



PSEUDO OBSTRUCTION RESEARCH TRUST

# PORT DIGEST

## PORT'S commitment to funding research

### Special points of interest:

- PORT's mission is to fund research into CIPO.
- We also aim to educate and spread awareness.
- We offer support to those affected by CIPO.
- Our next research project title is Microbiome and metabonomics in intestinal dysmotility.
- We have a partnership with Bowel and Cancer Research.

The Pseudo Obstruction Research Trust was formed, in 2006, with the aim to fund research into the rare and debilitating disease, Chronic Intestinal Pseudo Obstruction (CIPO). This is caused by severe impairment in the ability of the bowel to push food through, and is characterised by the signs and symptoms of bowel obstruction, but without a mechanical blockage being present. We also aim to promote education and awareness, and importantly to offer support, so no one feels alone. We hope this newsletter will help us fulfill all these aims.

To date we have funded over £750,000 towards research. Unfortunately due to the pandemic, the research we are planning on funding led by Dr James Wilshire, at St Mark's Hospital has been delayed. We are still committed to supporting this project as we feel a study that looks into the gut microbiome is of

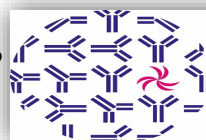
considerable interest.

During these strange times, PORT have still been busy looking at ways to maximise the future research that we can fund. PORT maintain a strong relationship with Bowel and Cancer Research, who help us identify and scrutinise potential research, and give us access to their medical advisory panel. They have recently appointed a new CEO, who is very keen to support PORT and help us fulfill our aims.

Recently, we produced a survey. Thank you to everyone who

completed this, This will give us more information into CIPO, both to present to medical professionals, and as a source of information for future research, The new CEO is very keen to help

PORT move forward in spreading awareness of the condition both among the general public and also within the medical profession, as it is currently a condition with little understanding and knowledge. Sue Stewart (PORT Chair) has been keeping in regular contact with her, and had a very productive and positive telephone call about the partnership between our two charities, and ideas of the direction we might take for the future. The new CEO articulated that she was very supportive of PORT and our ideas. She showed



**Bowel & Cancer Research**

her interest in our aims and her desire to build

on our existing relationship. Sue was able to talk in depth about CIPO and the impact of the disease, and particularly the pain it causes sufferers, and the CEO showed her empathy and support.

### Inside this issue:

- PORT's commitment to research **1**
- Fundraising **1**
- Personal Story Ruby Skye **2**
- Dr Nigel Meadows -Our Medical Trustee **3**
- Facebook Fundraisers **3**
- Useful Tips **4**

## Fundraising

We now have some events to look forward to for 2021, that will raise essential funds for our charity. Kilian Fitzsimmons-Wilson is a trustee for PORT. He has a son called Charlie, who suffers with CIPO. Kilian will be running the London Marathon for 2021, on behalf of PORT.

Callum Turner, Olivia Stewart's partner, will be running the Yorkshire Marathon for PORT in October 2021.

We'd like to thank Lily and Jacqueline Russo, at Beach Flamingo for their donation of £285, this summer. We are very grateful for their continued support.

Sue and Barry Stewart will be collecting a cheque from The Thurrock Bowls Club, on 4th October. We are very grateful for all the money they have raised for us over the years, and to Karen Morgan (Ashlee Johnson's (Trustee) mum) who put our name forward for their support.



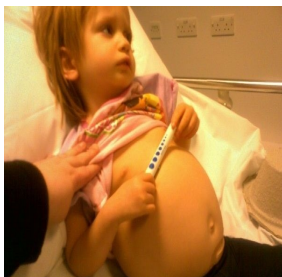
## Personal Stories

### Ruby Skye

My name is Ruby Skye and I am 13 years old. I had symptoms of a motility problem from before birth as they noticed on scans that my bladder was very big. When I was born I spent a few weeks in intensive care but was sent home, and they thought the main problem was my 'megabladder' which didn't empty so I was sent home with a catheter.

When I was about 7 months old I started to get more and more poorly, and this went on for a long time. I would struggle to tolerate milk feeds and food, and my tummy would become very big and full of air. I would start being sick with bile and need to go into hospital for fluids. This kept happening as often as every 2 weeks.

I was referred to Great Ormond Street when I was 2 years old. I do wonder what would have happened if I had been sent there sooner. My doctors decided to give me an Ileostomy and Gastrostomy when I was 3 but the surgery had problems and had to be redone twice. I became very thin and eventually had to start TPN. That admission was 9 months, my record!



