

## **2015 ASYABI Annual Public Report**

2015 has involved several activities for ASYABI which have included session meetings, public talks within churches, schools, etc. which led ASYABI to increase its reputation nationwide in the UK for the promotion of Sickle Cell Disease or Anaemia (SCD) in the UK.

The Association of Sickle Cell sufferers of Yorkshire and Africa and Basic Information also known as 'ASYABI' was founded in Leeds in the United Kingdom in June 2008 by a patient with Sickle Beta-thalassaemia which is similar to Sickle Cell Disease or Anaemia (SCD). It is a registered charity led by volunteers and people affected by Sickle Cell Anaemia aiming to provide self-support and information, advice and other helps needed to people and their families affected by sickle cell. Support and advice are provided by telephone, email and through home visits. ASYABI works with the support from Health Care professionals to ensure that individuals with sickle cell get the optimum service from health, education or social care. Since 2009, our self-help patient group well known as 'ASYABI' has been able to provide conferences, leaflets, etc. on this issue to raise awareness of sickle cell disorder in Leeds and Yorkshire. Our charitable work is aiming to increase the awareness on sickle cell as well as to help patients for a change of perception. Most patients come from minority and ethnical groups across the UK and Yorkshire.

According to ASYABI research on the ground, these patients with SCD suffer from social exclusion, isolation, even when they are hospitalized at St. James Hospital for sickle cell crisis (pain in the bones). They are totally isolated without any social support because of the lack of a self-help patient group like ASYABI which takes into account all these aspects. As patients we can understand their feelings and needs. This painful and chronic genetic condition that thousands of children and adults affected by sickle cell like us suffer held them to feel different from other children; as a result of this social exclusion, across the UK despite the fact there are more 14,000 of sufferers but less than 300 patients with this condition take part directly to social events, conferences and seminars on their own condition!

In Leeds, especially sufferers from those disadvantaged areas are the highest affected by this huge stigma, only 3 out of 40 patients attend public events because they do not want to be identified as sufferers of this painful and common genetic disorder; they feel shameful of their condition based on the high stigma associated to it. Sickle Cell Disease or Anaemia is an inherited blood disorder. It is not contagious. It is the result of the abnormal haemoglobin (HB) called HBS. Usually children and adults who are affected by sickle cell suffer from pain in the muscles and bones when they are in crises generally called (Sickle Cell crisis).

ASYABI has found out, through our own research, the following number of patients in Yorkshire and surrounding areas:

- St James's University Hospital, Leeds has 95 patients (adults),
- Bradford, 20 patients,
- Manchester Royal Infirmary, 267 patients (adults),
- Manchester Children's Hospital, 213 patients (children),
- Nottingham University Hospitals, 85 patients,

- Homerton Hospital, 80 patients,
- Sheffield Teaching Hospitals, 75 patients (adults),
- Sheffield Childrens Hospital, 63 patients (children)

According to NHS sources (<http://www.nhr.nhs.uk/pdfLinks.aspx>), there are more than 200 patients in the Yorkshire area which may suffer from Sickle Cell and associated illnesses which this project will target for support. In link to the current ongoing statistics provided by the National Haemoglobinopathy Registry (NHR), more than 200 patients from the Yorkshire area will directly benefit from this project. Please note that 95 patients (adults) from this figure are based in Leeds. According to the ongoing data of the NHR, the current estimation of patients with sickle cell in the UK is 5,457. However, this data is below the standard figures provided previously by the largest voluntary group in the field known as the Sickle Cell society who suggests that there are more 14,500 of sufferers with this condition in the UK but in connection to the higher stigma associated to this common and painful genetic condition, fewer patients give their consent to be registered in the government data base.

#### **Facts in the UK:**

- There are more than 14,500 of Sickle Cell sufferers in the UK.
- 240, 000 people are carriers of the Sickle Cell gene.
- 300 babies are born annually with Sickle Cell Anaemia or Disorder (SCD).
- Each year hundreds of children & adults will be left disabled or chronically sick.
- Hundreds will spend months in hospital or isolated at home.

Worldwide statistics, according to Dr Williams from Oxford University, 80% of cases are in Africa with 200,000 new born every year. Dr Jemima Dennis-Antwi, Regional Advisor (Anglophone Africa), International Confederation of Midwives, if nothing is done by 2020, the number of new born with this condition in Africa will be increasing by 400,000 every year. This condition affects many countries across the world (1 in 4 West-Africa and 1 in 10 Afro-Caribbeans, and is also found in people who originate from the Mediterranean, Asia and the Middle East. It is less common in Caucasians).

Based on the facts provided above including feedback and recommendations received from the front-line (patients and affected families). They have strongly advised and recommended ASYABI to multiply their actions for the awareness including the need of a long run proposal to support families and patients in the regular basis through advocacy, advice, regular support on the telephone, emails, home visits and hospitals visit including hosting seminars and conferences in order to reach patients and families who for most feel stigmatized and are not willing to present themselves as sufferers. Such activities according to some of them will inspire experience exchanges among patients and it will from time to time increase their self-believe, self-help and optimism to fight against this high stigma that they face for a change of perception.

