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 APPG for Sickle Cell and Thalassaemia has sought to examine the ways in which sickle cell disease and thalassaemia major can affect young people in their social, school and family life. The APPG met to consider the ways in which the issues can be addressed, such as through further education of frontline professionals who deal with children with sickle cell disease and thalassaemia major; and call for further action to be taken to improve the lives of young people with these conditions, and their families.

APPG Sickle Cell and Thalassaemia Meeting 25th March 2009

The APPG held a meeting to discuss the social aspects of sickle cell disease and thalassaemia major in children and young people on the 25th March 2009. This report reflects the presentations and discussions at this meeting.

Speakers:

Dr Karl Atkin – Senior lecturer in ethnicity and health at the University of York
Professor Simon Dyson - Director of the Unit for the Social Study of Thalassaemia and Sickle Cell at De Montfort University
Nordia James – Patient representative and founding member of young patient group 'Broken Silence'
Solomon Osinde – Senior Social Worker, NHS Islington
Dr Norman Parker – Consultant Haematologist, Whittington Hospital
Dr Alison Streetly – Programme Director, NHS Sickle Cell and Thalassaemia Screening Programme

Attendees:

Diane Abbott MP – Chair APPG
David Burrowes MP – Secretary APPG
Baroness Howells of St Davids – Member APPG
Holly Farrow, researcher of Andrew Rosindell MP – Vice-Chair APPG
Alison Potter, researcher of Sarah Teather MP – Vice-Chair APPG

Dr Lorna Bennett – APPG lead Trustee, Sickle Cell Society
Henry Burkitt – Novartis
Hannah Cameron – APPG Secretariat
Laura Collman – APPG Secretariat
Dr Elizabeth Dormandy **–** NHS Sickle Cell and Thalassaemia Screening Programme
Lorraine Gregory – Screening and Specialised Services, Department of Health
Sonia Lindsay – Oscar Birmingham
Elaine Miller – Coordinator, UK Thalassaemia Society
Elodie Miranda **–** Novartis
Roma Haigh – NHS Sickle Cell and Thalassaemia Screening Programme
Sarah Pearson – Hanover Communications
Stefano Pozzi **–** Assistant Director for the Child Health and Wellbeing PSA programme, Department for Children, Schools and Families
Elizabeth Rouse – Department for Children, Schools and Families
Dr Chris Sotirelis **–** Vice-President, UK Thalassaemia Society
Dr Jane Wai-Ogosu – Chair, Sickle Cell Society

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 her situation, leading to the subsequent hospitalisation of the child with a painful sickle crisis.

1.4 Schools being told a child has sickle cell disease or thalassaemia major appears to make no appreciable difference to reported poor treatment. Even when teachers are aware a student has the condition, they often do not understand the implications of this and the different manifestations of the condition between young people.

1.5 There is no statutory requirement on schools to administer medicines meaning students with sickle cell disease may not receive pain relief for mild / moderate crises when in school.

1.6 There is a lack of key resources in schools such as school nurses, to enable students with sickle cell disease and thalassaemia major to remain in school. There is also a lack

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 psychological needs of children and young people with sickle cell disease and thalassaemia major, and their families. This can make the consequences of the condition more difficult to deal with, especially as those affected can feel disempowered.

2.4 The structure of social welfare application forms does not allow the implications of these conditions to be accurately reflected. This means that allowances such as the disability living allowance are not given in a consistent fashion.

2.5 It is important that patients with sickle cell disease have dry, warm, and accessible housing. Social housing and benefits decisions often do not take into account the needs of families with children with sickle cell and thalassaemia major. Social Housing providers

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 in supporting children, young people and their families is poorly developed.

3.3 The important potential benefits of multi-agency care are not adequately realised.

3.4 Voluntary organisations for sickle cell and thalassaemia patients are poorly funded.

3.5 Even where it is beginning to be acknowledged that supporting families of children with sickle cell disease and thalassaemia major is beneficial, there is still much to be done in terms of increasing understanding and sharing good practice.

4. Recommendations

4.1 The APPG recognises the need for joint working between social services, educational services and healthcare staff, and calls for a stronger commitment from these sectors to work together to improve the social and educational needs for sickle cell and thalassaemia patients.

4.2 Children with long-term conditions and complex healthcare needs must have access to high-quality specialist services combined with appropriate care close to home. The development of care networks for sickle cell disease and thalassaemia major patients, including community health care services, the voluntary sector, education and social services, should be supported.

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 Department of Health work with bodies such as the Equality and Human Rights Commission, to tackle institutionalised racism in order for the treatment of young people with sickle cell and thalassaemia to be improved.

4.4 The various accreditation bodies and professional associations for professionals dealing with children and young people should include an understanding of the needs of patients with sickle cell disease and thalassaemia major in their syllabus and continued professional development programmes.

4.5 The APPG recognises the excellent work of the voluntary sector for sickle cell and thalassaemia major patients, particularly given that patients can be in hard to reach social groups. The APPG recommends that the government provide resources to support and expand the work of the voluntary sector in improving the education of professionals and developing outreach programmes in schools.

4.6 The APPG recognises the positive steps made by the Department for Children, Schools and Families and the Department of Health through the launch of their joint children's strategy in February 2009, *Healthy lives, brighter futures*. The APPG calls for these Departments to work with patient groups and other stakeholders to ensure that the child health strategy more fully addresses the needs of patients with sickle cell disease and thalassaemia major. For example:

- Managing Medicines in Schools – this guidance is due to be updated and supported with a new awareness-raising campaign. It will include guidance relating to children with complex health needs as well as clear statements of expectations of different partners including schools and PCTs. The needs of young people with sickle cell disease must be taken into account within the updated guidance, with respect to preventive measures and medication for pain relief.
- The Young People's Expert Patient Programme – Staying Positive – has been developed in response to the National Service Framework's commitment that young people should have the same access to self-care support as adults. It will promote the development of self-management programmes for children and young people being delivered through the voluntary sector and social enterprise, and will encourage local areas to assess how self-management programmes can be made available to their local communities. Young people with sickle cell disease and thalassaemia

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