

JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 23, 2025 – MAY 22, 2026)

Charity Registration No. 1161371

Trustees

Sheila Saye, Mala Saye, 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

Receipts: Fundraising, Donations and Grant Awards

Total receipts: £12,704

Donations: £3,638

Fundraising Event: £9,066

Payments: Grants, Fundraising Event and Operating Costs

Total Payments: £10,718

Grants: £9,297

Fundraising Event (Kingston Church hire, TEN License and Public Liability Insurance): £944

Operating Costs: £477

- CAF Bank Fees: £60
- JustGiving Platform: £216
- Website Hosting Security: £201

Grants Awarded by JSF

A total of £9,297 was awarded to the following 11 beneficiaries:

Victoria, Nayel, Bella, Zakariyah, Leo, Sean, Neil, Kieran, Seashell Trust, Swanick School and Sports College and Side by Side.

1. *Bella (November 2025)*

A 10 year old who has a diagnosis of Wolf-Hirschhorn Syndrome and duplication of short arm chromosome 8. Bella also has a cleft palate and presents with a complex and highly disordered profile of severe speech and language difficulties associated with her underlying diagnoses which make it difficult for her to make herself understood.

Bella lives at home with her parents and her younger sister and attends a specialist speech and language school which provides intensive support, structure and therapy.

Bella's mum tells us that she is a creative and curious young lady who thrives when she is engaged in hands-on playful activities. She especially enjoys dancing and is increasingly showing interest in using technology to support her communication, especially when it gives her independence to express her own idea and choices. One of Bella's biggest achievements is beginning to type short phrases and use symbols to express herself, which is a huge step given her complex speech and language needs.

The Speech and Language Therapist (SLT) who works with Bella at her school reports that she is a highly sociable and communicative young person. She has opportunities to use a school laptop and Clicker 8 software during structured sessions in school and both the class team and her family feel that Bella would benefit massively from having her own equipment. It would give her continuity between school and home and support her in all areas going forward.

Bella was awarded a grant of £700 to fund a laptop with a lower case colour coded keyboard, software and printer.

2. *Nayel (November 2025)*

A 6 year old who has autism and is non-verbal. Nayel lives with his mum, dad and sister and has help from his grandparents. His mum tells us that he is a very loving, happy little boy who loves swimming, trampolining and going to the park.

Nayel attends a specialist school which caters for pupils with complex needs. His SLT reports that he is highly motivated by the class iPad with the Proloquo2go communication app and will use it to make his wants and needs known. She believes if he had the same app to use with the home iPad it would provide continuity between school and home and support his progress. At present Nayel is working below age related expectations but with the correct interventions it is believed his communication skills will improve.

Nayel was awarded a grant of £250 to fund the Proloquo2go app.

3. *Victoria (November 2025)*

A 52 year old who suffered from a severe stroke in January 2024 which resulted in the loss of her speech and the use of the right-hand side of her body. Prior to this she was a happy, loving and sociable wife and mother whose hobbies included interior design, art and keep fit. Victoria is now unable to continue working and is being supported by her elderly parents and carers.

Since being discharged from hospital, Victoria has had regular therapy aimed at using a total communication approach to allow her to express her needs independently. She has been using a ClaroCom app on an iPad with good results. Her SLT told us that it increased her confidence and independence and meant she could communicate her needs with family and carers. Unfortunately, Victoria did not possess her own iPad and the available loan was only for a limited period.

Victoria was awarded a grant of £360 to fund the iPad and the Clarocom app.

4. Zakariyah (March 2026)

A 15 year old who has developmental delays, autism and is non-verbal. He lives with his mum, dad and an older and a younger sister, who are very supportive. His mum describes him as a sensitive, emotional, loving young man, but he is upset easily. Zakariyah loves to go swimming, playing on his trampoline and watching kids' programs.

Zakariyah's SLT told us that he communicates using boards in school and an iPad which he shares with another pupil, and it has to stay at school. However, the boards don't always have the vocabulary he needs which causes him high levels of frustration. Having a communication aid will improve his ability to communicate clearly, to be able to share his opinions and requests and to have his needs met. This will help reduce his frustration and improve his wellbeing. Zakariyah will also be able to take part in learning activities with greater independence and success.

Zakariyah was awarded a grant of £490 to fund an iPad with the Grid app and case.

5. Leo (March 2026)

A 14 year old who has chromosome 5 genetic disorder, severe apraxia of speech and global developmental impairment. Leo has been disabled since birth and his parents tell us that he is a happy and loving youngster who loves swimming, looking at picture books, and musical toys. Their aim is for him to continue achieving to his best potential.

