

JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 23, 2022 – MAY 22, 2023)

Charity Registration No. 1161371

Trustees

Sheila Saye, Mala Saye, Paul Davies

It should be noted that Barbara Martin resigned her position as Trustee in December 2022 due to other commitments. We would like to extend our thanks to Barbara for her hard work over the years and for her contribution towards the success of the charity.

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 £5,563 was raised through fundraising activities, donations and grant awards.

£3,972 was raised through donations.

£1,091 was raised by the following fundraising activities and events:

- Surbiton High School activities
- Swimathon

£500 grant was received from Buzzacott. (As per Buzzacott's charity objectives this grant must be used to support a young person based in London).

Operating costs which cover the CAF Bank and JustGiving platform fees amounted to £282. (Note CAF bank fees had been increased to £8 per month but subsequently reduced back down to £5 per month).

Grants Awarded by JSF

A total of £4,318 was awarded to the following 10 beneficiaries:

1. *Joshua*

A 19 year old with Cerebral Palsy. He is wheelchair bound, unable to complete day to day tasks independently and requires full time support for all aspects of his life. Joshua has no controlled movements in his arms or legs and requires them to be strapped down to prevent injury.

Joshua has good verbal communication skills to express himself and is able to access assistive technology which gives him a sense of independence. He uses assistive tech at home to control his environment (turn the lights on/off), play music and control his television.

In Joshua's learning environment he relies on support to write for him or control a laptop to access research. During his social time, Joshua needed support to play YouTube videos to show his friends. He began using Grid3 with voice activation during this academic year at college and the level of independence this gave him was significant. He was able to access the learning without full time support, conduct independent research and work/socialise more readily with his peers without support.

Unfortunately, due to his outdated technology, the device was no longer working which has halted Joshua's development of his independence. Having an iPad with

Grid3, controlled by voice activation, would allow him to continue to develop his independence both in his learning environment but also in other areas of his life.

Joshua was awarded a grant of £299 to fund the iPad.

2. Steven

A 54 year old who suffered a stroke and was transferred to the Hothfield Brain Injury and Rehab Centre.

His Speech and Language Therapist said that he now has speech difficulties and is not able to make his wants and needs known or to seek out information verbally or gesturally. His cognition is intact and has not been affected by this stroke, so he is very aware of his difficulties.

Steven cannot initiate speech or writing and he had been working on using an iPad with the Alpha Core grid set, which has a core vocabulary grid and qwerty keyboard; he was able to learn stock phrases and repeat these and is highly motivated to practice (which he does so in his room independently). It is hoped the more familiar he gets with the layout of the grid, and his language skills continue to develop, he will be able to create novel sentences independently.

Steven was using the rehab centre's iPad and did not have one of his own which meant that, once he was discharged from the centre, he would have no means to support his very limited communication.

Steven was awarded a grant of £370.59 to fund the iPad and case.

3. Maryam

A 6 year old who uses a wheel chair, although she can crawl. She understands some single words but does not have any verbal language. She can use her eyes and hands to point to things she wants. Her finger point is not accurate but she can use her whole hand to indicate what she wants.

Her Speech and Language Therapist (SLT) has trialled the use of different switches in school alongside communication charts and said that Maryam has been using a wobble switch in school successfully for the past few months. She was able to activate this one well, unlike some of the others. The switch has a recorded message on it that says “I have something to say” in order for Maryam to indicate her needs. The adult can then guide Maryam to use her communication charts to tell us whether she wants ‘more/ to stop/ help/ something different’.

Maryam’s mother was very keen to have a wobble switch at home so that she could build on developing Maryam’s communication at home.

Maryam was awarded a grant of £95.20 to fund the Wobble Switch.

4. Lleyton

A 7 year old who has been diagnosed with non-verbal autism and also suspected ADHD.

His Speech and Language Therapist said that Lleyton is very determined to communicate his needs and feelings and does this through sounds, facial expressions and some signs. He uses a low tech communication PECS book and is able to make requests using this for food and toys. However, it is clear from his responses to adults that he understands more than he can communicate.

