

Graves' Orbitopathy: Improving Outcomes for Thyroid Eye Disease—The Amsterdam Declaration

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 centers with expertise. Not all patients are offered effective treatments either because most are not referred early or are not referred 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 vastly improved by making centers of excellence more accessible to them.

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

Health care providers and professional organizations should recognize 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 minimize the morbidity associated with Graves' orbitopathy and improve the patients' experience and quality of life
- To 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 centers of excellence in management of this condition
- Create new centers 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 center of excellence
 - Appropriate management of thyroid dysfunction including use of radioiodine
 - Vigorous antismoking measures in patients at risk of or with Graves' orbitopathy
- Improve the existing research networks and develop further international collaborative research

Cosignatories of the Amsterdam Declaration

International professional organizations

Academia Ophthalmologica Europea
Academia Ophthalmologica Internationalis
American Thyroid Association
Asia-Oceania Thyroid Association
Asia Pacific Society of Ophthalmic Plastic and Reconstructive Surgery
Endocrine Society
European Association for Vision and Eye Research (EVER)
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)

International thyroid patient association

Thyroid Federation International

National professional organizations

All India Ophthalmological Society
American Association of Clinical Endocrinologists

The Amsterdam Declaration was signed at the Royal Netherlands Academy of Sciences in Amsterdam on October 30, 2009, during the 10th International Symposium on Graves' Orbitopathy, sponsored by the Academic Medical Centre, University of Amsterdam. This notice was submitted by Petros Perros and Wilmar M. Wiersinga.

Argentina Council of Ophthalmology (Consejo Argentino de Oftalmología)
 Argentina Society of Ophthalmology (SAO)
 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 (Deutsche Ophthalmologische Gesellschaft)
 Hellenic Endocrine Society
 Hellenic Society of Ophthalmic Plastic and Reconstructive Surgery
 Irish Endocrine Society
 Italian Association of Medical Endocrinologists (Associazione Medici Endocrinologi)
 Italian Society of Endocrinology
 Italian Society of Ophthalmic Plastic Surgery (Società Italiana di Chirurgia Oftalmoplastica, SICOP)
 Italian Thyroid Association
 Japan Thyroid Association
 Japanese Society of Ophthalmology
 Macedonian Endocrine Association
 Oculoplastic Association of India
 Ophthalmological Society of Portorico (Sociedad Puertorriqueña de Oftalmología)
 Philippine Society of Ophthalmic Plastic and Reconstructive Surgery (PSOPRS)
 Philippine Academy of Ophthalmology (PAO)

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 (Sociedad Espanola de Cirurgia Plastica Ocular y Orbitaria, SECPOO)
 Swiss Endocrine and Diabetes Society (SGED/SSED)
 Turkish Society for Endocrinology and Metabolism

National thyroid patient organizations

Association "Vivre sans Thyroïde"
 British Thyroid Foundation
 Finnish Thyroid Foundation
 Georgian Union of Diabetes and Endocrine Associations (GUDEAS)
 Italian Thyroid Patient Association
 La Asociación Mexicana de Tiroides
 Nederlandse Vereniging van Graves' patienten
 Norsk Thyreoideaforbund
 Ohne Schilddrüse leben e.V.
 Schilddrüsen-Liga Deutschland e.V.
 Schildklierstichting Nederland (Thyroid Patients Organization of the Netherlands)
 Svenska Sköldkörtel Föreningen.
 The Australian Thyroid Foundation Ltd.
 Thyroid Australia
 Thyroid Eye Disease charitable trust (UK)
 Thyreoidea Landsforeningen
 Instituto da Tiroide
 Japan Thyroid Foundation
 Thyroid Foundation of Canada/La Fondation canadienne de la Thyroïde
 Thyroid Foundation of St. Petersburg
 United States of America Graves' Disease Foundation
 Verein Schilddrüsengruppe Schweiz