

What is Chronic Intestinal Pseudo Obstruction?

Chronic Intestinal Pseudo Obstruction is a disorder of the digestive system known as a motility disorder, whereby the nerves and/or muscles in the gut don't work properly so the movement of food and fluid through the gut is disordered or absent. Although it usually affects the small intestine and large bowel, some people may experience difficulties linked to their oesophagus and/or stomach. The term "pseudo-obstruction" is used to describe the disorder because patients have symptoms normally associated with an obstruction somewhere in the digestive tract and yet no physical blockage is present.

It is rare, and can be life-threatening. Both children (including babies) and adults are affected. Symptoms include pain, abdominal distention, nausea, high volume vomiting, severe constipation or diarrhoea. This can result in patients becoming under-nourished because the bowel is unable to digest or absorb sufficient nutrients, or because eating is restricted to avoid unpleasant symptoms after food. Pseudo-obstruction usually causes severe pain, often requiring opioid analgesics such as Morphine or Fentanyl.

In many cases artificial nutrition is needed and this can take the form of nutritional drinks or nutritional feeds delivered directly into the stomach or small bowel via a tube. As a last resort, Total Parenteral Nutrition (TPN) is considered. TPN is a slow infusion of a solution of different nutrients delivered straight into a large vein leading to the heart through a surgically implanted catheter (such as a Hickman line), but TPN and the long term access through the line come with complications such as liver failure and infections of the line. If complications arise, bowel or liver and bowel transplantation may be required.

Fundraising - Can You Help?

Sue and Sonia work tirelessly in their fundraising efforts throughout the year, and greatly appreciate any help. Be it doing a fundraising event, sky dive, running a marathon or even just making a donation; anything to support their efforts to raise funds for research, making a difference to the lives of children and adults with this debilitating condition. To read stories of those affected by the condition, go to www.port-charity.org.uk.

If you would like to organise a fundraising event in aid of PORT please contact Sue or Sonia:

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PORT, founded in memory of
Emily Jasmine Frost
21st March 2003-7th May 2005



Pseudo Obstruction Research Trust (PORT) registered charity no. 1114217

PORT is a charity dedicated to raising awareness of a debilitating and often life threatening condition called Chronic Intestinal Pseudo Obstruction.

Founded by Sue Stewart and Sonia Frost in February 2006, PORT was registered as a national charity in June 2006. Sue and Sonia both have daughters affected by CIPs, meeting in The Royal London Hospital while their daughters were receiving treatment; tragically, Sonia's daughter Emily passed away from complications due to Pseudo Obstruction in 2005 aged only 2. The charity was founded in Emily's memory.

Sue and Sonia have greatly raised awareness of and funds for vital research into Pseudo Obstruction and Dysmotility. They have raised over £250,000 so far. Awareness among health professionals is increasing, as is research into this life-changing condition, all thanks to their dedication to improving the lives of children and adults suffering from Chronic Intestinal Pseudo Obstruction.

The 2014 Colourthon



Team PORT raised a fantastic **£7,656.28!**



The ladies behind PORT:
Sonia, left, and Sue.

PORT funded projects:

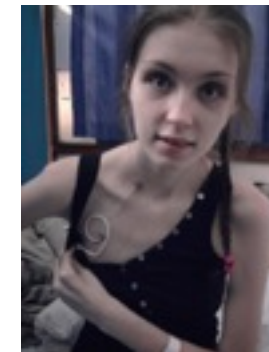
PORT is pleased to be helping to fund the new **Paediatric GI Physiology Department at The Royal London Hospital**. Here are Sue and Sonia presenting the first cheque of £20,000 to Dr Daniel Sifrim and team.



The Paediatric GI Physiology Department at the Royal London Hospital is considered one of the centres of excellence in the diagnosis and management of motility disorders in the UK. It is one of the largest supra-regional referral centres for children with functional and GI motility disorders, accepting referrals from throughout the UK. The GI Physiology Unit is equipped with state of the art diagnostic equipment originally for adult use, as in their adult Physiology Unit, but these have now been adapted to be used in children. The Unit is one of a few centres nationally and in Europe that can apply these technical advances to adult and paediatric patients and more importantly, with the expertise in the diagnosis and management of GI functional disorders, thereby improving the patient's quality of life. The department is led by Professor Daniel Sifrim, Dr Nigel Meadows and Dr David Rawat.

PORT are pleased to have donated £24,000 to purchase two bespoke combined pressure-impedance catheters for The Royal London Hospital. The catheters allow simultaneous measurements of pressure (motility) and flow (impedance) in the stomach and intestine. These catheters will be used in research in children with suspected intestinal pseudo obstruction. These catheters will increase the understanding of gastro-intestinal motility and transit in paediatric patients.

Another of PORT's donations have enabled the team at the Paediatric GI Physiology Unit to recruit a dedicated paediatric nurse. This nurse, Lucy, supports young patients and their parents during the investigations, and is a key worker in organising and documenting the department's activity. She has now been with the team six months and has helped them restructure the department to be more child-friendly, resulting in them now having two dedicated days in the unit every week. Lucy is currently performing 40-50 investigations per month.



PORT is funding the new **research project** by Professor Qasim Aziz, Professor Charlie Knowles and Dr Asma Fikree examining the **link between Chronic Intestinal Pseudo Obstruction and Ehlers Danlos Syndrome**.



Pseudo Obstruction Research Trust



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