

JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 23, 2018 – MAY 22, 2019)

Charity Registration No. 1161371

Trustees

Sheila Saye, Mala Saye, Barbara Martin

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, Donations and Grants

A total of £8,327 was raised through fundraising activities, donations, grant awards and limited sales of calendars.

£1,733 was raised through direct donations.

£6,094 was raised by the following fundraising activities and events:

- Royal Parks Half Marathon (1 bond place)
- 250 Mile Run Challenge and Corporate Matching
- Swimathon
- Surbiton High School activities

- Kings College School activities
- Walking Winos

A £500 grant was awarded by Buzzacott to benefit a young person living in a London borough. This has now been used to award a grant to a young man living in Hackney (details will appear in the next financial year).

Grants Awarded by JSF

A total of £3,958 was awarded in grants to the following 5 beneficiaries:

1. Eliza

A 7 year old with an underdeveloped cerebellum and microcephaly. This means that she is not able to use her hands, so needs help with every day care. She is also non-verbal and can only communicate through facial expressions and body language.

Eliza attended EyeGaze sessions twice a week at her school. She understood the concept of it and started to use the Grid 3 communications program to a point where familiar adults were able to interpret her needs and wants. Since these two sessions were limited to 20 minutes, she was unable to make significant progress.

Her parents and her Speech and Language Therapist felt that, if she had the system at home, they would be able to teach her to use it every day. She would rapidly develop her skills and start building up her vocabulary and symbols so she could tell her parents what she thinks, how she feels and what she needs.

Eliza was awarded a grant of £2,308 to fund this EyeGaze system.

2. Russell

A 4 year old who is autistic, has global developmental delay and is completely non-verbal with limited means of communication. Because Russell was unable to make himself understood, he became very distressed and upset.

His mother wanted him to have the Grid Pad PECS app to help him communicate.

She had watched Russell use this on a friend's iPad and he was able to create a sentence for the first time by pressing the relevant buttons. He said "I want crisps" and his face lit up when he heard the voice telling everyone what he wanted.

To date, Russell and his mum had been using the non-electronic version of PECs which is a system based on pictures and symbols using Velcro stickers. Although workable, it has limitations and they found it to be a very slow and often frustrating process.

Having this application on an iPad would enable Russell to make himself understood to those around him, wherever he goes.

Russell was awarded a grant of £350 to fund the Grid Pad PECS application.

3. David

A 40 year old who had worked as a chef from the age of 18 up until 2 years ago when, as a result of glaucoma, he started to lose his vision. He struggled to keep going but his vision deteriorated and he is now registered blind.

David has had to give up the job he loved, but he refused to be defeated by the events of the last two years. He decided to challenge himself to do something else and enrolled onto a Business and Administration course. Having successfully completed this course, David is now eligible to study for an Accounting qualification.

In order to continue with his studies, David needed a laptop with office applications and Zoomtext magnification software. This would also help him at home and in the office once he is in a position to seek employment.

David was awarded a grant of £885 to fund the laptop, applications and Zoomtext software.

4. *Joseph*

A 24 year old who was hit by a car last year and suffered Traumatic Brain Injury. He is now severely disabled, unable to speak and requires a wheelchair and assistance with all aspects of his daily life.

Joseph has been in a hospital rehabilitation unit since July. His Speech and Language Therapist says that he has been able to type out sentences on his iPad as a means to communicate his needs and wants, but he finds the text too small and struggles to make himself understood.

He was given a free trial of an iPad using the "Predictable" app which he was able to use to engage in conversation with people both familiar and unfamiliar to him.

It was felt that, if Joseph had access to this app on a permanent basis, it would improve his communication and his overall well-being.

Joseph was awarded a grant of £175 to fund the Predictable app.

5. *Sharon*

A 45 year old with a learning disability who is unable to read or write. She also suffers from anxiety and depression. Sharon relies on her father to help her manage her correspondence and affairs.

Unfortunately her father has Alzheimer's and he is really struggling. He is extremely concerned that she will not be able to manage when he can longer support her as there is no one else who can help her.

An Independent Living Co-ordinator at Age UK assisted Sharon in requesting a grant to fund a CPen Reader. This is a scanning pen which reads text out loud or discreetly through earphones. It has a built in English dictionary so word definitions are only a button press away.

The CPen would give Sharon some independence and reduce the risks of a vulnerable lady being exploited when her father can no longer help her.

Sharon was awarded a grant of £240 to fund the C-Pen reader

Other Expenditure

A total of £240 was spent to purchase 2 bond places for the Royal Parks Half Marathon in October 2018. The places have already been allocated with the expectation that they will be able to collectively raise at least £1,200.

With no additional overheads and very minimal operational costs (bank fees and online platform fees), all of the money raised by donors and supporters was used directly to fund grants.

Governance and Compliance

Nothing new to report this year following last year's focus ensure compliance with the General Data Protection Regulations (GDPR); this included production of a Privacy Notice and Data Protection Policy and implementation of procedures to ensure safeguarding of sensitive beneficiary data.

Achievements and performance (May 2015 – May 2019)

Since its inception in May 2015, JSF has awarded grants totalling £35,014 to 29 beneficiaries.

Total income over this 4 year period (excluding £5,000 start-up funds donated directly by co-founders) amounted to £39,680.

Because the charity relies on volunteers, has no overheads and runs with minimal operating costs, 98% of our total income goes directly towards grant awards.