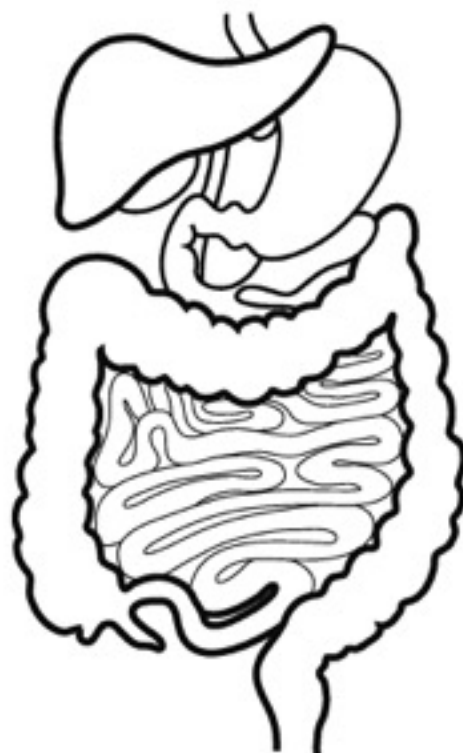




GI Neuromuscular Disorder Patient Health Passport



Name

D.O.B dd/mm/yyyy

Age

NHS number:

Address:

Telephone:

Home:

Mobile:

Email:

Next of Kin:

Name:

Relationship to you:

Mobile:

Home:

Address:

Email:

GP:

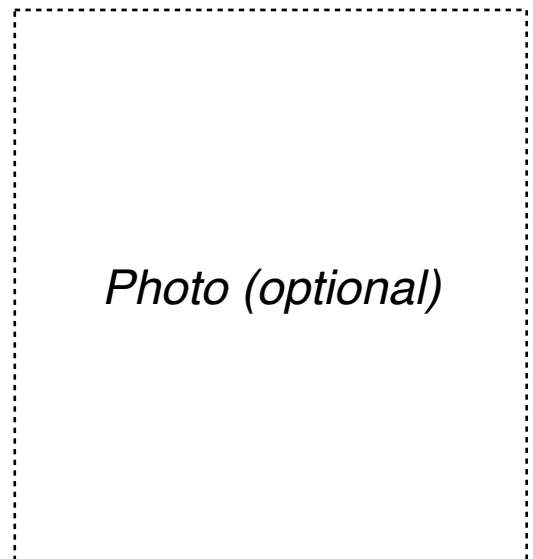
(Name)

(Surgery)

(Address)

Tel:

Fax:



List of Hospital Numbers:

Hospital/NHS Trust
Number

Hospital
Number

Hospital
Number

Hospital
Number

Hospital
Number

Allergies: (see Medication page for more info)

-
-
-

Diagnosis:

Condition(s):

-
-
-
-
-
-
-

Other details (tubes/line/TPN, bags, interventions, other important info)

-
-
-
-
-
-
-

Special requirements:

(i.e. wheelchair user, difficult to cannulate/poor access, fall risk, forms of medication i.e. meds must be liquid form or intravenous, requirements, other important risks and info)

-
-
-
-
-
-
-
-

History:

(Brief History/Summary)

Medication:

Regular Medication

Drug	Form	Dose	Time/routine
Drug	Form	Dose	Time/routine
Drug	Form	Dose	Time/routine
Drug	Form	Dose	Time/routine
Drug	Form	Dose	Time/routine
Drug	Form	Dose	Time/routine
Drug	Form	Dose	Time/routine

Emergency or Rescue Medication

Drug	Form	Dose	Time/routine
Drug	Form	Dose	Time/routine

Nutrition:

(TPN routine, tube feeding info and routine, special diet, fluid requirement)

Allergies:

Drug/substance - reaction

- Any info

Drug/substance - reaction

- Any info

Drug/substance - reaction

- Any info

Drug/substance - reaction

- Any info

Consultants

Name

Specialism

Address

Tel:

Name

Specialism

Address

Tel:

Name

Specialism

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Specialism

Address

Tel:

Other important professionals:

(Community Nurse, Dietician, Psychologist, Physiotherapist, OT, Social Worker etc.)

Name

Role

Address

Tel:

Fax:

Mob:

Name

Role

Address

Tel:

Fax:

Mob:

Name

Role

Address

Tel:

Fax:

Mob:

Name

Role

Address

Tel:

Fax:

Mob:

My care needs:

Personal Care:

Mobility:

Medical:

My Daily Routine:

00.00 -

01.00 -

02.00 -

03.00 -

04.00 -

05.00 -

06.00 -

07.00 -

08.00 -

09.00 -

10.00 -

11.00 -

12.00 -

13.00 -

14.00 -

15.00 -

16.00 -

17.00 -

18.00 -

19.00 -

20.00 -

21.00 -

22.00 -

23.00 -

When having surgery:

(Needs, considerations, common problems and requirements when having surgery)

Pre-op:

Post-op:

Previous reaction to anaesthetic?

