As Chair of the APPG on Sickle Cell and Thalassaemia I am pleased to introduce this booklet. The booklet is aimed at drawing together the views of service users, patient groups, health professionals and politicians to put forward a “Health Check on Services” – a review of the improvements that are underway and a recommendation of what still needs to be done.

The Sickle Cell and Thalassaemia APPG was set up in October 2008 to raise awareness of the conditions in Parliament. Sickle cell disease is now the most common genetic condition in England and is more prevalent than cystic fibrosis. Estimates suggest there are 12,500 sickle cell disease sufferers and 1000 patients with severe forms of thalassaemia in the UK. One of the reasons I am interested in this area is because the conditions predominantly affect people from Black and Ethnic Minority communities. I have friends, family and constituents who are and have been affected by these conditions, so I have had the benefit of first-hand testimony as to standards of care for patients in the NHS.

Whilst patient groups and a small group of committed professionals have worked hard to raise the profile of sickle cell and thalassaemia and have campaigned to raise standards of care, at the APPG we feel that recognition of the conditions in the public, amongst policymakers and professionals is still low. Also, worryingly, standards of care for patients is variable depending on where they live in the country.

The role of the APPG reflects these concerns. The work of the APPG involves discussing topics of importance to the sickle cell and thalassaemia community and reporting back to Parliament, with the ultimate aim of reducing health inequalities faced by sickle cell and thalassaemia sufferers.

Since its inception seven months ago, the APPG has brought together patients, clinicians and the Royal College of Physicians to discuss removing prescription charges for patients with sickle cell and thalassaemia. This led to an APPG response to the Department of Health’s consultation on prescription charges for long-term conditions. It is hoped that this intervention will persuade the Government to remove prescription charges for sickle cell and thalassaemia patients and will make a significant improvement to the lives of sufferers. The APPG has also discussed the social and educational impact of sickle cell and thalassaemia in a meeting with social workers, academic researchers, patients and representatives from the Department of Health and the Department for Children, Schools and Families. Following the meeting an APPG report on the issues raised was produced and both Government departments have done further work with patient groups to explore what can be done to reduce the social and educational impact of the conditions on young people.

From the APPG’s work so far it is clear that the Department of Health and NHS professionals have made a genuine commitment to raise standards of care, and services are improving. But there is still much more that needs to be done to improve the situation of service users. This means implementing the Standards of Care, developing clinical networks and educating health professionals to better understand the conditions. The ultimate goal of the APPG is to ensure service users are receiving the very best care and support; and we will continue to work with stakeholders to achieve this.

Diane Abbott MP
Chair of the All-Party Parliamentary Group on Sickle Cell and Thalassaemia
Sickle Cell disease and Thalassaemia: A Health Check
While many NHS professionals, the voluntary sector and other stakeholders are working hard to improve services, stakeholders tell us there remains much more to be done in order to improve medical provision, increase awareness, reduce geographical inequalities and ultimately improve the lives of patients with sickle cell disease and thalassaemia.

Recommendations
After listening to the views of stakeholders, some of which are outlined throughout this document, the APPG makes the following recommendations. These will inform the activity of the APPG in the next Parliamentary term.

1. Equality of access to care through better coordination in the NHS at a local and regional level

Managed clinical networks should be further developed within the NHS at local level, supported by the Department of Health. Managed clinical networks are coordinated networks of professionals involved in providing care across a geographical area. The development of clinical networks for sickle cell and thalassaemia is key to the improvement of care and support for patients and have the potential to reduce geographical inequalities in service provision in a cost effective way for the NHS. Clinical networks are key to implementing the recently published Standards for the Clinical Care of Adults with Sickle Cell Disease (2008), National Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2nd edition published October 2008) and Standards and Guidance on Transcranial Doppler Scanning for Children with Sickle Cell Disease (2009). The Department of Health has had noted ambition to implement clinical networks for sickle cell and thalassaemia. Managed clinical networks are already well established in some areas but in other areas are relatively non-existent. Implementing managed clinical networks across the country and sharing best practice should be a priority in order to reduce geographical inequality of care and assist patients in low prevalence areas in particular.

