Useful references


Parathyroid UK Clinical Advisory Team

- Professor Bill Fraser (Professor of Medicine, University of East Anglia)
- Professor Rajesh Thakker (May Professor of Medicine, University of Oxford)
- Professor Jeremy Turner (Consultant Endocrinologist, Norfolk & Norwich University Hospital)
- Mr Saba Balasubramanian (Consultant Endocrine Surgeon and senior lecturer, Sheffield) Consultants
- Professor Neil Gittos (Consultant Endocrinologist & Associate Medical Director, Birmingham)
- Professor Karim Meeran, Professor of Endocrinology, Deputy Director of Medical Education and Lead Clinician for Endocrinology, Imperial College, London
- Professor Peter Selby (Consultant Endocrinologist & hon senior clinical lecturer in Medicine, Manchester University)
- Professor Simon Pearce (Professor of Endocrinology, Newcastle University)
- Dr Brian Shine (Consultant Clinical Pathologist, Oxford University Hospitals NHS Trust)
- Dr Reto Perriss (Consultant Endocrinologist, Newcastle upon Tyne Hospitals NHS Trust)
- Dr Nick Shaw (Consultant Paediatric Endocrinologist, Birmingham Children’s Hospital)
- Dr Jeremy Allgrove (Retired Consultant Paediatric Endocrinologist, Barts & London NHS Trust)
- Dr Mo Aye (Consultant Endocrinologist, Hull & East Yorkshire Hospitals NHS Trust)
- Dr Duncan Brown (Consultant Endocrinologist, interim medical director at Royal Cornwall Hospital)
- Mr Radu Mihai (Consultant in Endocrine surgery & honorary senior clinical lecturer, Oxford)
- Mr Fausto Palazze (Consultant endocrine surgeon, and honorary senior lecturer, Imperial Centre for Endocrinology, London)
- Dr Rachel Crowley (Consultant Endocrinologist, St Vincent’s University Hospital, Dublin)
- Dr Hilary Bridge (Consultant Anaesthetist, Oxford)
- Dr Stephen Bellamy (GP, West Sussex)

About us

Please contact us for more information or if you’d like to get involved.

Parathyroid UK

Silk Mill House, 196 Huddersfield Road, Meltham, Yorkshire, HD9 4AW
Tel: +44 (0)1342 316315
Email: info@parathyroiduk.org

© Parathyroid UK September 2019
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.

What is Parathyroid UK?
Parathyroid 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. Parathyroid 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.

Better treatment: Parathyroid 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: Parathyroid 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.