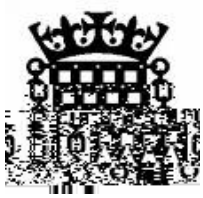

All-Party Parliamentary Sickle Cell and Thalassaemia Group

The Social Aspects of Sickle Cell Disease and Thalassaemia in Children and Young People

Report and Recommendations from APPG meeting March 2009

All-Party Parliamentary Sickle Cell and Thalassaemia Group

The social aspects of sickle cell disease and thalassaemia in children and young people

Report and Recommendations

APPG Sickle Cell and Thalassaemia

The APPG for Sickle Cell and Thalassaemia was set up in October 2008 by a group of cross party MPs and peers. The mission statement of the APPG is to reduce the health inequalities that are faced by sickle cell and thalassaemia patients in the UK by improving standards of care and by addressing other critical issues, as recommended by the key stakeholders. Members will seek to achieve this aim by engaging with parliamentary colleagues, the government, relevant professionals, and community and patient groups to raise awareness relating to the conditions and needs of patients.

Background:

Sickle cell disease and thalassaemia major are severe haemoglobin disorders, which affect mainly patients of black and minority ethnic groups. The conditions affect all aspects of a patient's life. Children and young people are particularly affected; both as they come to terms with their condition, and endure frequent painful symptoms and treatment. The social aspects of the conditions for children and their families include disruption to education and social life, which can often have implications for their future employment and social prospects. There is also a general lack of understanding in the health, education and social care systems.

The social and educational impacts of sickle cell and thalassaemia on young patients

Summary of issues

1. Educational services

1.1 A survey has found that young people with sickle cell disease miss an average of 16 days of school a year with 12% missing more than 63 sessions. Patients with thalassaemia major often regularly miss school due to frequent hospital appointments. There is a reported general lack of support to help pupils to catch up on the schoolwork they have missed. There are some good examples of schools where this is not the case, and there is the possibility to spread best practice with the right resources.

1.2 Generic guidance on supporting children with medical conditions in schools is not working to support young people with sickle cell disease and thalassaemia major in schools. Many schools are failing to allow students with sickle cell disease to drink water or avoid strenuous exercise, despite the fact that simple actions such as these can prevent painful sickle ‘crises’ – intense episodes of pain that can lead to hospitalisation. Students with sickle cell disease have an increased need to visit the toilet due to increased fluid intake, and again teachers often do not allow students to leave the class to do this.

1.3 Young children can find it difficult to articulate their symptoms and requirements to teachers and other school staff. The APPG heard of instances of a young patient with sickle cell disease being refused to be excused from swimming class despite explaining

of access within PCTs to appropriate advice and support from specialist clinicians or nurse counsellors to ensure that individual health care plans are adequately drawn up.

1.7 Sickle cell and thalassaemia predominantly affect black and minority ethnic populations. There remains underlying racial discrimination within the education system, which serves to enhance the barriers and misunderstandings that young patients with these conditions face in school.

1.8 Due to a misunderstanding of the improved outlook for people living with sickle cell disease and thalassaemia major, careers advice can be inadequate, and employment and training opportunities may be denied, leading to poor employment prospects for people living with sickle cell and thalassaemia.

1.9 Due to the reasons above, the potential of students with sickle cell and thalassaemia is not being realised, leading to poor educational and employment outcomes in many cases.

2. Social services

2.1 There is a concentration of people with sickle cell disease and thalassaemia major in London and other large urban areas, but social services from all over the country must be aware of the conditions and their social implications.

2.2 Sickle cell disease and thalassaemia major are too often dismissed as specialist healthcare issues and the day-to-day difficulties of living with the conditions are not generally understood by professionals in the social services.

2.3 Health and social care agencies have been slow to recognise and respond to the social and psych61 T8s.02 0 0j10.02 0 0 10dt 2 0 0953 Tm10.02 450.2717 r.o86hg4.1u410.02 0 0 1 Tc 0

usually lack insight into the needs of thalassaemia major patients. This can result in young people living in inadequate housing, which can contribute to a worsening of their symptoms.

3. Conclusions

3.1 There is a low level of awareness of sickle cell disease and thalassaemia major, and a specific lack of recognition of these conditions as long term, chronic conditions. This is particularly the case in education services, in contrast to medical services, which are relatively well developed. There needs to be some recognition of the important role that schools could potentially play in the management of children with long term conditions.

3.2 The role of social services, education, housing and employment

4.3 The APPG acknowledges the underlying problem of racism in some schools and health services and recommends that the Department of Children, Schools and Families and the

major can be a hard to reach, so cooperation with voluntary sector organisations is particularly important in this case.

4.7 The APPG recognises the benefits of screening at birth for sickle cell disease, and calls for Directors of Public Health to notify their Local Authority Director of Children and Young Persons, of the numbers of children born each year with the condition in the relevant local authority.

4.8 Information on sickle cell disease and thalassaemia major needs to be made available to teachers, support workers and school medical staff, within the portfolio of information which is currently available to schools.

4.9 Any future improvement to policy regarding standards of care for children should be inclusive of the needs of young people with sickle cell and thalassaemia.

The drafting and printing of this report was supported by an unrestricted grant by Novartis Oncology

EXJ09000054: Date of preparation: April 2009