2. More choice and flexibility for patients

Patients should be given choice and flexibility where possible to receive care closer to home, reducing disruption to employment and education. High quality care for all, the final report of the NHS Next Stage review led by Lord Darzi has promised greater choice and flexibility for patients. These principles of choice and flexibility should be borne out in practice wherever possible for patients with sickle cell disease and thalassaemia. There are some good examples of innovative practice where this is already happening, such as Home Care and Community Matron schemes for nursing staff to assess pain, and prescribe or administer pain relief for sickle cell crises in the patients’ home. In addition, all patients with thalassaemia and some patients with sickle cell disease require frequent blood transfusions which require long hospital appointments every few weeks. Patients should be allowed to receive blood transfusions at times that cause minimum disruption for their work and education activities, in order that they are given every chance to succeed in their education and career.

3. Health professionals must be properly trained about sickle cell disease and thalassaemia

Sickle cell disease and thalassaemia should feature more prominently in the training of health and social care professionals. While there are now many people with sickle cell disease and thalassaemia within the UK, there is widespread lack of knowledge of the conditions amongst medical and nursing staff who are not specialists in the area. Medical professionals such as A&E staff, midwives and general practitioners should have basic knowledge of the conditions and their management. This is particularly important, for example, when patients with sickle cell disease require acute care from A&E in the case of sickle cell ‘crises’ – intense episodes of pain that can lead to hospitalisation. Royal Colleges and other examining and professional bodies are encouraged to work with stakeholders to ensure syllabi appropriately include sickle cell disease and thalassaemia and that the conditions are a part of continued professional development training. Research and long term care on sickle cell and thalassaemia also suffer from the fact that there is very little training, status and funding for haemoglobinopathies compared with other specialties within the wider discipline of haematology.
4. Schools and social services should be more aware of sickle cell disease and thalassaemia

There must be greater awareness of sickle cell disease and thalassaemia among education and social care professionals. Education and social care agencies have been slow to recognise and respond to the needs of children and young people with sickle cell and thalassaemia, and their families. Young patients with sickle cell disease and thalassaemia often have their education disrupted by symptoms and frequent treatment related to their condition, and their needs are regularly misunderstood or ignored. Many schools, for example, are failing to allow students with sickle cell disease to drink water, go to the toilet, or avoid strenuous exercise, despite the fact that simple actions such as these can prevent painful sickle “crises”. Social services also need to be aware of sickle cell disease and thalassaemia in terms of the specific housing needs and social care requirements of patients, and administration of the Disability Living Allowance. The Child Health Strategy (published in February 2009) provides the policy framework through which some of these issues can be addressed. The APPG calls for the Department of Children, Schools and Families and the Department of Health to keep a cross-departmental dialogue and communicate with patient groups and other stakeholders to ensure that the Child Health Strategy addresses the needs of patients with sickle cell disease and thalassaemia.

5. The Government must work with the voluntary sector to provide patient support and community education

Social and outreach support is a key element of the holistic care that people with sickle cell and thalassaemia need. The voluntary sector currently offers a great deal of support and advice to individuals living with sickle cell and thalassaemia and their families on a variety of issues such as social and welfare support, housing, education, training and employment. Third sector organisations are uniquely placed to identify and interact with hard to reach groups. This is particularly important with sickle cell and thalassaemia, which affect predominantly black and ethnic minority communities who may be more likely to face general health and social inequalities. These genetic conditions also carry a social stigma in many communities, making voluntary sector organisations and local support groups even more important in reaching marginalised patients. They also provide an important role in educating the wider community including those who may be carriers of sickle cell or thalassaemia genes. Third sector organisations must be adequately resourced to provide these important outreach services.

6. Patients with sickle cell disease and thalassaemia should be exempt from prescription charges

In September 2008, the Prime Minister announced an ambition to abolish prescription charges for patients with long-term conditions over the next few years. Professor Ian Gilmore, President of the Royal College of Physicians has been asked to undertake a review of prescription charges that will consider how to define the range of long term conditions that should be exempted from prescription charges and how exemption from charging can best be phased in. The current cost burden of multiple prescriptions is a struggle for many patients to afford and the APPG strongly feels that sickle cell disease and thalassaemia should be included in the range of conditions that are exempt from prescription charges when the list is reviewed later this year.
**Sickle Cell Disease**

Sickle cell disease is a genetic blood disorder resulting from the production of faulty red blood cells. It is now the most common genetic condition in England, with an estimated 12,500 patients in the UK at present. Sickle cell disease is found mainly in people of African, Caribbean, Eastern Mediterranean, Middle Eastern and Asian origin.

