

WHO IS ACC SUPPORT UK?

ACC Support UK is a collaboration between 2 UK patient groups (AMEND and the NET Patient Foundation) who came together to share their services to help those affected by ACC.

WHAT CAN ACC SUPPORT DO FOR YOU?

Through the combined resources of AMEND and NETPF, ACC Support UK offers

- A specialist nurse helpline
- Free psychological counselling
- Free patient information resources developed with an expert medical advisory team
- Free patient events providing the chance to meet others and share experiences

Main aims of ACC Support UK

- Providing emotional support to patients and their families
- Providing reliable patient information resources
- Providing a link between patients and researchers

CONTACT US

AMEND, The Warehouse,
Draper Street, Tunbridge
Wells, Kent, UK, TN4 0PG

01892 516076

(General enquiries / counselling service)

0800 434 6476

(Specialist Nurse Helpline)

info@accsupport.org.uk

www.accsupport.org.uk

*"It's nice just to have
a cuppa and a chat
with other people in a
similar position"*
ACC patient



**Information and support for
all those affected by
adrenocortical
cancer**

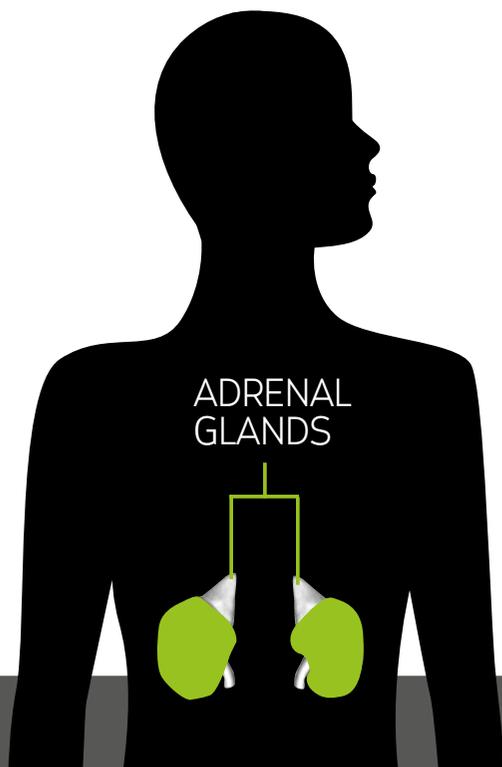


WHAT IS ACC?

ACC stands for Adrenocortical Cancer. ACC is often known simply as adrenal cancer and affects 1-2 people per million per year, making it a rare form of cancer. ACC occurs in the outer part of the adrenal gland. In adults, it most commonly occurs in the 4th or 5th decades of life. In children, the disease may be less aggressive and so treatment differs from that of adults. Scientists do not yet know what causes ACC although there is important research going on around the world.

WHAT ARE THE ADRENAL GLANDS?

The body has two walnut-sized adrenal glands, one above each of the kidneys. Even though the glands are small they are important as they



produce several hormones (the body's chemical messengers) that are important for life.

The inner area of the gland produces a number of hormones which help the body to maintain blood pressure and deal with sudden stress or threats. The outer area of the gland produces hormones called steroids. These steroids help the body to maintain blood pressure as well as salt and sugar levels. A steroid called cortisol is also an important messenger in our bodies' response to stress and illness.

HOW IS ACC DIAGNOSED?

ACCs are usually found because of the symptoms they cause but sometimes they are also discovered by chance if patients undergo a scan arranged for other reasons. ACCs may make higher than normal amounts of hormones than a healthy adrenal would, causing a variety of symptoms and even body changes. Some ACCs get very large and although these don't usually produce active hormones, they may cause symptoms by pressing on other organs. Children are more likely to have symptoms than adults.

HOW IS ACC TREATED?

For ACC, the treatment that offers the best chance of a cure is timely surgery by a specialist surgeon with follow-up and any further treatment managed by a team of doctors of different

specialties (a 'multidisciplinary team') that meets regularly to discuss ACCs. You should make sure that you have been referred to a multidisciplinary team which is experienced in caring for patients with ACC and other adrenal tumours.

DOES IT RUN IN FAMILIES?

Most ACCs do not run in families; however, a number of rare conditions can increase the risk of ACC. Therefore, if an individual with ACC has other members of the family diagnosed with cancer aged 50 years or less, they should ask for referral to their Regional Genetics Service.

WHERE CAN I GET MORE INFORMATION?

ACC Support UK, with the help of its expert medical advisory team, have prepared more detailed patient information booklets on ACC which are available to download for free from the ACC Support UK website. If you require a hard-copy please contact the general enquiries number on the back.

OTHER USEFUL ORGANISATIONS

NET Patient Foundation (Neuroendocrine Tumour Patient Foundation): www.netpatientfoundation.org

AMEND (Association for Multiple Endocrine Neoplasia Disorders): www.amend.org.uk