



Public Engagement: Lessons from stem cell science

A/Prof Megan Munsie

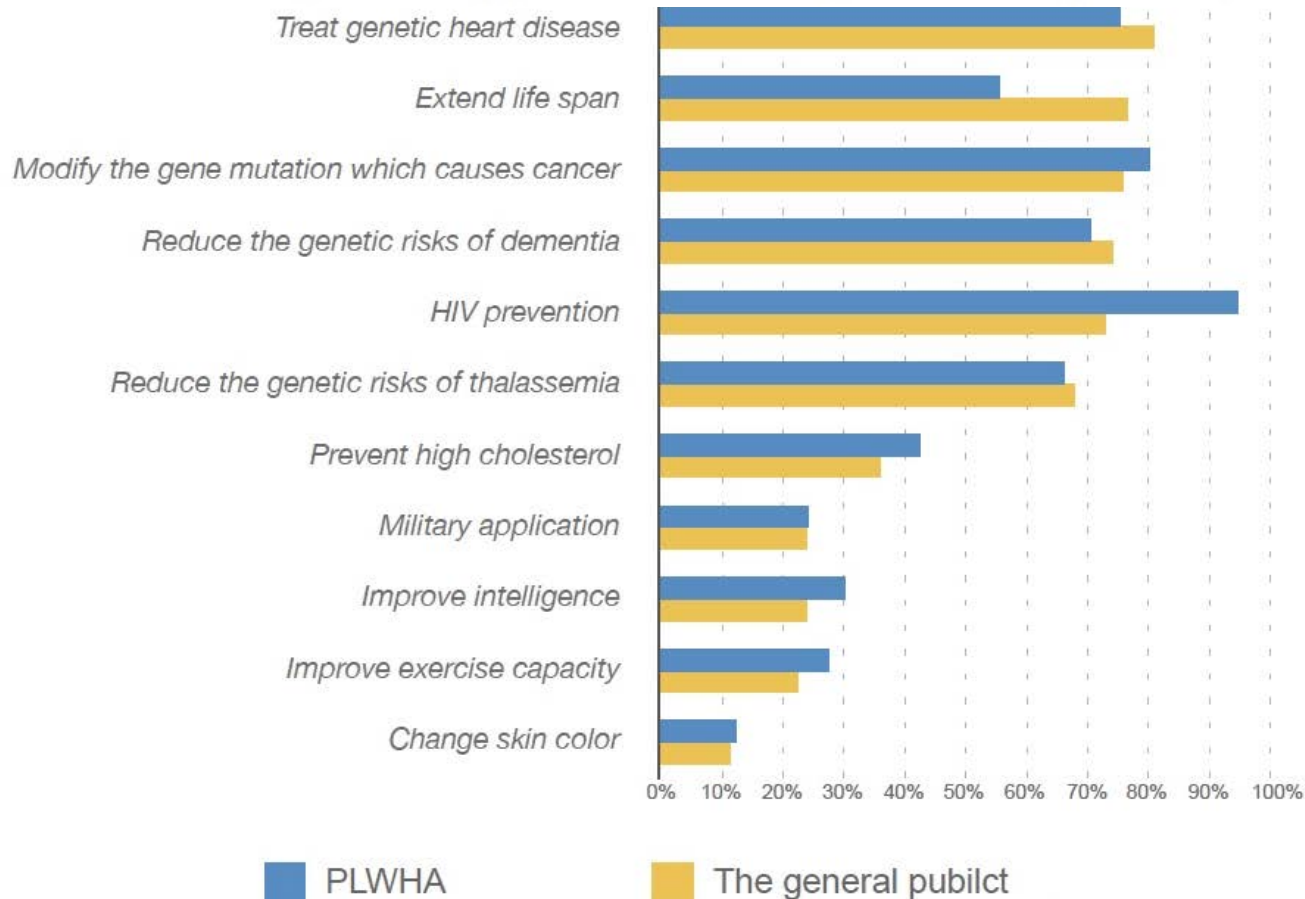
Centre for Stem Cell Systems

29 November 2018

High community expectations

Chinese Public Attitudes on Gene Editing

Acceptable applications for gene editing therapeutics



