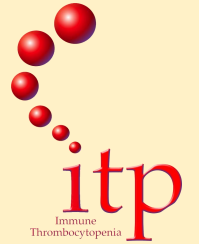


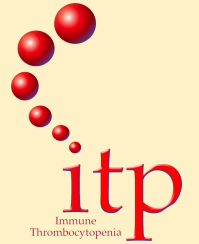
**a rare bleeding disorder**

# The ITP Support Association



# itp annual conventions

**The ITP Support Association**



# itp annual conventions

**what are their purpose ?**

**The ITP Support Association**



# itp annual conventions

**what are their purpose ?**

**EDUCATION**

**The ITP Support Association**



**EMPOWERMENT**

The ITP Support Association



itp annual conventions

**GUEST SPEAKERS**

**The ITP Support Association**



**GUEST SPEAKERS  
LISTEN AND LEARN  
FROM THE PATIENTS**

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# RESEARCH



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# FUNDS

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**ANNUALLY WE SUPPORT AND FUND**

**THE ADULT REGISTRY**

**THE PEDIATRIC REGISTRY**

**THE PREGNANCY REGISTRY**

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**We have also been ASKED  
To fund various research projects  
For instance  
FATIGUE  
FOOD INTOLERANCE**

# **The ITP Support Association**



**But we have also funded many other  
research projects.**

**Since the association was started  
YOU**

**have helped provided funds which we have invested into  
research.**

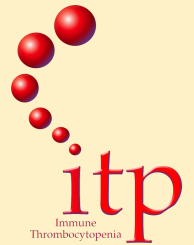
**This amounts to circa £750,000**

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**Clinical Study Group  
into  
Bleeding Disorders**

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**this was originally suggested,  
created and organised by  
UKHCDO**

**The UK Haemophilia Consultant Doctors Organisation**

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**number of bleeding disorders ?  
any ideas**

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**the project grew !**



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**NIHR**

**National Institute for Health  
Research Funds**

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## PSP

**Priority Setting Partnership  
With the  
James Lind Alliance**

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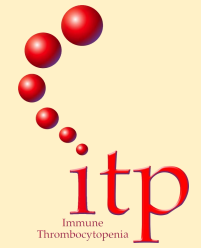
**Who you might ask  
is the  
James Lind Alliance ?**

