

Childhood cancer research in danger: report

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At a time when the effects of paediatric oncology research have meant that more and more children survive cancer, its funding is too low and dependent on short-term grants to be able to sustain this improvement in the long-term, says a report supported by the EU-funded 7th Framework Programme project Eurocancercoms and published on-line in *ecancer* today. The authors also looked at the citation impact of paediatric oncology papers and found that childhood cancer research is once again the poor relation; unlike cancer papers in general, paediatric oncology papers received fewer citations than the average for the journals in which they were published.

"Working in this kind of discouraging environment makes the achievements of <u>childhood cancer</u> research all the more praiseworthy", said Professor Richard Sullivan, from the Centre for Global OncoPolicy, London, UK, and one of the authors of the report. "About 80% of all childhood cancer patients now survive, due to massive improvements in diagnosis and treatment over the last forty years."

'The State of Research into Children with Cancer across Europe – New Policies for a New Decade' is published by the European Society for Paediatric <u>Oncology</u> (SIOPE) and the Centre for Global OncoPolicy. The report will be presented today (Wednesday 9 February) at a special event in the European Parliament to mark International Childhood Cancer Awareness Day to a wide range of EU policymakers as well as young cancer patients and parents. The authors set out to look at the current state of paediatric oncology research in Europe.



They found that countries with a larger oncology burden, such as those in Eastern Europe, tended not to collaborate in research with those with a better-developed research structure, and this in turn affected the care they were able to give young patients. "Paediatric oncologists from ten countries were asked about their national situations and the differences were striking", said Professor Kathy Pritchard-Jones, Cancer Programme Director at the UCL Institute of Child Health, London, UK and Past President of SIOPE. "For example, a respondent from Bosnia-Herzegovina cited lack of hospital space, no specialist paediatric oncology radiologists, and inadequate diagnostic facilities, with everything adapted to adult patients. The Czech Republic said that research grants were usually for only three years and there was little support for young scientists to attend international courses and congresses which could help harmonise the level of knowledge across European states."

In Italy, it was the fragmentation of childhood cancer care which concerned doctors, with nearly 50 centres specialising in paediatric haematology and oncology, and a lack of co-ordination between research laboratories and clinics. In comparison, Sweden has only six paediatric oncology units, which work closely together but, even there, there are problems of funding and a lack of experienced staff. The UK expressed concern about the effects of health service cuts on children's cancer care, and the fact that infrastructure changes had moved paediatrics alongside the adult cancer model, meaning that research for children now has to compete for funds at a much more visible level with research for adults.

The authors also found large differences in the provision of information on childhood cancer, with variations in the involvement of parental organisations, the use of digital media, and the adoption of a common national standard for information provision. "When a child is sick, the provision of accurate information to the patient and family is essential" said Professor Sullivan. "We believe that the establishment of a



European Common Information Portal could do much to tackle major deficiencies in information in countries with few or no patient organisations, or where the existence of a large number of languages make access to such information difficult."

The authors call for adequate long-term EU funding to support a Europewide clinical trials network for paediatric oncology. "This is an essential prerequisite for the effective testing and dissemination of new therapies and techniques", said Professor Pritchard-Jones. "We also need to study treatment outcomes, and for this the creation of a European Childhood Cancer Epidemiological Registry is essential. With these tools we can maintain the enormous progress that has been made in the past. Without them, we run the risk of jeopardising that progress and failing children who are dependent on us for their survival."

More information: Sullivan R, Pritchard-Jones K, Camporesi S, Lewison G, Vassal G, Ladenstein R, et al. (2011) The state of research into children with cancer across Europe: new policies for a new decade ecancer Vol 5 <u>doi:10.3332/ecancer.2011.210</u>

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