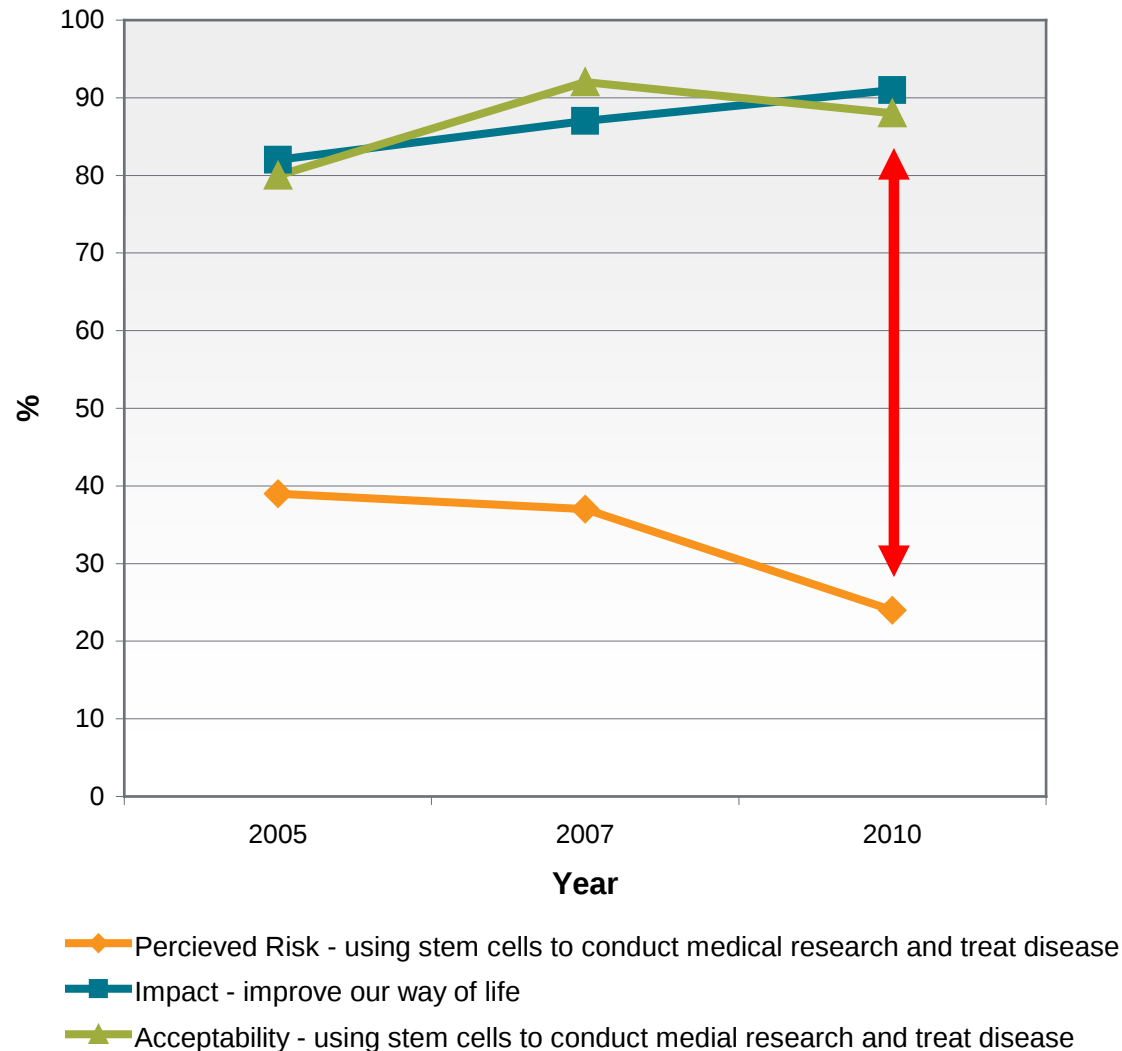
Liang Chen
Zhi'an Zhang



Most support, lowest perceived risk

Public Attitudes Towards Stem Cell Science in Australia

Data from Public Attitudes Towards Biotechnology in Australia www.innovation.gov.au



