



## 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.
- We are currently funding 3 research projects.
- We are currently reviewing 2 further projects, which will potentially start in summer 2020.

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. We are currently funding three research projects, at a cost of £149,544. We also have two research projects, whose applications are being reviewed, with a view to fund starting in Summer 2020. To fund this research PORT is using reserve funds. Therefore fundraising

over the next 2 years is even more important, so please do support our charity.

The first project involves harnessing MRI for the diagnosis of CIPO. PORT are funding £49,554 for this study, and will build on previous research from The Nottingham Gastrointestinal Magnetic Resonance Imaging group, and colleagues at University College and Queen Mary University of London. Using MRI should allow CIPO to be diagnosed by a test that is accessible and sensitive.

Additionally, PORT is funding £50,000 to study the potential of developing neurons for tissue repair. The team is being led by Professor Joe Martin, Professor of Pathology at Queen Mary, University of London. The potential of developing a therapy that could seed and migrate new functioning nerve cells could have a significant impact on quality of life,



Developing neurons for tissue repair

and potentially be a life line for some of the most poorly.

Finally, PORT is funding a study led by Professor Gareth Sanger, which will study a new approach to gastroparesis and nausea. This study in human tissue will help to pin point this mechanism, paving the way to the development of new treatments to help patients who suffer with this debilitating symptom.

## Inside this issue:

Personal Story	2
PORT Events	2
Zander Fagerson donates rugby shirt.	2
Personal Story	3
A glimpse inside PORT's activities	3
Many thanks to our fantastic fundraisers	3
Valuable Tips	4

## Charity single released for PORT.

Barney O' Driscoll, who himself suffers from Gastroparesis, and whose girlfriend, Katie Callaghan, suffers from CIPO, is releasing a charity single for PORT called 'Starving for a Cure.' The funds from the single will go to PORT. The single cover will feature pictures of PORT members, which have already

been collected. Barney has said about the single 'The song is called 'Starving for a cure' and it's about mine and so many others experiences with these disorders. It sends a message of much needed awareness and understanding for these misdiagnosed and misunderstood conditions. It goes into depth on the trauma

and suffering that is implanted all over the globe for people who can't find knowledgeable clinicians who will invest in their care'



## Personal Story-Rachael Green



My name is Rachael Green, and I was diagnosed with Chronic Intestinal Pseudo Obstruction aged 16. I had been ill for most of my childhood, but things became significantly worse, bowel wise, when I was about 14 years old. In 2001, at the age of 16, I was in total intestinal failure which meant I had to be placed on Total Parental Nutrition (TPN). In the subsequent years, due to the pain, sickness and vomiting escalating I was fitted with a PEG tube for drainage of my stomach contents and also with an ileostomy, for symptom control. Unfortunately for me I had multiple problems with the TPN as well as central venous access issues, which led me to being referred for a multi organ transplant in 2010. Due to my small size I had to wait three years for suitable organs to become available so by the time I got the transplant, in 2013, I was very sick which in turn meant I ended up having a very rocky ride post transplant, with numerous complications. The transplant gave me three wonderful years off TPN, but unfortunately in 2016, I had to recommence TPN again, due to having multiple problems with my transplanted bowel, and consequently once again suffering from malnutrition. This is far from an ideal option, now being heavily immunosuppressed, with the anti rejection therapy, and I continue to have multiple problems with the TPN, but as I am not a candidate for re transplantation this is the way life will be for me moving forwards.

*I have seen all the hard work that has gone into making PORT such a successful charity, in terms of the fantastic research they have funded, as well as the countless individuals that have been supported.*

Some days life can be extremely hard, especially going through a big transplant and being back to where I was, in regards to being dependent on Total Parental Nutrition and suffering with significant bowel dysmotility, severe pain and sickness. However, during the hardest times I have found getting involved and being supported by PORT, immensely valuable. I first met Sue and Sonia, when I was under the Royal London Hospital, as a teenager and had the privilege of meeting the gorgeous Emily. I have seen all the hard work that has gone into making PORT such a successful charity, in terms of the fantastic research they have funded as well as the countless individuals that have been supported, through the PORT community. This is so valuable as otherwise the journey can be very isolating. I look forward to getting more involved with PORT, and continue to see it flourish for many years ahead.

## PORT Events; The Colourthon and Curry Night



Both the Moonlight and Twilight Colourthon are FUN walks around Southend by night, with the emphasis being on FUN and FUND-RAISING. Entrants wear brightly coloured clothing and walk against the backdrop of Southend by night. In 2019, the event took place on

6<sup>th</sup> July, starting at 6pm, at Chadwell Park, Southend-on-Sea. The Moonlight Colourthon is a half marathon (13.1 mile course). The Twilight Colourthon is a shorter (6.1 mile/10k) walk, where much of the route is the same as the longer Moonlight Colourthon. In 2019, PORT was represented by a great team of 21 walkers, who together raised £6273.

On Thursday 26<sup>th</sup> September, at 7.30 pm, PORT held their curry night at the MAHARAJA restaurant. The evening was a great success, with excellent feedback, and an amazing £1,150.00 raised for PORT.



## Zander Fagerson, PORT Patron, donates rugby shirt



Rugby shirt signed by Scotland Team

Zander Fagerson, has been a Patron for PORT since 2018. He is a Scottish International rugby union player, who plays for Glasgow Warriors in the Pro14.

Zander had never heard of the illness Chronic Intestinal Pseudo Obstruction (CIPO) until he met Louise MacDonald, and her mum Carole who told Zander there is no cure. 'For me personally I think that's

unacceptable with the level of expertise in medicine. To then see Louise at the rugby, and how happy she was there, supporting Glasgow and Scotland, forgetting about her condition and enjoying the day really got to me. This is why I am proud to become a Patron/ Ambassador for PORT. I may not be able to find a cure, but if I can raise a bit of awareness or get a few more sufferers to a rugby

game and try and give them some relief, however small, I would feel I was making a difference.'

