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WCA NEWSLETTER

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Special Report

WCA Welcomes Plasma of Hope wanting to raise awareness of support available for people living with Sickle Cell and Thalassaemia



Plasma of Hope Director and CEO Marie-Claire Kofi

Walsall Community Association are keen to ensure that community members living with Sickle Cell and Thalassaemia know where and how to find the support they need.

Last week saw the final session of the Warm Hub, a four part series of events aimed at supporting community members with energy and cost of living advice, and health advice.

One of the recent additions to the Warm Hub is the advocacy group, Plasma of Hope, a charity that aims to make the lives of people living with sickle cell disease easier.

The organisation offers services across the West Midlands including Dudley, Wolverhampton and Sandwell, and last Wednesday Plasma of Hope Director and CEO Marie-Claire Kofi was at WCA's Warm Hub in Walsall.

According to information provided by the National Institute for Health and Care Excellence, sickle cell (a blood disorder that affects 1 in 2000 live births in England) occurs predominantly in people of African and African-Caribbean origin.

The condition can cause anaemia, and episodes of extreme pain. People living with sickle cell are at risk of complications that can cause stroke, blindness, damage to main organs and even (in extreme cases) death.

It's important that people affected by the condition know that information and support is available.

Marie-Claire Kofi of Plasma of Hope said, "Improving wellbeing and reducing the stigma by making people more comfortable around speaking about sickle cell are key to our aims. We want to eradicate that discomfort for people."



Plasma of Hope display with Leaflets and stickers

“A lot of people have reservations about talking to people, partly because of the misinformation associated with the condition such as being told that people with sickle cell can’t live a normal life and won’t live past a certain age.”

“I am here to say that I have sickle cell but sickle cell doesn’t have me. I try my best to live a normal life even with my sickle cell condition and I am advocating for others to do the same.”

“Our work at WCA offers an opportunity to gain an important perspective, particularly from the older generation, about the community’s understanding and awareness of sickle cell. We will keep advocating and spreading the message that it’s ok not to be okay.”

A 2021 report, ‘No-One’s Listening’ which was jointly published by the APPG on Sickle Cell and Thalassaemia and the Sickle Cell Society, found that ‘sickle cell patients too often receive sub-standard care’ from healthcare services.



Community members take part in Pal Fitness Education exercise session

According to the report these ‘care failings have led to patient deaths,’ and has ‘led many patients to fear accessing secondary care, or even outright avoid attending hospitals.’

The report makes reference to the inadequate investment in sickle cell care, pointing out that services are ‘under-resourced and understaffed,’ and that there remains a distinct lack of investment in sickle cell research and treatments ‘over decades, right up to the present day.’

WCA was formerly known as the Afro Caribbean Community Association. The charity, as well as serving the wider community, has a rich and renowned tradition of providing services of particular interest to the African and African Caribbean members of the community.

A spokesperson for the organisation said, “It’s vital that we continue to provide services to the most vulnerable members of our community. On this occasion our focus is on ensuring that people living with sickle cell know where to turn for information, support and advice.”

“We also want to raise awareness of what the condition is and how it can be managed or treated. As an organisation we are proud to be working with Marie-Claire Kofi and Plasma of Hope to achieve our joint aims.”

To find out more or to discuss how sickle cell affects you, contact :



Plasma of Hope

www.plasmaofhope.org
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