Exploiting the expectation gap: stem cell tourism

2008 – Warning signs:

- Claims of 'cure' and no risk
- Offered in places with poor/limited regulation
- One product, multiple diseases
- Unqualified providers
- Lack of clarity about 'treatment'
- High costs



Stem Cell Clinics Online: The Direct-to-Consumer Portrayal of Stem Cell Medicine

Cell Stem Cell 3, December 4, 2008

Darren Lau,¹ Ubaka Ogbogu,² Benjamin Taylor,² Tania Stafinski,¹ Devidas Menon,¹ and Timothy Caulfield^{1,2,*}

Stem cell therapy or snake oil?

NATURE BIOTECHNOLOGY VOLUME 23 NUMBER 12 DECEMBER 2005

Cell Stem Cell

ISSCR: Commentary

Cell Stem Cell 3, December 4, 2008

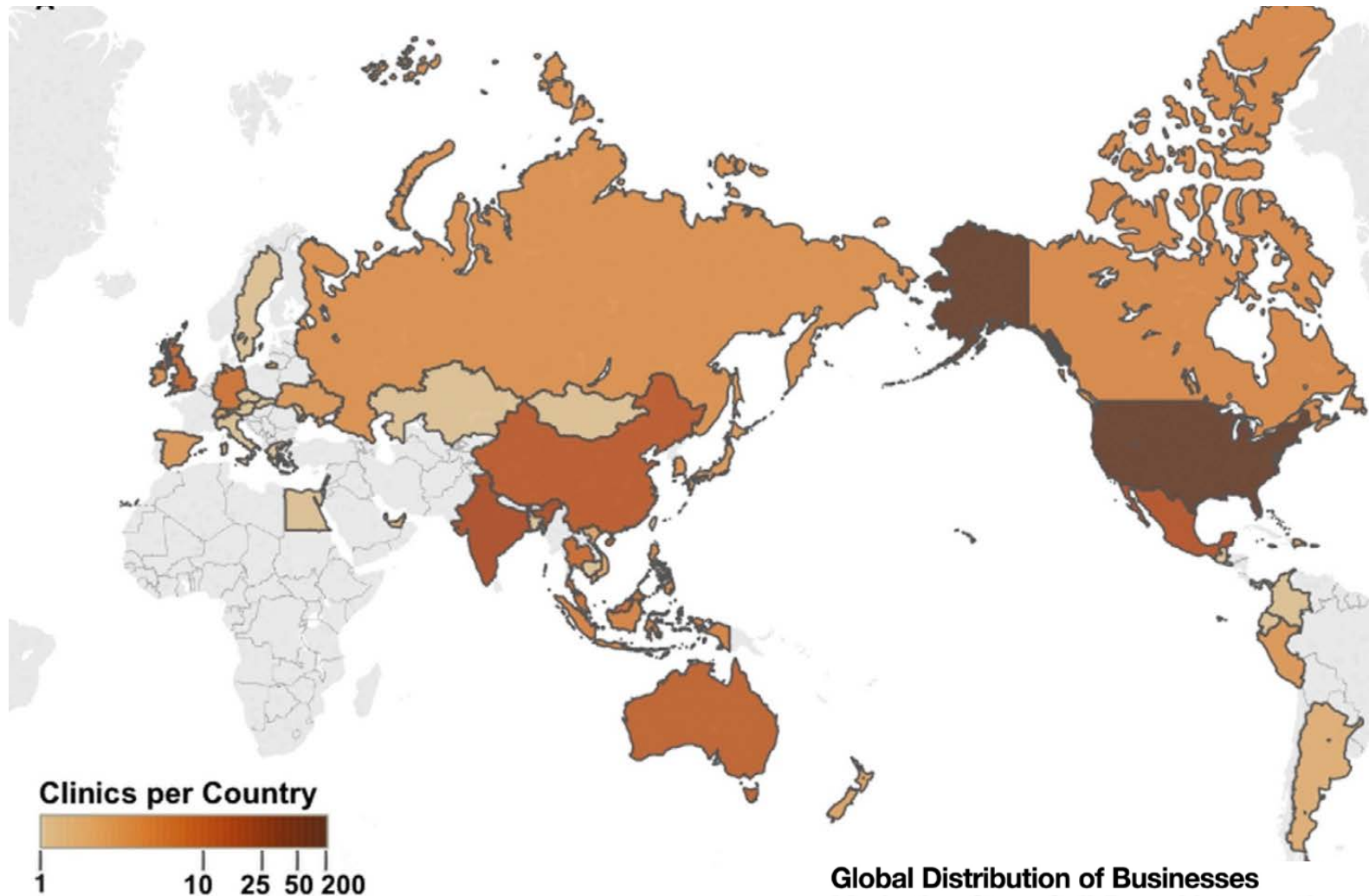
**New ISSCR Guidelines Underscore Major Principles
for Responsible Translational Stem Cell Research**



