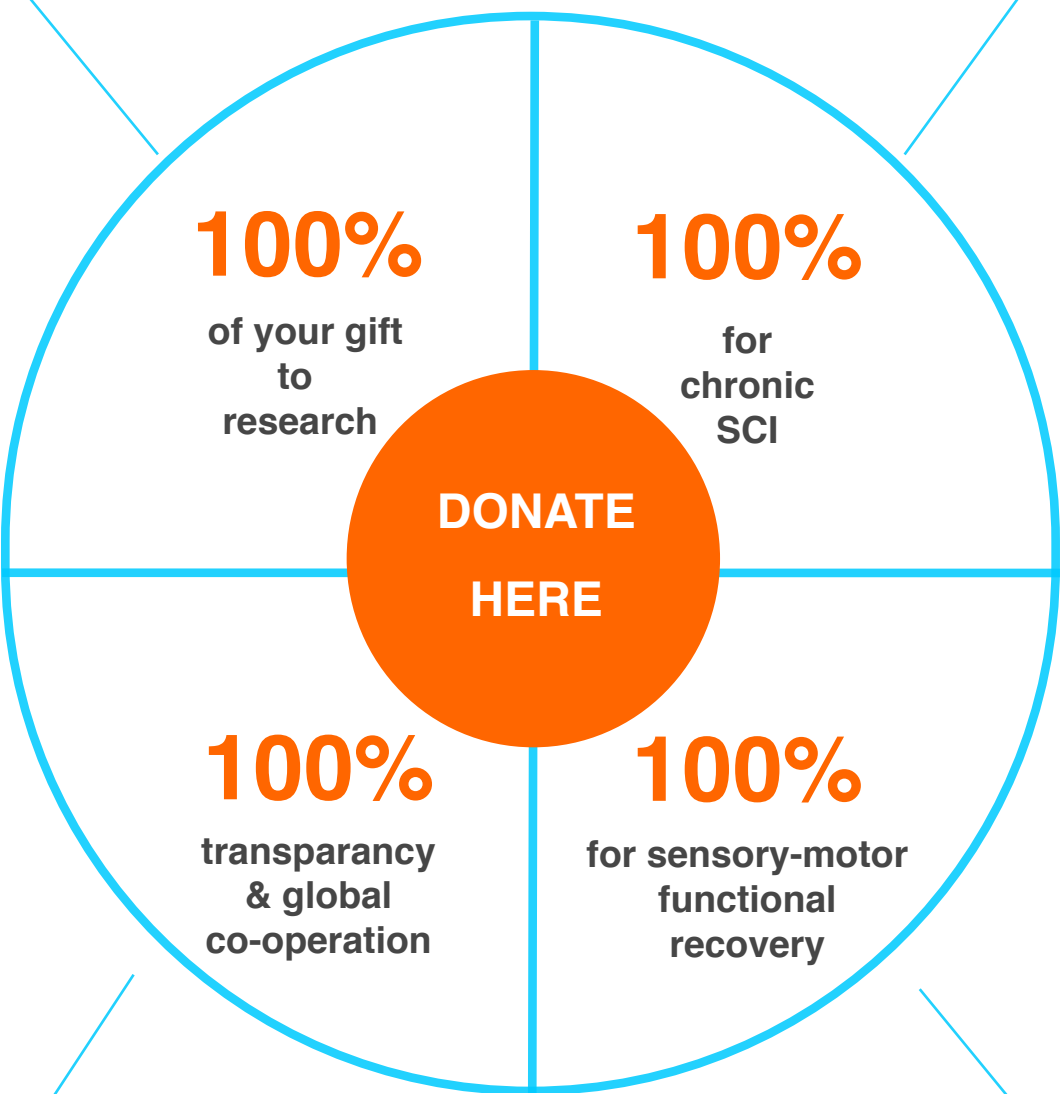
# GET INVOLVED



# 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!**



@endParalysis



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endParalysis foundation



## IN THE SPOTLIGHT:



In 2020 Corinne started her **Unfreeze Your Body & Mind Challenge** and took it upon herself to practice full body yoga on a regular basis and, last but not least, to raise money for research. This challenge is ongoing, **donations are still welcome.**

**Read more about  
Corinne's challenge**

(Over € 8,000 raised, all of which allocated to SCI research)

## UNFREEZE

by Corinne

## CHALLENGE

**Encourage  
Corinne**

to complete her challenge by  
making a donation  
to endParalysis,

**click here**



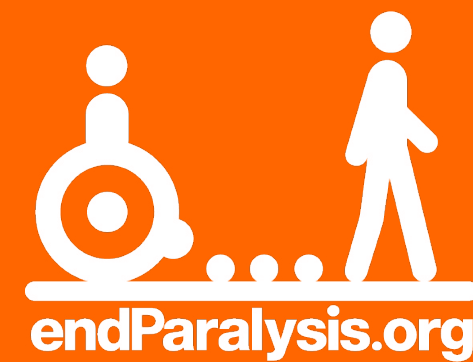


# Unfreeze Your Body!

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

Photo: ©endParalysis.org





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

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**Donate**

**Get involved**