The condition often results in red blood cells becoming ‘sickle’ or half-moon shaped. These sickle-shaped red blood cells can then get stuck in small blood vessels, resulting in blockages and reduced blood flow. These blockages can cause excruciatingly painful sickle ‘crises’, tissue and organ damage and potentially lead to strokes if they occur in the brain. Other complications of sickle cell disease include eye problems, infections, chest problems, delayed growth and puberty in children, leg ulcers and anaemia. However, with the right treatment and support, sickle cell disease and its complications can be managed and risks to the patient much reduced.

Broken Silence is a registered charity founded in 2004 by four teenagers with sickle cell disease in memory of their friend, Leona Dehaney, who died from complications relating to the disease. Nordia James represented the group at the APPG meeting in March, explaining how her condition was often misunderstood at school, sometimes leading to a worsening of symptoms and even hospitalisation.

The committed and energetic members of Broken Silence organise an annual talent show to raise awareness of sickle cell disease, and work within schools in their local area to educate young people and their teachers about sickle cell disease.

We as Broken Silence believe that it is good that a group such as the APPG exists to give a more dynamic push for the well being of people suffering from Sickle Cell Disease. It is nice to have Sickle Cell being mentioned in the lime light and hopefully this can progress so that everyone in the UK knows what Sickle Cell is. It will be a nice achievement if the APPG could encourage more medical research funding into Sickle Cell in aiding a cure for Sickle Cell Disease.

Broken Silence thinks that as far as improvements are concerned with regards in recognising Sickle Cell there is still a long way to go. We still need to break through on the fact that Sickle should be classed as a disability full stop and not judged on an individual basis with regards to gaining the Disability Living Allowance. It still needs to be talked about in depth within schools and the curriculum. The health service should have a better understanding and empathy when dealing with Sickle Cell patients because in past experiences members of Broken Silence have had first hand insight of dealing with staff from the health profession who lack training when it comes to Sickle Cell - we are seen as, what some would say, “bad tempered and aggressive”.

Sickle Cell can affect each individual differently. When a child is born with Sickle we need to recognise that we cannot predict the future of that individual, we cannot look at another child with Sickle Cell Disease and assume that both will be facing the same difficulties and health problems in life. We as Broken Silence are constantly working on educating society on Sickle Cell disease starting from people of a young age.
Donna is a patient with sickle cell disease based in North London. She explains that more needs to be done to improve awareness and education of professionals such as A&E staff.

People with sickle cell disease experience intense pain called crises as a result of the condition. More often than not I am in a lot of pain and I have to attend A&E often to receive pain relief. I think A&E staff need more training about sickle cell so they understand the level of pain we experience, or there should be specialist nurses on hand to help. I do receive a lot of help from specialist staff such as my consultant and other staff like counsellors at the Sickle Cell and Thalassaemia Centre. They are very helpful and supportive and I speak to them regularly. However there needs to be wider knowledge of sickle cell disease more generally in society which would help improve the understanding of employers and other public services. I also think prescriptions should be free for people with sickle cell as with other long term conditions.

A service user from London explains how her experience in hospital has improved since the publication of Standards of Clinical Care for Adults with Sickle Cell Disease.

I am an individual with sickle cell disease and I attend a North London Hospital.

In the past, when I have had a sickle cell crisis and had to go into hospital, I have become used to the delay and inconsistencies of pain relief and treatment. Some days are better then others depending on the staff on duty. You are not considered a priority, whether you get treated quickly or are made to wait. Although you are in intense pain but not screaming or shouting, some people assume that means that you are not in pain at all. I don’t know why some nurses do not have a basic knowledge of treating sickle cell pain. I am sure that cancer pain and heart pain are treated promptly or empathetically, so why not my pain? Am I not worthy of such care and treatment?

I can honestly say that when the Sickle Cell Standards were published and the APPG set up, I felt now we can all be treated fairly and consistently, whether you are in London or Manchester. When I recently had a sickling crisis and had to go to hospital for pain relief (after the publication of the Sickle Cell Standards) I was pleasantly surprised by the prompt treatment I received. It was such a noticeable change from my past experiences, and I hope that other sickle cell service users are also feeling the benefits from having the standards.

1 Davies SC et al, Health Technology Assessment 2000;4(3)
2 NHS Antenatal and Newborn Screening Programmes ‘Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care’ October 2006 and Sickle Cell Society ‘Standards of Clinical Care of Adults with Sickle Cell Disease in the UK’ July 2008
Thalassaemia

Thalassaemia refers to a group of genetic blood disorders that affect the body’s production of haemoglobin, the oxygen-carrying component of the red blood cells.