ISSCR

Cell
PRESS

Big business of selling stem cells



**Global Distribution of Businesses
Marketing Stem Cell-Based Interventions**

Cell Stem Cell 19, August 4, 2016

Israel Berger,^{1,2} Amina Ahmad,³ Akhil Bansal,³ Tanvir Kapoor,¹ Douglas Sipp,^{4,5} and John E.J. Rasko^{1,2,6,*}

Engagement - think global act local

'Inform'



Address regulatory ambiguity



Set professional standards



RANZCO | The Royal Australian and New Zealand College of Ophthalmologists
THE LEADERS IN COLLABORATIVE EYE CARE

AUSTRALASIAN COLLEGE OF SPORT AND EXERCISE PHYSICIANS

Understanding expectations



High hopes, high risk?

**A sociological study of stem cell
tourism**

Project partners:

Supported by:

To travel or not to travel



- Frustrated at lack of options and a race against time with Australia lagging behind
- Large financial & emotional cost
- Support from health professionals at home lacking
- 'Realistic' hopes

"There's no-one in Australia that can help us"

Ray & wife with PD travelled to China

"It's happening everywhere else but here"

Joe, spinal injury, considering treatment

"We were hopeful ... but we certainly weren't under the expectation that yes, this is going to work. You know, this is going to be the magic bullet".

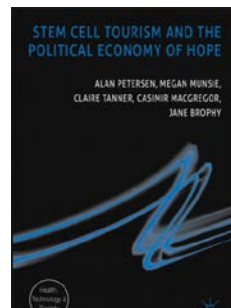
Peter took son with CP to USA for treatment

SOCIOLOGY OF HEALTH & ILLNESS

Sociology of Health & Illness Vol. xx No. xx 2013 ISSN 0141-9889, pp. 1-16
doi: 10.1111/1467-9566.12092

