Workshop on Rare Paediatric Tumours

Description:

Rare diseases (RD) are a threat to the health of European Union (EU) citizens insofar as they are life-threatening or chronically debilitating diseases with a low prevalence and a high level of complexity. Despite their rarity, there are so many different types of RD that millions of people are affected. As a guide, low prevalence is taken as prevalence of less than 5 per 10,000 persons in the EU. It is estimated that between 5,000 and 8,000 distinct RD exist today, affecting between 6% and 8% of the population in total—in other words—between 27 and 36 million people.

According to the EU definition, cancers are classified into the group of rare tumours when their prevalence in the general population is less than 50 out of 100,000 persons. However, prevalence has shortcomings as a measure for rarity for tumours, for this reason and according to RARECARE project an incidence cut point of 6x100,000 has been identified as the appropriate value to define rare cancers or a group of rare cancers. In comparison to cancer in adults, virtually all cancers in children are rare, but severe disease. Approximately 900 to 950 children are diagnosed with cancer each year in Spain. Childhood cancer is the main cause of disease-related death in childhood.

Rare malignant paediatric tumours are essentially "orphan diseases" and make up a variety of neoplasms with particular biological and clinical characteristics. Some of these tumours are rare at any age, but most of them are particularly rare in childhood and adolescents. Children with rare cancers are faced with the same challenges as other patients suffering for RD just because their condition is rare. Rare cancers are often misunderstood, misdiagnosed, or poorly investigated, and there are usually few treatment options. Thus, a substantial proportion of these exceptionally rare tumours are not registered within clinical registries or prospective therapy optimization studies.

Rare cancers are a challenge to clinical practice. Delay in diagnosis and sub-optimal treatment outcomes are common for rare cancers due to a lack of knowledge among physicians and pathologists, a limited expertise in the management of rare cancers (also because of the limited number of cases), a poor referral rates from general practitioners and pathologic misdiagnosis. Outcomes for rare cancers could be improved through the establishment of reference networks. Recently, major attention has been drawn to the diagnostic assessment and treatment of children and adolescents with such orphan diseases.

The close collaboration between paediatric oncologists-haematologists and epidemiologists would allow obtaining detailed clinical information about these tumours and developing of nested research projects on rare childhood cancer aetiology, management and outcome, both on a national and on an international level.
PROGRAMME

Monday, November 22

8:30 - 9:00  Registration
9:00 - 9:15  Opening Ceremony
            Manuel Escolar, General Director of Public Health,
            Regional Ministry of Health, Valencia

9:15 - 11:30  Identifying public health problem
9:15 - 9:30  Keynote lecture
            Conselleria Sanitat. València

9:30 - 10:00  RARECARE: Surveillance of rare cancers in Europe
            Gemma Gatta, Fondazione IRCCS, Istituto Nazionale
dei Tumori, Milano

10:00 - 10:30  Rare Paediatric Tumour in Spain
            Rafael Peris, Registro Nacional de Tumores infantiles
            (RINTI-SEHOP). Universitat de València

10:30 - 11:00  Situation of Rare Paediatric Tumour in the
            Comunitat Valenciana
            Mª Luisa Vicente. Dirección General de Salud Pública.
            Conselleria Sanitat. València

11:00 - 11:30  Discussion
11:30 - 12:00  Coffee break

12:00 - 14:15  Improving data collection
12:00 - 12:15  Keynote lecture
            Carmen Martinez. Escuela Andaluza de Salud Pública.
            Granada

12:15 - 12:45  HAEMACARE. Cancer Registry Based project on
            Haematological malignancies
            Milena Sant. Fondazione IRCCS, Istituto Nazionale
dei Tumori. Milano

12:45 - 13:15  Effect of coding on childhood tumours
            Rafael Marcos. Institut d’Investigació Biomèdica de
            Girona

13:15 - 13:45  Contribution of Tumour Bank to Cancer Registry
            activity
            Jose Antonio Lopez. Instituto Valenciano de
            Oncología. Valencia

13:45 - 12:15  Discussion
14:30 - 16:30  Lunch
16:30 - 17:30  The Italian TREP (Tumori Rari in Età Pediatrica)
            project
            Chairman: M. Carmen Martos. Centro Superior
            de Investigación en Salud Pública. Valencia

            Invited Speaker: Andrea Ferrari. Divisione di
            Pediatria Fondazione IRCCS Istituto Nazionale
            Tumori. Milano

Tuesday, November 23

10:00 - 12:15  Future perspectives in management and research
            Keynote lecture
            Manuel Posada. Instituto de Investigación de
            Enfermedades Raras. ISCIII. Madrid

10:15 - 10:45  How to address the management of rare
            paediatric tumours? Research perspectives
            Victoria Castel. Hospital Infantil La Fe. AVS.
            Conselleria de Sanitat. Valencia

10:45 - 11:15  Rare malignant tumours in children: differences
            and commonalities with adult
            Adela Carrete Neto. M.Aquinto, Oncología Pediátrica
            Grupo de Investigacion Clinica y Trasacional en
            Cancer H.1.La Fe

11:15 - 11:45  Research perspectives on rare haematological
            malignancies
            Pilar Giraldo. Hospital Miguel Servet. Zaragoza

11:45 - 12:15  Discussion
12:30  Closing section
            Isabel Muñoz. Director of the Centro Superior de
            Investigaclón en Salud Pública. Valencia

Date: November 22-23, 2010
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www.csisp.gva.es

Limited seats
Free registration at: eventos_csisp@gva.es
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Generalitat Valenciana