



Supportive services

Supportive services

People living with a rare condition can sometimes feel isolated and frustrated. However you are not alone and there are charities and support groups who all offer support and advice to patients and families.

Cystinosis Foundation UK

The Cystinosis Foundation UK registered as a charity in 1999 and has continued to provide support to all people diagnosed with cystinosis, their families and their relatives. The foundation works with cystinosis-related charities worldwide to help co-ordinate research support and maintain awareness of new treatments.

Website: www.cystinosis.org.uk

Cystinosis Research Network

The Cystinosis Research Network are based in the USA and are dedicated to supporting and advocating research, providing family assistance and educating the public and medical communities about cystinosis.

Website: www.cystinosis.org

Genetic Alliance UK

Genetic Alliance UK aim to improve the lives of people affected by genetic conditions and to raise awareness and improve information for patients and families. They provide a united voice for all those affected by a genetic condition and actively campaign on issues of policy and practice.

Website: www.geneticalliance.org.uk

Children Living with Inherited Metabolic Disorders (Climb)

Climb is a national organisation who works on behalf of children, young people, adults and families affected by metabolic disease. Climb is the UK's foremost provider of free metabolic disease information. Their vision is to provide support and information to children, young people, adults and families.

Website: www.climb.org.uk

Rare Disease UK

RDUK is the national alliance for people with rare diseases and all who support them. RDUK is campaigning for health departments across the UK to develop a strategy for rare diseases to ensure patients living with rare conditions have equitable access to effective services.

Website: www.raredisease.org.uk

British Kidney Patients Association (BKPA)

The BKPA is a well established charity that works to improve the quality of life for adults and children with kidney disease. They can offer information and advice to patients and families. They also award grants to patients and families to help with domestic bills, education and holidays.

Website: www.britishkidney-pa.co.uk

The National Kidney Federation

The NKF aims to promote best renal practice and treatment, and the health of those suffering from chronic kidney disease or who establish renal failure. The NKF supports the related needs of relatives and friends who care for kidney patients.

Website: www.kidney.org.uk

Kidney Research UK

Kidney Research UK campaign for better patient access to renal services and are dedicated to raising awareness of kidney disease. They award grants to kidney patients so that they can cope with the unexpected costs of their condition. They also operate a kidney information service to answer any questions patients may have about their condition.

Website: www.kidneyresearchuk.org

Helpful contacts

Cystinosis Foundation

Email: Available through 'contact us' section of website

Address: Cystinosis Foundation UK
174 Corwen Road
Tilehurst
Reading
RG30 4TA

Rare Disease UK

Telephone: (020) 7704 3141

Email: info@raredisease.org.uk

Address: Genetic Alliance UK
Unit 4D, Leroy House
436 Essex Road
London
N1 3QP

British Kidney Patients Association

Telephone: 01420 541 424

Email: info@britishkidney-pa.co.uk

Address: The BKPA
3 The Windmills
St Mary's Close, Turk Street
Alton
GU34 1EF

The National Kidney Federation

Telephone: (01909) 544 999

Email: nkf@kidney.org.uk

Address: The NKF
The Point, Coach Road
Shireoaks
Worksop
S81 8BW

Climb

Telephone: 0845 241 2173

Email: enquiries@climb.org.uk

Address: Climb Building
176 Nantwich Road
Crewe
CW2 6BG

Genetic Alliance

Telephone: (020) 7704 3141

Email: Contactus@geneticalliance.org.uk

Address: Genetic Alliance UK
Unit 4D, Leroy House
436 Essex Road
London
N1 3QP

Rare Disease UK

Telephone: (020) 7704 3141

Email: info@raredisease.org.uk

Address: Genetic Alliance UK
Unit 4D, Leroy House
436 Essex Road
London
N1 3QP

Kidney Research UK

Telephone: 0845 070 7601

Email: enquiries@kidneyresearchuk.org

Address: Enquiries Kidney Research UK
Nene Hall
Lynch Wood Park
Peterborough
PE2 6FZ