They tried the TD Snap app with him and he responded well, learning quickly to press ‘more’ when he wanted something and finding food pages by himself. He also was very interested in the feelings page and was looking at the adults to see their facial expressions when he pressed buttons such as ‘happy/sad’ and copying the facial expressions himself. Lleyton is not currently able to express how he feels using his PECS book and this will be very important for him to do as his behaviour can sometimes be challenging.

His school provided him with an iPad to trial in school but it would be beneficial for Lleyton to have a device at home to enable him to become more used to the app and to communicate much more fully with his family.

Lleyton was awarded a grant of £369 fund the iPad with the TD Snap App

5. *Jovan*

A 33 year old who is severely disabled as a result of a brain injury caused by a knife attack. He needs 24 hour carer support, is in a powered wheelchair, has muscle spasms and suffers from extreme fatigue. His communication is impaired. He is cognitively impaired and he suffers from regular seizures.

Jovan attends Headway East London (a charity day centre supporting people with brain injuries) one day a week and his music co-ordinator told us that he uses an iPad Pro and has become very proficient with a music making app (Garage Band). He has created a large library of hip-hop songs over the last five years. Some of his music has been used on videos, at art exhibitions and he has collaborated with a poet and dancers for an event at the Barbican.

Jovan becoming increasingly frustrated by only being able to express himself artistically through music for one hour a week whilst at Headway and it would benefit him greatly if he had an iPad Pro of his own so he could continue with the music and also use other accessibility apps.

Jovan was awarded a grant of £889 to fund a refurbished iPad Pro.

6. *Lewis*

A 6 year old who is severely autistic. At present he is non-verbal and is unable to make his basic needs known, or share his feelings with his family and friends. This results in frustration which manifests as hitting, scratching and biting others. More recently, Lewis has begun to bite his hands to demonstrate his frustration at not being able to communicate his needs.

His mother said that Lewis is a kind boy who has demonstrated that he is keen to increase his interaction by communicating with his friends, family, teachers, and peers. He adores his 8 year old brother with whom he can only communicate with using cuddles.

Lewis's Speech and Language Therapist has reported that Lewis has been trialing an iPad with Snap and Core app at school and has responded positively to it so far, smiling when he hears the app speak a message and aware that this is a way for him to communicate.

Since the technology that Lewis is using at school, cannot be taken home, his family are unable to replicate and reinforce the work Lewis is doing while he is at home. It is hoped that, in the long term, this technology will help Lewis to connect with people around him, make his needs known and alleviate the frustration that has, so far, resulted in Lewis harming himself and others.

Lewis was awarded a grant of £498.96 to fund the iPad and protective case.

7. Lily

A 10 year old who is severely visually impaired and also has cerebral palsy and ASD. Having very little sight and only able to use one hand makes life extremely challenging and frustrating for her.

Her teacher reports that she uses a range of assistive technology at school to support her to access the curriculum. Her severe visual impairment makes it very difficult for her to access written curriculum material and to record her work. She finds it difficult to work independently and also finds the demands of the school curriculum tiring, as she has to work very hard to use the vision she has to access adapted materials. Lily finds completing homework tasks difficult as her school technology is not portable. She is not able to access materials in the same way at home as she does at school, and this hampers her independence and ability to complete tasks.

The school felt that Lily would benefit greatly from having an additional monitor to use with her iPad at home, so that she is able to enlarge homework tasks and curriculum material. This would enable her to work more independently and would support her to complete homework tasks now and over the coming years. She is academically capable but needs the support of assistive technology across all areas of the curriculum, both at home and at school.

Lily was awarded a grant of £270 to fund the large screen to attach to the iPad. (£200 of the previous year's Buzzacott grant was used towards this grant as Lily is a young person based in London. Also, the family made a donation of £70 as a contribution towards the cost).

8. Ali

A 16 year old who has a diagnosis of Duchenne Muscular Dystrophy (DMD) - a condition which causes progressive muscle weakness leading to reduced mobility and functional abilities.

Ali uses a wheelchair and wears splints in school and, although he is able to communicate confidently, he finds it difficult to understand and register information. He needs to have information relayed to him in small chunks. His parents help him with all his care needs and household tasks, he is able to use a mobile phone, but cannot lift his arms.

