

# **JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 23, 2024 – MAY 22, 2025)**

**Charity Registration No. 1161371**

## **Trustees**

Sheila Saye, Mala Saye, Paul Davies

## **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 £2,644 was raised through fundraising activities, donations and grant awards.

£2,272 was raised through donations.

£372 was raised by fundraising activities and events carried out by:

- Surbiton High School activities

Operating costs which cover the CAF Bank and JustGiving platform fees amounted to £276. Fundraising event fees totalled £50 (deposit for the venue for 10<sup>th</sup> anniversary concert scheduled for 21 February 2025).

### Grants Awarded by JSF

A total of £7,112 was awarded to the following 12 beneficiaries:

Stacey, Daniel, Bradley, Aneesha, Austin, Ruchama, Jessica, Susan, Charles, Nazeem, David and Kaiden.

#### *1. Stacey (May 2024)*

A 48 year old who suffered a brain injury in 2002 and is non-verbal. She lives with her mother who is her only carer. Her mum has told us that Stacey has a good sense of humour, is sensitive, loving but is anxious with strangers. Stacey enjoys watching films and listening to music and loves to go shopping. Having had communication equipment for many years, which is no longer working and can't be repaired, it is very hard for Stacey. She has become used to being able to communicate when she is out and about and, in some ways it is harder for her now, than it was before she had her first device.

Without her device, she can still make her basic needs known but has lost her ability to express her more complex ideas. She was able, using her device, to communicate with people she didn't know and was able to participate in the community, e.g. ordering in a coffee shop or when on appointments to see medical professionals. This replacement speech aid would literally give her back her independence and the ability to socially interact.

Her condition is unlikely to improve and will likely deteriorate over time due to ageing. Stacey has been using a Lightwriter SL40 and has been supported by her Speech and Language Therapist who recommended the new version a Lightwriter SL50. Unfortunately there is no NHS funding available and she can't afford this equipment herself.

Stacey was awarded a grant of £1,000 towards the cost of the Lightwriter and the Sequal Trust funded the remainder.

## 2. *Daniel (May 2024)*

A 41 year old who was a Police Officer in the Metropolitan Police force. In 2021, during the Covid Pandemic, he was working on the front line emergency services when he contacted Covid Pneumonitis and suffered a Stroke. Following intensive and extensive treatment in hospital, he woke from an induced coma to discover he was paralysed on the left side of his body. In addition to his mobility challenges, the stroke left him with other brain damages consisting of: sight impairment, neurological seizures and cognitive damage.

He was using an old unreliable iPad which did not have a large enough screen to meet his visual requirements so he desperately needed a new large screen laptop to help with this and also a Track Ball Mouse for easier navigation due to his reduced hand mobility. Daniel and his family simply could not afford this themselves and he was referred to the Sequal Trust by his Occupational Therapist, backed by the Stroke Association, to see if the Trust could help get this equipment for a man who desperately needs it.

Daniel lives at home with his wife and she describes him as a loving, caring, sensitive husband. She said he tries very hard to remain upbeat but the stroke has, understandably, caused some long-term depression and he becomes frustrated at not being able to communicate effectively. She is hopeful that having a much more user-friendly laptop and mouse will open up his social world again and, more importantly, help with his mental health problems and general well-being.

Daniel was awarded a grant of £1,102 to fund the laptop with a track ball mouse.

### 3. *Bradley (September 2024)*

A 6 year old with complex health conditions: Cerebral Palsy, epilepsy, factor IX deficiency and dystonia.

Bradley is a very loving and caring child who enjoys swimming and would like to go on the stage when he is older. And he has said that he would like to help other children who have similar conditions. He is an intelligent boy and becomes frustrated when using paper-based communication aids.

Trials had been taking place on a communication device for two months and his mother said how amazing it was for him to be able to communicate. He was able to build sentences and communicate his wants and needs at home, at school and in his community. It increased his confidence and gave him the independence and control he really longs for.

The loaned piece of equipment was particularly useful when he had a surgical procedure as it gave him the confidence to communicate in a different environment. His Speech and Language Therapist (SLT) has recommended that, with the correct communication aid, his progress will continue. This will then have the potential to enhance his wellbeing, social interaction and ability to influence what is happening around him.

The recommended equipment is an iPad mini with TouchChat software and several others apps and accessories. It was felt that this package would best meet his current and foreseeable future needs. His family wants him to have the best chance in life but they simply cannot afford this equipment themselves.

Bradley was awarded a grant of £500 towards the cost of this system and The Sequal Trust funded the remainder.

#### 4. *Aneesha (September 2024)*

A 25 year old who suffers from Wilson's Disease, a rare genetic condition, which causes too much copper to accumulate in the body's organs. This affects Aneesha's speech, vision, dexterity, swallowing and her mental health.

She lives with her parents and has the full support of them and her brother and sister. This close family unit is very important to her as she is dependent on them. Her sister tells us that she is a caring, sensitive and a happy young lady who loves listening to audiobooks, going for walks and keeping in touch with family members.

