

JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 23, 2020 – MAY 22, 2021)

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 £6,166 was raised through fundraising activities, donations and grant awards.

£5,070 was raised through donations.

£1,096 was raised by the following fundraising activities and events:

- Surbiton High School activities
- Kings College School activities
- Marathon 2020 refund

Grants Awarded by JSF

A total of £9,522 to the following 9 beneficiaries:

1. Wayne

This award to fund an Orcam MyEye device was made in our last financial year but, due to the pandemic, the cheque for £1,500 was not cashed until July 2020 and was not included in last year's figures.

2. Ellis

An 11 year old with severe visual impairments, global developmental delay and hydrocephalus for which he has had to have several brain surgeries (shunt revisions).

His major challenges are his ability to access information due to his lack of sight. He struggles to read and engage with the world compared to other children his age.

His mother wanted him to be able to access information online to help advance his education and help him become more independent. He spends time with his uncle and has been able to use his laptop to great effect.

Having a similar laptop of his own would enable him to use the accessibility features (voice over text etc.) so he could do his schoolwork and keep up with the other children.

Ellis was awarded a grant of £999 to fund a Macbook Air.

3. Aiden

A 5 year old and, like his brother Ellis, he has also has hydrocephalus and has already had 5 brain surgeries (shunt revisions). He also has autism and sensory impairments.

He struggles with everyday interactions and his major challenges are dealing with new environments, new people and unfamiliar routines.

At school he had demonstrated great skills with technology and used an iPad with apps recommended by his paediatrician. It helped him learn and play in a way he found engaging.

Based on this, his mother and the paediatrician felt that if Aiden had his own iPad set up specifically for his needs, it would help with his home projects and provide him with opportunities to learn new skills and better interact with those around him.

Aiden was awarded a grant of £479 to fund an iPad Air.

4. Livability Nash College

Livability is a charity that supports people with disabilities and helps them connect with their communities.

Nash College, which is part of the Livability family of services, is a specialist further education college catering for students with a range of Special Educational Needs and Disabilities (SEND).

Their approach is to place particular emphasis on personalised learning, facilitating a range of communication needs and supporting students in the community and with future vocational opportunities.

The college identified the need for assistive technology as an important tool to help the students expand their communication skills and express themselves more independently.

As a starting point, they chose the Skyle iPad Pro device which would enable the students to control the iPad completely with their eyes, providing them with access to

a wide range of applications designed to assist and augment communication. This could support up to 30 students.

Livability approached JSF to see if there was an opportunity to collaborate on this project. We welcomed this opportunity to help these young people on their path to lead more independent and fulfilling lives.

Livability Nash College was awarded a grant of 2,973 to fund the Skyle and iPad Pro.

5. Terry

A 33 year old with autism and difficulties communicating on all levels: reading, writing and social relationships. He struggles with completing tasks and with all things financial – he requires constant supervision to carry out these tasks.

Terry had a short trial of the C-Pen (text to speech scanner) and during this time he was able to read labels of items that he was cooking for dinner and he was able to prepare his meal without supervision. He used the pen to read birthday cards from his family and to read the local newsletter. He loves comics and he was able to read these unaided.

Terry's Housing Support Worker and his mum could see that having the C-Pen would provide him with the independence to do things for himself without constant supervision. It would give him confidence in his abilities to do things for himself and to enjoy his hobbies.

Terry was awarded a grant of £240 to fund the C-Pen

6. Andrew

A 36 year old with severe spinal and brain injury and who is now a tetraplegic. He is currently in hospital but due to return to a new home soon. He will never recover, which means he will need care staff to help him with every day basic needs.

He can use his hands but has difficulty with a keyboard. But he is able to use a tablet. With a tablet he can control lights, tv, heating etc. which means he will be less dependent on care staff and he will also be able to keep in touch with family and friends.

Andrew wants to be able to work again and give something back to the community. He hopes to start work in graphic design and advertising as soon as possible. He was using a very basic tablet, but it lacked the functionality he needed to do his work and to install the apps that will provide him with more independence.

Andrew was awarded a grant of £912 to fund an iPad Pro.

7. Mia

A 10 year old with Tuberous Sclerosis and epilepsy. She is non-verbal and her family and teachers having been using a basic iPad app to communicate with her but she finds it frustrating as she is not always able to communicate her needs and preferences.

Her Speech and Language Therapist had been using a more advanced app called Snap Core First app which runs on an iPad and Mia responded very well. She had been set up with some core words and she understood the cause and effect of these words – such as Stop and More!

Mia's mother was very keen for Mia to have access to an iPad with this software at home, so that she could further develop her communication skills and enable her to better interact with her family.

Mia was awarded a grant of £429 to fund the iPad and Snap Core First app.

8. *Ian*

A 40 year old who has been registered blind since 2013 as a result of a genetic condition called Leber's Hereditary Optic Neuropathy and he also has MS. He is unable to read text at all, even with magnification and his vision is very blurred and out of focus. His MS impacts his mobility, and the combined effects of his conditions affect his ability to get out and about independently and also affect his ability to read, socialise, recognise people and cook.

He lives with his wife who helps him but he is trying to achieve as much independence as he can.

When Ian lost his sight he felt that he wouldn't be able to use a computer again and, for a couple years, he didn't even try as he couldn't see the screen and keyboard. Then, 2 years ago, he engaged with the services of sight loss charities and he met other visually impaired people who made him aware of technologies that could help him.

Now he can carry out some tasks using a smartphone with voice activated services, but he wants to improve his skills and knowledge and complete some online courses that will enable him to get back into work. He had previously been working in a warehouse but this became difficult due to his mobility problems.

He doesn't know if his goal is realistic, but his support worker from the Sight Loss Association says that he has been doing some voluntary work and feels that he has a lot to offer.

Ian has tried using a laptop with the Narrator software and this has made it possible for him to access and read online documents and websites etc. If he had a laptop with this software at home, he could work towards his goal and could also complete tasks such as online shopping and banking.

Ian was awarded a grant of £630 to fund the laptop and Narrator software.

9. Stratton Primary School

A Special Education Needs and Disabilities (SEND) school who identified the need for Assistive Technology to help support their students with remote learning and in the classroom

Two children were assessed by Tech Ability who provided suggestions as to assistive technology that would help support these children as well as other pupils with similar profiles.

The school had been fortunate to receive devices and connectivity support from the Government during the periods of remote learning, however this has been in the form of laptops or Chromebooks. The head teacher felt that they could help their children make significant progress if they had access to more assistive technology to complement these devices.

The desire was to be able to purchase headsets for individual children with cognition and learning difficulties to be able to dictate their sentences and hear the text read back.

It was also recommended that they have a range of different key board styles for children who find it difficult to locate the keys on a conventional keyboard.

And they also wished to purchase the Clicker app to help pupils who are unable to record their thoughts without pictorial support. Clicker had been recommended to the school as a resource that would help these children with their independence and success with writing.

Stratton School were awarded a grant of £1,360 to fund 30 headsets, 10 special keyboards and a 3 year subscription of the Clicker app for 10 devices.

Achievements and performance (May 2015 – May 2022)

Since its inception in May 2015, JSF has awarded grants totalling £51,655 to 44 beneficiaries.

This past year saw a slight shift in direction as we awarded 2 grants to educational establishments supporting students with Special Educational Needs and Disabilities. . These were good opportunities to maximise grant awards as each grant would support multiple individuals.

Total income over this 6 year period (excluding £5,000 start-up funds donated directly by co-founders) amounted to £52,879.

Because the charity relies on volunteers, has no overheads and runs with minimal operating costs, to date 98% of our total income went directly towards grant awards.