In December, Zander donated a one off rugby shirt, signed by the whole Scotland team. The shirt was auctioned to the highest bidder for £400. Many Thanks to Zander, and also to Louise and Carole.

## Personal Story-Cheryl East

PORT Charity is one charity close to my heart. Both myself and my daughter, Jocey, have Chronic Pseudo Obstruction, and my other daughter, Ellissia, may well develop it as she also has other health issues, the same as us, but on a slower progression. We all have stomas and absorption issues, as well as neuropathic gut disorder. Jocey, my youngest, also has deletion 1 syndrome. The Pseudo Obstruction has also led to many other health problems, for example kidney and liver issues for which I have trialed 2 lots of chemotherapy drugs, undergone biopsies and scans, and will be trialing a 3rd this year if my blood is stable enough. I have a wonderful consultant, Professor Anton Emmanuel, who allows me to trial things and helps fund them to try and give more information on my daughters conditions, if my health can stand, as I have accepted that there may not be a cure to help me, but with the help of PORT and my trials there maybe an answer to help my daughters and other children.

So PORT, to me, is a charity that is trying to break through this RARE disease and get some answers as Cancer WAS RARE it is now 90% curable thanks to charities funding research. Yes, our disease is rare and only affects a small % in the world but it is increasing in numbers, unfortunately, and I do believe there are many more cases undiagnosed due to the lack of knowledge with consultants, so the more publicity and awareness that is raised the more people will understand this condition and fingers crossed more help will come to PORT to help FIGHT THIS and SAVE LIVES!!



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## A glimpse inside PORT's activities

A lot of work goes on behind the scenes, to ensure PORT attains and funds the best possible research. In addition to frequent correspondence, each year Sue Stewart (Co-founder and Chair) attends 3 meetings, often with other trustees, Barry Stewart and Dr Nigel Meadows. Every year PORT sends out a research call and an additional call through Bowel and Cancer Research (B&CR), PORT has an arrangement by which we use the services and expertise of their medical advisory panel so that only robust research makes it through,

but importantly PORT are both involved and have the final say. The initial research call is sent out in early October, for research grants up to £50,000, with potential projects commencing the following summer. This year we have two potential projects which are currently being scrutinised. Please do watch this space!

Another event in the PORT calendar is the Big Bowel Event. This year, trustees Barry Stewart and Dr Nigel Meadows represented PORT, at The

Big Bowel Event. The event was held at CCT Venues, on 4th October. The event gives the opportunity for researchers to talk to the public about their projects, and make use of their insights as patients, family and friends. Typically, the morning gives an insight into the research, and the opportunity for involvement. The afternoon brings academics, and the public together to help shape the best research. This year, PORT had a stand at the event - an opportunity to increase awareness of our charity, and the work we do.



*Sue Stewart (Chairperson) at a meeting at the B&CR offices, Whitechapel with Neele Dellscraft, Postdoctoral Researcher of St. Peter Mansfield Imaging Centre, Nottingham University and Deborah Gilbert, CEO of B&CR. The meeting was to discuss protocol for the MRI research study, PORT have funded.*

## Many thanks to our fantastic fundraisers

We would like to thank everyone who supports our charity. We have a number of collection pots across the country. Many thanks to Farmer Autocare Ltd, Edinburgh, for their donation of £81, in December. Thank you to Cheryl East and all the staff and customers of Dreams Beauty salon, who have donated £108 from the sale of sweetie cones and our charity collection pot, in November, and also thank you to Marden post office for their donation, from our PORT charity collection pot. We'd also like to thank Kaylie Finch and the Earl Grey pub for holding a race night which

raised £112 for PORT.

Thank you to Arancee Navaratnam, Suzy Pyne and Ashlee Johnson, for being the first people to create birthday fundraisers for PORT, on Facebook. This is a really easy way to raise money for our charity, so please do consider setting one up when it comes to your birthday.

We've also had some amazing efforts of fundraising, from children and young people. We'd like to thank Nyla, who suffers from CIPO, and her friends, from Bristol Cathedral Choir School for organising a bake sale and raising £66.74. In September a group of children took

part in a 5K woodland walk and raised over £800 for PORT-thank you to all involved. In June, Milldown Academy organised a sponsored sport week, where PORT were supported. Many thanks to Pheebi, who also suffers from CIPO, and her mum Kelly Langdown for putting PORT forwards.

We are also very grateful to Sam McCarthy, for completing the Royal Parks half marathon, in October and raising over £2000, for PORT.

Thank you too, to The Drums Bowls Club, who presented PORT with a cheque for £725, after fundraising for PORT during 2019.



*Trustee, Barry Stewart presented with £725 cheque from Bowls club.*

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**We're on the web!**  
[www.port-charity.org.uk](http://www.port-charity.org.uk)

*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, organising an event, doing a cake sale, coffee morning or similar, 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.*

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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 advice and receive support.

One member posted about receiving a sunflower lanyard for hidden disabilities. This is a free product from Marks and Spencers. It's simple to apply-just email your name and address to Sunflower.Lanyard.Requests@customersupport.marksandspencer.com

Another national scheme is the CEA card. Anyone over the age of 8 years in receipt of either Disability Living Allowance (DLA) or Personal Independence Payment (PIP) is eligible. The card enables a disabled cinema guest to receive a complimentary ticket, for someone to go with them, when they visit a participating cinema. To apply you just need proof of eligibility, a photo and payment of £6.00. The card is valid for one year from the date of issue.

*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. January 2020.**