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dsd-LIFE

CLINICAL EUROPEAN STUDY ON THE OUTCOME OF SURGICAL AND HORMONAL THERAPY AND PSYCHOLOGICAL INTERVENTION IN DISORDERS OF SEX DEVELOPMENT (dsd).



dsd-LIFE is a collaborative project funded by the European Union Seventh Framework Programme (FP7/2007-2013) under Grant Agreement N° 305373



This is dsd-LIFE

The multidisciplinary dsd-LIFE project consortium consists of 15 experienced and well-known international scientists in the areas of endocrinology, psychology, quality of life, surgery, gynaecology, ethics and health services research.

The project stands for sustainable improvement of clinical care for patients with disorders of sex development (DSD). Areas that are of high importance for life quality will be studied: general quality of life and psychological well-being, psychosexual development, satisfaction with treatment, actual health status and patient rights. In particular the project aims to focus on patients' views, ethics and cultural context. Patient support groups have been contacted to integrate their perspectives into the study protocol and for further advice in the course of the study.

The recruitment of participants will start in autumn 2013. It will be performed by the study centres, associated hospitals and through patient support groups but also through the international DSD registry. Standard operating procedures (SOPs) to perform the study in a standardized manner in all study centres have been developed and physicians, psychologists and nurses have received training to work according to these procedures. Standard routines for quality assurance and data integrity have been implemented; queries and quality reports will be provided.

On the basis of the collected data the evaluation and development of clinical guidelines is set up, thoroughly coordinated by the national coordinators, who closely interact with the project coordinator Dr. Köhler. The results of the study will be disseminated through scientific and health care societies and published in correspondent journals. They will further be disseminated to patients with DSD through the patient support groups.

What we want to do

The first aim of dsd-LIFE is to improve treatment and care of patients with different conditions due to hormonal imbalances of the gonads or adrenals, which are summarized under the medical term differences/disorders of sex development (DSD). This broad group of conditions include Turner Syndrome, Klinefelter Syndrome, Mixed Gonadal Dysgenesis, Androgen Insensitivity Syndrome (AIS), XY and XX Gonadal Dysgenesis, Androgen Biosynthesis Defects (e.g. 5-Alpha-Reductase-2 and 17-Beta-HSD-3 Deficiency), Congenital Adrenal Hyperplasia (CAH) and Hypospadias.

Very little is known about the long-term outcome in this group of conditions in terms of long-term health, quality of life and psychological well-being. For this reason dsd-LIFE will evaluate the medical status, psychological well-being and general quality of life of patients with the different conditions, in order to develop new European guidelines for care and treatment for the different condition. The study also will explore the views of affected persons on a number of ethical issues.

The second aim of the study is to inform and educate medical professionals, nurses, schools and the general public in Europe about needs and care of individuals with these rare conditions.

The priorities, in terms of medical and psychological issues, vary considerably between the different conditions. The study will take account of these diverse concerns.

Key Data

Start Date: October 1st 2012

Project Duration: 4 years

Project Costs: € 2.999.956

What will be the outcome?

DSD-Life will have an important impact and will improve the quality of life of persons with DSD in Europe through

- Improvement of comprehensive clinical care in DSD
- Development of evidence-based guidelines for clinical care of individuals with DSD
- Dissemination of clinical guidelines to health care professionals
- Encouragement of adolescents and adults in self management of DSD
- Empowerment of parents, children and adults with DSD in everyday life
- Reduction of stigma through informing health care and pedagogic staff and the general public
- Increase the knowledge on health outcomes in individuals with DSD
- Implementation of a sustained network of centres of excellence for multidisciplinary care of DSD in Europe