School staff say that Ali has grown so much as he has progressed through school; he has a cheerful disposition, great personality, a lovely group of friends, he is confident and friendly with others. Writing essays, course work and exams are very stressful for him and writing directly onto paper and a laptop is very tiring as his hands get tired because of his condition. He prefers to use a laptop, but using the keyboard is a challenge as he is a slow typist, and this, coupled with a need to spell check frequently, slows him down. Using the keyboard makes the whole process of writing disjointed and very stressful and he often has to ask for help.

Ali has tried the Nuance Dragon Professional Individual Speech Recognition software and his mother said that he was able to write without getting tired and that he could be himself. He felt it was great because he could also edit what he had written without touching the keyboard. He said that he has great ideas in his head and with this he can actually write them down without anyone making judgments. He also wants to keep a diary about his condition, his life, feelings and thoughts and this will be such an easy way to do that privately. His mother says that she believes this software will make a world of difference for Ali as he is a bright young man and that it will give him the encouragement to carry on in life.

Ali was awarded a grant of £679.99 to fund the Dragon Software. (The family made a donation of £100 as a contribution towards the cost).

9. Carlito

A 12 year old who is autistic with limited speech and learning difficulties. His understanding of language is far greater than his use of it and, at present, he can only express some of his wants and needs by using gestures, noises, eye contact and the odd short word. So he remains largely non-verbal.

Carlito attends a local Special Educational Needs school where he has had access to the school's shared communicational device and with it he has begun to initiate conversations, respond to questions and indicate choices. Unfortunately, as this aid belongs to the school, he has limited use of it.

Carlito lives at home with his mother and has great support socially and emotionally from family and close friends. He does try to engage with others during play and social activities but it's extremely hard work and frustrating for all concerned, especially for him and his mother knows that having a speech aid would transform his life.

The school's Speech and Language Therapist has said that obtaining a device of his own would improve his independence, confidence, education and give him a far

greater ability to participate and cope with life in general, all of which would be extremely beneficial to his overall health and wellbeing.

After trialling him on various devices she recommended that an iPad with Grid 3 software would be the most appropriate communicational device for all his current and foreseeable future needs.

Carlito was awarded a grant of £570 to partially fund the iPad with the Grid 3 software. (£70 of the previous Buzzacott grant and £500 of this year's Buzzacott was used towards this grant as Carlito is a young person based in London. The Sequal Trust provided the remaining funding of £1,000).

10. Dean

A 58 year old who has profound dyslexia and, despite having a high IQ, his is still unable to read or write basic words. He spent several years working as a case study with Marjorie Lishman of the Dyslexia Institute, aiding in training teachers to recognise dyslexia among students back in the 1990s. Dean's dyslexia has affected his daily life profoundly for his whole life, preventing him from acquiring qualifications and jobs, and ultimately affecting the trajectory of his life. This has kept him in manual work, despite having very strong engineering skills.

Up until recently Dean has been able to rely on his partner who, despite being physically disabled, was always paramount in supporting all management of life admin such as reading and assisting with bills and payments, making applications for benefits and all other written communication needs. Unfortunately, she suffered multiple strokes and a heart attack in 2018 and now, on top of her severe mobility issues, she is no longer able to realistically manage any paperwork.

As such, they are now struggling to manage the administrative side of supporting their household, often missing important information in letters and falling into arrears and debts with various bills. Dean has, in recent years, had quite a drop in self-worth, balancing being a primary caregiver and the isolation of that role, with further

barriers to accessing his hobbies, such as engineering, carpentry, music history and philosophy.

His care practitioner advised that Dean have a text to speech C-Pen scanner which will enable him to independently read bills and letters, preventing missing important payment deadlines and meetings. It will also enable him to manage his partner's medication by being able to read her prescriptions and allocating medications correctly at the correct times. Ultimately it will provide him with a better quality of life as a carer and in accessing literature that interests him for his hobbies.

Dean was awarded a grant of £276 to fund the C-Pen reader

Achievements and performance (May 2015 – May 2023)

Since its inception in May 2015, JSF has awarded grants totalling £61,108 to 60 beneficiaries.

Total income over this 8-year period (excluding £5,000 start-up funds donated directly by co-founders) amounted to £64,120.

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 this decreased to 95% due to a reduction in funds received and an increase in CAF Bank fees.