



ESCIF European Spinal Cord Injury Federation www.escif.org

ESCIF SCI research group update

ESCIF Congress 2014



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Agenda

- ESCIF research group
 - Who and what
 - Update on “unproven” therapies
- SCI research
 - Key lines and progress
 - Challenges and conditions
- Endparalysis Foundation
 - Introduction
 - Proposed partnership

ESCIF research group

- Who?
 - Jane Horsewell
 - Harvey Sihota
 - Corinne Jeanmaire
- What?
 - Information (regenerative research)
 - Education (research vs “unproven therapies”)
 - Advocacy (for more research)

Unproven therapies...

- Continue multiplying...
- A recent “brilliant” example: Repair Stem Cells Institute



BREAKING NEWS
Spinal Cord Injury
‘Cutting Edge’
Stem Cell Treatment

ONLY \$9,750

 **RSCI**
REPAIR STEM CELLS INSTITUTE
www.repairstemcellsinstitute.com

RSCI misleading communication!

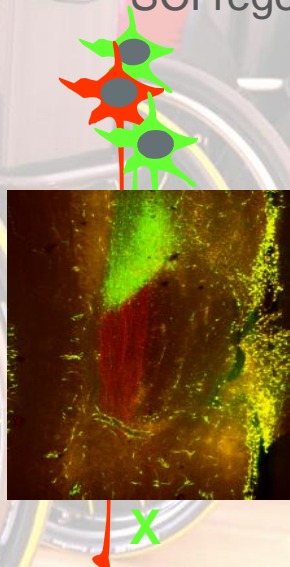
"Repair Stem Cells **Institute** Unveils New Spinal Cord Injury Stem Cell Treatment"

"RSCI's mission is to assist people to make **educated** choices about their medical conditions and treatments, **giving them a chance** to lead longer and more fulfilling lives than they could expect by continuing with **no-hope standard medicine.**"

"...the world's **only stem cell patients' advocacy group** Patient decisions are directed by Dr. James Braly of Illinois, the world's #1 stem cell **nutritionist.**"

Source: RSCI facebook page 2014

SCI regenerative research



Injured spinal cord

Key issues

Nerve cell death

Axons do not grow

Scar formation

Key Research

Stem cells

Growth factors

ChABC
Anti-NoGoA
Cellular bridges

A few key research projects

- Epidural stimulation+ chemicals: [Pr Courtines](#)- CH
- Epidural stimulation: [Reeve Found./ Pr Harkema](#)- USA
- IPSC (Induced Pluripotent SC): [Pr Tuszynski/ Lu](#) – USA
- Peptide: [Pr J.Silver](#) - USA
- Chondroitinase (Ch'ABC) and Gene therapies: [Spinal Research](#) – UK-NL- USA
- Autologous Olfactory Mucosal Cells : [Pr Franklin- UK](#)



A few key trials (humans)

- Human Neural Stem Cells: Stemcell Inc ([trial](#) in CH & Canada)
- Neural stem cells: Neuralstem Inc ([trial](#) in the USA)
- Bio-gel/ scaffold: Invivo Therapeutics ([trial](#) in USA- **ACUTE** SCI)

More on : www.clinicaltrial.gov or [here](#)

Conditions for success

- More funding!
 - More international collaboration / consortia
 - A more goal-driven approach (→human)
 - A more integrative approach (→combination therapies)
 - Better legislation (speed!)
- **More SCI-patient advocacy** (and fundraising)



Endparalysis foundation

Introduction



WHY?

Endparalysis Foundation's mission...

To help **accelerate research towards curing chronic Spinal Cord Injury (SCI)**, by:

- 1 Fundraising to co-finance **high-impact research** projects
- 2 Setting up a global **collaborative network** aimed at identifying and bridging the gaps to cure

We only fund projects that are...

- Duly evaluated & approved by one of our partners' **Scientific Advisory Board**
- Scientifically rigorous & financially sound
- Contributing to translating therapies with a **real potential of being successfully applied to humans**
- Contributing to overall scientific progress towards curing SCI

We are...