Leo attends the Side by Side school and his SLT told us that he is highly motivated to communicate and makes visible attempts to talk but when he opens his mouth, nothing comes out. This is extremely frustrating for him and it affects his emotional well-being. She felt that having a tech device of his own to communicate would transform Leo's life both at home and school, he would be able to connect with others and communicate clearly what he is thinking.

Leo was awarded a grant of £598 to fund an iPad with the Prologuo2Go App.

6. Sean (March 2026)

A 12 year old who has autism and is non-verbal. He lives with his dad and brother. His dad describes him as a happy child with a great sense of humour who loves playing with Lego, drawing and trips out. Sean previously had an iPad and software from the Sequal Trust which he has come to rely on for all his communication needs but, unfortunately, over time, this started to fail and has become unreliable.

Sean attends a special school which provides for secondary aged students with a diverse range of special needs. His school SLT told us that Sean is very dependent on his communication device and can become frustrated when it lets him down. She felt that to keep up with his education and to be able to communicate with those around him, he needed a new reliable device.

Sean was awarded a grant of £405 to fund a new iPad with a rugged case.

7. Neil (March 2026)

A 52 year old who suffered a stroke in 2020 which caused severe damage to the area of the brain responsible for speech. Neil lives at home with his brother and sister-in-law and has help from a team of carers. His family describe him as a sensitive and creative person, who can become nostalgic and frustrated at his inability to make himself understood.

Neil's SLT reports that he has no voice and is unable to communicate verbally. His only means of communication is gesturing and this is unlikely to change in the future. She has conducted a recent trial with an iPad with Grid for iPad software which has been very successful and she felt that if Neil had a device of his own it would greatly improve his quality of life and mean he can communicate with a much broader range of people. His family are unable to afford this device themselves and sought our help.

Neil was awarded a grant of £520 to fund an iPad with the Grid app and case.

8. Kieran (March 2026)

A 21 year old who lives at home with his mum and dad and has been diagnosed with autism, epilepsy and learning and behavioural difficulties.

Kieran previously had a laptop and software from the Sequal Trust which he has come to rely on for all his communication needs but unfortunately, over time, this started to fail and has become unreliable. Kieran is in college on a four day per week placement and he attends a specialised centre for one day a week.

His parents are very supportive and say that he is normally a happy young man but can become extremely upset and emotional when he can't make himself understood. He enjoys accessing the internet to watch YouTube and play games. They simply want him to have the best chances in life available to help him reach his full potential. Having a replacement piece of equipment will continue to improve his communicational skills, education and relieve some of the frustration he currently feels.

Kieran was awarded a grant of £480 to fund a laptop and software.

9. *Seashell Trust (March 2026)*

Seashell supports children and young people aged 4–25 with the most complex needs in the UK. As one of only a handful of specialist providers, they serve young people from over 34 Local Authorities because they cannot access the expert care, support, and education they need locally.

The students at Seashell are among the most vulnerable and disadvantaged, living with profound, multiple disabilities and life-limiting conditions. These include severe learning and communication difficulties, multi-sensory impairments, neurological conditions such as autism, physical disabilities and mobility challenges, acute health issues, and rare genetic syndromes.

By focusing exclusively on low-incidence, high-need cases, they work with young people who have extremely rare and complex conditions. For example, one student has Syngap1 – a genetic disorder causing intellectual disabilities, speech and motor delays, epilepsy, behavioural challenges, and vision loss – only 3 UK cases exist.

Many of the children and young people have multiple and complex impairments that make interacting with the world extremely challenging. Some are non-verbal or have limited communication; others face sensory, physical, or cognitive barriers that restrict independence, learning, and social connection. These challenges often lead to social isolation and prevent students from developing vital life, communication, and social skills.

Assistive technology in the form of iPads provide an essential tool for breaking down barriers to communication and enabling students to connect, form relationships, and build confidence and independence. The impact of the use of iPads is best told through the stories of individual students at Seashell, like Arthur: Arthur is profoundly deaf and, due to an absence of auditory nerves, cannot be aided and has no access to sound. He also has Cortical Visual Impairment (CVI), causing his vision to fluctuate significantly, sometimes minute to minute, and leading to visual fatigue. When Arthur arrived at Seashell, he had very limited functional communication.

To support Arthur's understanding and reduce anxiety, staff introduced programmes on an iPad tailored to his needs. These programmes helped Arthur make choices, anticipate upcoming activities, and understand transitions in a clear, accessible way. The visual and interactive nature of the iPad reduced his reliance on inconsistent signing and gave him a reliable communication tool. The use of iPad programmes significantly improved his understanding of routines and transitions, reducing anxiety and promoting emotional regulation. Today, Arthur can engage more confidently, make choices, and participate in activities with greater independence and calm.

