



Lyme Disease Action

September 2010
Where do we go from here?

1



Department of Health says

"Reliable information about Lyme disease is readily available..... on the HPA's website"

"the detailed information for clinicians on diagnosis and treatment represents the best available synthesis of current medical advice"

"there is no new scientific evidence on the diagnosis and treatment of Lyme disease"

We hear this again and again – how do we move things forward?

2



Start at the beginning

How do you know what treatment works?

**James Lind,
1716-1794**

A ship's surgeon who tried to find the answer for scurvy in 1749



3



The first clinical trial?

James Lind allocated two sailors with scurvy to each of these possible treatments.

"a quart of **cyder** a day"

"twenty-five gutts of elixir **vitriol** 3 times a-day"

"two spoonfuls of **vinegar** 3 times a-day"

"a course of **sea water**... half a pint every day"

"two **oranges** and one **lemon** every day"

"the bigness of a **nutmeg** 3 times a day"

Oranges and lemon won easily. The Admiralty had favoured vinegar and the Royal College of Physicians the sulphuric acid. It took a fair trial to find the answer.

4



James Lind Alliance

The James Lind Alliance (JLA) is funded by the National Institute of Health Research and the Medical Research Council. It provides an infrastructure and process to help patients and clinicians work together in partnership in order to influence the prioritisation of future research.

JLA Priority Setting Partnerships (PSPs)
analyse uncertainties

JLA PSPs

agree shared priorities among treatment uncertainties

JLA PSPs

alert research funders to shared priorities

5



Priority Setting Partnerships

These are a partnership between

- A Patient Organisation
- A Clinician Organisation

Partners must be affiliated to the James Lind Alliance (JLA) to show their commitment to the aims and values of the JLA.

LDA is now a James Lind Alliance Affiliate

As are a number of clinician organisation with whom we now hope to engage in a partnership to move things forward under an official umbrella.

6