



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 metaboomics in intestinal dysmotility.
- Kilian Fitzsimmons-Wilson is planning to run the 2021 London Marathon, with a goal to raise £10,000 for PORT.

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.

Whilst many events had to be cancelled for 2020, we have an exciting fundraiser planned for 2021. Kilian Fitzsimmons-Wilson, is planning to run the 2021 London Marathon. He has set an ambitious target of £10,000 but has already done exceedingly well on the fundraising front, having raised 78% of his target so far. Kilian is a trustee for PORT, and both

a great representative for the charity and for Pseudo Obstruction, as his son Charlie suffers from the disease. He has not taken part in any type of run before, so his drive and determination to achieve this for PORT is inspiring. He has been posting some videos to update people on the progress of his training, whilst generating support. He and his wife Lindsey have already come up with a number of initiatives to raise the funds, from scratch cards to selling craft items as well as a drive for January to get others involved in the running too. He started a specific group for this called 'Run a Marathon with Kilian' To date the group have completed over 40 marathons between them and have raised over £1,000 towards Kilian's fundraising efforts.

If anyone of you would like to contribute to Kilian's funds please do check out his Virgin Giving page where you can donate. Some people have given one off donations, others have given a set amount on a monthly basis and still others have organised events or fundraisers themselves to raise money towards Kilian's marathon. Please do consider supporting this venture.



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Our 'Guess the Name of the Elf' fundraiser

This year has been a hard year for fundraising, so we have had to come up with novel ideas. Over the Christmas period we launched a scratch-card fundraiser where we sold 100 squares, for £10 each. Each square had the name of an elf. Once we had sold all the squares we scratched off the winner with a live Facebook video. The winner won a prize of £250. In order to collect payment we set up



a dedicated Virgin Giving page for the event with all money, including gift aid going to PORT. Thank you to everyone who took part, and who shared the fundraiser and encouraged family and friends to take part too. We raised £1202.50, and then when winnings were deducted £952.50 for PORT. Congratulations to Wendy Purdie, our winner!

Personal Stories

Kaylie Finch

I was around 3 years old when my mum noticed that things were not quite right with me. I always had a distended stomach, and pain, and suffered with kidney infections. I started having ultrasounds and investigations around this time but nothing was ever detected.

Throughout my first decade I suffered with lots of stomach pain. My mum would often find me asleep on the bathroom floor or in the empty bath where it was cooler and helped me cope with the extreme heat I experience when I am in pain.

Other than the stomach pain and kidney infections I lived an almost completely normal life until the age of 16 when I very quickly started losing weight, and began to feel very full after minimal amounts of food. Soon after this began, I started to vomit frequently.

I was seen by my GP, on a few occasions, with no explanation of what was causing my weight loss or vomiting. It didn't take long for me to become very unwell. A doctor was called to my house and my mum was informed that he needed to call an ambulance. I was then admitted to hospital. In the first few days and weeks my parents had lots of heated conversations convincing doctors I was not suffering from an eating disorder. Things changed very quickly after a doctor entered the room as I vomited. He could tell from the colour of that vomit that this was a bowel issue, and things started moving forward from then on.

I had a venting PEG tube fitted in my stomach to vent anything I ate or drank, and I was started on TPN to feed me though a line in my neck. By the time these lines were put in place I weighed just 5 stone.



I was given a Barium Swallow and due to a family history, I was then diagnosed with very probable Familial visceral myopathy with Pseudo obstruction of the duodenum.

After 2 months in my local hospital I was then transferred to St Mark's hospital with the end goal to be discharged home on TPN, my intestine was in failure and would not absorb anything including fluids. I was now just turned 17 and spent the next 3 months in hospital in London, a few hours away from all my family and friends. This was tough and at times very lonely, but St Mark's is always somewhere I feel safe and I am forever grateful for their ongoing care.

I spent the next 7 years in and out of hospital with infections and line blockages.

Life today is quite different to how it was in my 20s. I am now in my 30s and, right now, I am fully able to sustain my own weight and eat food. Outwardly I would appear as if there were no health issues at all. I have two children and an extremely supportive partner; I have a part time job, and try to have enough energy for some sort of social life too. I do however suffer pain daily; I have extreme bowel pain that can lead to loss of consciousness. It can sometimes feel I have new issues almost weekly with nerve and deep muscle pain, fatigue, problems controlling my temperature, headaches, kidney infections, issues with my teeth from years of vomiting and scar tissue pain from Hickman lines and PEG tube sites.