Seashell was awarded to a grant of £1,160 to fund 4 iPads with cases and screen protection.

10. Swanwick School and Sports College (March 2026)

All the students at Swanick School and Sports College pupils present with a wide range of complex Special Educational Needs and Disabilities. These include autism, moderate to severe learning difficulties, specific learning difficulties, speech, language and communication needs, physical disabilities, and visual/hearing impairments.

Many of the students experience difficulties understanding language, expressing themselves, interpreting social cues, and managing social interactions. This can lead to frustration, reduced confidence, and challenges forming relationships.

A significant number of students have moderate to severe learning difficulties, which affect their ability to process information, retain knowledge, and work independently. The students are all significantly below chronological expectations and tasks that their peers in mainstream might complete quickly can require significant repetition, structure, and scaffolding. This impacts progress across the curriculum and increases reliance on tailored teaching and assistive technology.

Approved C-Pen exam reader scanning pens allow students better access to exam text. They also provide support with reading and writing throughout the school year

in classrooms, allowing those who need them for exams the opportunity to familiarise themselves with the technology over time.

Equipping learners with exam reader scanning pens, will remove barriers to accessing the curriculum and assessments, create more equitable exam conditions, and help students demonstrate their true knowledge and abilities. This investment will have long-term benefits for both academic outcomes and student wellbeing, while delivering a sustainable, high-impact solution across the school community.

The school trialled three loaned pens in school for a month with great successes reported from both staff and students.

Swanwick School was awarded a grant of £2,300 to fund 10 C-Pen Exam Reader Scanning Pens.

11. *Side by Side (May 2026)*

Side by Side is an independent special school for children and young people aged 2-19 from Hackney and Haringey. They support children and young people with a range of special educational needs and disabilities (SEND), including autism, Down syndrome, severe and profound learning difficulties, sensory impairments, and complex communication needs. Many of the children are non-verbal or minimally verbal, requiring specialist support to communicate effectively.

Communication barriers mean that thoughts, feelings, and needs remain unexpressed. This often leads to frustration, anxiety, and social isolation. Children may struggle to form relationships, participate in learning, or make even simple choices about their day.

By addressing communication barriers, the school is not only supporting learning, but also emotional wellbeing, confidence, and inclusion in the world around them.

The school was seeking funding to purchase 5 specialist iPads, each with durable protective cases and Makaton-based communication software/apps, to be used as assistive communication devices. The purchase of new iPads would support their Makaton approach. Makaton is a language programme that combines signs,

symbols, and speech to enable children to communicate. It supports the development of essential communication skills such as attention and listening, comprehension, memory, recall, and expression.

Side by Side were already using iPads successfully, including those funded by the Janki Saye Foundation in 2024. These devices continue to have a profound and lasting impact, and they were keen to extend this opportunity to more children.

Based on the success they have already seen, they are committed to giving more children this life-changing opportunity.

Side by Side were awarded a grant of £2,034 (the total cost of the project was £2,434 but they were able to secure £400 from another charity).

Achievements and performance (May 2015 – May 2026)

Financial Summary

Since its launch in May 2015, JSF has awarded grants totalling £85,010 to 87 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, we celebrated our 10th anniversary with a fundraising concert. The event minus the costs (church hall hire, licenses etc) raised £8,122. However donations relating to the event, brought this total closer to £9,200. We owe thanks to Tom Cridland and his band, the staff at St. John's Church, Michael and his volunteers for running the bar and raffle and all those who provided raffle prizes and all those who made donations.

This year, operating costs represented 3.75% of our total income.

Business Model

In 2024, 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.

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 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.

JSF now receives grant requests directly from the Sequal Trust. Individuals who approach JSF directly are referred to the Sequal Trust for the assessment process. The JSF Trustees continue to provide approval, following which we 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 and they 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.

The Sequal Trust provides us with updates on JSF beneficiaries so that we can continue to include these on our website and 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

JSF continues to receive grant requests but, in the case of individual requests, 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. We are still looking at the metrics to determine how many requests originating from JSF are being processed.

JSF also receives requests from schools and colleges and organisations supporting young people. We, the Trustees, agreed that we should continue to review these independently, as the Sequal Trust only processes requests from individuals. This is working well, and as can be seen in this report, this year, we issued grants to the Swanwick School, the Seashell Trust and Side by Side.