- Scientifically rigorous
- Collaborative (no duplication of efforts)
- Lean, agile
- Goal-driven
- Transparent: 100% donations to research
- Pragmatic but innovative
- Realistic but passionate!



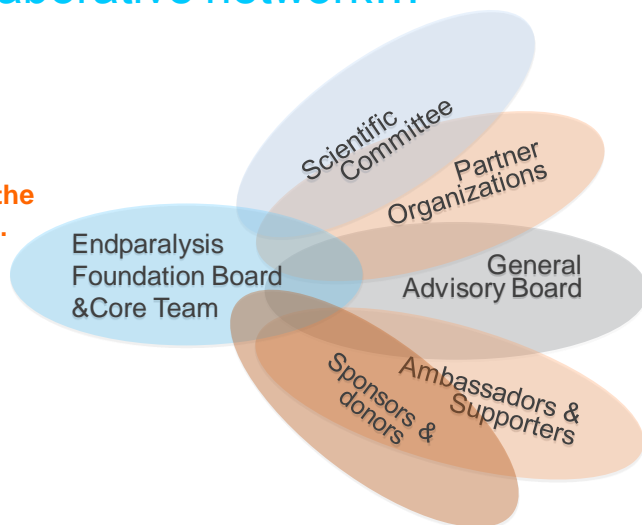
Our collaborative network
Our team of experts

WHO

Our collaborative network...

It's not about the organization...

It's about collaborating towards the GOAL!



Our experts...

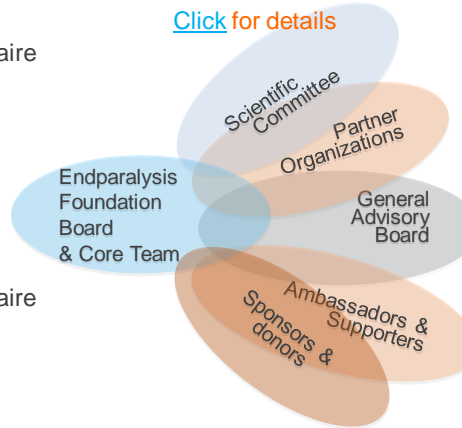
Board:

Corinne Jeanmaire
Jaap Pipping
Jos vd Wouw
Dr Mark Bacon

Core Team:

Corinne Jeanmaire
Ruth Purves
Amina Abed
Chris Powel

[Click for details](#)



Scientific Committee:

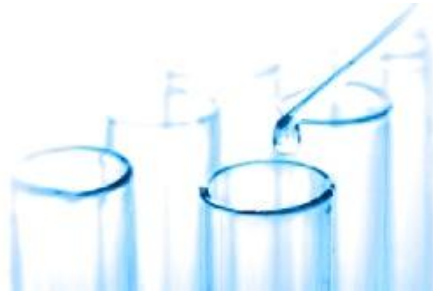
Pr Verhaagen- NL
Pr Jerry Silver- USA
Pr Elly Hol- NL
Dr Mark Bacon- UK
Christal Powel- US

Partner organizations:

Spinal-research.org- UK
Dwarslaesie.nl - NL
U2FP.org- US

Advisory Board:

Jos Dekkers- DON - NL
Jo Baltus - NL



Our first research project

WHAT

1st project: Chondroitinase (Ch'ase) to clinics

Target: to ready a promising therapy for clinical translation. The Ch'ase enzyme has shown encouraging results at pre-clinical stage. If successful on humans, it may **enable patients to improve/ recover respiratory, hand function & bladder control and possibly ambulation.**

Led by: Spinal Research/ [ISRT](#) (UK non-profit organization)

Our funding target: **50K Euro by end 2014**



ESCIF - ENDPARALYSIS

Proposed partnership – goal

Collaborative SCI regenerative research advocacy,
e.g.:

- Increasing awareness (SCI realities and costs)
- Promoting the need for a flexible cure roadmap
- Promote the need for increased targeted funding
- Promoting the need for accelerated translational and/or clinical trial processes in Europe.

Challenging the status quo...

Lean, flexible, agile,
we will keep focusing on **ONE SINGLE goal:**

Help cure chronic spinal cord injury!





THANK YOU!

More info on www.endparalysis.org

