

The PST was set up by a group of patients and carers following the 2013 AGSD-UK conference. We agreed to set up the PST to reach out to others with Pompe, to offer support and advice to both newly diagnosed and existing patients. We also felt we could have a role in working on AGSD-UK projects that would be of interest and benefit to Pompe patients, carers and families. The members of the PST are scattered around the country but communicate via email and meet once or twice each year.

*Our main goals for the PST are to:*

- Offer support in confidence to Pompe patients
- Develop projects related to Pompe disease
- Update the Pompe Community with Pompe news
- Advise the AGSD-UK on resources needed by the UK Pompe Community
- Contribute to the AGSD-UK Pompe workshop
- Promote International Pompe Day
- Act as a patient advisory body for medical research

**AGSD-UK 0300 123 2790**

AGSD-UK office address: Old Hambledon Racecourse Centre,  
Sheardley Lane, Droxford, Hampshire, SO32 3QY  
Email: info@agsd.org.uk



**Jane Lewthwaite**

I am the AGSD-UK Specialist Care Advisor for Pompe disease and am always happy to discuss non-medical issues and answer any questions. I can also help you with benefits applications and signpost or refer to services.

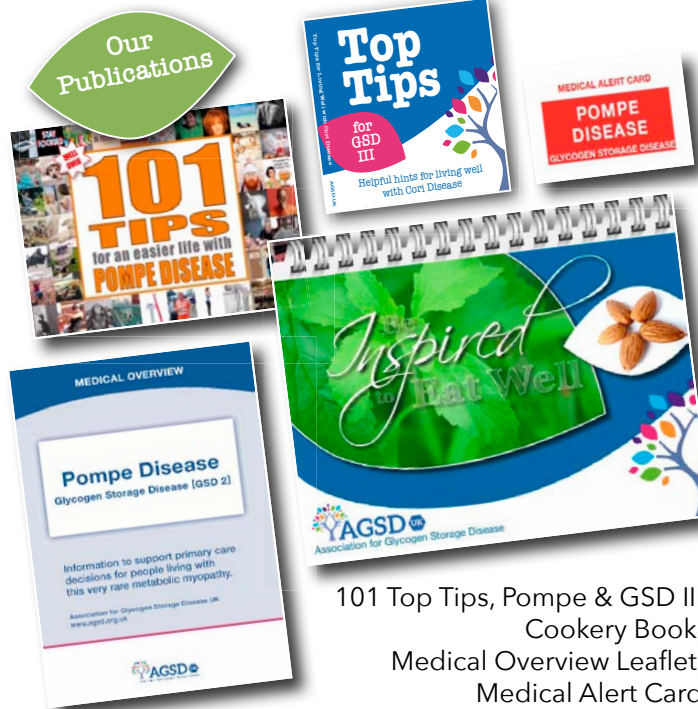
Email: [jane.lewthwaite@agsd.org.uk](mailto:jane.lewthwaite@agsd.org.uk)

*The Pompe Support Team needs you!*

If you can spare some time and would like to be part of the PST, get in touch.

[pst@pompe.org.uk](mailto:pst@pompe.org.uk)

[www.agsd.org.uk](http://www.agsd.org.uk)



101 Top Tips, Pompe & GSD III  
Cookery Book,  
Medical Overview Leaflet,  
Medical Alert Card

*What do you think we need next?*

# Meet the PST



## Pompe Support Team

Glycogen Storage Disease Type 2

Being diagnosed with this rare disease comes as a shock, but please don't panic, you are not alone. There are over 160 people in Britain that have also been diagnosed with Pompe. Although we are a small group, we have a wealth of knowledge, experience and understanding of what you are going through. We're just like everyone else; we have hopes, dreams and ambitions, these can still be realised, Pompe does not change this.

Learning to live and adapt to changes can be stressful and at times, overwhelming.

You are not alone; there is help and support available for you, your family, carers, friends and colleagues.

*Why not become a member of AGSD-UK and support the charity that supports you?*



## Angela Biggs

I was diagnosed with Pompe around 24 years ago. I was living abroad and my diagnosis took a fairly long time, first being seen by an orthopaedic surgeon for hip weakness and ending in a trip to the UK for an analgesic-free muscle biopsy (not done anymore, luckily). At the time I was told I should get mentally prepared to go into a wheelchair. It may cheer some of you up to know that I can still walk, albeit badly, although I usually use a chair whilst out to avoid falls.

Email: [pst@pompe.org.uk](mailto:pst@pompe.org.uk)



## Theo Biggs

I am carer to my mum, Angela Biggs, who has Pompe disease. I've been caring for her pretty much full time since I left school. I have never really known her as an able bodied person.

If you'd like to discuss any aspect of caring, I would be happy to talk about it or try to find a solution to any problems you may have.

I have also enjoyed raising money for the AGSD-UK

Email: [pst@pompe.org.uk](mailto:pst@pompe.org.uk)

Association for Glycogen Storage Disease (UK) Ltd

Company registered in England number 06981121

Registered office: Crowe Clark Whitehill LLP, Black Country House,

Rounds Green Road, Oldbury, West Midlands, B69 2DG



## Gemma Seyfang

I live in Essex and was diagnosed in August 2016.

Upon my diagnosis I was upset and scared but the support from our **Pompe Family** was incredible - it was nice to know that someone else understood how I felt.

I love raising awareness of Pompe Disease using social media. My fiancé and two sons are very understanding of my difficulties and they are very supportive.

I have decided to focus my energy on being positive and help others who are newly diagnosed and am looking forward to being that person that can reassure others, just as they reassured me at the beginning of my journey.

Email: [pst@pompe.org.uk](mailto:pst@pompe.org.uk)

## SPEAK OUT!

PST members want to raise awareness of Pompe disease, diagnosis and treatment.

They will talk to medical teams, professionals, industry and just about any group wanting to know more.

If you would like a speaker please phone 0300 123 2792



## Vicky Clarke

I live in the Rhondda valley in South wales, I was diagnosed with pompe in 2008. After my diagnosis I was scared even though I had amazing support from family and friends.

I found it easier to come to terms with everything after I found a group on social media who helped me so much with everything about the condition and their experiences. There is always help there for you, which is why I have decided that I would love to help other newly diagnosed people.

Email: [pst@pompe.org.uk](mailto:pst@pompe.org.uk)



## John Foxwell

I was diagnosed in 2016 after having breathing difficulties and struggling to bend or to lift things. Being diagnosed with Pompe

was frightening at first, and the information on the web was all doom and gloom. I went to the 2016 AGSD conference where I met a group of supportive and capable people who gave me help and advice. It was only after speaking to others that I realised I have lived with the symptoms of Pompe all my life. I'm here if you need a chat or just someone to email.

Email: [pst@pompe.org.uk](mailto:pst@pompe.org.uk)

Find Facebook pages on Pompe It offers a great source of initial information and support. Try Pompe Friends or Cure Pompe Disease to start.