Aneesha's Speech and Language Therapist (SLT) reported that she had been trialled on an iPad with the Predictable software which made a huge difference to her and, in effect, gave her a voice. She could communicate with her family and society, which increased her independence, self-esteem and confidence.

Having a device of her own would greatly improve her quality of life and means she can communicate with a much broader range of people. Her family are unable to afford this device themselves.

Aneesha was awarded a grant of £480 to fund the iPad with Predictable software and a rugged case.

#### 5. *Austin (September 2024)*

An 8 year old with Downs Syndrome, and who also suffers with autism, deafness and a visual impairment, all of which make communication extremely difficult.

His mother tells us that he is a happy, caring child who loves Lego duplo, cars, trains and anything with wheels.

Austin attends a school which specialises in helping children with severe learning difficulties reach their full potential. The school Speech and Language Therapist (SLT) has trialled Austin on an iPad with the Proloquo2Go app and reported that this made a huge difference to him. She believes that this device would allow him the opportunity to develop his communication skills and provide him with the means to express himself, improving confidence and independence over time.

Austin's family have managed to pay for the iPad themselves but they needed help to fund the communication app.

Austin was awarded a grant of £250 to fund the Prologue2Go app.

#### *6. Ruchama (September 2024)*

A 7 year old who was born with unbalanced chromosome translocation (a rare genetic disorder) which has caused severe global developmental delay. She also suffers with dystonia, epilepsy and has a heart condition.

Her mother tells us that she has a wonderful sense of humour and is very caring. She enjoys sensory play, and she loves music and dancing.

Ruchama attends a special school, and works closely with a Speech and Language Therapist (SLT) who tells us that Ruchama can only articulate a few words inconsistently. She had the use of a school iPad but she could not take this home with her, which effectively means she was leaving her voice in school each day. Without the use of a communication device she can become distressed as others do not understand what she wants.

The SLT feels that having a device of her own would give Ruchama continuity between school and home and would allow her the opportunity to develop her communicational skills and provide her with the means to express herself, improving her confidence and independence over time.

Ruchama was awarded a grant of £900 to fund an iPad with the TD Snap Communication app.

#### *7. Jessica (September 2024)*

A 41 year old who suffered a bleed on the brain which later resulted in a stroke. She lost all movement on her right side and is only able to verbalise Yes-No. After receiving initial care on the stroke ward at Mount Gould Hospital, Jessica is now in a nursing home placement in Plymouth. Her Speech and Language Therapist (SLT) reports that there might be some potential for improvement with therapy input but she is unlikely to regain full verbal output or use of right limbs. A recent trial conducted by the SLT on an iPad with the Grid App was very successful and meant that she could use it to make requests and communicate her wants and needs.

Jessica was a healthy and active person before she had the stroke and it is hoped that after rehabilitation and with the right support in place she may be able to return home. Having this device would give her the ability to socialise and communicate and give her a sense of independence. The SLT has suggested that the iPad with grid for iPad would be the best equipment for Jessica, both now and in the future.

Jessica was awarded a grant of £750 to fund an iPad with the Grid App and case.

#### *8. Susan (May 2025)*

A 68 year old who was diagnosed with cancer of the voice box in November 2013, and has fought to keep her voice. Unfortunately, she has had to have a laryngectomy (removal of the voice box). Susan lives with and is supported by her partner, with her daughter visiting regularly. She describes herself as a kind and caring person, who is willing to help others. Susan really loves to be sociable but after surgery she is unable to express herself or interact with others to share her thoughts and feelings with them. She is finding this change extremely frustrating to cope with.

Susan's Speech and Language Therapist (SLT) reports that she had a trial on the BlomSinger EL2000 which has made a huge difference to her and in effect given her a voice. She was able to communicate with society, increasing her independence,

self-esteem and confidence. Having a device of her own would greatly improve her quality of life and mean she can communicate with a much broader range of people. Her family are unable to afford this device themselves and have turned to us for help.

Susan was awarded a grant of £370 towards the cost of the BlomSinger EL2000 and the Sequal Trust funded the remainder.

#### *9. Charles (May 2025)*

A 29 year old who has a diagnosis of Cerebral Palsy and has learning difficulties; he has been disabled since birth and is non-verbal. Charles lives with his Mum and has a very close supportive family who all play a big part in his life. His Mum tells us that he is a very happy, sensitive and funny young man. Charles and his Mum have joined Chickenshed theatre company which she says has changed his life. He attends 3 or 4 times a week and if there is a show he is there every day. Charles loves being part of the group and to be an accepted and valued member. Having his own piece of equipment will allow him to participate even further. Charles also enjoys taking trips on steam trains and has ridden on the Flying Scotsman.

His Speech and Language Therapist (SLT) said that he has been loaned a piece of equipment which is due to be returned shortly. The equipment has improved his behaviour, as he is less frustrated as he is able to communicate what his needs are, especially when he is in pain. It has also relieved his frustrations when going to medical appointments.

