

# Workshop on **Rare Paediatric Tumours**

## Description:

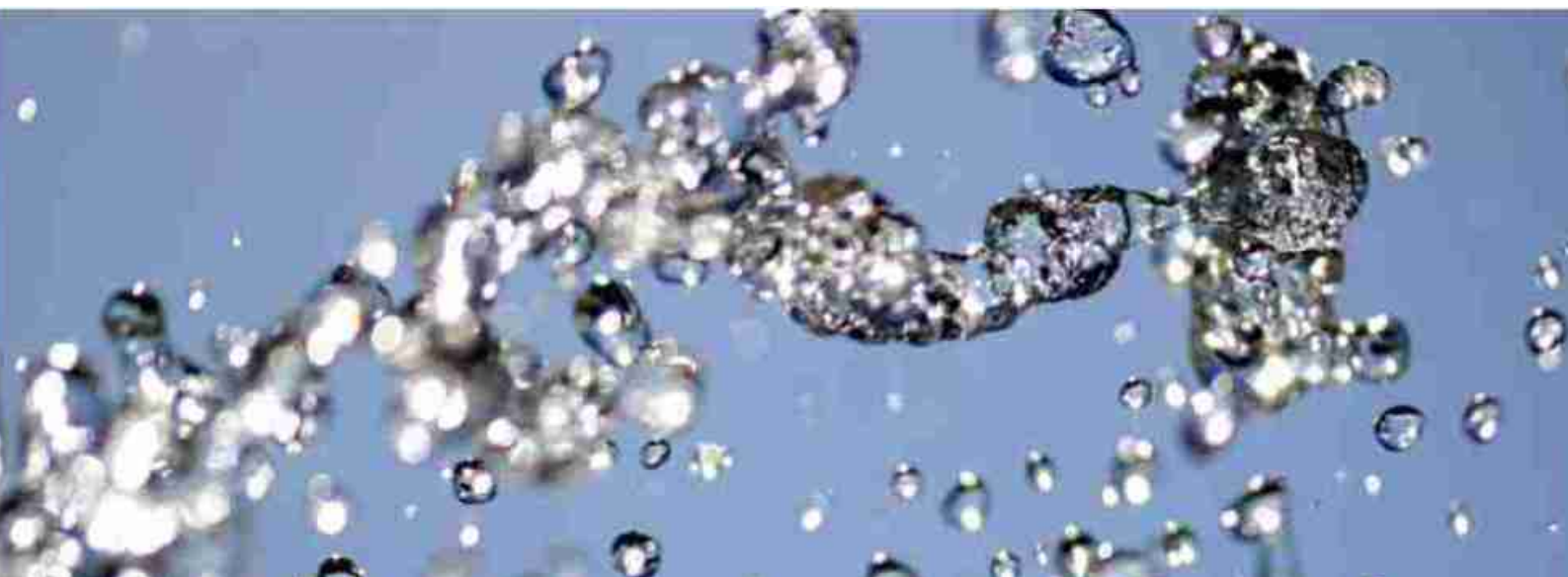
Rare diseases (RD) are a threat to the health of European Union (EU) citizens insofar as they are life-threatening or chronically debilitating diseases with a low prevalence and a high level of complexity. Despite their rarity, there are so many different types of RD that millions of people are affected. 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.



**Monday, November 22**

**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 Et  Pediatrica) project  
*Chairman: M. Carmen Martos. Centro Superior de Investigaci n en Salud P blica. Valencia*

*Invited Speaker: Andrea Ferrati. Divisione di  
Pediatria Fondazione IRCCS Istituto Nazionale  
Tumori, Milano*

**Tuesday, November 23**

10:00 - 12:15	Future perspectives in management and research
10:00 - 10:15	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 Cariete Nieto, M.Adjunto, Oncología Pediátrica  
Grupo de Investigación Clínica y Traslacional en  
Cancer H.I.La Fe

**11:15 - 11:45** Research perspectives on rare haematological malignancies  
*Pilar Giraldo, Hospital Miquel Servet, Zaragoza*

11:45 - 12:15 Discussion

**12.30** Closing section  
*Isabel Muñoz. Director of the Centro Superior de Investigación en Salud Pública. Valencia*



**Date:** November 22-23, 2010

**Location:** Centro Superior de Investigación en Salud Pública. (Salón de actos)  
Av. Cataluña, 21; 46020 Valencia. Spain.  
[www.csisp.qva.es](http://www.csisp.qva.es)

**Limited seats**

**Free registration at:** [eventos\\_csisp@gva.es](mailto:eventos_csisp@gva.es)

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**Organization:** Centro Superior de Investigación en Salud Pública (CSISP)

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