

Challenges Encountered in Clinical Trials in CF

A Patient Perspective

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Introduction

- All about me!
- My experience of clinical trials
- Difficulties and barriers
 - Practicalities
 - Personal worries
- Advice from patients and parents

This is Me!



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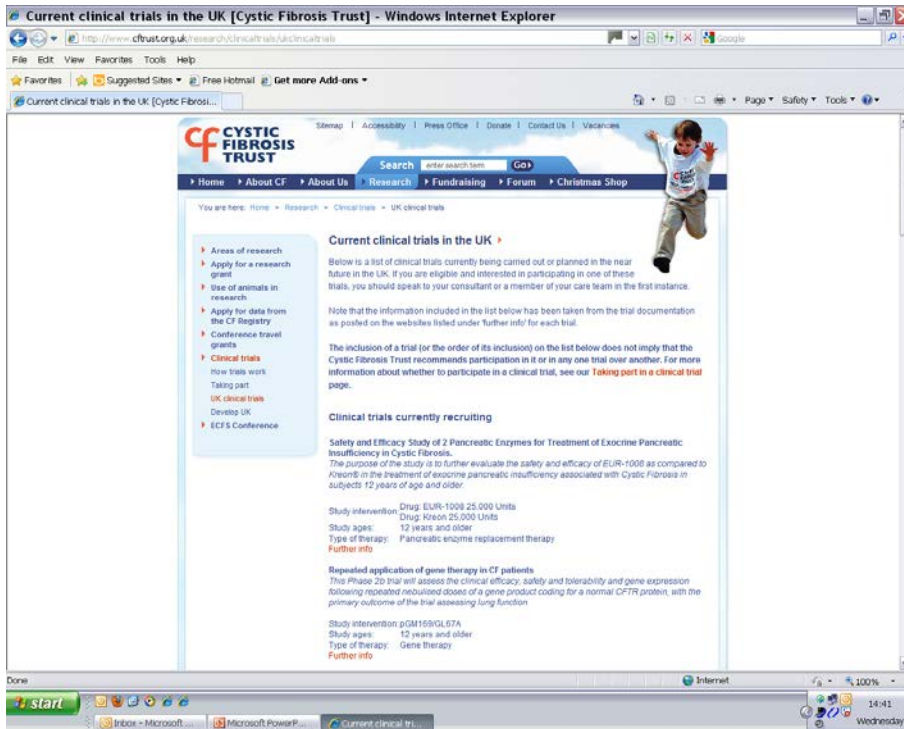
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Why I take part in trials



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What's that?



- Not hearing about trial in first place
- CF Trust has dedicated section on website

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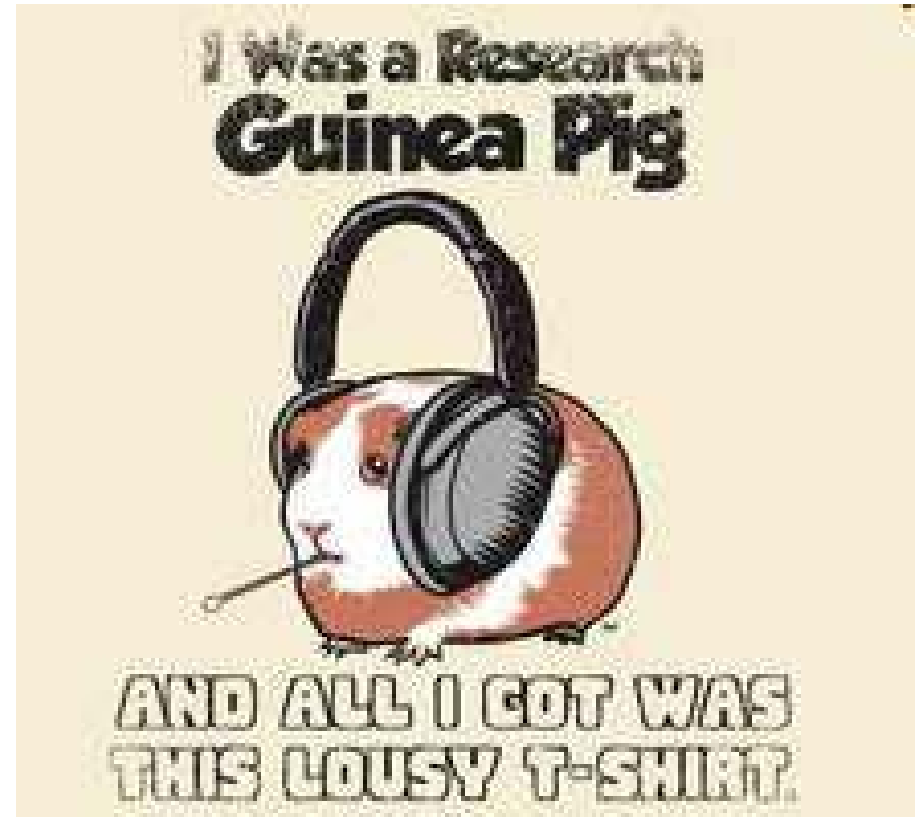
Time

