

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

**G**raeves' 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
  - halving the time from presentation to diagnosis
  - halving the time from diagnosis to referral to a centre of excellence
  - appropriate management of thyroid dysfunction including use of radioiodine
  - vigorous anti-smoking measures in patients at risk of or with Graves' orbitopathy
- Improve the existing research networks and develop further international collaborative research

## NEWSLETTER

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

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

The Amsterdam Declaration 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).

For further information on the Amsterdam Declaration contact Dr Petros Perros [petros.perros@nuth.nhs.uk](mailto:petros.perros@nuth.nhs.uk).

<b>TABLE</b>	
<b>Cosignatories of the Amsterdam Declaration</b>	
<b><i>International professional societies</i></b>	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)
<b><i>National professional societies</i></b>	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

	<p> 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 </p>
<b><i>Thyroid patient associations</i></b>	<p> Association "Vivre sans Thyroïde"  British Thyroid Foundation  Finnish Thyroid Foundation  Italian Thyroid Patient Association  Nederlandse Vereniging van Graves' patienten  Schildklierstichting Nederland  Svenska Sköldkörtel Föreningen  Thyroid Eye Disease charitable trust (UK)  Thyroid Federation International  Verein Schilddrüsengruppe Schweiz  United States of America Graves' Disease Foundation </p>