

# Patient Involvement in Clinical Trials



**BY RICHARD WEST**

# Behcet's Syndrome



- In the UK, 1 in 100,000
- In Turkey, 100 - 400 per 100,000
- Known as the Silk Road disease

# Symptoms



- Ulcers of mouth, legs, genitals and anywhere inside the body
- Non deforming arthritis
- Erythema nodosum
- Uveitis – causing partial/ total blindness
- Neuro Behcet's – migraines, strokes, seizures and meningitis.
- Fatigue

# Membership in the UK



- 600 known sufferers
- Patient organisation started over 25 years ago
- 8 Trustees
- Very active membership

# Treatment



- No known cause or cure
- No diagnostic test
- Major problems with diagnosis
- Steroids, other drugs that suppress the immune system

# Clinical Trials



- Only one known clinical trial in the UK in the last 20 years
- Use of biological drug Alfa Interferon
- Has shown in other countries to change the course of the disease

# How we helped



- We contacted members on our database about the trial
- 80 volunteers – mainly from our database took part in the trial – still ongoing
- £10,000 given for injector syringes
- We had an input into trial protocols
- Lessons learnt from this trial

## Other Help



- Approached medical people involved with Behcet's research and offered our help
- Blood samples given
- Genetic testing project
- £1000 from us to replicate results in UK

# Who can help you?



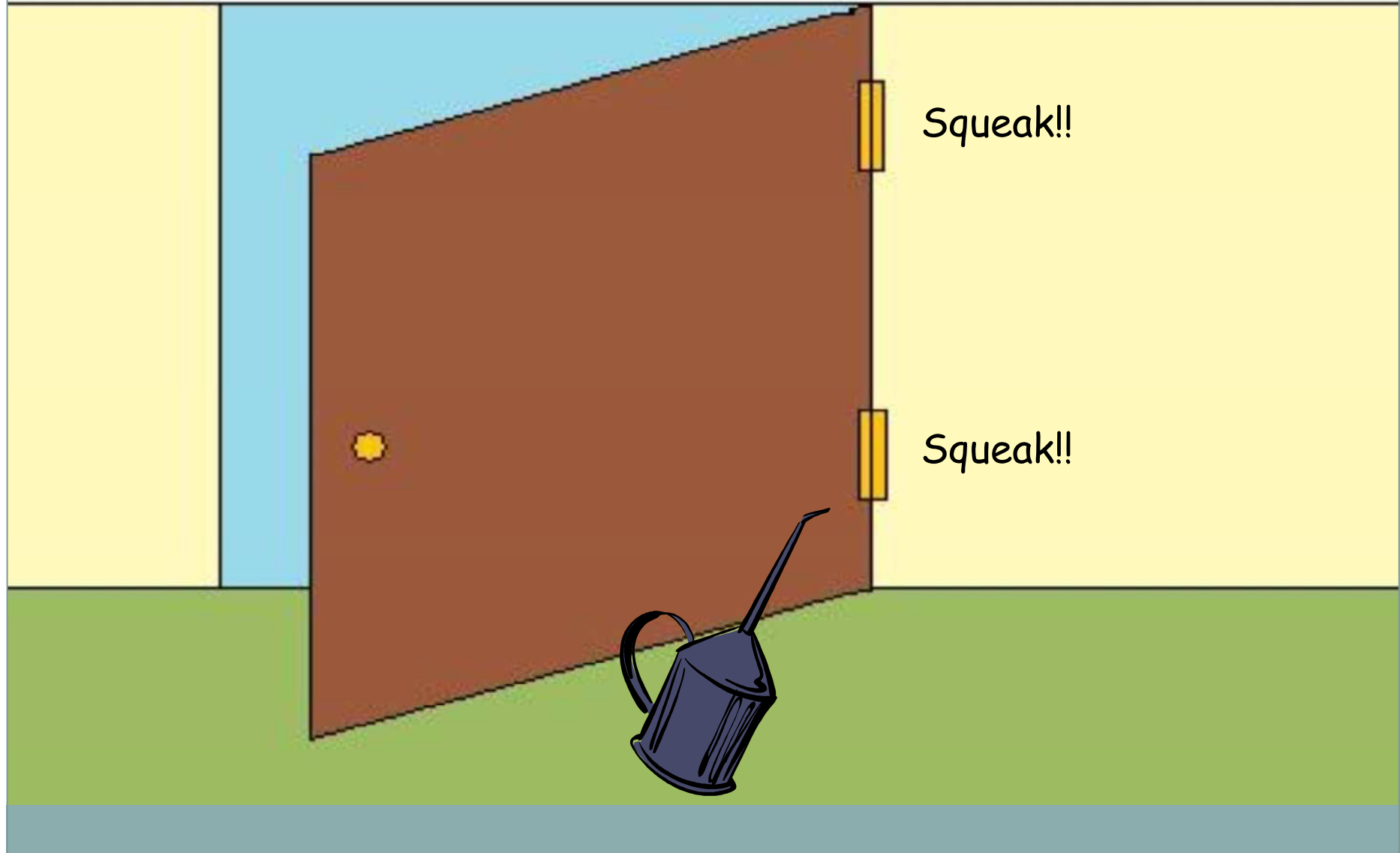
- Other patient organisations
- Umbrella groups
- Health authorities
- Doctors
- Eurordis
- And many others

# Eurordis Leaflet about Clinical Trials



- Clinical Trials for Rare Diseases
- The need for a charter
- Speak to Francois

Remember it's the squeaky door that  
gets oiled



An aerial photograph of the Great Wall of China, showing the stone wall and watchtowers winding across a series of green, forested mountains. The wall is built on a ridge, and the surrounding landscape is lush with green trees and some rocky outcrops. The sky is a clear, pale blue.

The Great Wall of China  
was built over a period of  
more than 2000 years

But someone had to lay  
the first brick