



Lyme Disease Action

Patients' Workshops Summary

The following slides are the results of patient workshops in which patients discussed their own experiences in 2 groups. The hurdles were effectively the same in the two groups, but the priorities were slightly different and have been kept separate.

1



Hurdles - diagnosis

- Failure of diagnosis – luck of the draw
 - GPs don't consider Lyme
- Clinical diagnosis is not routinely performed; everything is based on the test result
- Negative tests from Southampton overrule clinical indications.
- No definitive test but CMO update claims the Southampton test **is** definitive
- Test not being used correctly
 - 'negative' not explained correctly
 - Manufacturer's instructions ignored

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Hurdles - diagnosis

- GPs 'frightened of consequences of going beyond the positive test
- Institutionalised bullying via the HPA, PCT, GMC, etc.
- Lack of GP and specialist knowledge but still deciding NOT to treat
- There are no Lyme specialists in the UK
- Patients' experience seeing many different doctors and specialists with no holistic overview
- No lateral thinking – 'closed shop'

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Hurdles - treatment

- HPA giving clinical advice – this is NOT their role
- Lack of treatment – too little, too late!
 - Length & strength of treatment not known
 - Protocols not known
- Patients 'labelled'
- No provision for treatment except private which is very expensive
- No recognition by NHS of chronic Lyme
- Drugs for treatment are cheap but private treatment costs are very high and NHS indirect routes are expensive

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Hurdles - Other

- Labelled
- Can't work
- Insurance
- Perception by other people

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One group's tally

• Had antibiotics and got better	ALL
• Sought private treatment	10
• Had NHS treatment	3
• Negative test result	7
• Self diagnosis	8
• Psychiatric symptoms	10
• Treatment monitored	10
• Rash	5

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Group 1 Priorities

1. **Failure of diagnosis** – luck of the draw
 - GPs don't consider Lyme
 - Negative test despite clinical indications
No definitive test
1. Awareness and education is still patchy (awareness first??)
2. Research needed into chronicity and its treatment - (but even early treatment often too little too late.)

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Group 2 Priorities

1. Enabling doctors
We desperately need doctors who will treat us.
1. Education – everyone

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