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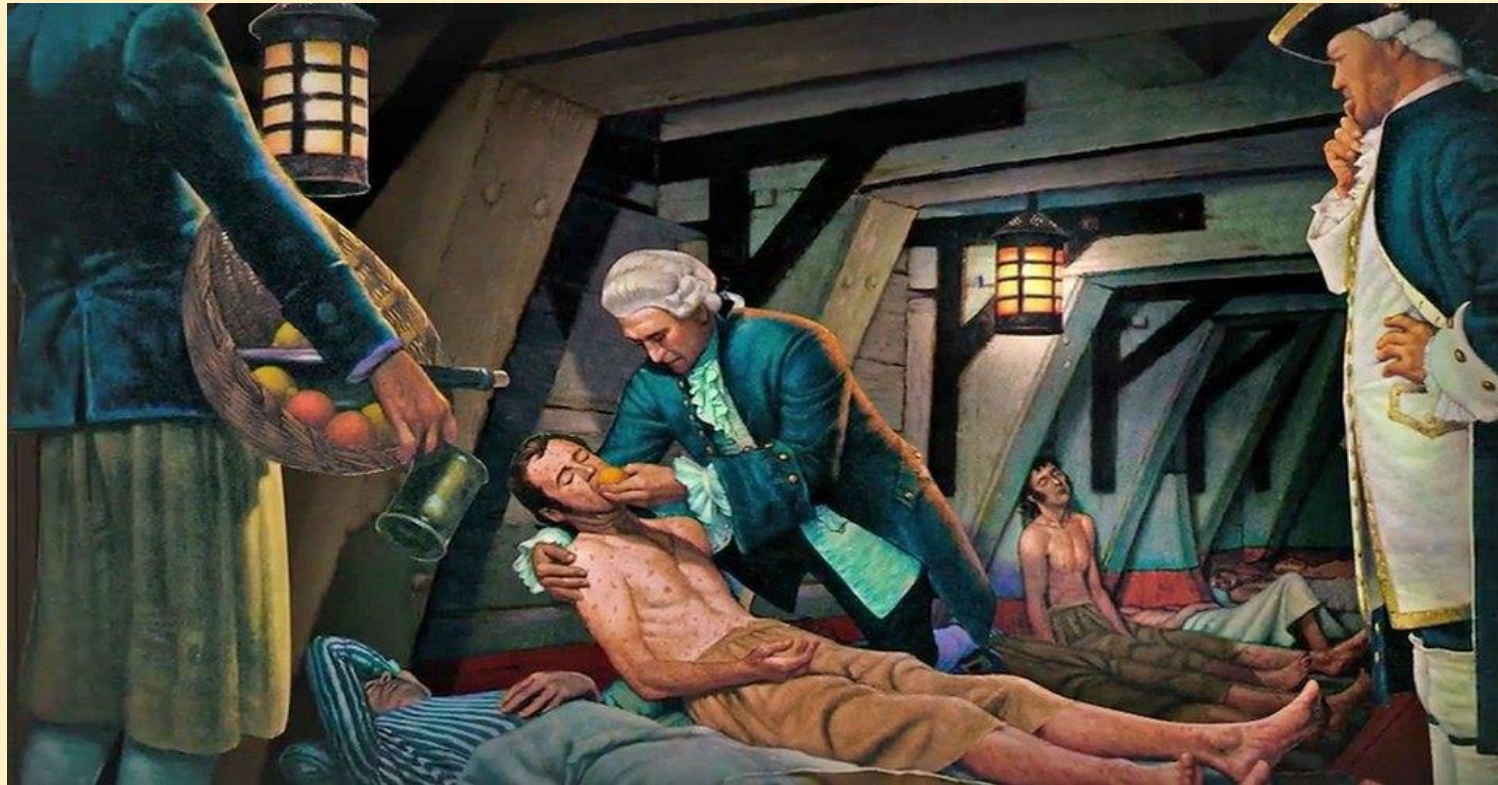


**James Lind  
conducted the first known  
clinical trial**

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The answer is scurvy.



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## Bleeding Disorders PSP

**Identify the unanswered questions about bleeding disorders treatment from patient and clinical perspectives**

**Not restricted to haemophilia and related inherited bleeding disorders**

**Prioritise those that patients and clinicians agree are the most important, for research**

**Publicise and take the results to research commissioning bodies to be considered for funding**

**Led by a Steering Group**

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## Patient reps:

### Haemophilia Society

Liz Carroll  
Dr. William McKeown  
Patrick Gallagher  
William Woolard

### ITP Support Forum

Derek Elston

### Postpartum Haemorrhage Support Group

TBC

## Analytics:

### HCD Health Economics

Charlotte Camp

### University of Chester

Jamie O'Hara

## Clinical reps:

### • UKHCDO

- Prof. Mike Laffan
- Prof. Peter Collins
- Dr. Susie Shapiro

### • Blood Transfusion service (NBTS)

- Dr. Simon Stanworth

### • Physiotherapists

- David Stephensen

### • Haemophilia Nurses Association

- Dr. Kate Khair

## Facilitator:

Sheela Upadhyaya – JLA Advisor

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**On the 24<sup>th</sup> April 2017, the PSP went ‘LIVE’ with an on line survey.**

**We need you to think of all you have learnt about ITP and consider the aspects that you would like to be researched. You may have only one.**

**You may have multiple subjects.**

**This is your opportunity to register what you think is important to you and the ITP community.**



# The ITP Support Association



**WE NEED YOU**

# The ITP Support Association



**[www.stopthebleeding.org.uk](http://www.stopthebleeding.org.uk)**

**Facebook - @StopthebleedingUK**

**Twitter - @StopbleedingUK**