

Press Release

Brussels, 6th December 2013

More has to be done to enhance cure and quality of cure for children and adolescents with cancer in Europe, study shows

An outstanding <u>article on childhood cancer 5-year survival</u> in Europe has been published on the *Lancet Oncology* today. This scientific paper presents the latest results from <u>EUROCARE 5</u>, a cancer registry-based project on survival and care of cancer patients in Europe. This study shows **no improvement in survival of children with tumours that have the worst prognosis. Moreover, unacceptable disparities in survival still exist across Europe**. The article was presented today during the **high-level round table** on the *"Key Determinants of Inequalities in Cancer Survival across Europe"*. This important event, hosted by the Member of the European Parliament (MEP) <u>Alojz Peterle</u> and organised by <u>MEPs Against Cancer (MAC)</u>, was attended by approx. 50 people, including DG SANCO Deputy Director <u>Martin Seychell</u>.

SIOPE welcomes the outcome of the study, thus it provides **fundamental information** for patients and professionals in paediatric oncology. EUROCARE5 data will be instrumental in the definition of objectives and planning of future activities. SIOPE recognises **the crucial work done by the registries** to monitor the effects of actions set up by the paediatric oncology community. SIOPE congratulates the EUROCARE team for their successful engagement and wishes to thank MEP Against Cancer for organising the event.

Looking at the Europe-wide picture across the different disease areas, EUROCARE5 points out that, while there has been an improvement in survival for some categories of tumours, **over the last 10 years there has been no improvement in survival of children with tumours that have the worst prognosis** (brain tumours, neuroblastoma and sarcomas), along with acute myeloid leukaemia.

The other key finding of the study is that there are **still unacceptable disparities in survival** of children and adolescents with cancer **across Europe**:

- Survival is generally lowest in Eastern Europe: the survival rate there is 10 to 20% lower than in Western Europe;
- Disparities became larger for cancers with poor outcomes (AML, ependymoma, osteosarcomas, Ewing sarcoma and rhabdomyosarcomas).

During the meeting Pr Gilles Vassal, SIOPE president, took the floor to congratulate EUROCARE5 team and in particular Gemma Gatta. The data provided by EUROCARE5 are fundamental for SIOPE in order to understand where we have to work more. He stressed 4 main points:



- Childhood cancer is still a public health issue: even though 80% of children can be cured with current standard treatments. Indeed, 6000 young people die each year of cancer, the first cause of death by disease beyond one year of age;
- It is worrying to see that <u>no progress has been achieved for paediatric malignancies with</u> <u>the poorest prognosis</u>. Access to innovative therapies is still limited in Europe despite the Paediatric Medicine regulation and change in the implementation of this important European law needs to be done, now, to better address the needs of children and adolescents with cancer;
- The cost of drugs is not a major issue since the vast majority of drugs curing paediatric cancers are off-patent and generics. However, **drug shortage** observed across the world is threatening availability of the life-saving medicines;
- Setting up in each country a health organization based on specialized centres, multidisciplinary teams and high level training (as described in <u>SIOPE Standards of Care</u>) is likely to increase access to standard care for children and adolescents across Europe. It is worrying that 40% of national cancer plans currently in place in Europe do not address specifically the needs of children and adolescents with cancer.

In this regards, <u>SIOPE</u>'s the strategic goals is to **increase** both **cure** and **quality of cure**. Up to **500 000 European citizens** are **survivors** of a paediatric cancer and it is estimated they will be **1** Million by 2020 – 2025.

This is why one of the key priorities for <u>SIOPE</u> is **to address the existing inequalities of access to standard treatments, care and clinical research** for childhood cancer patients and survivors across Europe. Not only this objective figures in the strategic plan and road-map for the next 15 years of paediatric oncology in Europe, set up together with the <u>ENCCA</u> project, but SIOPE is today collaborating in a new EU-funded project, <u>EXPO-r-NeT</u>, which will connect pre-existing reference centres of excellence and seek mechanisms to facilitate movement of information and knowledge rather than patients whenever possible, to address the existing inequalities in healthcare capabilities in the different countries. Moreover, our Society already addressed this topic through different initiatives, like the <u>Standards of Care for Children with Cancer</u>, a widely recognised reference document to evaluate progress in drug development, treatment and care in treatment centres all over the continent, which has also been acknowledged by the *Lancet Oncology* paper itself.

Finally, our Society is to address the **long-term toxicity and cancer treatment consequences in survivors**, an issue closely link to the central theme of today's event. SIOPE has focused its research and advocacy efforts to monitor and prevent late effects in childhood cancer patients and survivors through the project <u>PanCareSurFup</u> (led by <u>Pancare</u>) and the <u>ENCCA WP13</u> on the quality of survivorship, which includes the innovative <u>Survivorship Passport</u> initiative.



More information

- The Lancet Oncology article <u>"Childhood cancer survival in Europe 1999 2007: results of</u> <u>EUROCARE-5 - a population-based study</u>"
- SIOPE website and position papers, articles and other publications
- EUROCARE <u>website</u>
- MEPs Against Cancer (MAC) website

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