022. AUTOINFLAMMATORY DISEASE IN CHILDREN - THE SPECTRUM OF CONDITIONS SEEN IN THE SCOTTISH PAEDIATRIC AND ADOLESCENT RHEUMATOLOGY NETWORK CLINICS

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Background: The Scottish Paediatric and Adolescent Rheumatology Network (SPARN) is a National Managed Clinical Network that was established in 2009. The remit of SPARN is to ensure that all children with rheumatic conditions are diagnosed promptly and managed appropriately by local multidisciplinary teams, with input from a paediatric rheumatologist supporting each network clinic. As SPARN has established, patients with a wide variety of rare auto inflammatory conditions have been identified, diagnosed and are locally managed within the network clinics.
Aims: We wished to demonstrate the spectrum of autoinflammatory disease seen in SPARN network clinics. We wished to understand the ability of the network to deliver local expert management to children with rare conditions.
Methods: Patients with autoinflammatory disease were identified from the 13 SPARN network clinics in Scotland. Retrospective review of case notes and electronic records was undertaken to determine diagnosis, genetic mutation and treatment.
Results: A total of 40 cases (definite and probable) were identified from clinics in 7 Health Board areas around Scotland. Cases seen are shown by diagnostic categories in Table 1. 17 children (10 CAPS, 3 TRAPS, 1 MVKD and 3 others) received anakinra during the course of their treatment; 8 remain on it. 5 children with CAPS moved on to canakinumab with good benefit. One child in the miscellaneous group unsuccessfully tried canakinunumab. 5 children received tocilizumab, 2 with MVKD and 1 with CAPS responded well. 2 children responded well to anti-TNF therapy. 9 children received colchicine alone or in combination. 8 children (all miscellaneous or interferonopathy categories) received various conventional immunosuppressive agents as part of their treatment. One child with an Interferonopathy responded well to ruxolitinib. These treatments have been initiated and are administered locally by specialist multidisciplinary teams across Scotland.
Conclusions: The development of SPARN has resulted in increased recognition, diagnosis and treatment for these rare and complex conditions. All therapeutic agents used have been facilitated by locally based teams, improving compliance and quality of life for children and families. SPARN has achieved its aim of providing equity of access to the best possible care for all children with rheumatic conditions in Scotland regardless of geography and in supporting locally delivered care via a network of services with specialist multidisciplinary teams working in partnership with expert teams from the tertiary centres. SPARN proposes the development of clear diagnostic and therapeutic pathways for these rare conditions for use within the network.