



DECLARATION

MADE BY THE GLOBAL PITUITARY PATIENT COMMUNITY

21st October 2012

Preamble

- Patient groups from across the world that support patients with pituitary disorders are concerned about the diagnostic delays that create unnecessary burdens for patients and the differences that exist in the provision of treatment and care worldwide.
- We believe that all patients should be treated equally regardless of their race, nationality, faith, age, sex or economic status.
- This document is a consensus declaration from the pituitary patient groups that assembled in Zurich, Switzerland on 19-21st October 2012. It identifies a set of basic standards which we call on health care professionals, hospital administrators and health authorities to adopt and to build upon for the benefit of the patients they serve.

DECLARATION

We, the undersigned pituitary patient groups, collectively call on all those responsible for the diagnosis, treatment and care of patients with pituitary disorders to:

1. Make sure that information about pituitary disorders are collected systematically in a national or international registry;
2. Raise awareness about distinctive signs and symptoms of pituitary disorders;
3. Ensure that patients are diagnosed promptly and accurately in order to reduce the burden of disease and improve treatment outcomes;
4. Ensure that patients have surgery carried out by a dedicated, experienced neurosurgeon (minimum of 20 pituitary surgeries per year) and receive treatment from a neuro-endocrinologist. In addition, patients with pituitary disorders should be cared for in high quality, specialized units with multidisciplinary teams that include specialist nurses;
5. Treat patients in line with internationally accepted guidelines and consensus statements on the management of pituitary disorders, where they exist, and ensure that the resources required to deliver treatment according to the guidelines are available;
6. Ensure that patients with pituitary disorders have access to information about their disease and treatment strategies, and the need for long-term follow-up;
7. Provide patients with the psychosocial support necessary to live with the consequences of their disease;
8. Address the social stigma and discrimination experienced by patients because of the impact of pituitary disorders on physical appearance;
9. Make sure that emergency services understand the importance of replacing hydrocortisone if a patient requires emergency treatment and surgery;
10. Conduct research to increase understanding about pituitary disorders, to develop new diagnostic tests and treatments, and to identify new approaches to improving patients' quality of life.

We, the pituitary patient community, commit to working together to raise awareness about pituitary disorders and the need for timely diagnosis and access to optimal treatment and care.