

THE AMSTERDAM DECLARATION GRAVES' ORBITOPATHY: IMPROVING OUTCOMES FOR THYROID EYE DISEASE

On the 30th of October several professional medical societies and patient-led organisations joined forces in signing the Amsterdam Declaration. The ceremony took place during the 10th International Symposium on Graves' orbitopathy (Figure 1).

The Amsterdam Declaration (Table 1) is about improving care for people with thyroid eye disease focusing on early diagnosis and intervention, collaborative research and education.

In total 68 cosignatories (14 international professional societies, 43, national professional societies, 11 patient-led organisations) have thus far supported the Amsterdam Declaration (Table 2).

For further information on the Amstrerdam Declaration contact Dr Petros Perros petros.perros@nuth.nhs.uk.

TABLE 1 Graves' orbitopathy: improving outcomes for Thyroid eye disease The Amsterdam Declaration 2009

Graves' orbitopathy affects hundreds of thousands of people in the world every year. It causes pain, discomfort, double vision, disfigurement and sometimes blindness. People suffering with Graves' orbitopathy have a poor quality of life and long-term psychosocial morbidity. The quality of care received by the majority of people affected by this condition can be improved. Conventional treatments are effective when used appropriately and by centres with expertise. Not all patients are offered effective treatments either because most are not referred early or not at all. People at high risk of developing Graves' orbitopathy can be identified and effective risk management can potentially lessen the severity of the disease.

The care of people with Graves' orbitopathy can be improved vastly by making centres of excellence more accessible to them.

In October 2009, international experts on Graves' orbitopathy, representatives of professional organisations and patient representatives met in Amsterdam and unanimously agreed on the following:

Health care providers and professional organisations should recognise the need to improve the care of people with Graves' orbitopathy and support plans for implementing better care and prevention.

The general objectives are:

- to minimise the morbidity associated with Graves' orbitopathy and improve the patients' experience and quality of life
- prevent the development of Graves' orbitopathy in people at high risk

The 5-year targets are:

- Raise awareness of this condition among health care professionals and managers
- Establish pathways of referral and care

- Support existing centres of excellence in management of this condition
- Create new centres of excellence in localities where they are lacking
- Establish audit and monitoring mechanisms of quality assurance of provision of care to people with Graves' orbitopathy
- Implement measures to reduce the incidence and morbidity of the disease by
 - o halving the time from presentation to diagnosis
 - o halving the time from diagnosis to referral to a centre of excellence
 - o appropriate management of thyroid dysfunction including use of radioiodine
 - o vigorous anti-smoking measures in patients at risk of or with Graves' orbitopathy
- Improve the existing research networks and develop further international collaborative research

TABLE 2
Cosignatories of the Amsterdam Declaration

International professional societies

Academia Ophthalmologica Europea
 Academia Ophthalmologica Internationalis
 American Thyroid Association
 Asia Pacific Society of Ophthalmic Plastic and Reconstructive Surgery
 European Association for Vision and Eye Research (EVER)
 Endocrine Society
 European Group on Graves' Orbitopathy
 European Society of Endocrinology
 European Society of Orbital Plastic Reconstructive Surgery
 European Thyroid Association
 Iberico-American Society of Ophthalmic Plastic and Orbital Surgery
 International Thyroid Eye Disease Study Group
 Latin-American Thyroid Society
 World Society of Pediatric Ophthalmology and Strabismus (WSPOS)

National professional societies

All India Ophthalmological Society
 American Association of Clinical Endocrinologists
 Argentina Council of Ophthalmology
 Argentina Society of Ophthalmology
 Belgian Endocrine Society
 Belgian Thyroid Club
 Bielschowsky-Gesellschaft für Schielforschung und Neuroophthalmologie
 British Oculoplastic Surgery Society
 British Thyroid Association
 Chinese Society of Ophthalmology
 Cyprus Endocrine Society
 Danish Thyroid Association
 Dutch Endocrine Society
 Finnish Endocrine Society
 French Endocrine Society
 French Society of Ophthalmic Plastic Reconstructive and Aesthetic Surgery
 German Endocrine Society

German Thyroid Board
German Society of Ophthalmology
Hellenic Endocrine Society
Italian Association of Medical Endocrinologists
Italian Society of Endocrinology
Italian Society of Ophthalmic Plastic Surgery
Italian Thyroid Association
Irish Endocrine Society
Japan Thyroid Association
Japanese Society of Ophthalmology
Macedonian Endocrine Association
Oculoplastic Association of India
Ophthalmological Society of Portorico
Philippine Society of Ophthalmic Plastic and Reconstructive Surgery
Philippine Academy of Ophthalmology
Polish Thyroid Society
Romanian Society for Endocrinology
Royal College of Ophthalmologists (UK)
Serbian Endocrine Society
Slovak Endocrine Society
Società Oftalmologica Italiana
Society for Endocrinology (UK)
South African Society of Oculoplastic Surgeons
Spanish Society of Ophthalmic Plastic and Orbital Surgery
Swiss Endocrine and Diabetes Society
Turkish Society for Endocrinology and Metabolism

Thyroid patient associations

Association "Vivre sans Thyroïde"
British Thyroid Foundation
Finnish Thyroid Foundation
Italian Thyroid Patient Association
Nederlandse Vereniging van Graves' patienten
Schilddrüsstichting Nederland
Svenska Sköldkörtel Föreningen
Thyroid Eye Disease charitable trust (UK)
Thyroid Federation International
Verein Schilddrüsengruppe Schweiz
United States of America Graves' Disease Foundation