The Amsterdam Declaration on Graves' Orbitopathy

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Published in:
Thyriod

DOI:
10.1089/thy.2010.1618

Citation for published version (APA):
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“The pathogenesis of Graves’ orbitopathy is still poorly understood. Through research into the normal and abnormal situations, approached by different disciplines, might elucidate the problems and enable better management to prevent this disfiguring disease.”

This statement holds true now as it did nearly 20 years ago (1). Some patients have an excellent outcome, while others may suffer a long and debilitating illness. Those who do well are not the recipients of new breakthroughs in treatment. The variance in outcome is to some extent a reflection of inequalities in availability of expertise and delivery of medical and surgical treatments that have changed little for decades (2,3).

FIG. 1. Signatories of the Amsterdam Declaration on Graves’ Orbitopathy, October 30, 2009. Front row from left to right: Professor S. Gullu (Turkish Society for Endocrinology and Metabolism), Dr. P. Perros (European Group on Graves’ Orbitopathy), Professor J. Lazarus (Society for Endocrinology, UK and British Thyroid Association), Dr. M. Salvi (Italian Thyroid Patient Association), Dr. U. Slama (Finish Thyroid Foundation), Dr. Y. Inoue (Japan Thyroid Association), Dr. C. Dayan (Thyroid Eye Disease Charitable Trust), Professor M. Alevizaki (European Society of Endocrinology), Professor C. Daumerie (Belgian Endocrine Society and Belgian Thyroid Club), Professor L. Bartalena (Italian Society of Endocrinology), Ms. L. van ‘t Riet (Schildklierstichting Nederland), Dr. C. Schalin-Jantti (Finnish Endocrine Society), Mrs. J. Hickey (British Thyroid Foundation), Mr. N. de Jong (Nederlandse Vereniging van Graves’ patienten). Back row from left to right: Dr. C. Lane (British Oculoplastic Surgery Society), D. O. Vonica (Romanian Society for Endocrinology), Professor T. Davies (American Thyroid Association), Dr. P. Dolman (International Thyroid Eye Disease Study Group), Dr. H. Ramos (Latin America Thyroid Society), Professor M. Mourits (European Society of Orbital Plastic Reconstructive Surgery), Professor G. Krassas (Hellenic Endocrine Society), Professor W. Wiersinga (European Group On Graves’ Orbitopathy), Dr. G. von Arx (Verein Schildrüsengruppe Schweiz), Dr. A. Eckstein (Bielschowsky-Gesellschaft für Schielforschung und Neuroophthalmologie), Dr. L. de Heide (Dutch Endocrine Society), Dr. C. Marcocci (Italian Thyroid Association), Professor J Orgiazz (French Endocrine Society), Dr. E. Nyström (Thyroid Federation International), Professor P. Laurberg (European Thyroid Association), Professor G. Kahaly (German Endocrine Society and German Thyroid Board), Professor R. Bahn (Endocrine Society), Professor C. Hintschich (German Society of Ophthalmology), Dr. L. Baldeschi (Italian Society of Ophthalmic Plastic Surgery).

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Similar considerations drove clinicians, patients, and politicians to formulate the St. Vincent declaration for people with diabetes (4). The St. Vincent Declaration was daring and as it turned out overambitious in its proposed timeframe for change, but it was ultimately a success. It brought diabetes to the top of the agenda for health providers, health economists, and clinicians. It provided the leverage required to improve diabetes care, not through exotic new treatments, but by building the infrastructure necessary to allow healthcare to reach those who needed it.

The parallels between care delivery in diabetes and Graves’ orbitopathy (GO) inspired the Amsterdam Declaration, which appears in this issue (see page 351) (5). This document highlights that patients with GO can and should receive better care. It draws attention to improving quality of life of patients, prevention, and swifter care, preferably in centers of excellence. It also sets specific 5-year targets for health care providers.

A few months ago this vision was put forward to international and national professional societies and thyroid patient organizations. The response has exceeded all expectations. On the October 30, 2009, during the 10th International Symposium on Graves’ Orbitopathy, the Amsterdam Declaration was signed (Fig. 1). To date, the Amsterdam Declaration has been signed by representatives of 82 organizations including all the sister thyroid associations, 15 international professional societies, 44 national professional societies, and 23 patient-led organizations (see Notice on page 351) (5).

So, the principles and concept have been firmly agreed upon. Now the hard work begins!

References


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