Tidsskriftet Tidsskrift for Den norske legeforening

New interest group for red blood cell disorders

FROM THE SPECIALTIES

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Congenital red blood cell disorders are traditionally rare in Norway, and the focus on treatment and follow-up has been limited. A multidisciplinary approach is needed to ensure optimum, equal health care for patients with these disorders.

Sickle cell disease and thalassemia are congenital conditions frequently seen in Asia, the Middle East, the Mediterranean countries and Africa. The incidence is also expected to increase in Norway as the composition of the population changes. These diseases are associated with a shorter lifespan and lower quality of life, but early diagnosis and good follow-up can reduce morbidity and mortality (1, 2). Many aspects of a patient's health can be impacted by these diseases, and interdisciplinary follow-up that also takes socio-economic factors into account is necessary.

Congenital red blood cell disorders in Norway

We do not know exactly how many patients have congenital red blood cell disorders in Norway, or how they are diagnosed, treated or followed up. In 1996–97, there were only approximately 60 patients with sickle cell disease and thalassemia requiring transfusion in Norway (3), but there is reason to believe that the number is significantly higher today. The incidence of other congenital red blood cell disorders is also unknown. We need to map the prevalence of these disorders and then standardise diagnostics, treatment and follow-up to ensure that patients have equal access to treatment regardless of where they live in Norway. Clinicians also need a forum to discuss patient care and disseminate knowledge.

Regular transfusions have, for many years, been the leading treatment for thalassemia (4). Patients with sickle cell disease are treated with hydroxyurea to prevent sickle cell crises, and some also receive regular exchange transfusions. Certain patients are candidates for allogeneic stem cell transplantation, but this currently only applies to children with sibling donors. Other treatment options are being developed and will eventually be available in Norway.

New interest group

On 27 September 2022, the Norwegian interest group for congenital red blood cell disorders was founded as a sub-association of the Norwegian Society of Haematology. This is an interdisciplinary group for everyone who is involved in the diagnosis, treatment or follow-up of children and adults with such disorders. The group's aim is to help ensure equal access to optimised diagnostics, treatment and follow-up in a lifetime perspective for patients in Norway with hereditary red blood cell disorders. We want to make contact with healthcare personnel who treat this patient population with a view to working together to ensure that they receive optimum, equal health care.

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Publisert: 20. February 2023. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.22.0731
Received 6.11.2022, accepted 29.11.2022.