

Prioritization of a Research Topic

Lester Firkins

XII Cochrane Annual Meeting

Milan November 2007

Introduction

Who am I

My personal journey

What did it teach me

Is this the way research should be

An alternative approach -

The James Lind Alliance

Who is Lester Firkins

Middle aged , Middle Class, White, Male.

35 years in UK Banking Industry

Conventional

Content with rules and structure

Performance and achievement driven

Fairly well read - with a broad understanding of most things

Medicine and Research is looked after by others - and always in my best interest

My money is well spent

My journey starts here ...

Ellis Firkins

First Class Honours
graduate in Design
Technology

Teacher at major UK
public school

Died on 1st March
2001 from vCJD

QuickTime™ and a
TIFF (Uncompressed) decompressor
are needed to see this picture.

My Journey in summary

Chair of Human BSE Foundation for two years

Consumer Workshop on vCJD clinical trials

Co- Chair Prion-1 Clinical Trial

Co Chair New Therapies Scrutiny Group

Member of NICE appraisal on the
decontamination of instruments

Chair James Lind Alliance

Human BSE Foundation

One of two UK Charities

Challenging and confrontational

An effective Government Lobby

BSE Enquiry

Food Standards Agency

Department of Health

Consumer Workshop on CJD Trials

Medical Research Council and DH

“To enable consumer understanding of clinical trial design and provide an opportunity for consumers and researchers to share ideas”

Strong support for trial design

Strong support for collecting research

Need for design to be flexible to accommodate emerging therapies

Acknowledgement that it is good to be involved

MRC Prion1 Clinical Trial

2004 - A partially randomised patient preference trial to evaluate the activity and safety of quinacrine in human prion disease

Trial Steering Committee

Sir Iain Chalmers and Lester Firkins

Why Quinacrine?

Daily Mail

New Therapies Scrutiny Group

MRC Committee to look for emerging therapies

Co- Chairs;

Sir Mike Rawlins and Lester Firkins

Recommendations for future research funding and effort

Theatre of conflict and dysfunction

The Missing Element

Systematic Review

..of treated and untreated patients with human prion disease

To be published in November 2007

Results too late to influence Prion-1 (now closed)

Flupirtine may have been a wiser option than Quinacrine (but no media lobby)

One of the few systematic reviews was of tetracycline - completed by Mario Negri Institute

Clear evidence that publication has been hindered by interests

The Unspeakable Element

Minimal International Collaboration

Academic Jealousies

Directive from Chief Medical Officer on how UK Institutions must work together

Monthly meeting between Heads of Research Units to ensure that they work together

Isolation for those families who dare to challenge convention

The Isolated Element

Pentosan Polysulphate

Promoted by one man looking after his son

2003 - High Court agreement for (unapproved) therapy to be administered

3 patients still alive - longer than “normal”

No coordinated monitoring whatsoever

Mutual distrust leading to complete lack of learning and patient care

What have I seen

A hugely expensive Trial can be set up with no formal understanding of what has been done in the past

Media can influence decisions more than grounded knowledge (Quinacrine)

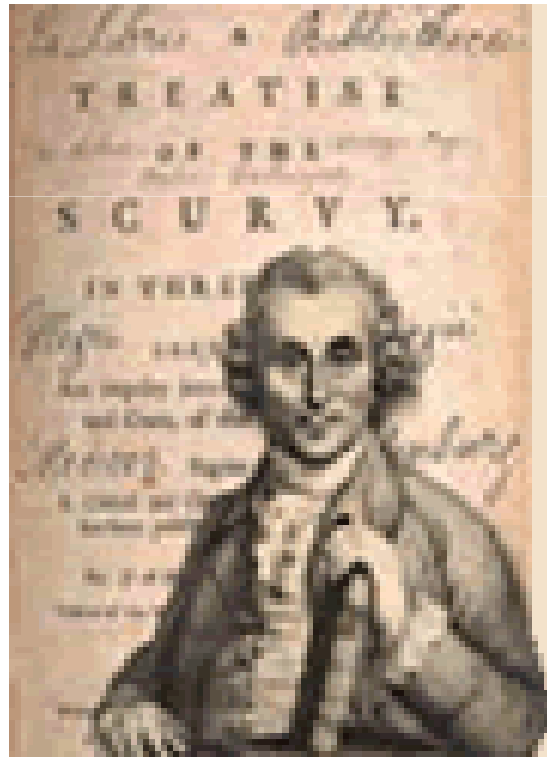
Unless potential therapies find a “friend” their application can be frustrated

“Patient First” promoted as an aspiration - but not if it conflicts with academic interests

Dysfunction and jealousies betray the interests of patients and their families

What about a formal programme - an option

James Lind Alliance



The James Lind Alliance



Formed in 2004 by;

Royal Society of Medicine

James Lind Library

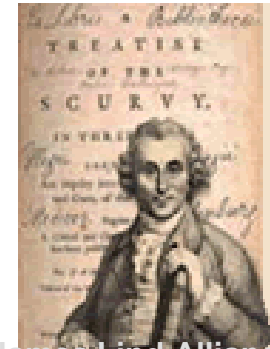
INVOLVE

Funded by DH and MRC - till 2010 to see
if it works

Tackling Treatment Uncertainties -
together (Clinicians and Patients)

Who are we ..

We are a small team – 3 part timers!



James Lind Alliance



Sally
Crowe



Lester Firkins



Patricia Atkinson

.... **But primarily our Affiliates**

What are our objectives



Support “Working Partnerships” of clinicians and patients (and their carers) to prioritise “Treatment Uncertainties” into a list for research funders to address

Support and raise the profile of proper involvement for all people with an interest in medical research

Identifying, assembling and publishing uncertainties in DUETs



JLA Working Partnerships analyse these uncertainties

JLA WPs agree shared priorities among treatment uncertainties

Making research funders aware of these shared priorities

JLA-WIFM - Patients

Real involvement in
their problems

Share of Voice

Someone showing an
interest

Participation



JLA-WIFM ... Clinicians

Opportunity to share
their unique
knowledge and
perspective

Getting their personal
and professional
concerns over
“Uncertainties”
acknowledged and
addressed



JLA-WIFM - Researchers

Ideas that make a real difference

Support in the Ethics process

Participation within the research itself

Advocates and disseminators

Seeing the difference in people's eyes



JLA - working partnerships



Asthma

Prioritised list produced

BMJ article in preparation

Urinary Incontinence

Starting to harvest “Uncertainties”

18 Participating Organisations

Epilepsy

Harvesting “Uncertainties” from existing literature

Vitiligo

Grant application pending

Thank You

Pleased to be able to tell my story

Will it make a difference

Make us think

I may not be typical - but I am normal

If you like the sound of what JLA is trying
to achieve - then please affiliate

www.lindalliance.org

