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# About Hypopara UK



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*Hypopara UK was set up in 2005 by Liz Glenister, a former teacher, after a 12-year search for information about her unnamed and unacknowledged condition following her operation for thyroid cancer in 1992.*

## What is Hypopara UK?

Hypopara UK is a national patient organisation and charity, supporting over 1,500 members, and is advised by an eminent team of endocrinologists and other specialists. Hypopara UK is supported by occasional grants and donations, and continues to set up Hypopara groups around the world.

## Hypo vs Hyper

**Hypoparathyroidism (HPTH or Hypopara)** is a rare disorder in which insufficient or ineffective levels of parathyroid hormone lead to low levels of calcium. It may be inherited, associated with other disorders, or most commonly may result from neck surgery. The lack of parathyroid hormone leads to hypocalcaemia, or low blood calcium, a potentially life-threatening condition.

**Primary hyperparathyroidism (PHPT)** occurs when too much parathyroid hormone is released which, in turn, leads to high levels of calcium and can cause various potentially dangerous conditions.

## Why are we needed?

Maintaining serum calcium levels can be a challenge as there is no approved replacement hormone, current therapy is not ideal and regular monitoring is not always accessible when needed. Permanent post-surgical HPTH still occurs at unacceptably high rates. Long term renal outcome is not good and patients on the brink of crisis are still not being recognised.

Patients with a rare condition often feel vulnerable and isolated. Finding others who are also learning to manage these rare or uncommon conditions and who can share experiences can be a life-changing moment. Patients still find it difficult to get the treatment they need; there is little understanding of how to manage these conditions and, as with many rare disorders, many doctors may never see a patient with a parathyroid disorder.

## What do we do?

We focus on supporting patients, raising awareness and providing information to patients and doctors alike. We also work closely with our clinical advisors to bring about better treatment.

## Our activities

**Better treatment:** Hypopara UK initiated a successful campaign by patient groups to bring about a clinical trial of parathyroid hormone (PTH-184) for use in the treatment of hypoparathyroidism, as part of a global REPLACE study sponsored by NPS Pharmaceuticals, Inc which we hope will shortly become available. The UK trial centre was headed by our lead Clinical Advisor, Professor William Fraser.

**Guidelines for treatment:** We have long campaigned to bring about treatment guidelines. We are delighted to have been involved with both the BTA Guidelines for the Management of Thyroid Cancer (July 2014) and the European Society of Endocrinology Clinical Guideline: Treatment of chronic hypoparathyroidism in adults (June 2015), and to have worked on both sets of accompanying patient information leaflets.

**Advocacy:** We have worked hard to bring patient needs to the notice of health professionals through direct contact as well as attending meetings of professional bodies and holding awareness evenings in hospitals. We also advocate on behalf of individual patients.

**Research:** Hypopara UK is committed to supporting research work on all aspects of parathyroid conditions. As well as becoming involved in clinical trials and research proposals, we are aiming to build a research resource based on our current 1,500+ strong membership. We also maintain an ongoing collection of key research to provide a reliable overview of current understanding on all forms of hypoparathyroidism and hyperparathyroidism as well as thyroid/ parathyroid surgery. If you would like your paper to appear on this site, please contact us.

**Networking:** Hypopara UK is a member of Genetic Alliance UK, Rare Disease UK, the Thyroid Cancer Alliance, National Voices, and Eurordis, the voice of rare disease patients in Europe.

**Raising awareness:** We have a comprehensive website and make effective use of social media. We involve local media, speak out in the press, have a growing collection of patient stories and participate in fundraising events such as the London Marathon.

**World Hypopara Awareness Day:** Together with the Hypoparathyroidism Association in the USA and other groups around the world we have established 1 June as a worldwide awareness day for hypopara.

**Peer support for Hypopara patients:** We offer support in a number of ways. We run a busy 24/7 online forum and Facebook group, we answer queries by email and run 2 telephone help lines. We are currently setting up local groups across the UK and Ireland so that patients will be able to meet fellow patients in their area.

**Patient information leaflets:** In conjunction with Society for Endocrinology Bone & Mineral Special Interest Group, Hypopara UK has prepared free patient information leaflets on Hypoparathyroidism and Primary Hyperparathyroidism which are available to order from us.

**Patient case studies:** We have a growing number of 'Living with Hypopara' stories about patients with post-surgical, genetic and idiopathic Hypopara on our website, which we can make available for educational purposes as case studies and for teaching medical students.