CCLG releases first in a series of guidelines to help with the management of rare childhood tumours

Tuesday 29 June, 2021

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Children's Cancer and Leukaemia Group (CCLG) has today (June 21) published the first in a series of new clinical guidelines to support clinicians in managing the diagnosis, treatment and follow-up of a rare type of childhood tumour.

Children's endocrine tumours and tumour syndromes are exceptionally rare, differing in cause and presentation from endocrine tumours in adults, which are more common and whose management is led by endocrine oncology specialists.

This rarity in children and the resulting lack of consistent management can often lead to poor outcomes, and therefore necessitated the development of evidence-based guidelines to address the inequalities of care and to drive improvements in outcomes for young patients with these tumours.

As a result, more than 150 multi-professional experts came together in 2013 to begin developing these guidelines, building on work first published in 2005 and leading to today's publishing of this new guideline for the management of unexplained pituitary stalk thickening or central diabetes insipidus, the first in a series of eight covering a specific rare endocrine cancer.

Endorsed by the Royal College of Paediatrics and Child Health (RCPCH), the guideline has been developed using the internationally recognised AGREE-II criteria for developing clinical guidelines, a robust methodology which ensures guidelines are produced consistently by appraising the available evidence before making recommendations.

As expected for such a rare disease, the guideline development group identified a lack of high-quality evidence in this area, and therefore used a process known as Delphi consensus to gather international expert opinion to support the recommendations made in the guideline.

Dr Helen Spoudeas, Consultant Paediatric Encocrinologist and Chair of the Rare Endocrine Tumour Guidelines Project Board, said: "This consensus guideline is intended to be a reference document for clinicians presented with the challenge of recognising the importance of the many cross-specialty presentations of these rare conditions in children and young people, and referring them on to specialist teams.

"The lack of high-quality evidence in the field was expected, and the guideline development process identified a clear need for both national specialty advisory panels to support the treatment of these diseases and a national registry for the evaluation of outcomes in these rare – but eminently curable – tumours.

"We have identified areas for further research and it is time to prioritise this neglected area of practice.

"Only by ensuring age-appropriate care and the vital collaboration between all of the multi-disciplinary experts required can we hope to reduce life-long side effects and improve long-term health.

"This guideline is an important step towards achieving this, and we are immensely grateful for the expertise, professionalism and dedication of all the individuals involved in bringing this piece of work to fruition."

Dr Manuela Cerbone, Endocrine Fellow and co-leader on these guidelines, added: "These seemingly benign conditions are extremely challenging to manage, as while they may be incidental, they can harbour a rare malignancy in around 40% of cases in children and young people.

"We hope this first consensus guideline will provide a best practice framework in this complex and niche area of childhood pituitary disease for endocrine, radiology, oncology and neurosurgery professionals."

The full guideline, and a management summary, is now available on the CCLG website https://www.cclg.org.uk/professionals/rare-endocrine-tumour-guidelines
and also published in The Lancet Child & Adolescent Health journal at

https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(21)00088-2/fulltext.

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

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