Tidsskriftet Tidsskrift for Den norske legeforening

New interest group for red blood cell disorders

FROM THE SPECIALTIES

NINA HAAGENRUD SCHULTZ

Nina Haagenrud Schultz, specialist in haematology and senior consultant at the Department of Haematology, Oslo University Hospital, Rikshospitalet.
The author has completed the ICMJE form and declares the following conflict of interest: She has received fees from Bayer and BMS for giving talks on anti-coagulation.

ANNE GRETE BECHENSTEEN

Anne Grete Bechensteen, specialist in paediatrics and head of section in the Department of Paediatric and Adolescent Medicine, Oslo University Hospital, Rikshospitalet.
The author has completed the ICMJE form and declares no conflicts of interest.

EIRIK BREKKA TJØNNFJORD

Eirik Brekka Tjønnfjord, senior consultant at the Thrombosis Unit, Østfold Hospital Trust, Kalnes, and researcher in the Department of Haematology, Oslo University Hospital, Rikshospitalet.
The author has completed the ICMJE form and declares no conflicts of interest.

ÇIĞDEM AKALIN AKKÖK

Çiğdem Akalin Akkök, specialist in immunology and transfusion medicine, and head of section in the Department of Immunology and Transfusion Medicine at Oslo University Hospital.
The author has completed the ICMJE form and declares no conflicts of interest.

MARTE HOLMBOE BERG

marteholmboe.berg@lds.no
Marte Holmboe Berg, specialist in haematology and senior consultant at the Department of Haematology, Lovisenberg Diaconal Hospital.
The author has completed the ICMJE form and declares no conflicts of interest.

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.

REFERENCES

1. Hoppe C, Styles L, Vichinsky E. The natural history of sickle cell disease. Curr Opin Pediatr 1998; 10: 49–52. [PubMed][CrossRef]

2. Cao A. Quality of life and survival of patients with beta-thalassemia major. Haematologica 2004; 89: 1157–9. [PubMed]

3. Graesdal JS, Gundersen K, Holm B et al. Talassemi og sigdcellesykdom i Norge. Tidsskr Nor Lægeforen 2001; 121: 678–80. [PubMed]

4. Furuseth MT, Alme C, Garvik LJ et al. Alloimmunization in transfused patients with constitutional anemias in Norway. Transfus Apheresis Sci 2021; 60: 103257. [PubMed][CrossRef]

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