Charles was awarded a grant of £450 to fund an iPad, the GoTalkNow app and a rugged case.

#### *10. Nazeem May 2025*

An 8 year old with autism, Global Development Disorder and a speech delay, and as is common with autism he is non-verbal, which makes communication extremely difficult for him.



He lives with his Mum and his younger sister and has a strong and supportive family network. They describe him as a bright, caring and loving child with a sensitive and gentle nature and he brings joy to those around him. Nazeem enjoys listening to music and spending time outdoors, he loves water and sensory play, which helps him relax and engage with the world. Nazeem finds it very difficult if his daily routine changes and he particularly dislikes any loud noises.

Nazeem recently had a trial on a loaned piece of equipment which was very successful and his Mum said that it felt like he finally had a voice. His Speech and Language Therapist tells us that if he had his own device, it would allow him to express himself more freely. A communication device will improve his quality of life and support his developmental needs.

Nazeem was awarded a grant of £540 to fund an iPad with Grid for iPad and a rugged case.

#### *11. David (May 2025)*

A 49 year old who had a Haemorrhagic stroke 5 years ago which has resulted in Aphasia and Apraxia, causing him severe impairment of linguistic capabilities. He lives with his wife and two children and his wife describes him as a very caring positive person. Before his stroke, David was an IT Director of his own company, who loved playing football and was an expert at fixing computers.

David's Speech and Language Therapist tells us that his condition is unlikely to improve but the equipment that she is recommending will give him an effective way of communicating. It would have set phrases/sentences which will allow him to communicate with others in a variety of settings. Family would be able to update these as needed and it would help increase his confidence when socialising with others.

David was awarded a grant of £420 to fund an iPad with the text to speech app and a standing case.

## 12. *Kaiden (May 2025)*

A 19 year old who has a diagnosis of Angelman Syndrome. This is a genetic disorder which causes problems with speech and balance, mental disability, and sometimes, seizures. Like most people with this syndrome, Kaiden requires constant care.

The Sequal Trust had first supplied Kaiden with a communication aid in 2018 but this has now deteriorated and urgently needs to be replaced. Kaiden lives with his Mum, who is his main carer and she describes him as a happy young man who loves watching You Tube, swimming and being taken out. Having a communication device has been life-changing for Kaiden. It allows him to interact with family, friends and peers and has had a huge impact on his confidence, independence and mental wellbeing.

Kaiden was awarded a grant of £350 to fund an iPad 10.2 with a rugged case

### **Achievements and performance (May 2015 – May 2025)**

#### Financial Summary

Since its inception in May 2015, JSF has awarded grants totalling £75,794 to 76 beneficiaries.

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

This financial year, operating costs and fundraising event fees represented 12% of our total income.

#### Business Model

Last year, the Trustees agreed to a change in our business/operating model by forging a collaboration with the Sequal Trust who have very similar charity objectives to JSF.

## *Background*

From a JSF perspective, the key drivers for this decision are to improve our effectiveness, benefit from increased purchasing power and to make better use of our very limited resources. Also, by working with another charity, we can reach a more beneficiaries with a wider range of disabilities requiring support. The Sequal Trust has a very robust assessment process which enables them to properly vet potential beneficiaries and they also work closely with Speech and Language Therapists to ensure that the recommended equipment is best suited to individual needs.

From an operational perspective, this means that JSF now receives grant requests directly from the Sequal Trust instead of from individual applicants. Individuals who approach JSF directly are now referred to the Sequal Trust for the assessment process.

The JSF Trustees continue to provide approval, following which we now make the payment directly to Sequal Trust and they handle the logistics of purchasing and delivery.

All devices are issued on a lifelong loan basis which allows the Sequal Trust to retain responsibility for all technical maintenance and repairs to the equipment and so support is ongoing. They also provide phone support also which eases the worries for individuals.

Also, as the Sequal Trust now has 3 people working in the office, they have introduced a "full circle" follow-up system. They will contact beneficiaries on a regular basis to ensure that everything is working well for them and that they are making the best use of the assistive technology. And they hope they will be able to encourage more updates from the client with photos and progress.

Updates are passed on to JSF in cases where we have provided grants, and that will enable us to continue to include these on the JSF website and in our Newsletters. This means that our supporters can still see the direct impact of their fundraising and donations. We know that our donors are attracted to JSF because we can provide this level of transparency.

### *Update*

Since forging this relationship with the Sequal Trust we have funded 12 grant requests. JSF continues to receive grant requests, but we now send them a response directing them to the Sequal Trust, requesting that they mention JSF as the referral so that their request does not get lost or overlooked. This issue is being addressed by the Trust but is still a work in progress.

Also, through regular contact with the Sequal Trust, we ensure that we get follow up photos and stories from our beneficiaries so that we can add this to our website and newsletters. This is to ensure that our donors and supporters continue to receive updates on how their funds are being put to use. While we are beginning to receive photos and follow ups again, this is still a work in progress.