

### Phaeochromocytomas

- *Living with Uncertainty\**
- *Talking to Children & Young People About PGL Syndromes*
- *How to Choose your Medical Team*

### Video and audio resources

- *Patient experience films on PPGL syndromes*
- *Resources for Children: Cartoon about PPGL syndromes (ages 5-8)*

You can view all the above and download them for free from our website: [www.phaeoparasupport.org.uk](http://www.phaeoparasupport.org.uk)

AMEND has received endorsements for its information resources from the Society for Endocrinology, the British Association of Endocrine & Thyroid Surgeons, the British Society for Paediatric Endocrinology & Diabetes and the UK & Ireland Neuroendocrine Tumour Society.

### Need to talk with someone?

Friends and family can be a good source of support when coming to terms with your diagnosis, but there might be times when you feel it would help to talk through difficult feelings with someone outside of your usual support networks. You could ask to be referred to a counsellor through your GP or specialist. Alternatively, **Phaeo Para Support UK's free specialist Counselling Service** provides a limited number of sessions of confidential online or telephone counselling with a specialist rare disease counsellor. The service is available to all registered Phaeo Para Support UK and AMEND patient members and their families. Membership registration is available via our website.

*'Literally life-saving' (service user)*

*'An amazing service' (service user)*

You might also be interested in joining our private **patient-only social media groups**

for registered members of PPSUK where you can be in contact with others in similar situations. Please visit our website to join and for more information.

*"This is an awesome group - you'll get a lot of great info and support" (social media member)*

*"Emailing you has made me feel like I am not alone in this, and I am very glad I contacted you." (patient)*

### About Phaeo Para Support UK

Phaeo Para Support UK is a Group managed by the Association for Multiple Endocrine Neoplasia Disorders (AMEND) for the benefit of those affected by phaeochromocytoma and paraganglioma syndromes. AMEND is a charity registered in England and Wales (number 1153890). It provides support and information services to families affected by endocrine tumours and syndromes. AMEND encourages research into the conditions by funding annual research awards. It hosts a patient information event every year and runs social media forums connecting patients from around the world. Membership is free.

Please visit our website for more information or to make a donation:

[www.phaeoparasupport.org.uk](http://www.phaeoparasupport.org.uk)

Find us on Facebook ([www.facebook.com/PhaeoParaSupportUK](http://www.facebook.com/PhaeoParaSupportUK))

Follow us on Twitter (@PhaeoU)

Scan to go to our website:



Registered charity no. 1153890

Tel: 01892 516076

Email: [info@amend.org.uk](mailto:info@amend.org.uk)

[www.amend.org.uk](http://www.amend.org.uk)

Membership is FREE

# Dealing with Diagnosis



written by Kym Winter

If you are reading this leaflet, it's likely that you - or someone you know - have recently been diagnosed with a **phaeochromocytoma / paraganglioma syndrome, or PPGL for short.**

### *What is PPGL?*

PPGL syndromes are conditions that may cause multiple tumours called paraganglioma or phaeochromocytoma. These syndromes are caused by gene changes (mutations) that can be passed down in families (see our separate book on PPGL Syndromes). Sometimes the tumours may make greater than normal amounts of hormones, the body's chemical messengers, which in turn may cause a range of different symptoms. These tumours grow in certain cells of the body that mean they are classed as neuroendocrine tumours or neoplasms (NET or NEN). All the tumours in PPGL syndromes can occur alone (sporadic) and separately from an inherited syndrome.

A PPGL syndrome is a life-long condition that shows up in different ways depending on which type you have. If you were not given information on your PPGL syndrome by your medical team, please visit the Phaeo Para Support website ([www.phaeoparasupport.org.uk](http://www.phaeoparasupport.org.uk)) or call PPSUK/AMEND on 01892 516076 / 841032.

To be told you have any type of medical condition can be a challenge. The most important thing at the moment is to remember that:

- a) there is no right or wrong way to react, and**
- b) you are not alone**

### *What now?*

Over the next few weeks and days, you might experience conflicting and changing feelings or emotions. You might want to:

- find out as much as possible about your PPGL syndrome as quickly as you can, or
- push it to the back of your mind and forget about it completely, or
- think about nothing else

These reactions can take time to settle and are all a normal part of coming to terms with your diagnosis. This process takes different lengths of time for different people. In addition, it is likely that over the next few months you will have further tests and hospital appointments in order to help work out how best to manage your condition. This is important because PPGL syndromes can affect different people in different ways, even in the same family.

There is no single way to feel about your diagnosis. You might feel:

- **Anxiety or fear** – perhaps about how your condition might impact on your future
- **Anger** – ‘about why this is happening to you
- **Relief** –if you have been suffering with difficult or confusing symptoms for some time it can help to know what has been causing these
- **Disbelief or denial** – ‘it can't be true'; ‘this isn't happening to me'
- **Injustice** – ‘it's not fair', or a sense of unfairness and bitterness
- **Worry** – about possible treatments, your long term health, or for other family members, partners or children
- **Guilt** – about how it might impact your work and family life

**Remember: coming to terms with a diagnosis takes time and is different for everyone.**

### *Early Days*

In the early days it can help to recognise that you are trying to come to terms with a great deal of information, and what that might mean for you and your family. This takes emotional energy.

It can help to reduce the number of other practical or emotional demands on yourself for a few weeks whilst you deal with this. You might find that you are more tired, cross or weepy than usual, or that you eat and drink more or less than normal. Recognise these as signs of being under stress, and seek the support of those around you with whom you feel comfortable enough to share your thoughts and feelings. This might include family, friends, your GP or a specialist counsellor such as the one available through Phaeo Para Support UK's free Counselling Service (see below). There are also peer support groups available through PPSUK.

It is also not unusual to want to ‘forget about it all' for a while, or to try to ignore your diagnosis. This might be helpful in the short-term in order for you allow yourself to get used to the idea at a deeper level, but in the long-run it is important to notice and acknowledge if you begin missing hospital appointments either because of other commitments, or because you can't face them. This is because with PPGL syndromes you are an essential member of your own care team.

### *Becoming an active member of your own Care Team*

Now that you have a diagnosis of a PPGL syndrome, you will be offered specialist life-long care to make sure that you stay well, and to help identify any problems as early on as possible. This might feel reassuring, or a lot to get your head around. It might feel like both of these things. If you are

struggling with this aspect of your condition, do talk to someone. Phaeo Para Support UK has other patients who would be happy to talk to you, as well as a free confidential **telephone Counselling Service** (see below). You can also ask to be referred to a counsellor by your GP.

It can help to remember that you are the most important person in your care team, and that you can work with your hospital team by:

- Attending all your appointments
- Working pro-actively with your specialist team (e.g., taking correct medication doses, staying as active as possible and learning about what symptoms to watch out for)
- Letting your GP or specialist know if you notice any new symptoms or changes in your health.

In this way, your condition can often be managed very well throughout your lifetime and lessen the effect that it has on your everyday life.

### *Other Resources*

Phaeo Para Support UK and AMEND have produced several information resources to help patients with PPGL syndromes to understand and manage the conditions. These are available for both adults and children. Information on the disorders, and on some of the issues surrounding being a patient with a PPGL syndrome are available to download for free at [www.phaeoparasupport.org.uk](http://www.phaeoparasupport.org.uk) or by contacting AMEND on 01892 516076 / 841032.

#### **Information Booklets**

- *Patient Information booklets: Hereditary Phaeochromocytoma & Paraganglioma Syndromes (PPGL Syndromes),*