The symptoms can affect babies from as young as 3 months. Thalassaemia can delay the body’s development and growth, cause jaundice, an enlarged liver or spleen, weak bones that can break easily, and facial bone deformities. The most severe form of thalassaemia, beta thalassaemia major, is invariably fatal if untreated\(^3\).

There are around 1000 beta thalassaemia major patients in the UK, with more than 214,000 people in the UK carrying the beta thalassaemia gene. Thalassaemia occurs most frequently in people of Mediterranean, Middle Eastern and Southern Asian ancestry. About 79% of babies born with beta thalassaemia in the UK have parents of Indian, Pakistani or Bangladeshi ancestry. Through treatment with frequent blood transfusions and iron chelation, most patients with thalassaemia can manage their condition\(^4\).

Sobia Afridi is a parent of a young service user based in Oxford. It is hoped that the development of managed clinical networks would go some way to help with the feelings of isolation that patients in low prevalence areas like Oxford feel.

My daughter is 5 and has Major Thalassaemia. We live in Oxford where there are hardly any Thalassaemia patients and the ones that I am aware of are not keen to talk to you. As parents we feel very isolated as we have no contact with other parents. What is more worrying is that our daughter does not meet other kids with Thalassaemia.

We are also in a ward where all the other kids have conditions like cancer. There needs to be links with nearby hospitals where patients and parents can meet and not feel isolated. The UK Thalassaemia Society does a great deal but they need more funds to help with the problems patients and parents face with this long-term illness.

\(^3\) UK Blood Transfusion&Tissue Transplantation Services Handbook of Transfusion Medicine, Fourth edition : January 2007
Available at: http://www.transfusionguidelines.org.uk/index.asp?Publication=HTM&Section=9&pag eid=1132

\(^4\) UK Thalassaemia Society. Types of Thalassaemia. Available at: http://www.ukts.org/pages/major.htm
Neelam Thapar is a thalassaemia patient based in North London. Here she tells us how living positively with her condition with the right support and treatment helps her live life to the full.

My name is Neelam Thapar and I am 40 and take great pride in saying it as many did not think I would get to this age!! I have been working for the past 19 years in a University where I am a Senior Careers Consultant. I also volunteer with the UK Thalassaemia Society to speak to others with Thalassaemia about confidence and career issues. Having Thalassaemia can pose many challenges, but at the same time it has also given me an inner strength to be able to set goals to have a quality of life. Complying with the treatment can be a test of that strength but there is no choice, as not doing it would result in eventual death. Much of my success can be attributed to my family, as it has been vital to have a supportive family where Thalassaemia is not hidden. Being Asian, I am aware how difficult this can be and I would like to see more work done to breakdown stereotypes about illness.

The treatment and impact of the hospital experience is equally as important and I can safely say that there are times where hospitals feel like the second home!!! Coping with endless treatment and maintaining a fighting spirit to keep going has been helped by the experience of going to hospital at a time to suit my lifestyle with a dedicated nurse and medical team but this is often built on relationships which go back years. If staff leave, it often takes time to establish new ones. The hospital experience is vital – if it doesn’t work it can become a focus for patients to give up and neglect their treatment especially as adults when we are trying to combine full time careers and be carers to our families.

Health inequalities

The introduction of the NHS Sickle Cell and Thalassaemia Screening Programme to provide antenatal and newborn screening has led to huge improvements in the diagnosis and early treatment of thalassaemia and sickle cell disease. However, there remain wide variations in the quality of treatment and care of sickle cell and thalassaemia patients through childhood and on to adulthood. Despite pockets of excellence within the NHS, patients with sickle cell and thalassaemia often feel their condition is inadequately understood and managed by the health service, particularly in areas of low prevalence. This was highlighted in the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, which concluded that acutely ill patients with sickle cell disease are frequently not offered support from sufficiently experienced medical staff. It also noted that the cause of death of many patients remains unclear. Patients with thalassaemia and sickle cell disease also face misunderstanding from the education services, social services and employers, leading to additional health and social inequalities.

