

JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 2017 - MAY 2018)

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 and Donations

A total of £9,999 was raised through fundraising activities, donations, gift aid and limited sales of calendars.

The majority of funds (£6,374) was raised through the following fundraising activities and events:

- Royal Parks Half Marathon (2 bond places)
- Crazy 4 Run Challenge
- 250 Mile Run Challenge
- Surbiton High School activities

Additionally, a grant was received from the St James's Place Charitable Foundation. They were so impressed with the work of JSF that they agreed to grant the maximum amount of £2,500.

Grants Awarded

A total of £12,708 was awarded in grants to the following 5 beneficiaries:

1. *Daniel*

A 19 year old with cerebral palsy, epilepsy, global developmental delay and chromosomal disorder. He is wheelchair bound and totally dependent on his family and carers for all aspects his daily life.

Daniel has no verbal communication but understands what is being said to him. He communicates through smiling and by having people close to him interpreting his behaviours and levels of movement/agitation.

Currently Daniel has access to a children's hospice where his Occupational Therapist (OT) is helping with his transition for when he has to leave at the age of 21. They trialled the EyeGaze system to see if it could support Daniel as a communication tool and allow for skills development as well as enabling him to play and socialise through games and activities.

Daniel immediately understood how to interact with EyeGaze and showed evident enjoyment, concentration and understanding of cause and effect. Based on this, his family arranged to loan the system for one month to see if Daniel could engage with the system at home over a longer period of time.

With the help of his sister who personalised the system for his needs, Daniel was able to develop and improve his skills and this has been a very positive process for the family as a whole. His OT observed him using EyeGaze in his home environment and noticed he was playing more complicated cause and effect games and could pick out words and pictures to relay his choices to his family. She felt that continued use of EyeGaze would allow Daniel have more choice in his day to day activities and would enable him to further develop his skills.

Daniel was awarded a grant of £5,000 to fund the EyeGaze system.

Daniel uses the EyeGaze most days and is learning new skills as well as enjoying trying new games and activities. Having the EyeGaze has helped Daniel keep busy and occupied and enabled him to be involved in activities with the whole family.

And he says "Thank you for all your help and support in getting me an eye gaze computer".

2. Zahava

A 16 year old with bilateral dystrophy with functional visual loss. Her main difficulties are reading (she loves to read and is an aspiring author) and day to day activities such as using public transport, shopping, preparing food etc.

Schoolwork is especially challenging for Zahava; she is studying for her exams and struggles to read printed text.

She had tried various magnification devices with limited success, but then she trialed the Orcam MyEye device and was immediately hooked. This is a wearable device which reads any printed text on any surface including newspapers, books, restaurant menus, supermarket products and street signs, instantly relaying it to the user through a built-in mini speaker.

Her mother very much wanted to provide Zahava with the Orcam device so that she could enjoy books again, complete her studies, go out with her friends and generally become more independent.

Zahava was awarded a grant of £2,200 to help fund the Orcam MyEye.

Zahava sent us an email in which she says "Earlier this month I receive the Orcam MyEye which you so kindly helped to fund. It's something I knew would help me massively and without your help I would never have been able to get it. Since getting it I've been able to gain a level of independence that has already had such a strong impact on my day-to-day life. I wanted to write to you in order to say the biggest thank you. I am I honestly so very grateful to you for this and it has already had such an impact on my lifestyle that is solely due to your generosity..."

3. Craig

An 18 year old with a profound learning disability, motor and sensory skill problems, cortical visual impairment and symptomatic epilepsy. He is mostly wheelchair bound and requires 24 hour support for all aspects of his personal care and basic needs. Craig has limited ability to make choices.

Last year, while still at school, Craig began a period of assessment using the EyeGaze device with specialised software. Using his eyes to control this device, Craig was able to participate in a number of activities and he demonstrated his understanding of cause and effect.

Now he has left school, his parents and care manager feel that, if Craig had permanent access to an EyeGaze, he would further develop his ability to interact with his support workers - it would give him a "voice", enabling him to communicate his own choices and desires, make himself understood and help him engage in stimulating learning activities.

Craig was awarded a grant of £4,500 to help them fund an EyeGaze system. We will follow up on Craig's progress once the system has been installed and Craig starts to use it.

4. Moray

An adult who has had a spinal cord injury since 1999. He is wheelchair bound and requires 24 hour care.

He has been using a laptop with voice activation software to do voluntary work as a psychologist in the NHS. This laptop is no longer functioning and he needs replacement to continue to be a little independent and carry on doing voluntary work. Ideally he wants to be able to do some paid work if he can.

Moray managed to secure a grant of £500 from the charity Aspire, so we awarded him the remaining £600 towards the cost of the laptop and software. Although this grant was approved in November 2016, there was delay from Moray's side in progressing this so the grant was awarded on October 2017.

5. Laura

An adult with Laura was born with complete bilateral blindness. She had to learn Braille when she was very young and, whenever possible, would use technology to help keep up with her studies and to read, which she loves.

She has a white cane and a guide dog, but craves more independence. She wants to be able to read train and bus timetables etc. when moving around so that she doesn't have to rely on family and friends to provide so much support.

She is studying to become a therapist and will soon graduate. So far she has

managed to do her course work using a computer and having family or colleagues read information for her.

In order for Laura to progress, she felt that an iPad which has Voice Over functionality, would help with her work, enabling her to access important information, as well as carrying out research and sending emails to colleagues. And since the iPad is small enough, she can carry it around with her to help her while she is out and about.

Laura was awarded a grant of £359 to fund an iPad.

Other Expenditure

A total of £139 was spent to purchase 1 bond place for the Royal Parks Half Marathon in October 2018. The place has already been allocated to an individual at CoopSys who have pledged £1,000 sponsorship.

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

Governance and Compliance

A significant amount of work took place to ensure compliance with the new General Data Protection Regulations (GDPR). A Privacy Notice and Data Protection Policy has been produced and procedures are now in place ensure safeguarding of sensitive beneficiary data.

Additionally, emails from JSF Newsletter subscribers have been received and logged to show explicit consent to stay on the email distribution list.

Achievements and performance (May 2015 – May 2018)

Since its inception in May 2015, JSF has awarded grants totalling £31,056 to 24 beneficiaries.

Total income over this 3 year period (excluding £5,000 start-up funds donated directly by co-founders) amounted to £31,353.

Because the charity relies on volunteers, has no overheads and runs with minimal operating costs, the grant awards total of £31,056 amounts to 99% of our income.