



National Information
Centre for Metabolic
Disease

General Information
Leaflet

supporting families, changing lives

Climb Building, 176 Nantwich Road, Crewe, Cheshire, CW2 6BG

Freephone: **0800 652 3181**

Climb is the only charity in the United Kingdom that provides support on all Metabolic Diseases with links Worldwide

Email:	info.svcs@climb.org.uk	Website:	www.climb.org.uk
Family Services:	0845 241 2172	Development Services:	0845 241 2173
		Facsimile:	0845 241 2174



Registered Charity No. 1089588. Company Limited by Guarantee No. 4267454

Patron: Her Grace The Duchess of Westminster.

President: Phil Collins L.V.O.

Executive Director : Mr Steven Hannigan MIOD, ACML

"Supporting Families, Changing Lives"



Rebekah - CSID

Climb is a charitable organisation that offers free, confidential and impartial support to both families and professionals worldwide. We hold information on over 700 different inherited metabolic disorders, all of which cover a wide spectrum of symptoms and individual needs. However, the problem that all families face is the sense of isolation that comes with being affected with a rare metabolic disease. Many GP's and medical professionals may not encounter the vast majority of these disorders in their entire career so specialist help, support and information may be difficult for

families to access. **Climb** aims to improve the awareness of metabolic diseases among medical professionals and in doing so improve the services that are currently available.

Services offered by Climb

- Our **Freephone Helpline** is available as often as needed for families to phone us for support and information. Our highly trained Family Advisers offer information and support on the wider aspects of inherited metabolic disease and **Disability Living Allowance (DLA)**, other benefits, **holiday insurance** and a whole range of other topics.
- We have **disease specific information** and a **family-friendly summary** for every inherited metabolic disease. This is available to both families and professionals.
- We are in touch with a large range of **specialists** and **pharmaceutical companies** from across the world who are able to answer more technical queries from families about different diseases and their treatments.
- Our **Family Contacts Network** puts families in touch with each other to share experiences and to reduce the sense of isolation. There are now over 600 families that have joined our network.
- Our **Internet Forums** have also been set up for families to join and offer each other advice from a parent's or carer's perspective. These have proved to be extremely popular.
- The **Children and Young People's Service** is available for young people to take part in. Young people can contact us about a range of different aspects of growing up. One of the main concerns amongst young people is the transition from paediatric to adult care services. The service is also available to the siblings of those affected by a metabolic disease.
- **Our E-Newsletters** are sent out to families and professionals to enable them to be kept up to date with ongoing trials and new treatments that become available.

Conference

Climb's Conferences are held annually and are generally focused on a group of disorders. Both families and professionals are invited to attend. There are a number of seminars that include presentations from specialists.

These are about different aspects of the disorders and any new developments in treatment and understanding. There is usually a question and answer session and an opportunity for families to meet each other. The children and young people are invited to attend the crèche or a trip or workshop that has been organised by **Climb**. Conferences are subsidised for members.



Raising Awareness

Climb can help with any fundraising events by providing sponsor forms, collection boxes and other awareness or promotional material. **Climb** also produces tailored material about metabolic diseases to raise awareness either among the medical profession or the general public. This can include disease specific posters and summaries for hospitals, schools or fundraising events. On top of this we also provide information for genetic students and can give presentations with prior notification.

Research

Amongst the hundreds of research programmes that **Climb** has funded are:

- Canavan Disease
- Congenital Adrenal Hyperplasia (CAH)
- Congenital Disorders of Glycosylation (CDG)
- Galactosaemia
- Glycolipid Storage Disease
- Lactic Acidoses
- Malonyl CoA Decarboxylase Deficiency
- Phenylketonuria (PKU)
- Porphyrria
- Prenatal Diagnosis
- Pyruvate Dehydrogenase Deficiency
- Urea Cycle Disorders
- Tyrosinaemia

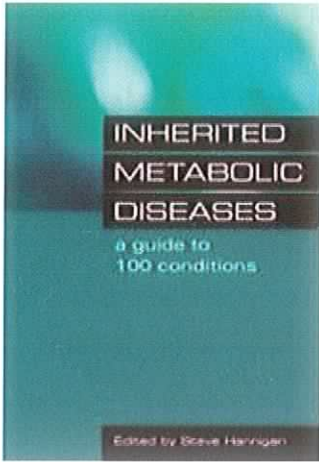


Fraser - Undiagnosed

... and a specialist nurse working with the BME communities in Birmingham.

Climb is very active in the metabolic disease world, participating in many groups and networks which provide care to families. **Climb** is included on the Screening Committee and has links with many national bodies and European networks.

Climb's Achievements



Climb has now been established for over 25 years and has grown significantly. We now support over 700 different disorders and **Climb** is supported and trusted by a wide range of specialists. We are the only support group to cover all of the metabolic diseases and a number of other conditions for which support is not otherwise available. In the past two years alone, **Climb** has published its first book entitled *Metabolic Diseases - A Guide to 100 Conditions* and has funded its first Metabolic Nurse who is based at Birmingham Children's Hospital. Currently **Climb** is providing Satellite Meetings for families where they can come and meet staff and other families face to face in a venue that is local to them.

Some Facts about Climb

- ✓ **Climb** is the only organisation to support all of the inherited metabolic diseases.
- ✓ The work that **Climb** does and the information provided is backed and approved by medical specialists.
- ✓ **Climb** is recognised as a unique specialist service.
- ✓ **Climb** provides long-term support from diagnosis to care and bereavement for all those affected by inherited metabolic diseases.
- ✓ **Climb** ensures that all information, support and advice is tailored to individuals needs and delivered at the pace of the family or professional.
- ✓ **Climb** supports all young people through transition, from paediatric to adult care services and continues any support throughout adulthood.

