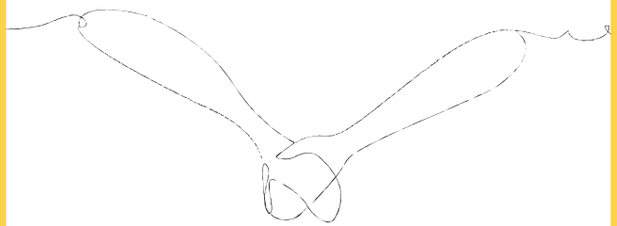
Who are AMEND?

A UK-registered charity since 2003, AMEND is run by patients for patients with the help of an expert medical advisory team. The charity produces a wide range of excellent patient information resources, provides patient support including a professional counsellor helpline, awards research grants, and hosts a well-respected website. AMEND represents patients at professional medical meetings, organises patient area meetings, hosts an annual Patient Information Day, and works tirelessly to ensure that no one living with these rare conditions feels alone.



Main Aims of AMEND

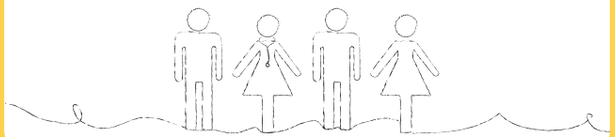
- Providing emotional support to patients
- Providing information resources approved by our expert medical advisory team
- Encouragement of research into the conditions
- Raising awareness of the conditions with the medical profession and the public
- Encouraging improvement of the care and management of patients

Membership Benefits

- Three newsletters per year
- Patient Information Day invitation and AGM voting rights
- Access to private social media groups
- Email alerts of breaking news and research opportunities

Membership

Membership is free but registration is required. For membership registration forms, or for a free copy of a detailed Patient Information Book, please see our website, call the number below, or write to the address below.



Contact Us

Tyler House, 58-66 Morley Road, Tonbridge, Kent, TN9 1RA

(01892) 516076

info@amend.org.uk

www.amend.org.uk

AMEND

Association for Multiple Endocrine Neoplasia Disorders

Registered UK Charity Number 1153890

AMEND

Association for Multiple Endocrine Neoplasia Disorders

Education, Support and Friendship for all those affected by

MEN Syndromes and Associated Conditions

What is MEN?

Multiple Endocrine Neoplasia disorders are inherited syndromes — this means they can be passed down in families. MEN disorders cause more than one gland of the endocrine (gland) system to develop tumours, both benign (not cancer) and cancerous. The affected glands then over-produce hormones (the body's chemical messengers), which in turn cause a variety of different symptoms. Each growth may occur alone and independently of MEN. Early diagnosis and treatment are essential to help reduce the impact of these conditions on the patient.

MEN type 1

In MEN1 tumours may develop in the parathyroid glands in the neck, pituitary gland in the head and the pancreas in the abdomen.

MEN type 2

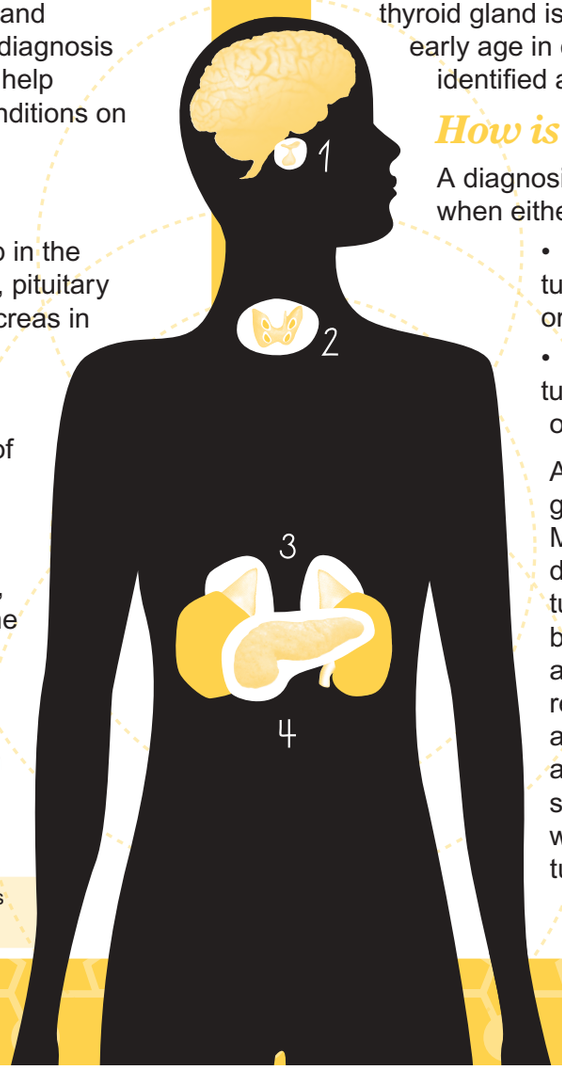
There are 3 distinct subtypes of MEN2:

MEN2a may present with tumours of the thyroid and parathyroid glands in the neck, and the adrenal glands near the kidneys;

MEN2b may present with tumours of the thyroid and adrenal glands, and the gut. In addition, patients with MEN2b may have long fingers and toes and an unusual distinctive facial appearance. MEN2b may also be referred to as MEN3.

FMTC (Familial MTC) presents only with hereditary cancer of the thyroid gland.

Although most of the tumours in MEN2 are benign (not cancer), the thyroid tumours are always cancerous (medullary thyroid cancer), and can occur in early childhood. For this reason, surgery to remove the thyroid gland is usually necessary at an early age in children who have been identified as having MEN2.



1 pituitary 2 thyroid and parathyroids
3 adrenals 4 pancreas

How is MEN Diagnosed?

A diagnosis of MEN is made when either:

- A patient has 2 or more tumours common to MEN, or
- A patient has only 1 tumour but a family history of MEN

A patient may have the gene change that causes MEN but not yet have developed any of the tumours. This person may be called a "MEN carrier" and should be offered regular tests and follow-up appointments at an endocrine clinic in the same way as a patient who already has MEN tumours.

In many people (although not all) the gene change may be identified by genetic testing, but this should only be done after specialist genetic counselling. Genetic testing and counselling services are available throughout the UK on referral from your GP or specialist.

Associated Conditions

AMEND also offers support, information and contact with other patients with the following conditions:

- non-hereditary (sporadic) adrenal gland tumours (phaeochromocytomas and adrenocortical cancer (ACC))
- non-hereditary (sporadic) medullary thyroid cancer (MTC)
- inherited paraganglioma syndromes (SDHx disorders)
- familial (inherited) isolated pituitary adenoma (FIPA)

Other Useful Organisations

Pituitary Foundation
Tel: 0845 450 0375/0377
www.pituitary.org.uk

British Thyroid Foundation (BTF)
Tel: 01423 810093
www.btf-thyroid.org

NET Patient Foundation
Tel: 0800 434 6476
www.netpatientfoundation.org

Addison's Disease Self Help Group (ADSHG)
www.adshg.org.uk

Genetic Alliance UK
Tel: 020 7704 3141
www.geneticalliance.org.uk

Links to other useful organisations around the world are available via our website at
www.amend.org.uk