Having Thalassaemia does not stop someone from working and having a career yet it can cause so much emotional difficulty in knowing whether to disclose to your employer. More work with employers is necessary to promote reasonable adjustments in the work place such as flexible working to allow people with hidden illnesses to work and contribute to the economy with their skills especially if they cannot get their treatment out of hours. The role of voluntary organisations is vital in working with daily issues covering the whole life cycle of a family that is living with Thalassaemia where we older patients use our experiences to organise activities at a local level. But I would now like these experiences to be used more at a national level to influence strategies to have a wider reach in educating health professionals and the wider community. By developing relevant policies for health and community, education and employer engagement, it will help children and adults with Thalassaemia reach their full potential in life to be able to make informed decisions to achieve their hopes and aspirations.
Thank you for the opportunity to comment on the progress being made in development of services for sickle cell and thalassaemia.

I am sorry I cannot be with you in person today but welcome the opportunity through this statement to raise awareness of these long-term, chronic, debilitating conditions and to register support for the work of the APPG in bringing this to the attention of MPs and the wider public. As a nurse I know that the impact of thalassaemia and sickle cell can be devastating not only for those affected but also their families and carers. In England alone, there are currently more than 12,500 patients with sickle cell and an estimated 850 patients with thalassaemia major.

Because we take this issue seriously, we introduced a national antenatal and newborn screening programme. This programme is the first worldwide linked screening initiative and is led by Dr Allison Streetly. It is identifying some 350 affected babies a year and through early intervention is estimated to save the lives of some 15 infants annually. Progress in implementing the screening programme has been achieved in partnership with key stakeholders, most of whom will be present today, such as the Sickle Cell Society, the UK Thalassaemia Society, the UK Forum on Haemoglobin Disorders, clinicians and other committed professionals in the field. The Archbishop of York chairs the steering group, and it is a privilege to have such a champion supporting this area.

But it is not just about screening. Working with and through stakeholders such as yourselves, our aim is to support high quality patient centred clinical services and to explore ways of providing a more holistic approach to care. Our strategy for supporting people with long-term conditions includes embedding support for self care so that people feel more confident and in control of their condition and offering everyone with a long term condition a personalised care plan by 2010. The aim is to ensure that people receive better co-ordinated, holistic packages of care, tailored to their individual needs. Ultimately, these developments and improvements, including clinical networks, need to take place in the field with the co-operation and collaboration of clinicians, other health professionals and importantly with commissioners, if they are to be really sustainable.

There are other initiatives that are helping us to move the agenda forward. These include:

- establishing a National Haemoglobinopathy Register to allow us to collect details on patients with sickle cell and thalassaemia. This will provide valuable information on patient numbers, complication rates and outcomes, which is an important factor underpinning the quality care agenda. Ensuring all patients are registered will take time, as informed consent is required. The specialist societies have been a great help to us in this matter;
- funding of training posts for registrars, nurse consultants and clinical scientists to increase the number of staff with specific expertise in haemoglobin disorders;
- working with the Royal Colleges to improve the education and training of staff about haemoglobin disorders;
- collaborating with stakeholders and colleagues in the Department for Children, Schools and Families to make sure children with both short and longer term health conditions get the integrated care and support they need to cope with the effects of their illness, and, most importantly, play a full part in school activities;
- the review of prescription charges by Professor Ian Gilmore, President of the Royal College of Physicians, due to report this autumn. The review has sought the views of the public, clinicians and patient representative bodies on how exemption for people with long-term conditions should be phased in.

In conclusion, I hope you will agree that we have come a long way in raising awareness of and developing services for haemoglobin disorders -- particularly in the last few years. What we have done has been achieved collectively. We need to build on this for the future.

Ann Keen MP
Parliamentary Under-Secretary of State
Department of Health
All-Party Parliamentary Group on Sickle Cell and Thalassaemia

All-Party Parliamentary Groups are groupings of MPs and Lords with members from all of the main parties. They meet relatively informally and bring together stakeholders and interested parties to discuss a particular issue of concern.

The All-Party Parliamentary Group (APPG) on Sickle Cell and Thalassaemia was set up in October 2008 by a group of MPs and Peers from all three of the main political parties. 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, health professionals, and community and patient groups to raise awareness relating to the conditions and needs of patients.

The Sickle Cell Society and the UK Thalassaemia Society provide direction to the group, with the input of the NHS Sickle Cell and Thalassaemia Screening Programme. Other interested stakeholders are consulted regularly and are kept informed of activity and various professionals have been invited to share their views directly with MPs and Peers in APPG meetings.