Therapeutic journeys: the hopeful travails of stem cell tourists

Alan Petersen¹, Kate Seear² and Megan Munsie³

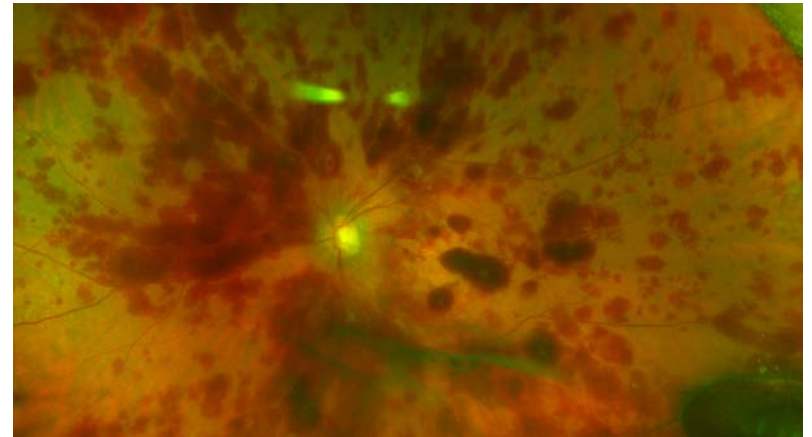


High cost of failure to inform

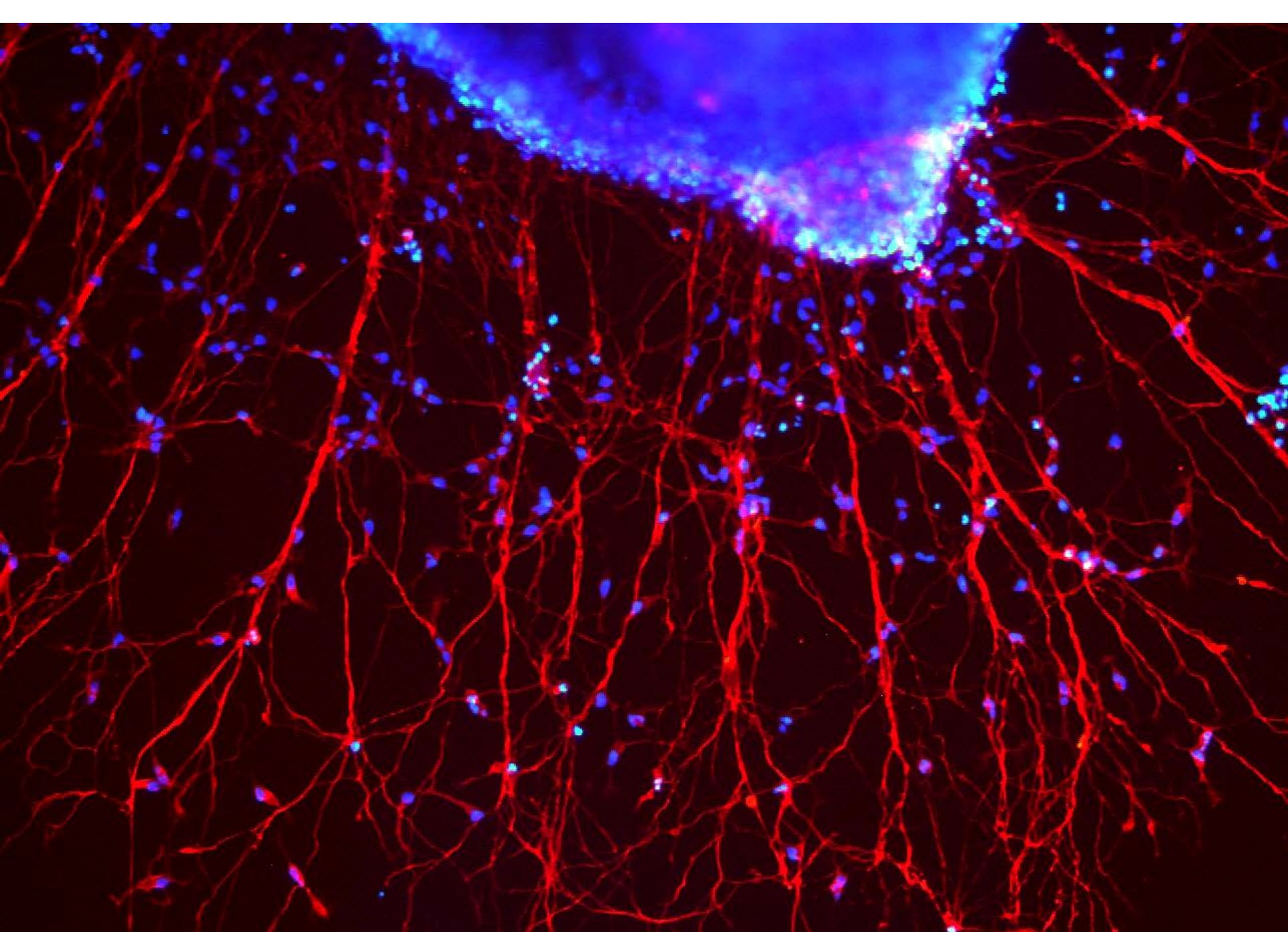
"It came down to the worst that could happen was nothing really...we could spend our money and have gotten no result..."

Lisa - took child with CP to Germany

The New York Times
Patients Lose Sight After Stem Cells Are Injected Into Their Eyes



Vision Loss after Intravitreal Injection
of Autologous "Stem Cells" for AMD



Perception of choice

