

JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 23, 2021 – MAY 22, 2022)

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 £5,677 was raised through fundraising activities, donations and grant awards.

£3,610 was raised through donations.

£1,567 was raised by the following fundraising activities and events:

- Surbiton High School activities
- Kings College School activities

£500 grant was received from Buzzacott. Note this grant has not been used yet as it is ringfenced to support a young person based in London, as per Buzzacott's charity objectives.

Operating costs which cover the CAF Bank and JustGiving platform fees amounted to £312.

Grants Awarded by JSF

A total of £5,135 was awarded to the following 6 beneficiaries:

1. *Lucy*

A 7 year old with Autism Spectrum Disorder, severe speech, language and communication difficulties and also sensory processing difficulties.

She requires constant help, encouragement and supervision and often becomes upset as she is unable to consistently express her feelings, wants and needs. The family engage in a lot of adult led activities and also follow a Speech and Language Therapy (SALT) program.

Lucy had been using the Prologuo2Go app on an iPad and she demonstrated exceptional progress, using a range of vocabulary including nouns, verbs and adjectives. This provided Lucy with the ability to communicate so that she could express herself and enabled her to start to assert her independence.

In order for Lucy to continue her development she required a new iPad to replace the her old one which was no longer functional.

Lucy was awarded a grant of £329 to fund an iPad.

2. *Kye*

A 14 year old who has autism, learning disabilities and also visual and hearing impairments. In August 2016, Kye was awarded a grant to fund an iPad which he

has been using for 5 years both, at home and at school. He was set challenges using various apps and was able to complete these, progressing his learning immensely.

During the pandemic, the iPad had been Kye's main form of communication with both his family and friends and this helped to reduce his anxiety.

The iPad has now been damaged, beyond repair and his mother requested a grant to fund a new iPad so that Kye could continue to develop and thrive.

Upon inspection of the old very damaged iPad, Kye was awarded a grant of £591 to fund a new iPad.

3. *Chaos and Calm*

The Chaos and Calm Community Interest Company (CIC) supports families caring for children with disabilities, providing them with opportunities for learning, play, socialisation and communication.

They had been running sensory play sessions to support 21 families, all of whom have a pre-school aged child with a disability. All of these sessions are supported by a qualified special needs teacher.

The one constant topic raised by the families is that of communication as it is so vital to their child's development and happiness.

The project manager believed it was important to allow families to experience, first-hand, the types of Assistive Augmentation Communication (AAC) that are available and to try them out with their child in a safe, secure and friendly environment.

The technologies required for these sessions were the Assessment Switch Kit, Blue2switch and an iPad with software including Proloquo2go and Mychoicepad.

Chaos and Calm was awarded a grant of £1,757 to fund the Switch devices and the iPad with the Proloquo2go license.

4. Nathan

A 9 year old who was diagnosed with significant speech delay at the age of 3. He has limited vocabulary and his mother uses visual aids to support him.

She had used an app called Talk Tablet on a free trial basis and noticed that Nathan had been making improvements in his language and choices of words to responses. She wanted to purchase the app so that she could customise it in order to continue with his development and to set a target of words and phrases for him to achieve each week. She felt that this would make a huge difference to Nathan's speech and overall wellbeing.

Nathan was awarded a grant of £80 to fund the Talk Tablet.

5. Shane

A 57 year old who was admitted to Hothfield Brain Injury Rehabilitation and Neurological Centre in April this year following a stroke.

As a result of his stroke, he has upper and lower limb weakness and has suffered a significant loss of use and understanding of language.

Since being admitted to Hothfield, Shane had been seen twice daily by a Speech and Language Therapist to work on his speech using low and high tech communication aids.

His therapist reported that he had a very low motivation to use low tech aids, probably due to the fact that his vocabulary was very limited.

However, he has shown a very high level of motivation for high tech communication aids and has been using an iPad with the Grid software which was loaned to the centre. During this time, Shane was able to carry the device around on his

wheelchair and was able to use it for making requests, indicating feelings, seeking out information and telling jokes!

The therapy team were concerned that, without this communication aid, Shane would not be able to communicate his basic wants and needs or to join in social opportunities which he actively seeks out. It would also mean that he would be unable to gain more independence and improve his mental wellbeing.

Shane was awarded a grant of £365 to fund an iPad. The Grid software was funded by the Clinical Commissioning Group (CGC).

Shane has since taken the iPad to the optician and managed to choose the colour of his glasses and he uses it regularly to ask to call his bank. The staff at the care home are very impressed with this device and can really appreciate how beneficial it is. They are working with him to help increase his vocabulary.

6. *Scarlett*

A 16 year old who was born with a unique chromosome re-arrangement that has resulted in profound and complex learning disabilities. She has minimal communication skills, sensory processing disorders, behavioural problems and she is on the autistic spectrum.

Scarlett's father told us that prioritising development of her communication skills has always been key in order to enhance her day to day life experiences.

The family have been supported by the local NHS Speech and Language Therapy department and, over the years, they have tried a range of communication techniques and basic communication aids.

In order to move Scarlett forward, they trialled the Smartbox Talk Pad communication aid with Grid 3 software. This 3 week trial proved extremely successful. Scarlett found the system very intuitive and she used the device

intentionally by pressing buttons meaningfully and in context to communicate. She preferred using this device rather than the communication books she had been used to. One of her teachers said “*Scarlett has had lots of one on one on her Talk Pad and working on her communication. The iPad really seems to be opening up the world for her, not only as a communication aid but for social interaction. We observed students coming over to sit next to Scarlett at break time and they were using the device with her. Scarlett was really enjoying that peer interaction and it was great to watch her so happy with people of a similar age.*”

After the trial, everyone felt that Scarlett would benefit from having her own Talk Pad 10. It would give her a voice and would enable her to have much wider interactions with her school peers, family and community.

The system is easy to set up and customise and can be remotely accessed by her family or school to quickly edit, maintain and develop. This will enable her to continually progress.

Scarlett was awarded a grant of £2,013 to fund the Talk Pad 10.

Achievements and performance (May 2015 – May 2022)

Since its inception in May 2015, JSF has awarded grants totalling £56,790 to 50 beneficiaries.

Total income over this 7 year period (excluding £5,000 start-up funds donated directly by co-founders) amounted to £58,556.

Because the charity relies on volunteers, has no overheads and runs with minimal operating costs, on average, 98% of our total income went directly towards grant awards. However, this financial year, due to a reduction in funds received and an increase in CAF Bank fees, our operating costs (CAF Bank fees and JustGiving fees) represented 5.5% of our income.