

## **JANKI SAYE FOUNDATION ANNUAL REPORT (MAY 23, 2019 – MAY 22, 2020)**

**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 £6,709 was raised through fundraising activities, donations, grant awards and limited sales of calendars.

£1,267 was raised through direct donations.

£4,942 was raised by the following fundraising activities and events:

- Royal Parks Half Marathon
- London Marathon (to be run in 2021)
- Swimathon
- Surbiton High School activities

- Kings College School activities
- Zayan's Innovation

A £500 grant was awarded by Buzzacott to benefit a young person living in a London borough.

### Grants Awarded by JSF

A total of £5,619 to the following 8 beneficiaries:

#### 1. *Ifti*

A 16 year old who is autistic and has severe learning difficulties. He is non-verbal and finds it difficult to get his message across to make requests and communicate his basic needs without visual support.

When Ifti is in the community or with less familiar adults, he is unable to communicate with them. He tries to communicate using eye contact and gestures, but is unable to make himself understood.

Ifti attends a special school, where he has been using the Picture Exchange Communications System (PECS) and, more recently, the Clicker Communications app on an iPad mini. His Speech and Language Therapist found that he responded well to this app and has been gradually building up a vocabulary and forming short sentences.

It was felt that, if Ifti were to have access to the iPad mini with the Clicker app at all times, he would have a voice throughout the day to communicate with his family and others in the community. It would build up his confidence, improve his quality of life and allow him to continue his development when he leaves this school in September to go to a new school. The new school will not have assistive technology.

*Ifti was awarded a grant of £632 to fund the iPad and the Clicker Communications app.*

## 2. *Iziah*

A 16 year old who is autistic and has severe learning difficulties. He is non-verbal and finds it difficult to get his message across to make requests and communicate his basic needs without visual support.

Iziah attended a special school in Hackney where he had been using the Clicker Communication app on an iPad mini. His Speech and Language Therapist found that he demonstrated a great aptitude with the Clicker app and was able to generate requests and sentences. She observed that he was becoming increasingly independent.

As Iziah is now 16, he will be going to a new school which does not provide assistive technology. He would benefit from having his own iPad mini with the communications software which will enable him to have a voice throughout the day at his new school, at home and in the community.

Again, this would give him the tools to further develop and improve his quality of life

*Iziah was awarded a grant of £612 to fund the iPad mini, a protective case and the Clicker Communications app.*

## 3. *William*

A 15 year old who has Autistic Spectrum Disorder and learning difficulties. He is non-verbal and mainly communicates using behaviour and gestures. He is able to understand much more than he is able to communicate which leads to high levels of frustration for him and those trying to interact with him.

William was assessed at school by his Speech and Language Therapist and has been accessing an iPad with the Clicker Communication app at the school since March 2018. While he has made good progress at school he is unable to communicate his needs at home.

It had not been possible for William to meet targets set for him outside of the school setting without having access to an iPad at home so he was put forward for a trial with a loaned device for a 2-week period during the summer break. After 2 weeks, William had managed to meet his targets and his mother reported that he was able to ask her for specific things without her having to guess.

Next year, when he is 16, William will have to leave this school and will no longer have access to the iPad and communications software. Having a device of his own would further support William's independence as he gets older. Without this he is unable to communicate leaving him socially isolated which obviously impacts on his quality of life.

*William was awarded a grant of £599 to fund the iPad mini, and the Clicker Communications app.*

#### 4. Stephen

A 59 year old who suffered a stroke in 2014. He was in hospital for 4.5 months, was paralysed on the right side, lost his speech and had no understanding of even the simplest of instructions.

5 years later he still receives therapy but has made remarkable progress. Despite having no speech or understanding for 18 months, he is now able to work with minimal help on pronunciation and reading. Since accessing the speech programs set up by his Speech and Language Therapists, his vocabulary has greatly improved.

While he is totally reliant on his wife for all basic aspects of living, he continues to work hard on his recovery.

The old laptop that he had been using completely stopped functioning and could not be repaired. So in order to be able to continue with his reading and practice his speech, Stephen needed a new laptop, ideally with a touchscreen.

His wife says the fact that she can even consider this type of technology is remarkable given the severity of the stroke. Recovery is very very slow, but Stephen was so determined right from the very first day and she has promised to give him every chance so that he can get as well as he possible can.

*Stephen was awarded a grant of £449 to fund the laptop.*

His wife sent us this message *“Thank you so very much....I honestly can’t thank you enough for helping us with this. What a wonderful gift you have given my husband. Thank you for putting that smile on my husband’s face”*

## 5. *Louis*

A 9 year old and with Downs Syndrome. He has very delayed motor skills and finds it difficult to form and write letters and numbers. He has a short attention span and limited verbal communication. It is very difficult for people who do not Louis to understand what he trying to say.