My life changed for the better once I was on TPN. I didn't have to have all the milk feeds, and my tummy wasn't uncomfortable all the time, and I didn't have many admissions! I started nursery and just loved it! It completely changed everything. Nursery got me a 1:1 who was trained up in everything and they continued to

school too. I loved being at school and with friends.

Over the years I have had many surgeries and tests. We think I've been down to theatre over 40 times. I am very lucky that I don't get line infections (touch wood!) so really TPN has been such a lifesaver. I have had 3 lines, the most recent one lasted 5 years but became blocked. I have had my colon removed as it made me very poorly with colitis and I was on steroids for a year. I feel much better now it has been removed. There are obviously problems



along the way.. I get really bad Small Bowel Bacterial Overgrowth which has to be treated with antibiotics. I have also had prolapses from my stoma which ended up in a few trips to A&E before eventually having surgery to prevent it. I had a very bad bowel obstruction when I was 7 which would get a bit better so it went on for a long time. I ended up very poorly and needing emergency surgery, They said I had peritonitis and a collapsed lung, as well as collections in my abdomen!

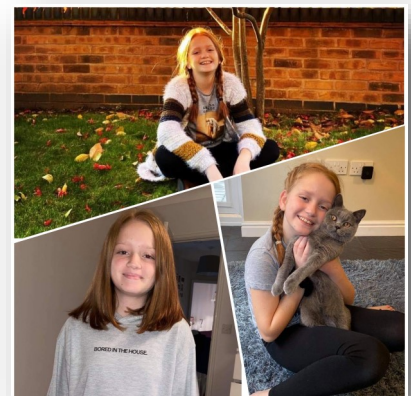
My tummy really struggles when I eat, and so 2 years ago my doctors said I shouldn't eat anymore. This has been the hardest thing I have ever been through because I am constantly SO hungry, it is so hard. I can't explain what a battle it is every day. It does make me very sad sometimes.

We went for Genetic Counselling when I was 11, and all had our

genes tested. Mine came back with a very, very rare defect called ACTG2 which causes bowel and bladder problems. More recently my liver bloods have been a bit worse so I am going to meet with the team at Kings to see what I can do to protect it better.

Life today is amazing! I am in Year 9 now and I like school. I am a drummer and love performing. I really love hanging out with my friends. I have made a few friends online through PORT who have similar conditions to me, One girl, called Mallorie, I have known since I was a baby, even though she lives in the USA! We are so similar in every way, and have met up 3 times! It is really good to have someone to talk to who knows what I am going through. If anyone needs any support they can contact my mum who will put us in touch! That's another reason why PORT is so important because it provides support and puts people in touch with each other!

I want to raise lots of funds for PORT because they do an amazing job and there's hardly any research into this condition. Sue and Sonia, and all the supporters have already done so much for this condition and it's our job to help them! I want other children to not have to go through what I went through.



## Dr Nigel Meadows, Our Medical Trustee

**Nigel Meadows MD  
FRCPCH**

I have always wanted to be a doctor for as long as I can remember. I am not really sure why, as none of my family are medical at all. I spent most of my childhood bandaging my parents and sister!

While studying I thought I would always be a surgeon. To my surprise I won the final year prize in paediatrics. It looked like someone was trying to tell me something! When I qualified, I worked in a general paediatric unit at Charing Cross Hospital, with Hugh Jolly. He was very charismatic, and the radio doctor. I learned a lot from him, particularly the importance of listening and learning from

children and parents themselves.

My interest in Paediatric gastroenterology developed when I started working at the Queen Elizabeth Hospital for Children in Hackney. It specialised in gastroenterology having been established at the time of gastroenteritis epidemics in the East-End of London. I worked for Prof Walker-Smith, one of the first paediatric gastroenterologists in the country. He encouraged my interest in nutritional support, and together we were one of the first in the country to send children home on TPN.



The main symptoms of the patients I saw were difficulty in feeding, and severe abdominal pain. Unfortunately, this had often been ongoing for months and in some cases, years.

The diagnosis of pseudo-obstruction has always been difficult. It is based on clinical symptoms, and things such as dilated gut on an x-ray. Lately we have been fortunate to use a small intestinal impedance manometry catheter, which we obtained from charitable donations from PORT.

The treatment is mainly good nutritional support.

Pro-kinetic agents are often used, but unfortunately are often not very successful.

