

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: Mile House, Bridge End,
Chester le Street, DH3 3RA Email: info@agsd.org.uk
Registered Charity no 1132271



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.

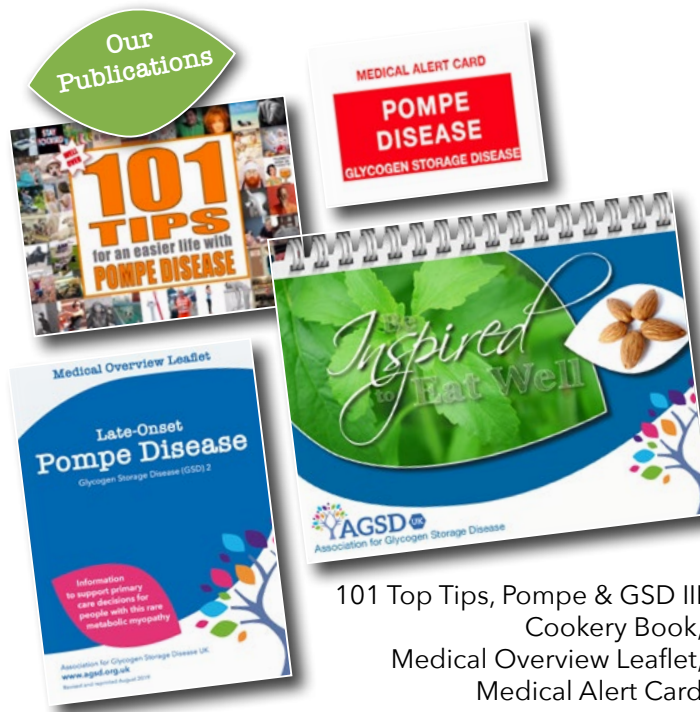
Email: jane.lewthwaite@agsd.org.uk

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

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 200 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 for a few years 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.

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



Vicky Clarke

I live in the Rhondda valley in South Wales, I was diagnosed with Pompe in 2008 a year after my two brothers were also diagnosed. When I was diagnosed I found out I was also pregnant so I started enzyme replacement therapy in April 2009 after my son was born.

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



Gemma Seyfang

I live in Essex and was diagnosed alongside my sister 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. [Email: pst@pompe.org.uk](mailto:pst@pompe.org.uk)



Ben Parker

I live in the county of Shropshire near the Welsh border. I was diagnosed with Pompe in November 2007. I know how scary and difficult it can be coming to terms and living with Pompe and this is the main reason why I am volunteering my time to try and help other people in a similar position. We're here for all patients, carers or family members and would welcome any questions, queries or just a chat.

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



Donna Beresford

I have only recently been diagnosed, 2018 after 4 years of investigation, over which my symptoms got worse. My diagnosis was a massive relief and after visiting Salford Hospital where I was given lots of information about Pompe and a leaflet about the AGSD. I went to the AGSD Conference which was a life changer for me. I now have a whole new family, my Pompe Family. I came away so positive that I really wanted to be involved in the PST, raising awareness and helping others with Pompe.

[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)



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

