



Talking to family and friends

Information for patients with Type 1 Gaucher disease
who have been prescribed Cerdelga

Talking to family and friends

Support and Networks

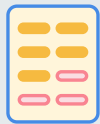


▼ This medicine is subject to additional monitoring. This will allow for quick identification of new safety information. You can help by reporting any side effects you may experience. If you get any side effects talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard.

What support can they provide you?

Having the right type and amount of social support is really important as it will help you to manage your Gaucher Disease type 1 even more effectively.

What kind of support can be useful?



Practical Support

Such as lifts to appointments, collecting your prescriptions or helping round the house



Information Support

Such as giving you new information, and making suggestions or recommendations about living with Gaucher Disease type 1



Emotional Support

Such as being there to listen to you when you need it, giving you a hug, and reassuring you when you may feel a bit low

How to increase and improve your support networks

- ▶ Make sure you **ask people for support** - if you don't ask they might not know you need it
- ▶ **Don't just rely on one person** - make sure you have a wide network of support
- ▶ **Feel confident** to say you are OK if you don't need any support
- ▶ Use **local support networks** or online support groups- these often include people who really understand your experience (see the next pages for information)
- ▶ Remember it is a 2 way process- **family and friends will need support from you** too even if they don't ask!
- ▶ **Have some fun** - take time out to spend time with those close to you, doing something you really enjoy, such as a film at the local cinema

Where can you go to get more information?

Links to National Treatment Centres, current research, useful information and links to other organisations in the UK and around the world

The Gauchers Association

The Gauchers Association provides support and advice to patients and their families, supports research, and provides educational opportunities to specialist doctors to increase the knowledge of Gaucher Disease.



Telephone
01453 549 231



Website
www.gaucher.org.uk

JNetics

JNetics is a registered charity dedicated to improving the prevention, diagnosis and management of Jewish genetic disorders in the UK.



Telephone
020 8123 5022



Website
www.jnetics.org

Where can you go to get more information? (Continued)

Rare Disease UK

RDUK are the national campaign for people with rare diseases and all who support them. They provide a united voice for the rare disease community by capturing the experiences of patients and families.



Telephone
020 7831 0883



Website
www.raredisease.org.uk

Genetic Alliance

Genetic Alliance work on a variety of issues faced by families and individuals with genetic conditions. They aim to provide information, support families, and influence the services needed by these patients. Their work falls into different categories: reproductive techniques; diagnosis; medical research; healthcare and delivery; access to treatments; and living and education.



Telephone
020 7831 0883



Website
www.geneticalliance.org.uk

Genetic Disorders UK

GDUK is a charity that provides advice and support for individuals and families affected by genetic disorders. They aim to provide help through diagnosis, day-to-day management of the disorder and the impact on families. Their database enables people to get in touch with other families in the same position and advise how to set up a support group.



Telephone
0800 987 8987



Website
www.geneticdisordersuk.org

Climb

Climb is the leading patient organisation for Inherited Metabolic Disorders, supporting thousands of patients worldwide.



Telephone
0845 241 2173



Website
www.climb.org.uk



Family Team
0800 652 3181 / Monday - Friday 10am - 4pm

Becoming a Gaucher Disease advocate

If you have the time, you might want to think about becoming a Gaucher disease advocate. This involves helping other people with Gaucher disease type 1, and you can be as involved as you want to be. You don't need to have any special skills or qualifications, and you don't need to be an expert in Gaucher disease – just the willingness to give some of your time to help others.

What does a Gaucher disease advocate do?

There are many ways to be an advocate. Some things you might consider include:

- ▶ **Joining a patient association** or support group, such as The Gaucher Association
- ▶ Running a **blog** about your experiences
- ▶ **Offering your contact details** so that other people can come to you for advice
- ▶ **Teaming up** with someone else who has Gaucher disease type 1 to ensure they get the right treatment advice and care
- ▶ Helping to **raise awareness** of Gaucher disease type 1
- ▶ Working with specialist doctors or patient associations to **represent people with Gaucher disease** type 1 and give them a voice