The main difficulty in managing patients with pseudo-obstruction has always been a lack of understanding of the condition by the profession. The other huge challenge I see is trying to control the pain adequately and safely without aggravating the overall motility of the gut.

I became a trustee of PORT, because I have always been involved the charity since its inception. There are no other funding bodies for intestinal pseudo-obstruction, and research is so badly needed,

## Facebook fundraisers

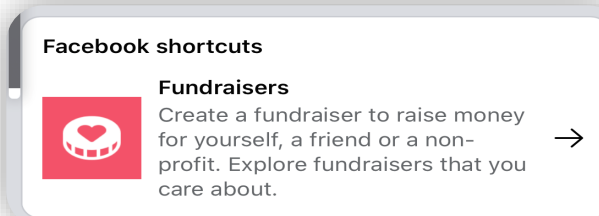
We are so thankful to all those that support our charity, and would like to thank all those that have taken up the opportunity to create Facebook fundraisers. To date, since setting up this feature at the end of last year, PORT has raised £7,473 from these fundraisers.

This money is more important than ever at this time, and we would like to encourage others to set up fundraisers to raise money for our charity. It really is such a simple way to raise funds, and all funds raised make a difference!

The most common fundraisers have been birthday fundraisers. If you have registered your birthday on Facebook, you will be sent a message asking you if you would like to set up a birthday fundraiser. You will be then led through the steps, and given the op-

portunity to choose Pseudo Obstruction Research Trust to support. If you don't have your birthday registered on Facebook, or you wish to create a different fundraiser, such as a medical fundraiser, you just need to type 'fundraiser' in the

Facebook search bar, and then click to create the fundraiser where you can then choose to support our charity.



During the process of setting up your fundraiser you can set your goal amount and the end date (both of these can be changed once the fundraiser has started). All money raised makes a difference to our charity, helping to fund life changing research into the cruel disease Chronic Intestinal Pseudo Obstruction and severe dysmotility.

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**We're on the web!**  
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*The Pseudo Obstruction Research Trust (P.O.R.T.) was formed by Sue Stewart (Chairperson) and Sonia Frost (Trustee), in 2006, in memory of Sonia's daughter Emily Jasmine, who passed away in 2005 from complications of CIPO aged only 2.*

*The aim of the charity is to fund research into C.I.P.O. and raise public and professional awareness into this serious and sometimes fatal illness. With £750,000 of research and equipment funded so far, we need support to raise a minimum of £50,000 per year to fund this research.*

*P.O.R.T.'s mission is to fund research into CIPO, raise public and professional awareness of the condition, and improve understanding of and treatment options for CIPO.*

*The charity also provides support to patients and their families. We offer a Facebook support group and we're always open to people messaging and emailing for support and advice. We cannot give medical advice, but we can point you in the right direction.*

*P.O.R.T. always needs support both from companies and individuals. If you or your friends/family fancy raising some money, doing a sponsored challenge, asking your local shop if they'll put a collection tin on their counter or supporting us by making a donation, then this will be greatly appreciated. Likewise if you are a business or a company please do consider offering us financial support.*



To donate using our Text Giving Code, just text PORT, with the amount you would like to donate to 70085.

E.g. PORT 5, 10 or 20 to 70085



## Useful Tips

We are always pleased to offer support and help to one another. Our closed Facebook group is a great forum, to ask questions, share tips and advice and receive support.

For those that have CIPO and are dependent on TPN, not being able to eat can be hard. Depending on tolerance some may be able to take some liquids. If so, having different flavour drinks may be helpful, and ice lollies may help with cravings. There are many flavours of ice lollies, including vegetable flavours for variety.

Many of us have to take medication. Dosette boxes, or pillboxes can be very helpful to keep medications organised. There are lots of different types available. There are some that are daily, and some that are weekly. The issue with some of them is there is not much room, or more than one compartment for each day. The ANABOX has 5 compartments for a day, with each compartment being large enough to fit a good number of pills. It is small enough to be able to be portable, and to put in one's bag, but large enough to fit lots of pills.

*If you have any hints or tips you would like to share, or if you would like to share your personal story, in a future edition of the newsletter, then please do get in touch. Likewise, if you have any suggestions or recommendations then please do contact us.*

**Disclaimer: Please note, that whilst every effort has been made to ensure the accuracy of this newsletter, information may not be comprehensive, so please always seek professional advice. September 2020.**