

Parents start charity in memory of tragic tot

Bereaved couple to help others with home adaptations

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THE parents of a Turners Hill boy who died from a rare muscle wasting condition are running a charity in his memory.

Three-year-old Sullivan Smith died in January 2015 after a brave fight with a condition known as congenital fibre type disproportion, which causes muscle weakness.

It is so rare it only affects 200 people worldwide, and Sullivan's case was rarer still, in that it affected his heart as well as all of his muscles and his breathing.

Sullivan spent the first nine months of his life in hospital and his parents were in the process of adapting their home, in Selsfield Road, so he could live there long term when the youngster unexpectedly passed away.

Now, 18 months after parents Fiona and Richard first made plans to set up a charity in his memory, Sullivan's Heroes has been launched in a bid to help fund home adaptations for other disabled children.

Mrs Smith, 43, said: "It has been a long and involved process to get the charity set up. We are focusing on families in the Sussex and Surrey area for now but long term hope to help people nationwide.

"I have been pretty much working



NEW CHARITY: Fiona Smith with son Sullivan who died last January

Photo by Stuart Douglas

on the charity full time, it keeps me busy. Our aim with the charity is to help as many people as possible."

Mrs Smith said that she has got a great reaction from people in the area as well as businesses she has

approached, who have donated time, money and resources.

As well as fundraising to provide grants for families towards their child's home adaptations, where the costs can greatly exceed that of a coun-

cil grant awarded, the charity also provides a website platform where families can set up their own fundraising towards the building costs.

Mrs Smith said: "There are crazy costs involved. Our adaption was costing more than £100,000. Even a ramp outside your home can cost £8,000. The council grant is for around £30,000, which is great, but families are left with raising thousands of pounds."

Accessible

Mrs Smith said Sullivan's Heroes already have two families signed up who they are helping in fundraising towards their child's new fully accessible bedroom and bathroom, and have another four in the pipeline.

Mr Smith said: "It has taken us over 18 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.

"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."

■ To find out more about Sullivan's Heroes or, to donate, go to www.sullivansheroes.org