



CIANNA'S SMILE ANNUAL

TRUSTEE REPORT

2018

Registered charity number 1173030

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Administration

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Charity number 1173030

Registered charity name Cianna's Smile

Names of the charity trustees who manage the charity

Treasurer: Hayley King

Secretary: Melissa Connor

Chairperson: Zoe Tocoks

Advisors

Financial advisor: Roger Williams

Banking: Metro Bank, Broad Street Reading

Committee members

Joyce Connor, Sarah Jane Grant, Ashleigh Ali, Lisa Gatherer, Cynthia Dirisu, Esther Chan, Deborah Walker, Louise Chandler, Rosiland Slade and Emanuel Essah.

Governance and structure

Type of governing document: Constitution

How the charity is constituted: Charitable incorporated organisation

Trustee selection method: Vote at AGM

How new trustees are inducted: Training provided by the organisation

Summary of the objectives set out in the governing document

The preservation and protection of good health and the relief of sickness of people who suffer from sickle cell in the Thames Valley area by such means as the trustees think fit including but not limited to the provision of information, support, comfort, services, facilities and social events.

Who are we

Cianna's smile is a small registered charity that offers support to families affected by Sickle Cell disease (SC) who are residents within the Thames valley area. Our aims are to reduce the isolation felt by families who are affected by SC, to raise awareness of the condition and to educate both healthcare professionals and members of our community to help better understand the condition.

Sickle cell is one of the most common genetic diseases in the world, but most have never heard of it. We must change this to help improve the lives of those who suffer from the condition. There is a huge lack of empathy towards those with SC as it is often misunderstood and the severity of it and the complications it can cause are unknown.

The organisation was founded by Hayley King in July 2012 and named after Hayley's daughter Cianna who has Sickle Cell Anaemia. The charity became registered in May 2017 and has gradually progressed and become a familiar name within the community.

Summary of the main activities undertaken for the benefit

May 2018- Cianna's Smile donated 300 sleep mask and earplugs to the Children's wards at the Royal Berkshire hospital in Reading. Parents find it difficult to sleep in the unfamiliar setting of the ward. The bright lights and beeping from the machines all through the night can be difficult to ignore and sleep deprivation leaves parents and carers feeling exhausted and not at their best to care for their sick child. The sleep sets were gratefully received. The feedback from the hospital has been that the parents thought it was a great idea and really helped them during the stay.

June 2018- the organisation held a stall at the East Reading festival. We met several sickle cell patients that were keen to use our services and have since been in contact. This was a great opportunity for the organisation to have face to face interaction with members of our community and to also provide relevant information and awareness of Sickle cell and our organisation.

July 2018 – We were privileged enough to once again be a community partner with the NCS the challenge for the third year running. The 15 to 17-year-old plan a campaign and assist the charity with any way they see fit. We also gave a business presentation to 60 15 to 17 years old who provided constructive feedback on how we as an organisation could improve our community

engagement, social media interaction and website design. The feedback was beneficial as it helped us to review these points from a younger audience's perspective.

August 2018 – For the third year running we held an awareness event at The Sonning lock tea rooms where we offered face painting, crafts and a second-hand book sale to raise awareness and funds. This was a great way of interacting with members of the public and we spoke to a few people that were carriers but did not know anything about Sickle Cell nor did they understand that it could be passed down to their children. This opportunity was great for us to help offer support to those people. One gentleman whose mother had just been found to have Sickle Cell trait, but he did not realise that he himself and his children may also be carriers because of this. It was a great event and many families interacted with us and asked many questions.

September 2018- The Cianna's Smile Sickle Cell action group had a family day out at 4 Kingdoms adventure park. The children were all very excited and it was a great opportunity for them to meet others with the same condition. The family fun club was set up to encourage families who live in the Thames Valley area to get together and have a time where they can forget about hospital appointments and the families can meet others living with the Sickle Cell. This reduces isolation and the risk of mental health illnesses.

Annual Sickle cell awareness charity ball was a great success! The annual ball was held at the glorious Penta hotel in Reading. The generosity of our guests and donations of raffle and auctions prizes from local businesses resulted in raising over £2400 on the night. With such positive feedback from guests we are excited to be already planning our 2019 ball.

October 2018- Another partnership with The NCS the challenge team and the young people made great effort in producing 20 posts for the organisation to use for social media posts. They also took the time and effort to not only raise enough money to fund 40 art therapy bags, they purchased the contents and packed them for us to distribute to children with Sickle Cell at the haematology clinics at the 6 hospitals within the Thames Valley area.

November 2018- The Cianna's Smile sickle cell action group took 3 families to see the new movie of The Grinch. The children were so excited to both see the film and spend time with their friends in the group. It is always a great privilege to be able to make a positive impact to the lives of those who face so many challenges in their life.

Achievements and performance

The charity has established strong relationships with local businesses and other charitable organisations. We have continued to raise money for numerous projects and continue to provide support through multiple outlets for families affected by Sickle Cell. We have held several successful events to raise both awareness and raise funds.

Statutory deceleration

The trustees declare that they have complied with their duty to have due regard to the guidance on public benefit published by the commission in exercising their powers or duties.

2018 Financial summary

Donations and funds raised

Running costs

Sickle cell action group and campaign costs

2019 plans and objectives

The aims of 2019 are to

- Provide 6 Sickle Cell action group recreational activities for families affected by Sickle Cell
- To expand our outreach to adult patients who have Sickle Cell and living in the Thames valley
- To obtain funding to provide additional educational and alternative support to those affected by Sickle cell such as nutritional advice, self-care plan, counselling and alternative therapies.
- Improve community engagement via fundraising activities and educational talks
- Gain 10 new volunteers to help with the running of the organisation and events
- To further educate and raise awareness to members of the public by offering 2 advocacy training days annually and an annual Black history month talk on Sickle Cell
- To network and form partnerships with more existing Sickle Cell organisations in the UK
- To build on our impact within the community by inviting guests to participate in events and social media.