The APPG Stakeholder Views

The APPG is an important symbol of hope for thousands of men, women and children affected by sickle cell disease.

For thirty years, the Sickle Cell Society, as ‘the voice of the sickle cell community’, advocated for services such as screening to be initiated and for improvement in public awareness, professional education and most of all, for good standards of care and support for people with sickle cell disease. Even with the progress that has been made over the years, such as the implementation of a world class screening programme, many patients continue to express concern that their condition was not a priority for the NHS.

Since the pledge was made to form the APPG at the launch of the Sickle Cell Society’s ‘Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK’ in July 2008, more and more patients are reporting positive health care experiences. The Society has had for example, consistent reports from service users regarding improvements in the way health professionals are assessing and treating their pain in accident and emergency departments.

As a patient organisation, the Sickle Cell Society believes that significant progress has already taken place, since the APPG’s first meeting of October 2008. The Society welcomed the opportunity to present to the APPG, the case for exempting vulnerable patients from prescription charges and to highlight concerns regarding the experience of children with sickle disease at school.

The APPG’s future activities over the next Parliamentary term are of great interest to us, as key to addressing inequalities. We are keen to be engaged effectively to play our role as a voluntary body, in shaping cost effective services for the future, which is inclusive of ‘grass roots’ health and social care initiatives, building on our 30 years experience of working with marginalised communities affected by sickle cell.

The Society is very grateful to Diane Abbott APPG - Chair and all the other MPs involved in the APPG to date. Sickle cell patients and their families believe that with these committed MPs working hard on their behalf, this provides high level recognition of the issues they face, enabling them to feel more hopeful for the future.

Dr Lorna Bennett FRSA
Sickle Cell Society
APPG lead trustee
The UK Thalassaemia Society is a national charity that provides support and advice to patients and their families. Thalassaemia is an unfamiliar condition to most people in the UK and, until recently, I am sure that very few Parliamentarians had ever heard of it. Since the APPG on Sickle Cell and Thalassaemia began its work in December 2008, however, we have been tremendously encouraged by the interest and enthusiasm of the member MPs, who have taken our patients’ issues to heart.

One of the most important of these is the creation of managed clinical networks; to standardise the quality of treatment. We welcome the fact that the APPG will be examining this issue in 2009/10. The establishment of these networks is a core element of UKTS’ National Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2nd edition published October 2008). We look forward to working with our partners in the APPG to ensure that all thalassaemia patients in the UK have access to the same high quality of care, regardless of where they may live.

Elaine Miller
Coordinator
UK Thalassaemia Society

The NHS Sickle Cell and Thalassaemia Screening Programme offers screening to all pregnant women (and where relevant fathers-to-be) and all newborn babies. It is also working closely with the Department of Health on the development of managed clinical care networks. We strongly welcome the formation of the APPG in raising political and wider public awareness of sickle cell and thalassaemia and the need for investment in care and screening. We have been delighted by the way in which these previously much misunderstood conditions are moving into the mainstream of the NHS and are extremely grateful to members of the APPG for their interest and support.

In the past few months we have made significant progress in many of the key areas identified by the APPG. We are working hard both to evaluate and develop our own training package, PEGASUS; to embed training about sickle cell and thalassaemia within the generic training provided to a wide range of health professionals; and to develop accredited courses through universities. We also have a very ambitious programme of direct public outreach, media work, information resources and dissemination to reach out to both the wider public and health professionals. This is tackling education in the broadest sense and working to challenge stigma and build understanding.

We have recently published standards for offering Transcranial Doppler Scanning, which seems to be emerging as an important tool in reducing the incidence of stroke for patients with sickle cell disease. We have also secured funding to deliver training for the health professionals offering TCD. Securing funding is essential to the development of care and we have worked with commissioners to establish a commissioning framework (the Specialist Services Definition Set) for specialist care. We have also worked closely with the Department of Health to specify how services will be structured and delivered.

Dr Allison Streetly
Programme Director
NHS Sickle Cell and Thalassaemia Screening Programme
The Work of the APPG
Prescription Charges for Patients

In September 2008, the Prime Minister announced an ambition to abolish prescription charges for patients with long-term conditions over the next few years. Professor Ian Gilmore, President of the Royal College of Physicians has been asked to undertake a review of prescription charges that will consider how to define the range of long term conditions that should be exempted from prescription charges and how exemption from charging can best be phased in.

