Vital new report launched on top priorities for children’s cancer research

Friday 7 July, 2023

The launch of the final report of the Children’s Cancer Priority Setting Partnership (PSP) was marked with special event in London last week (28 June).

The report is the culmination of a collaborative work that began in 2019, when Children’s Cancer and Leukaemia Group (CCLG) and The Little Princess Trust (LPT) partnered with the James Lind Alliance (JLA) to identify the research questions that are most in need of answering, according to those they matter to the most.

Its aim was to produce a list of the 10 most important research priorities in children's cancer, from the perspectives of patients, their families and carers, and the health professionals who treat and care for them.

With topics of healthcare research in children’s cancer often driven by the interests of researchers and the pharmaceutical industry, what is most important to children, their families and the professionals who care for them, may sometimes be overlooked. Recognising the need for input from people with lived experience of childhood cancer, CCLG and LPT funded the PSP so that researchers and research funders are aware of the issues that matter most to the people who could benefit from the research.

Following a rigorous process of surveys, interviews and workshops designed by the JLA – a non-profit making initiative that brings together patients, carers and professionals to identify and prioritise unanswered questions that they agree are the most important - the top priorities for children’s cancer research were found.

Young patients, childhood cancer survivors, parents, carers and family members, as well as cancer professionals were invited to participate in this process and there was a special emphasis on talking to young children to make sure their opinions were heard. The final questions reflect the breadth of the cancer experience for children and families - including diagnosis, relapse, experience in hospital, support during and after treatment and the long-term impact of a cancer diagnosis.

The findings were presented at the launch event, which brought together charities, researchers and research funders, as well as those affected by childhood cancer. Members of the project team spoke about the importance of the PSP, while the audience heard from a childhood cancer survivor and parents of childhood cancer patients about what the report means to them.

Ashley Ball-Gamble, Chief Executive of CCLG, said: “It was fantastic to be able to present this pivotal piece of work and showcase how we’re shaping the future of children’s cancer research. The PSP report truly represents a new beginning in children’s cancer research as, for the first time, we know what is important to children with cancer and can focus our work and resources accordingly.

“We received great feedback from those in attendance, and the room was filled with an incredible amount of positivity and enthusiasm from people determined to create positive change. It’s now imperative that we do so by turning the priorities into actual research.”

Faith Gibson, Professor in Child Health and Cancer Care at the University of Surrey and Great Ormond Street Hospital for Children and member of the PSP coordinating team, said: “We were really pleased how well the report was received on the evening - now we need action. This action can be taken by any member of the children’s cancer community as these research priorities belong to everyone.

“Importantly, at the launch, we had key funders of cancer research who now need to listen to the voices of these participants as they have told us what questions they want answered by future research.”

Phil Brace, Chief Executive of The Little Princess Trust, said: “We were delighted to have been able to joint fund this Children’s Cancer Priority Setting Partnership with CCLG as we always knew that the results would be vital in ensuring all those involved in funding research and supporting children with cancer were aligned and focused on what is important to those affected the most by childhood cancer.

“LPT Founder Wendy Tarplee Morris, who was a member of the steering group, saw first-hand the rigour that went into every element of the process to ensure the outcome was as accurate and valuable as

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“As Wendy said during her presentation at the launch, ‘now that we have this fantastic tool, it is important that we as funders use it to measure against our own research strategies’. And we would encourage other funders, and indeed researchers to do the same.”

Read the full PSP report and find out the top priorities in children’s cancer research here.

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