



williams
SYNDROME FOUNDATION

Write to us: Suite 2367, 145 – 147 Boston Road, Ealing W7 3SA



19 December 2017

Dear Sirs,

I am writing to thank you for your extremely generous donation of £25,000 made via Elcot Capital Management to the Williams Syndrome Foundation.

The Williams Syndrome Foundation is a very small charity serving a population with very particular needs. We rely entirely on fund raising and donations to provide both evidence based information and practical resources for people with the syndrome, their families and the professionals around them.

Williams Syndrome is a randomly occurring congenital condition caused by a deletion on chromosome 7 which can accurately be diagnosed by genetic blood testing. It is estimated, however, that only one in thirty GPs ever sees a patient with Williams Syndrome so it is vital that awareness of the condition is raised and that the quality of information and advice pertaining to the condition is guaranteed.

Williams Syndrome causes a plethora of medical, psychological, behavioural and educational problems.

The heart condition, supra valvular aortic and/or pulmonary stenosis can be an indicator of Williams Syndrome and in some Williams Syndrome people can be very serious, even fatal. Hypersensitivity to noise (both pitch and volume) is a very common problem for people with Williams Syndrome and can plague their day to day living and render painfully intolerable sounds which the rest of us barely acknowledge.

Early issues can include failure to thrive as a baby - low birth weight, feeding problems, significant sleeping problems, hernias and very delayed development. Raised calcium levels can lead to excessive vomiting and dehydration and if not recognised and treated can be extremely dangerous.

Issues arising as people with Williams Syndrome develop include hyperactivity, short concentration span, visuo-spatial and depth perception difficulties (making uneven floor surfaces and the use of stairs difficult). Other problems include sensory integration disorder (including difficulties with textured foods) and obsessions about certain things to the exclusion of all else which causes major problems with behaviour and learning.

Often the nuances of the Williams Syndrome are missed owing to the superficially sociable and talkative nature of those with the condition. Uninhibited behaviour and an over friendliness towards strangers, emotional immaturity and a complete lack of understanding of danger all make people with Williams Syndrome extremely socially vulnerable and psychologically fragile. Depression and anxiety are both common amongst the population.

Whilst there is a spectrum of ability and potential, people with Williams Syndrome are not able to live without lifelong support.

The Williams Syndrome Foundation is fortunate to be backed by a panel of eminent medical experts who commission high calibre research into this rare and unique condition and provide user - friendly advice to those with the condition and their families and carers.

WILLIAMS SYNDROME FOUNDATION LIMITED

Learn more www.williams-syndrome.org.uk Email us enquires@williams-syndrome.org.uk Call us 0208 567 1374

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The Foundation also puts people with Williams Syndrome and their families in touch through a network of regional representatives and local programmes of social and information events and providing much needed respite and holidays for people with Williams Syndrome and those who care for them.

Without help and support such as that received from the Sandhu Foundation, we would not be able to support our population and, given the rarity of the condition, they would have nowhere else to turn. We are enormously grateful to you for such an extraordinary donation to our charity.

Best wishes

Yours faithfully

A handwritten signature in blue ink that reads "Lizzie Hurst". The signature is written in a cursive style with a large, stylized flourish at the end.

Lizzie Hurst
CEO, Williams Syndrome Foundation