

JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 2016 - MAY 2017)

Charity Registration No. 1161371

Trustees

Sheila Saye, Mala Saye, Ian Edwards

Finance Director

Paul Davies

Structure, governance and management

The Janki Saye Foundation (JSF) was registered with the Charity Commission on 21 April 2015 and is constituted by the Trust Deed.

Objectives and activities

The objects of JSF, as governed by the Trust Deed, are to provide relief of disability for public benefit by providing grants to fund specialist equipment, in particular, but not exclusively that will aid and assist communications for individuals with disabilities and special needs.

The aim of JSF is to raise funds in order to provide grants to fund assistive technologies for individuals with disabilities and special needs. Applications for grants are reviewed and approved by all trustees before any funds are released.

Achievements and performance

Fundraising and Donations

A total of £13,403 was raised through fundraising activities, donations, gift aid and limited sales of canvas bags and calendars.

The majority of funds (£10,695) was raised through the following fundraising activities and events:

- Nightrider
- Just So Funny Comedy Night
- London Marathon (1 bond place)
- Hackney Half Marathon
- Brockwell Lido Swimathon

- Tough Mudder
- Surbition High School activities

Grants Awarded

A total of £12,502 was awarded in grants to the following 13 beneficiaries:

1. *Kinjal*

A 15 year old with muscular dystrophy and severe scoliosis. This means she is profoundly disabled, but intellectually unimpaired. She is wheelchair bound and has to sit in a reclined position for most of the day as the scoliosis compromises her breathing and swallowing.

Kinjal is totally dependent on her mother for all her physical day to day needs such as bathing, eating and drinking. She also relied on her mother to hold her books in order for her to complete her school work.

Kinjal was awarded a grant of £5,976 to fund high end technology – Grid Pad Eye communication aid with MyGaze Tracking camera which enables her control her wheelchair, access her computer and complete her homework without the aid of her mother.

2. *Ian*

An adult who lost the sight in one eye following an accident at the age of 15. The vision in his other eye has since deteriorated and he is now registered blind. His sight loss affects every part of his day to day life and impacts his independence. He had been employed in a workshop for the blind but lost his job 4 years ago when it closed down. Following that his wife died having been ill with cancer.

Ian then felt ready to return to work; he desperately wanted to find a job but lacked the necessary skills.

While volunteering at an RNIB resource centre, Ian learnt how to use a computer with software called Zoomtext that enlarges text and reads out what is on the screen for him. He also uses a keyboard which has bold, high contrast letters on it. Ian gives

up many hours to volunteer at the centre; he does a fantastic job of supporting other people who have lost their sight and is an asset to the team.

Ian was awarded a grant of £1,274 to fund a computer with the Zoomtext magnification software so that he could develop IT skills at home and also have access to email, online shopping and social media. This helps to provide him with a degree of independence and become less isolated.

3. Henry

A 5 year old with autistic spectrum disorder and global developmental delay. He is unable to care for himself and lives in his own world.

Henry was awarded a grant of £414 to fund an iPad with special apps which enables him to communicate with his family and learn motor skills.

4. Alfie

A young man who suffered a severe traumatic brain injury following an assault in 2013. He was left wheelchair bound and his speech was mostly unintelligible. He had been in a brain injury centre since June 2014 and received intensive neuro-rehabilitation for extensive physical and communication difficulties.

He used a low tech alphabet chart to communicate in the beginning, and was managing with that but it proved difficult for his communication partner to follow what he was saying. He was then given the loan of an iPad with the Grid Player app installed and he used this very successfully around the centre and also out in the community.

Alfie was awarded a grant of £363 to fund an iPad with a wheelchair mount and the Grid Player app which enabled him to get his message across to his communication partner, interact with his family and help him with his rehabilitation process.

5. Greg

A young adult with visual impairment, learning difficulties, epilepsy and kidney failure. He is wheelchair bound and non-verbal.

Greg was awarded a grant of £135 to fund a Little Step by Step communicator, a simple device which enables him to communicate with people around him and improve his quality of life.

6. Kye

A 9 year old who is autistic, has learning disabilities and visual and hearing impairments. He is very isolated and has no understanding of risks to his safety.

Kye was awarded a grant of £429 to fund an iPad with apps that provide him with some independence and enables him to develop communication and motor skills.