Around 4 years ago I was also diagnosed with possible PTSD from the trauma of my journey with this illness. Mental health is something that is hugely impacted with an illness such as this. Having Pseudo obstruction has come with lots of hard times but also so many happy ones. I am the person I am today because of all that I have experienced, and I am strong because of it and grateful for the life I have.

PORT charity came into my life around 7 years ago. PORT to me is never being alone. It is always having someone that can understand or answer questions that a GP, and sometimes specialist consultant cannot answer. PORT is a community where people come together to support each other, where we celebrate each other's happy news but to also send love in unimaginable times too. Because of PORT I am never the only person that is going through the things I experience. I have somewhere to share, ask and learn. Everyone with a rare illness like this one needs a place like PORT.



PORT is extremely special, and I am so grateful that it is in my life.

Some of our fantastic fundraisers

Despite many events being cancelled with financial consequences we have still received some much appreciated support.

Carole and Louise Macdonald organised bids for Scotland Rugby Strips signed by the Scotland team, and donated by our amazing Patron, Zander Fagerson. This has raised over £1,000 for PORT charity. Pre Covid, Carole and Louise would regularly go and watch Scotland play. This is how they met Zander, and when he spoke to Louise he became aware of CIPO and wanted to help in any way he could.



Norman Turner kindly made a generous donation of £500, in memory of his mum. Thank you so much to him.

We would also like to thank Fay Taylor, who organised donations to be made to PORT charity in memory of Malcom Parton and raised £1018.75. Fay's daughter Chloe suffers with CIPO, Malcom was her grandad.

We'd like to thank all those that made donations, especially over the Christmas period, including those who chose to donate to PORT instead of sending Christmas cards.

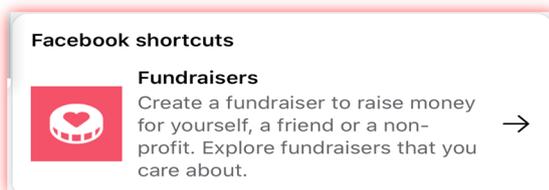
Back in October, The Drums and Thurrock Bowls club generously donated £1,000 as well as some items to potentially raffle for the future. We are so grateful that they have chosen PORT as their charity to support for the future. We'd also like to thank Karen Morgan for nominating PORT charity.

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 £8,182 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 option 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.

Special mention must go to Ruby Skye whose medical fundraiser raised an amazing £1,090 for PORT, and Rosina whose fundraiser in memory of her husband raised £2,105.

Another easy way to raise money, if you ever use amazon, is to shop through amazon smile, and each time you shop PORT will receive a donation. To date PORT has received £42.68 from donations collected this way, and we have 21 people supporting PORT using amazon smile. It would be great if more people could use this opportunity to raise money for PORT. You can also download the amazon smile app to make this easier.

Some ideas of how to fundraise during lockdown

Donate your birthday - Either set up a [birthday fundraiser](#) as above or donate the money you may have spent on [going out](#), other things you could donate include the money you would have spent on [shop lunches](#) or the [commute](#).

Giving as you shop - Use [amazon smile](#) or [easy fundraising](#) to collect donations as you shop.

Sponsored silence or **fitness challenge** - Walking, running, cycling, or anything you would find a challenge.

Give it up - The possibilities are endless, [alcohol](#), [coffee](#), [tv](#). It could be for a day, a week or a month.

Hold a **virtual event**, for example a **virtual quiz**, where you could charge £5 to enter.



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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 pain is often a major issue and good solutions are few and far between. Whilst surgery and/or medications may be offered by medical teams, sometimes natural approaches can be of value. Heat is very much a friend, whether this be a hot water bottle or sipping hot water, may give some relief.

For a variety of different reasons individuals may struggle significantly with the cold weather. Some things that may help include leg warmers, thermal clothing, and slipper boots as many may suffer with cold and circulation to the extremities such as the feet. If one requires a wheelchair when going out, not moving may exacerbate the coldness felt, so lots of blankets and warm clothing are essential!

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. February 2021.