Louis has found it hard to operate a traditional computer, even with a special mouse. He has specialist support from a centre for children with autism and they lent him an iPad. This helped his motivation and really helped to hold his attention and enhance his learning experience.

Having his own iPad with the Clicker Connect app, as recommended by his Speech and Language Therapist, which Louis can use at school and at home, would enable him to express himself and become an independent learner across all subjects. He would be able to form his own sentences which will help to improve his level of communication and give him more confidence.

*Louis was awarded a grant of £361 to fund the iPad and the Clicker Connect app.*

## 6. Emaan

A 9 year old with lissencephaly and significant developmental delay. She is wheelchair bound and has some arm movements but these are not always controlled. She has more controlled movement of her head and eyes. She is non-verbal and expresses how she feels through her facial expressions and sounds.

Emaan had been trying to use a range of means to communicate, including eye contact, facial expressions, reaching out to others and objects. She also had some low tech communication devices such as symbol charts and symbols. But all of these devices relied on assistance from others.

She then trialled an EyeGaze device, practicing using her eye pointing and fixing on a range of different games. She did well with this and it was felt that if she had full time access to an EyeGaze device, she would be able to continue to practice all of her skills with games. And then she would be able to develop some independent communication to express her needs and wants and thoughts, and wouldn't be so reliant on others to help her to communicate.

Her Speech and Language therapist said this would be incredibly important for Emaan in the future she could start on her journey of being an independent communicator.

Another charity "Wipe Your Tears" were able to provide £3,000 towards the cost of this equipment.

*Emaan was awarded a grant of £1,667 to fund the remaining cost of the EyeGaze device. (Due to the Covid-19 pandemic, Wipe Your Tears have not yet made their payment, so Emaan is still waiting for the technology)*

## 7. Wayne

A 37 year old who has been registered blind since 2011 and also has type 1 diabetes. He has also had pancreas and kidney transplants.

Wayne relies on a guide dog who can help him to follow practiced routes and he struggles to carry out daily tasks such as cooking, reading, shopping, choosing clothes, taking his medication, recognising people, reading body language and social cues, and paying for things.

Wayne lives on his own and wanted to be as independent as he can. He has some daily living equipment that helps with making drinks and some meals but he still he has to rely on family, particularly his elderly parents and he regularly has to video call them to ask them to identify things for him.

Wayne was very dependent on his mother to help with medication which is required twice a day following his transplants and he was worried as to what would happen if she was not around to help

Wayne trialled the Orcam MyEye ( a wearable text to speech reading device), and he felt that it helped with navigation, reading street signs, reading shop signs and signs at the train or bus station. It also helped with shopping, as the device can read labels and barcodes. Having the Orcam at home also helps with reading cooking instruction on packets etc. The device also helps with facial recognition when with family and friends.

Wayne and his support worker felt that the Orcam would have a big impact on his independence and his confidence and it would make him less reliant on others. It would also help to provide his parents with some respite as they get older

Wayne saved up £2,000 to help fund the device.

*Wayne was awarded a grant of £1,500 to fund the remaining cost of the Orcam Eye. (Cheque has not yet been cashed due to Covid-19 pandemic, but Wayne is in receipt of the Orcam Eye)*

#### 8. Michael

A 27 year old who is registered blind. He had been using a Macbook Pro since university which then broke down, beyond repair.

He said that not having access to this device has made him realise how much he relies on this technology with voice over software and dictation capabilities.

It enables him to access email, use the internet for access to educational resources and online advice and guidance and to keep in touch with family and friends using social media.

*Michael was awarded a grant of £1,299 to fund a new Macbook Pro.*

*Message from Michael "Absolutely amazing foundation... The support and help you guys provide is indescribable, the gift of independence you provide is beautiful and I thank/-you whole heartedly! Mike"*

#### Other Expenditure

£396 was spent to purchase 1 bond place for the Virgin Money London Marathon 2020. The place was allocated with a fundraising target of £2,000. Due the Covid-19 pandemic the event has been postponed but a total of £1,053.75 has been raised so far.



With no additional overheads and very minimal operational costs (bank fees and online platform fees), all of the money raised by donors and supporters was used directly to fund grants.

### Governance and Compliance

Nothing new to report this year.

### **Achievements and performance (May 2015 – May 2020)**

Since its inception in May 2015, JSF has awarded grants totalling £42,133 to 36 beneficiaries.

Total income over this 5 year period (excluding £5,000 start-up funds donated directly by co-founders) amounted to £46,713.22.

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