7. Jordan

2 and a half years old with a rare form of cancer (Childhood Central Nervous System Atypical Teratoid/Rhaboid Tumour). He will be in and out of hospital for the rest of his life.

This cancer has affected his ability to speak so the only way he can communicate with his family and hospital staff is by using flash cards.

Jordan's family wanted to give him the Grid 3 application to run on an iPad. The software can be personalised to his specific needs, enabling him to use his eyes or touch the screen to communicate with people around him.

Jordan was awarded a grant of £480 to fund the Grid 3 software (the iPad was donated by another charity).

8. Robyn

An 18 year old with Mosaic duplication (chromosome duplication) and Spina Bifida. She is wheelchair bound and has no functional verbal communication. At school she was given the use of an iPad with the Prologuo2go communication application. This enabled her to do her school work and it also supported her social interaction.

As she was about to leave school and transition into a day care facility, her mother and teachers were very concerned that, without the iPad, she will no longer be able to communicate effectively. This would impact her ability to become more independent.

Robyn was awarded a grant of £658 to fund the iPad and the Prologuo2go app

9. *Ethan*

A 5 year old with global developmental delay and autistic spectrum disorder. He relies on an adult for all of his basic needs and, as he is still unable to express himself verbally, he communicates his needs by leading an adult by the hand.

He is at a special severe learning difficulties school where they encouraged him to communicate using an iPad with the Picture Exchange Communication System (PECS). They felt it would help Ethan's development enormously if he were to have an iPad with PECS at home as it would help him communicate and interact with his family.

Ethan was awarded a grant of £420 to fund an iPad.

10. *David*

An 8 year old with Angelman Syndrome, epilepsy, hyperactivity and sleep disorder. He is completely non-verbal and, because he cannot communicate his needs, he becomes frustrated which leads to him engaging in harmful activities such as hitting himself on his legs.

His speech and language therapists recommended the use of the Prologuo2go communication app to help David make himself understood and to give him a voice, both at home and in the community.

David was awarded a grant of £200 to fund the Prologuo2go app

11. *Reisy*

A 5 year old with Global Developmental Delay, Dyspraxia and ADHD.

Due to her limited communication skills and uncertainty about how to respond, she presents difficult and challenging behaviour. It is felt that her frustration in not being able to express herself exacerbates the situation and results in tantrums.

She is at a special school and teachers have identified a language program called Makaton which uses signs and symbols and will help make Reisy's social and educational experiences more enjoyable. It will also help her develop her vocabulary so that she can ultimately improve her speech and language skills.

Reisy was awarded a grant of £409 to fund the Makaton symbols program.

12. Asemah

An adult with a rare condition called LOGIC syndrome which causes excessive growth tissue to develop in various areas including the larynx and eyes. This has resulted in breathing difficulties, speech impairment and severe visual impairment; she is registered blind.

Asemah wanted to improve her quality of life and increase her independence. She loves to read and is currently doing a poetry workshop and also learning creative writing.

She required the Prodigy Connect (video magnifier and text to speech conversion) with a distance camera which enables her to see objects around the house and on kitchen shelves, enabling her to become more independent.

Asemah was awarded a grant of £1,405 towards the cost of the Prodigy Connect 12. Two others charities also provided grants.

13. Charlie

A 4 year old who is severely autistic, has global development delay, significant special educational needs and is non-verbal.

Charlie needs constant care and supervision for all aspects of his daily life. He is easily distressed and finds it difficult to interact with those around him.

His educational psychologist noted that, on occasions, Charlie managed to use apps on his support worker's iPad. She recommended that he have one of his own with special applications as that would help him develop attention skills and enable him to make choices and communicate his preferences.

Charlie was awarded a grant of £339 to fund an iPad.

Other Expenditure

A total of £2,850 was spent on events, marketing, merchandise, online fundraising platform fees and bank fees.

It should be noted that £2,100 related directly to fundraising activities, and was necessary to advance the cause and objectives of JSF.

The cost of events was recovered through ticket sales, sponsorship money and donations. The other costs were covered by reserves held from donations made by the co-founders in 2015.

With no additional overheads or running costs, all of the money raised by donors and supporters was used directly to fund grants.