

THE AMSTERDAM DECLARATION

GRAVES' ORBITOPATHY: IMPROVING OUTCOMES

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