HAEMOPHILIA PATIENT LIFETIME

Introduction

• Patients with haemophilia often face a number of psychosocial challenges; therefore, they may require support and guidance from healthcare providers.

• The HERO (Haemophilia Experiences, Results and Opportunities) initiative aims to provide insight into the psychosocial issues associated with living with haemophilia. An overview of the HERO programme is shown in Figure 1.

Methods

Survey design

• The HERO quantitative survey (ClinicalTrials.gov identifier NCT01322620: The HERO psychosocial effects of living with haemophilia) is a multinational, community-based survey to involve 1200 subjects from 12 countries (Figure 3).

Eligible subjects will complete one of two web-based questionnaires according to whether they are adult male patients with haemophilia or parents/caregivers of children with haemophilia.

In countries where internet access is limited, subjects may be allowed to complete a paper version of either the patient or parent/caregiver questionnaire, as appropriate, which will be sent to them by post. This will be the case in Algeria.

Survey population

• Each country will recruit 100 subjects comprising 50 adult male patients with haemophilia and 50 parents/caregivers of children with haemophilia.

Inability to understand and comply with written and verbal instructions

Provision of informed consent before the start of any survey-related activities

Survey Timelines

As of 1 July 2011, protocol finalisation/ethics approval had been arranged in 8/12 countries and survey recruitment has started.

Findings from this survey will be available in late 2011/early 2012.

Expected Results and Conclusions

• The HERO quantitative survey findings are expected to enhance understanding of living with haemophilia and illustrate how psychosocial factors influence both patients and parents.

• These data will help to identify any areas of need and may ultimately inform the development of new comprehensive strategies to improve haemophilia management.

References


Acknowledgement

This paper is a part of the HERO (Haemophilia, Experiences, Results and Opportunities) initiative and was supported by a grant from Novo Nordisk A/S.

Figure 1. HERO programme

• To explore how psychosocial factors are associated with treatment outcomes,

• To quantify the range of parents'/caregivers' attitudes and responsibilities associated with haemophilia and involve patient experts in the development of new strategies for improving the management of haemophilia.

• To provide a cross-cultural perspective on all of the above.