



People with MS as Co-Pilots?



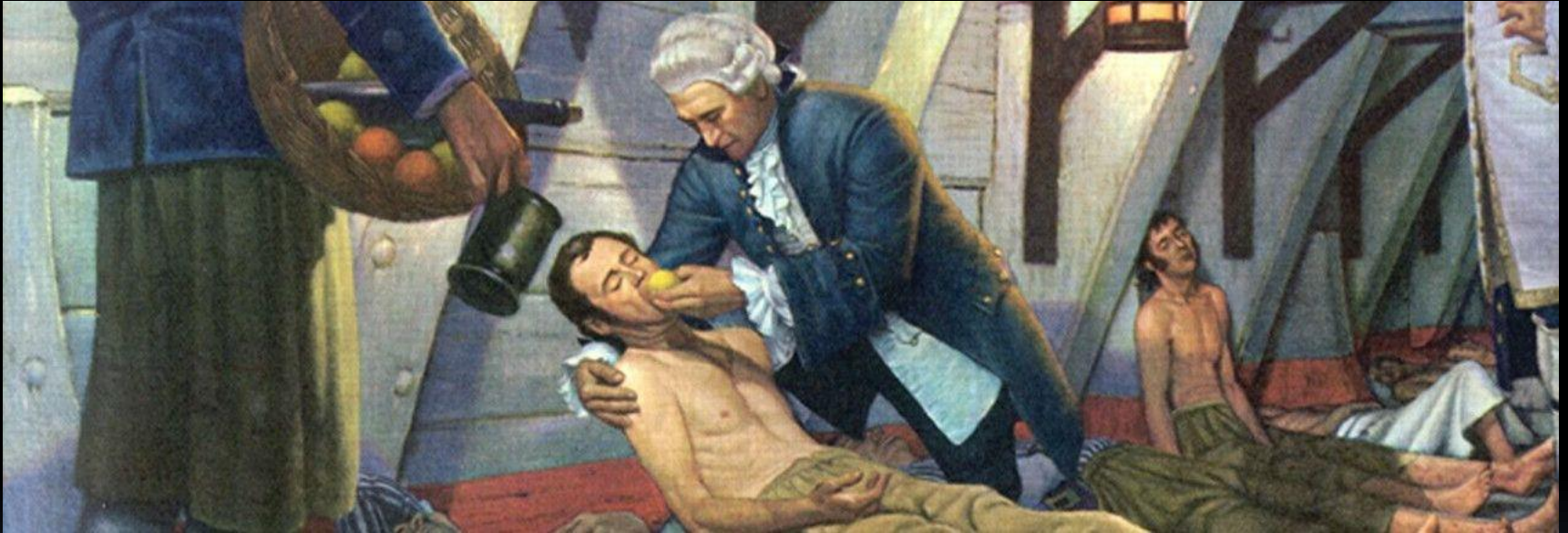
Alexis Donnelly (Trinity College Dublin)

Scientific Steering Committee,
(Progressive MS Alliance)

... and this is me..

- University lecturer (computer science)
- ~30 yrs living with progressive MS
- Scientific Steering Committee (International Progressive MS Alliance)





First Clinical Trial (1747, HMS Salisbury)

- Scurvy was a problem in the Royal Navy
- 6 arms (6 days):

❖ Citrus fruits (2)	❖ Bigness of Nutmeg (2)
❖ Elixir vitriol (2)	❖ Sea-water (2)
❖ Vinegar (2)	❖ Cider (2)

- Captain Cook required a diet of fresh fruit & vegetables
- Little mortality on >3 year voyages...



A
T R E A T I S E
upon ON THE *Asylum*
S C U R V Y.
IN THREE PARTS.
CONTAINING
An Inquiry into the Nature, Causes,
and Cure, of that Disease.
Together with
A Critical and Chronological View of what
has been published on the Subject.
By JAMES LIND, M. D.
Physician to his Majesty's Royal Hospital at *Hisler*
near *Perthmouth*, and Fellow of the Royal
College of Physicians in *Edinburgh*.
The THIRD EDITION, enlarged and improved.
L O N D O N :
Printed for S. CROWDER, D. WILSON and G.
NICHOLLS, T. CADELL, T. BECKET and Co.
G. PEARSON, and W. WOODFALL.
MDCCLXXII.

Degrees of Patient Involvement

Degree of Involvement	Example
Co-Navigators	+ Trial Design / Endpoints / Assay
Advocate + Participant	+ Recruitment / Dissemination
Participant	Tissue / Questionnaire

Thank You All

- Attitude of gratitude... BUT...
- "Patient" is also IM-patient

>>> **Progress please!** <<<

- Let's make a deal...
- Solve the problem ... I will nominate for NP ...

Guiding Research Direction

- Gnarled old scouts ...
 - who know territory...
 - for which no map has yet been drawn...
-
- We take risks too!
 - (Pharma companies do too)



JAMES STEWART

*hits his
'Glenn Miller Story'
standard again in*



The Far Country

COLOUR BY
TECHNICOLOR

JAMES STEWART RUTH ROMAN CORINNE CALVET

"THE FAR COUNTRY" U

Colour by TECHNICOLOR

with WALTER BRENNAN

JOHN MCINTIRE JAY C. FLIPPER HENRY MORGAN STEVE BRODIE

Story and Screenplay by BORDEN CHASE

Directed by ANTHONY MANN Produced by AARON ROSENBERG

A UNIVERSAL-INTERNATIONAL PICTURE
G.F.S. RELEASE



Selection & Preparation

- Commitment
- Understanding of the Research Process
- Training, if necessary
- Eloquence
- Advocacy
- Presence in the room may change discussion
- Wide Consultation
- Comfortable with the media
- Importance of trust

Which Clinical Trial?

- Public involvement increasingly the norm
- Perceived risk
- Degree of Involvement
- Difference in our lives (magnitude & likelihood)
- Societal cost implications
- Importance of trust



Thank you + Questions?