- Amount of time – patients have a life too!
- Travelling
- Timing of visits
- We hate patient diaries they
- are time consuming

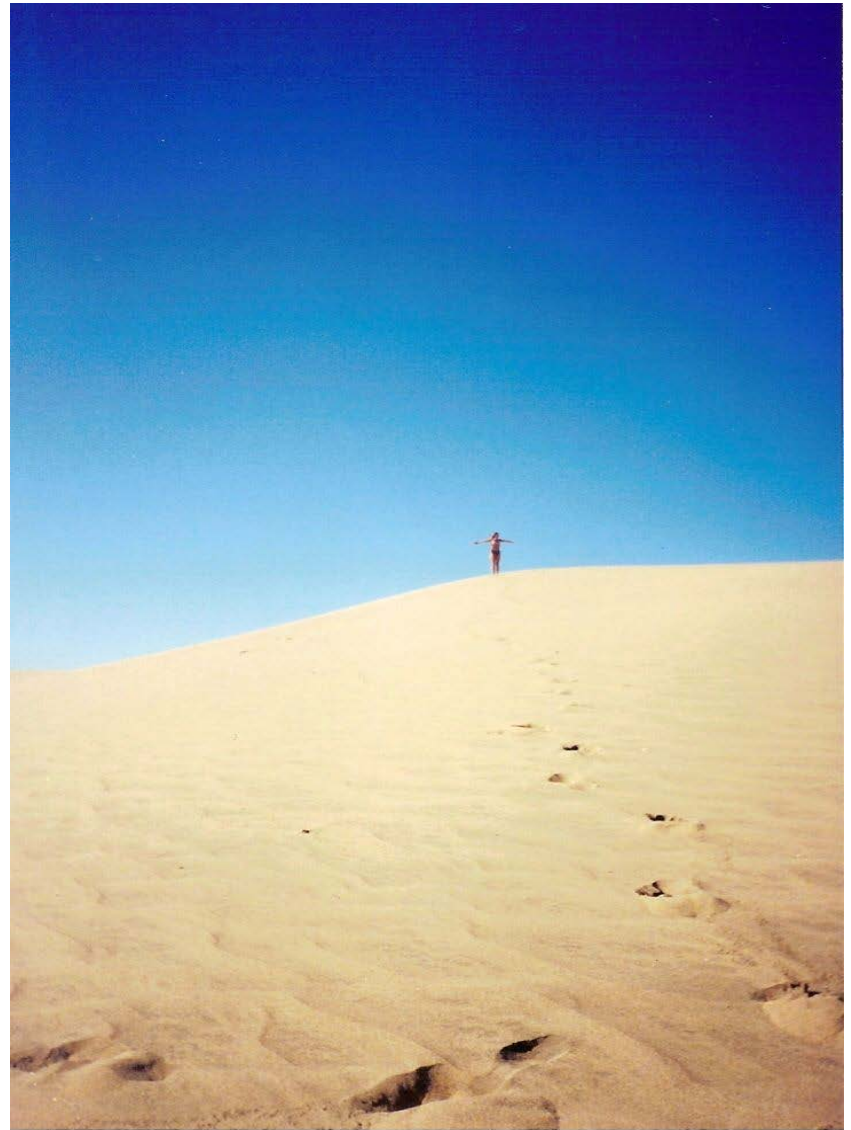


Communication

- Information
- Consent forms
- Lack of education
- Trust
- Updates / feedback / outcomes
- Part of the team



Oh, I do like to be beside
the seaside!



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Other

- Cost
- Unpleasant tests
- Perceived relevance
- Media / publications reporting negative results

Worries

- Placebo
- Unpleasant tests
- Affect on care by CF Team
- No personal benefit
- Not safe – a gamble
- Pressure
- Negative results



Advice from patients

- Ensure study information is clear and easily understood – in ‘patient language’
- Ensure good communication with participants – e.g. updates/feedback/outcome
- Consider the impact the trial could have on patients
- Be honest and open with participants
- Consider whether payment ‘incentive’ will attract right participants for the right reason
- Know the patient well and be realistic about the demands on the patient

Thank you for listening

Contact us

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