World
Alliance of
Pituitary
Organizations

DECLARATION
BY
THE GLOBAL PITUITARY PATIENT COMMUNITY
October 12, 2012 | Zurich, Switzerland
全球脑垂体患者群体宣言
2012年10月12号|苏黎世，瑞士

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Preamble

- Patient organizations 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.

序言

- 世界各地脑垂体疾病的患者组织都在关注诊断延迟给患者造成的不必要的负担，以及在提供治疗和护理方面存在的差异。
- 我们相信所有的患者都应该得到平等的对待，无论他们的种族、国籍、信仰、年龄、性别或经济状况如何。
- 本宣言是2012年10月19日至21日在瑞士苏黎世召开的全球脑垂体患者群体的一致声明。籍此我们确定了一套基本标准，呼吁医疗卫生专业人员、医院管理人员和卫生主管部门为了所服务的病人的利益采纳和建立这些标准。

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 50 pituitary surgeries per year) and receive treatment from a neuro-endocrinologist. In addition, patients with pituitary disorders should have access to high quality, specialised 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 and improve Quality of Life;

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.

宣言

我们，以下署名的脑垂体患者群体，共同呼吁所有负责诊断、治疗和护理脑垂体疾病患者的人:

1, 倡导可以在国家或国际合作层面上系统地收集有关垂体疾病的信息;
2, 促进对垂体疾病的独特临床体征和症状的认识;
3, 确保垂体疾病患者能够得到及时、准确的诊断，减轻疾病负担，提高治疗效果;
4, 确保患者接受的手术是由专业的、富有经验的神经外科医生主刀 (每年至少 50 例垂体手术量)，并接受神经内分泌科医生的诊疗。同时，脑垂体疾病患者必要时能够得到高水平的专业多学科团队，包括专科护士的会诊指导;
5, 遵循国际公认的脑垂体疾病管理指南和共识对患者进行治疗，并确保可获得根据该指南提供治疗时所需的资源;
6, 确保垂体疾病患者能够获取有关其疾病和治疗策略的信息，并被嘱咐需要长期随访;
7, 为患者提供必要的心理支持，使他们能够面对疾病带来的后果，提高生活的质量;
8, 致力改善患者因脑垂体疾病对外貌的影响而在社会上遭受到的诽谤和歧视;
9, 确保急救医疗部门了解，如果患者需要紧急治疗或手术时氢化可的松替代的重要性;
10, 开展研究以增进对垂体疾病的了解，开发新的诊断实验和治疗方法，交流并采纳新的方法来改善患者的生活质量。

我们，垂体疾病患者群体，致力于共同努力以增进对垂体疾病的认识，确保更及时的诊断，以及最优化的治疗和护理的可及性。