The Amsterdam Declaration on Graves' Orbitopathy

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Why Is There a Need for a Declaration on Graves' Orbitopathy?

For decades, clinicians who manage patients with Graves' orbitopathy (GO) have been anticipating the emergence of new effective therapies for the management of this condition. That dream has yet to come true, but it has become apparent that conventional treatments such as steroids and surgery, when applied at the appropriate time and by centres that have accumulated sufficient experience and expertise, can lead to very satisfactory results.

No idea is ever entirely new and the Amsterdam Declaration is no exception. Its predecessor is the Saint Vincent Declaration for diabetes, signed exactly 20 years earlier [1]. Like diabetes, GO is responsible for prolonged ill health, the available services are variable [2–5], and there is a strong feeling that outcomes can, and should improve. The objectives of the Amsterdam Declaration are to improve care of patients with GO and to prevent it occurring in patients who are at risk. There are specific 5 year targets focusing on raising awareness, defining pathways of care, supporting centres of excellence, establishing audit and monitoring mechanisms, and implement measures to reduce the incidence and morbidity of the disease.

Why Is the Declaration Called the Amsterdam Declaration?

The concept of a declaration on Graves' Orbitopathy was conceived in April 2009 by some members of EUGOGO. The 10th International Symposium on Graves' Orbitopathy, scheduled to take place in Amsterdam at the end of October 2009, was fast approaching and it seemed entirely appropriate to announce and sign the declaration at that meeting.

Fig. 1. Signatories of the Amsterdam Declaration on Graves' Orbitopathy, October 30th 2009.

What Is the Text of the Amsterdam Declaration?

The official document is given in appendix 1.

Who Signed the Amsterdam Declaration?

Having formulated the Amsterdam Declaration, EUGOGO canvassed for support from professional societies and thyroid patient-led organizations. The response surpassed all expectations. The Amsterdam Declaration was signed at the Royal Netherlands Academy of Sciences in Amsterdam on the 30th October 2009 (fig. 1). By early 2010, the Amsterdam Declaration was supported by 82 organizations including all 4 international thyroid sister associations, 15 international professional societies, 44 national professional societies and 23 patient-led organizations (appendix 2). There can be no doubt that there is a global support among the thyroid community for the Amsterdam Declaration. The real challenge is how to turn a wish list into results.

Can Other Societies Still Sign the Declaration?

Other learned societies and patient associations involved in GO are very welcome to sign the declaration. To become a cosignatory please contact the secretary of EUGOGO Mario Salvi in Milano, Italy, via E-mail (mario@mariosalvinet.it). The more cosignatories, the higher the chance that the objectives of the Amsterdam Declaration will be reached!

Appendix 1: 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 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.

Appendix 2: Signatories of the Amsterdam Declaration

International Professional Organisations

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 organisations

All India Ophthalmological Society
American Association of Clinical Endocrinologists
Argentina Council of Ophthalmology (Consejo Argentino de Oftalmologia)
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 Española de Cirugía Plástica Ocular y Orbitaria, SECPOO)
 Swiss Endocrine and Diabetes Society (SGED/SSED)
 Turkish Society for Endocrinology and Metabolism

National thyroid patient organisations

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.
 Schilddrüsenstichting 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 Tiroides
 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

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