In order to empower its work in the UK; ASYABI has put together a new proposal titled: **“Raising Awareness and Reaching Marginal Communities with Sickle Cell Anaemia or Disease (SCD) for a Change of Perception”**. This project is the main part of the new extension of ASYABI service to increase the awareness on this

marginal condition for the public. According to our research on the ground, most of these patients suffer from social exclusion, isolation, even when they are hospitalized at St. James Hospital for sickle cell crises or transfusions. They are totally isolated without any social support because of the lack of a self-help patient group like ASYABI which takes into account all these social aspects & challenges. This painful and chronic genetic condition lead most of us and from the childhood to feel different from other healthy children and as a result of this; it led most patients to develop one kind of self-stigmatization; but it is comprehensible because a few decades ago and until now in some or most of developing; children with sickle cell are seeing as dying kids 'He/she will die tomorrow or before he/she gets 18 or 21 years old'. This stigma led for decades now affected families and patients not to disclose or to speak out about the condition of their children with sickle cell. These analysis on the ground can be logical explanation on as to why in UK despite that there are more than 14,500 patients with this illness in UK; but less than 300 of them including families take part to public events related to their cause. In Leeds, where there are 95 patients (adults) less than 3 out of 40 patients attend public events because they do not want to be known as sufferers; they feel shameful of their condition. Our work is aiming to help them for a change of perception and self-believe by inspiring and encouraging them for self-believe through the experience and advocacy of ASYABI Founder who is a suffer himself and shall lead this proposal. patients with sickle cell have had a very hard childhood associated to isolation and social exclusion that we call 'self-stigmatization' due to the lack of funds towards patients groups to support families in the social aspects and not just medically. According to experts in this field (haematologist doctors); stress can provoke Sickle Cell crisis (pains in the bones, joints, articulations, etc.). So helping patients with this condition through self-believe, self-help, etc contributes a lot in reducing the rate of their admission to hospitals with acute crisis (severe pains).

One of the most recent case studies for the year ending 2015: A 62 years old patient with Sickle Cell Disease by the end of 2015 his Personal Independence Payment was stopped. He was referred to ASYABI with a quotation to its Chair & Project Manager by a Researcher from Sheffield University who in the past years had worked with ASYABI via its Chair & Project Manager who took part to her research as a member of the Advisory Group on 'Living Warm with Sickle Cell Disease'. He had emphasized the group during this research on the high stigma associated to Sickle Cell Disease (SCD); based both on his own experience as a sufferer and his position for more than sixteen (16) years as a patient leader for Sickle Cell Charities worldwide. So the researcher who was the main responsible of this research had referred this vulnerable 62 years old man to ASYABI based on its leader competence and knowledge in the field that she had experienced and listened to pending this partnership. ASYABI did a letter asking for reconsideration to the authority involved with this matter. A month later ASYABI received a call from this 62 years old to thank you so much as ASYABI input led to his support to be reinstated with no need to go to the Court.

As a result of the great charitable work done by ASYABI for the promotion of this marginal cause in the UK. By the middle of 2015, ASYABI had been asked by the National Institute for Health and Care and Excellence (NICE) to nominate a 'Patient Expert on Sickle Cell Disease (SCD)' who will be taking part to regular consultations related to SCD drugs and medical technologies that may be adopted or rejected for

the improvement of care within the NHS to those affected by chronic disorders such as SCD. Mr. Olivier Mmounda A Nyam based on his long experience in the field both as a patient Chair & Project Manager was nominated. ASYABI did on the same year its first statement on an on-going consultation which took place in September 2015 on the automatic blood exchange for patients with SCD. On behalf of ASYABI, Mr Nyam had been asked in the beginning of 2016 to apply to work with NICE as a Lay Member for two (2) years. ASYABI also took part as a supplier and Member in the Advisory Capacity for two different academic researches with: Sheffield University on 'Keeping Warm with Sickle Cell Disease (SCD)' and with York University on 'Anti-natal Screening for Parents who in the past three years have had a child with SCD in the UK. ASYABI charitable work is being known and acknowledged nationwide in the UK.

Please note that this program can be supported by any organization or individual to help ASYABI to properly support and address this cause. Any donation can be made payable at: HSBC Bank, Account name: **ASYABI UK** - Account number: **54721349** Sort code: **40-27-15** - Make any cheque payable to: **ASYABI UK**

On request ASYABI Business Plan with more details on this proposal can be sent to you by email. Thank you.

**Report made by ASYABI on 2<sup>nd</sup> of February 2016**  
[www.asyabi.co.uk](http://www.asyabi.co.uk)