

Parents want to help families who have nowhere else to turn



Fiona and Richard Smith with Sullivan, also inset

# Couple set up charity in memory of their son

**By Siobhan Ryan**

**Health reporter**

siobhan.ryan@theargus.co.uk

A COUPLE have set up a charity in memory of their young son who was born with a rare genetic muscle disease.

Sullivan's Heroes will help families of disabled children pay for the cost of adapting their homes to make their lives more comfortable.

Sullivan Smith died in January last year shortly after his third birthday.

He was born with a condition called congenital fibre type disproportion (CFTD) and also suffered from the heart disease cardiomyopathy.

There are only around 200 cases of CFTD reported worldwide and only four chil-

---

## background

**CONGENITAL fibre type disproportion is a form of muscular dystrophy and characterised by muscle weakness and wasting.**

**It is a rare condition and the genetic basis of it is not yet known. Common features of the condition include poor muscle tone, delay in achieving motor milestones, breathing problems and possible bone deformities.**

**There is currently no cure, or effective treatment for CFTD but management of the condition is very important.**

**Researchers worldwide are exploring many avenues in an attempt to develop more effective treatments and hopefully a cure.**

---

dren are known to have had the two conditions combined.

Sullivan's parents Richard and Fiona, 43, from Turners Hill, near Crawley, had to adapt their home for their son's needs so he could live comfortable and safely.

They discovered there was little in the way of financial assistance for families like theirs and had to set about

fundraising through various initiatives to meet the costs.

Sadly Sullivan passed away shortly before work on their home was completed and since then Mr and Mrs Smith have been focusing their efforts on supporting other families.

Mrs Smith said: "We have now vowed to drive the charity onwards in Sullivan's

memory, as a lasting legacy to our inspiring and truly amazing little boy."

As well as fundraising to provide grants for families towards their child's home adaptations, where the costs exceed that of a council grant awarded, Sullivan's Heroes also provides a website platform where families can set up their own fundraising towards the building costs.

The charity is now looking for donations from individuals and businesses alike to ensure ongoing grants can be met for families and their disabled children.

The Smiths are delighted to already have received significant support from ethical pet retailer Pets Corner with an initial £6,000 donation, plus a further pledge from the company to donate £5,000 per year. Other companies

have also donated both funds and resources and individuals have been taking part in sponsored events but much more is always needed.

Mr Smith, 46, 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 we have now been able to realise this incredibly important resource in our son's memory for families in the same situation we were, with nowhere to turn.

"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 or make a donation, visit [sullivansheroes.org](http://sullivansheroes.org).