New survey launched to identify top research priorities for cancer in children.

Wednesday 9 September, 2020

A new survey which aims to shape the future research priorities for childhood cancer has been launched today, during Childhood Cancer Awareness Month (September).

Young patients, parents, carers and members of their families, as well as professionals, will be invited to complete the survey to find out the top 10 unanswered research questions about childhood cancer.

The survey has been launched by the Children's Cancer Priority Setting Partnership (PSP), set up in partnership with the James Lind Alliance (JLA) and funded and supported by Children's Cancer and Leukaemia Group (CCLG) and The Little Princess Trust.

The PSP survey launches today and will close on 31st December 2020. A prioritisation process involving a stakeholder group, guided by the JLA, will work through the survey responses to agree a list of top 10 research priorities and unanswered questions that will steer areas for future high-quality research to help tackle childhood cancer.

Around 1,900 children under the age of 15 are diagnosed with cancer each year in the UK[1]. While research over the last 40 years means that mortality rates as a result of childhood cancer have decreased by 70% since the early 1970s[2], around 230 children die from cancer each year, and many more children have long-term side effects from the intensive treatment required.

> Ashley Gamble, Chief Executive of CCLG said: "We're delighted to be able to launch this crucial survey today. As a funder of childhood cancer research, we want to ensure that our priorities align with those of patients, their families and clinicians and reflect their experiences. By understanding their priorities, we can understand what research will lead to the biggest impact."
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> Wendy Tarplee-Morris, Research Manager at The Little Princess Trust said: "We're very pleased to be able to support this vital work. Children with cancer and their families have a unique set of needs and experiences, and it is important that they have a voice in shaping the research agenda."
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> Rachel Hollis, Clinical Chair of the PSP and Honorary Children's Cancer Nursing Advisor at Leeds Teaching Hospitals NHS Trust said: "Topics for research in children's cancer are often decided by the interests of researchers and the pharmaceutical industry. This may overlook what is important to children, their families and the professionals that care for them. I'm honoured to Chair the Children's Cancer PSP which has been established to identify gaps in research and 'unanswered questions' on children's cancer, as identified by children, parents, families and professionals."

The PSP is led by a steering group representing parents of children with cancer, childhood cancer survivors and a broad range of professionals working in the field of paediatric haematology and oncology. A research team at The University of Surrey is supporting the work of the PSP.

The survey will be available at https://cclg.uk/PSP-survey

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