Yes / No

If yes, what happened?

Getting to know me:

Me, interests, hobbies, hopes and dreams, what I like to do, my favourite things, what things I enjoy etc. Include a photo or more than one if you'd like. Photos really do make a difference.

The term GI Neuromuscular Disorders, also known as functional bowel and motility disorders, includes (but isn't limited to) the following conditions:

• Chronic Intestinal Pseudo Obstruction • Gastroparesis • Severe Dysmotility • Slow Transit Constipation • Colonic Inertia • Achalasia • Gastro-Oesophageal Reflux Disease •

These disorders affect the nerves and muscles and thus motility of the gut, causing wide-ranging symptoms including severe abdominal pain, abdominal distension, high-volume vomiting, nausea, constipation or diarrhoea, and some also cause swallowing and bladder problems. Common complications of these conditions are Small Intestine Bacterial Overgrowth, Intestinal Failure and nutritional deficiencies, and periods of exacerbation of symptoms, in CIPO this is known as a pseudo-obstruction.

A pseudo-obstruction is where the patient has classic symptoms of an obstruction without any physical or mechanical blockage being present, and in other conditions there may simply be an acute exacerbation of their symptoms. In the case of a pseudo-obstruction, the patient is frequently admitted to hospital, vomiting (possibly faecal vomiting), suffering severe distension, in an awful lot of pain and x-rays will show fluid levels and dilated loops of bowel. Decompression of the digestive system via NG tube is advisable, or via a PEG if they have one, and intravenous fluids given until the gut settles. Pain relief, antiemetics and antispasmodics can relieve symptoms, but one must take care not to give too much opioid pain relief or antispasmodics or give them for too long as they can slow the gut further, delaying recovery from a pseudo-obstruction.

Patient may rely on feeding directly into the stomach or small bowel, through NasoGastric, NasoJejunal, PEG, PEG/J or Jejunostomy tubes. It is more likely with GINMDs for patients to be jejunally fed as the stomach frequently doesn't empty, and jejunal feeds are usually tolerated better. Other patients, where Intestinal Failure has developed, will require Total Parenteral Nutrition (TPN) through a Hickman Line, Port-a-Cath or PICC line, which may be temporary or long term. TPN may be topped up with intravenous fluid to replace fluid losses, and patients may also be dependent on intravenous medication due to a lack of absorption in the intestines. TPN in these patients comes with greater risk due to the gut problems which can lead to gut bug translocation, which can settle in the line causing line and bloodstream infections and sepsis, so in patients with a central line, a spike in temperature of over 38° means they must have blood cultures taken peripherally and from the line to rule out a line infection. Patients may also have an Ileostomy, or less frequently, a Colostomy, or others such as an ACE or Caecostomy tube/stoma. Ileostomies are used to decompress the bowel, or to bypass the affected section of bowel if it is limited to the colon, and the ACE and Caecostomy are used to flush the bowel out with enemas from the top of the colon rather than rectally. Patients, if the bladder is affected, may also have a Mitrofanoff, Suprapubic Catheter or even Urostomy/Ileal Conduit, or may self catheterise intermittently, to manage urological problems.

Patients may have a very complex and involved history, so please listen to the patient/parent, as they will be your most valuable source of information. Work with them, as they live with these conditions and know what works in certain situations. Also, please liaise with the patients' specialist teams or other consultants and ask advice, as they know the patient best and can advise you on how to manage their condition. It will streamline their care and make it more time-efficient and cost-effective if you work with the patient/parent and the patients' regular or specialist teams.



The **Pseudo Obstruction Research Trust** (PORT) is a small charity funding research into Chronic Intestinal Pseudo Obstruction and other rare GI Neuromuscular Disorders, also called functional bowel and motility disorders. We have been a charity since 2006 and have funded more than £300,000 of research and research equipment so far.

PORT also supports patients via phone and email but also our Facebook Support Group, with over 900 members, where people can talk to others in a similar situation, ask them advice and share tips. Though we cannot give medical advice to patients, we can support them in their lives, in accessing appropriate, specialist support, advise on managing the condition in their day to day life and with things such as education and work, and we can offer a listening ear and comfort them through what can be a very isolating condition.

We have a team of medical professionals including Professor Qasim Aziz, Dr Nigel Meadows, Professor Charles Knowles, Professor Jeremy Powell-Tuck, Dr Nikhil Thapar, Professor Jo Martin and others, supporting our work and advising us.

We've funded research, adult and paediatric research nurses, diagnostic and research equipment and the start-up of the Paediatric GI Physiology Unit at The Royal London Hospital. PORT aims to continue to develop and grow, fund more research and save and change more lives.

Pseudo Obstruction Research Trust

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Twitter:

@PORTCharity

Facebook Group:

Pseudo Obstruction Research Trust

YouTube:

Pseudo Obstruction Research Trust