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Sullivan's Heroes

Building brighter futures for disabled children. By Lynn Smith

There are numerous families in the United Kingdom living with disabled children who find that they need to adapt their homes to meet the child's care and health requirements. Whilst specific council grants may be available towards the cost of adapting properties, in many cases these may fall short of the total costs and families find that additional funds, which can often be quite substantial, are required for the building project. Finding these additional funds can be an issue.

Based in Turners Hill, West Sussex, Sullivan's Heroes supports disabled children in Sussex, Surrey and counties further afield, by offering fundraising support specifically for these vital home adaptations. The charity provides a fundraising platform and financial grants to help families create the optimal environment to continue to care for their disabled child at home, safely and with dignity.

Fiona and Richard Smith set up the charity having



been through the process of adapting their house for their son Sullivan, discovering in the process that there was little in the way of financial assistance towards costs of adaptation that exceeded the council awarded Disabled Facilities Grant (DFG). The overall costs of the Smith's adaptations were way in excess of that provided by the DFG and, unable to find a specific charity that might help with their funding, Fiona and Richard set about organising their own fundraising.

Born in December 2011, Sullivan was diagnosed as having an extremely rare form of muscle myopathy, called Congenital Fibre Type Disproportion, resulting in general muscle weakness. He was also diagnosed with severely impaired cardiac function, cardiomyopathy. The extreme rarity of having the two conditions combined is illustrated by the fact that Sullivan was only the fourth recorded case worldwide.

During 2014, with the support of friends, family, the local community and sometimes complete strangers – all now known affectionately as Sullivan's Heroes – ninety percent of the target was raised. The Smiths describe the response and support received as, "overwhelming and heartwarming." Sadly, after successfully raising funds themselves through various initiatives, to meet the costs of their home adaptations, Sullivan passed away in January 2015 shortly before the work on the family's home was completed.

As a result of their experiences, Fiona and Richard decided to set up a charity to assist other families in situations similar to their own, to help those families carry out their own fundraising for their child's needs. As Fiona says: "Each one of them also classifies as one of 'Sullivan's Heroes', for the obstacles they tirelessly endure and overcome each and every day."

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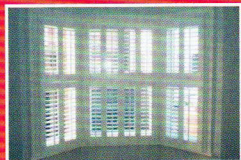
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Registered in August 2015, Sullivan's Heroes website was officially launched and became operational in February 2016.

Fiona and Richard vowed to drive the charity in Sullivan's name: "As a lasting legacy to our inspiring and truly amazing little boy." Since then they have strived to build brighter futures for other families in their son's memory through the fundraising efforts of Sullivan's Heroes; seeking donations from individuals and businesses alike to ensure ongoing grants are available for families and their disabled children. In addition to providing grants towards the cost of home adaptations, the charity provides a website platform where families can set up their own fundraising towards building costs. Families such as the Gee family whose nine year old son, Noah, suffers from Cerebral Palsy, and who needs to be lifted everywhere. The Gee's are aiming to raise £45,000 towards property adaptations that will allow a wheelchair accessible lift to be installed straight into Noah's bedroom along with a ceiling hoist and an adapted bathroom so that all of Noah's personal care needs can be met with dignity.

Since its launch, Sullivan's Heroes has supported eleven disabled children and their families, through fundraising for their child's home disability adaptations. The charity has also provided advocacy and information around their home adaptations for over sixty other families and their child's relevant social care and health workers. The charity's plan is to increase the number of families being supported year on year as the charity grows, and to support more families nationwide as funds increase.

Fundraising success has already been seen with two families having reached their targets required for their building adaptations works. Plus grants have been paid to three families towards their works in progress, which will enable them to complete those home adaptations, necessary to fully meet their child's care, health and safety needs.

Richard Smith says, "It took us over eighteen months to overcome all the hurdles to get Sullivan's Heroes off the ground, but we are absolutely delighted that



we have now been able to realise this incredibly important resource in our son's memory for families who are in the same situation we were, with nowhere to turn."

He added, "We don't have the skills to save lives, but we certainly have the ability to change lives and that is what we are setting out to do, just like the many people who have helped us as parents and Sullivan throughout his life."

Sullivan's Heroes receives no government or statutory funding and so relies heavily on donations from companies, charities and the general public as well as various fundraising events and activities. The charity has also received support from local organisations and charities donating both direct to the

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charity and to the families it supports, with local companies providing funds, services and resources to the charity; fundraising events hosted by local organisations plus direct donations together with sponsored events

and fundraising activities - such as marathons, skydives and cycle races - undertaken by members of the public. Key fundraising events throughout 2016 included popular sales of jewellery and gifts at local fetes, carnivals, school fairs and companies, and Sullivan's Heroes will be attending many events throughout 2017, continuing with the jewellery and gift sales, and running fundraising campaigns throughout the year.

Fiona and Richard are the charity's sole members of staff, unpaid, and, as yet, there is no requirement for volunteers to assist with the running of the charity, although Fiona Smith says that this requirement may

change as the charity grows. The charity welcomes volunteers to assist at fundraising events and activities throughout the year, and potentially for administration duties. Interested volunteers need have no particular expertise or background - "just a desire to help raise awareness of the charity and raise funds for disabled children" - although a current driving licence would be beneficial, home working opportunities are also available.

When asked what she sees as the greatest challenge faced by Sullivan's Heroes in the future, Fiona Smith's reply echoes that of most self-funded charitable organisations: "The greatest challenge faced by Sullivan's Heroes is to raise sufficient funds to ensure that all families applying to the charity for a financial grant for their disabled child's building adaptations can be supported."

Fiona and Richard would like to thank all everyone who has helped them build the charity to this point - and to invite anyone who has any fundraising events, activities and ideas they'd like to share; or who would like to apply for a grant or to fundraise through Sullivan's Heroes, to get in touch with them.

Sullivan's Heroes

Contact: hello@sullivansheroes.org
www.sullivansheroes.org

**Sullivan's
Heroes**
Building brighter futures
for disabled children