In December 2008, the APPG brought together patient groups and clinicians with a representative of the Royal College of Physicians involved in the conduct of the Review in order to explain the financial burden that prescription charges place on patients with sickle cell disease and thalassaemia. The Consultant Haematologist present explained the severity of the situation, saying that in her professional experience she was concerned that some patients did not collect their prescriptions due to the cost, potentially endangering their own health.

The APPG formally responded to the Royal College of Physicians/Department of Health consultation, strongly advocating that sickle cell disease and thalassaemia are among the long term conditions included in any exemption from prescription charges. MPs who are members of the APPG also raised the issue in the House of Commons. The review will report to the Minister for Public Health and the Secretary of State for Health in Autumn 2009.

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

Sickle cell disease and thalassaemia 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.

In March 2009 Patients, academics, social work and clinical professionals came together to explain some of these issues to members of the APPG and senior officials from the Department of Health and Department for Children, Schools and Families.

Following the meeting, the APPG produced a report recognising the need for joint working between social services, educational services and healthcare staff, and calling for a stronger commitment from these sectors to work together to improve the social and educational needs for sickle cell and thalassaemia patients. The Department of Health and Department for Children, Schools and Families have since met with patient groups to address some of the concerns expressed at the APPG meeting.

The Social Cell help campaign

Sickle cell disease and thalassaemia are likely to require an “office style” job so must achieve their maximum educational potential. Children with sickle cell need to be encouraged to attend school regularly; some studies have shown that school attendance is below average but our local experience is that they can do as well as their peers.
I feel as a Member of Parliament that health conditions which primarily target minority populations in the UK should receive the attention and resources they deserve – just as much for community cohesion as for the important health benefit this brings.

Tim Boswell
Conservative MP for Daventry
Treasurer of the APPG on Sickle Cell and Thalassaemia

It has been a great honour for me to be an office holder in the All-Party Parliamentary Group on Sickle Cell and Thalassaemia. My main contribution this year has been a Westminster Hall debate which I secured in February. I was glad to have the chance to bring the issue of care of thalassaemia patients to the Government’s notice. The fact that there has never been a debate on the subject in Parliament before is symptomatic of the low profile this dangerous disease has. It is my hope that the Government will now consider forming clinical networks to provide systematic, specialised care across the country; and that it will support promising lines of research for cures such as from umbilical cord blood. I was pleased that the Government Minister, Ann Keen, was very receptive to my speech and I will continue to do my best to ensure that the Government does not default on its assurances.

David Burrowes
Conservative MP for Enfield
Shadow Minister for Justice and Secretary of the APPG on Sickle Cell and Thalassaemia

It was a pleasure to initiate the APPG on Sickle cell and Thalassaemia. I have been raising funds for the Sickle Cell Society since I was just 16 years old. As I became older I realised that Sickle Cell is prevalent in my family, from my brothers to my niece and nephew. The work that the Society has done in raising awareness of the issue and ensuring that babies are tested at birth are invaluable. I hope that this group will continue to go from strength to strength and that one of our first victories will be free prescriptions for patients with sickle cell disease and thalassaemia.

Dawn Butler
Labour MP for Brent South
Assistant Government Whip

Members of the APPG

The success of the APPG depends on the support and commitment of the MPs and Peers who are members of the group. Stakeholders are extremely grateful to those MPs and Peers who have taken the time to listen to stakeholders’ views, and advocate for better services on their behalf. This year a number of members have asked parliamentary questions to the Government, tabled Early Day Motions and secured time to debate sickle cell and thalassaemia in Parliament.

Sickle cell and Thalassaemia affect many of my constituents. All too often they have not only to battle the pain and disability caused by the disease, but relative ignorance by employers, schools, and housing departments. The APPG exists to raise awareness of the condition in Parliament and to campaign for better services for people affected by the condition. Medical research for a cure is vital, but in the meantime, it is our duty as Members of Parliament to make sure our constituents get the best care possible and the support they need to live a full life.

Sarah Teather
Liberal Democrat MP for Brent North
Shadow Minister for Housing Vice-Chair of the APPG on Sickle Cell and Thalassaemia
Officers and Members of the All-Party Parliamentary Group on Sickle Cell and Thalassaemia

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David Burrowes MP  Conservative
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Karen Buck MP  Labour
Dawn Butler MP  Labour
David Drew MP  Labour
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Kelvin Hopkins MP  Labour
Baroness Howells  Labour
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Sadiq Khan MP  Labour
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