

Annual Review 2017-18

Making every moment count:
for the whole family



**Shooting
Star Chase**
Children's Hospice Care



Foreword



Welcome to our annual review, which will give you an insight into the impact our work has had over the last financial year.

2017/18 has been a landmark year for children's hospices. With several high profile cases involving children's end-of-life care brought to the public's attention and the release of a new NICE quality standard, *End of life care for infants, children and young people*, a light has been shone on children's palliative care in a way that it, arguably, never has before. What else has been highlighted though is just how little

government funding children's hospices receive. This, combined with the increasingly complex needs of children with life-limiting conditions, leaves many families unable to access vital care and support.

Thankfully, due to the strength of our service – both Christopher's and Shooting Star House are rated overall Outstanding by the Care Quality Commission positioning Shooting Star Chase in the top 3% of health and social care services in England – we're able to support babies, children and young people with incredibly complex care needs such as those on long-term ventilation. But, perhaps, the greatest strength of our service is the care we provide to the entire family supporting them through the unthinkable. We will always support the whole family and, as you can see from page 28-29, our future plans will ensure that each and every family receives a responsive and holistic service based on their specific, individual needs.

Whilst 2017/18 remained a challenging year financially, thanks to the incredible

efforts of our donors and fundraisers and the steps we have taken to increase our sustainable income, we saw a positive impact on our funding gap with a smaller deficit than in the previous year. However, we still have a long way to go and key to this is finding new ways to increase our support and income. Towards the end of 2017/18 we undertook some independent market research to better understand our supporters and awareness of Shooting Star Chase across our catchment area. We found that only a relatively small

"An outstanding rating puts Shooting Star Chase in the top 3% of health and social care services in England."

percentage of those surveyed could identify us as their local children's hospice service and it became clear that we needed to strengthen our

brand, and our communication, to improve awareness. So, after careful consideration, we have been reviewing the name of our charity and plan to change it to Shooting Star Children's Hospices in early 2019. For more information on our brand development please visit shootingstarchase.org.uk/brand-development.

I'm proud that we continue to provide a safe and much-needed children's hospice service to our supported families and would like to take this opportunity to thank you, our supporters, for helping us to do this. Whether you've made a one off donation, taken part in a challenge event, nominated us as your company's charity of the year or left a gift in your Will, with just 10% of our income coming from government funding you really have made a huge difference to hundreds of families living in unimaginable circumstances.

Ken Hanna
Chair of Trustees

Our care service 2017/18 in numbers

We support families from diagnosis to end of life and throughout bereavement with a range of nursing, practical, emotional and medical care. Our care is for the whole family, offering a **bespoke service** to suit each member's individual needs, and is available **365 days a year**.

Over
2,000
telephone
contacts

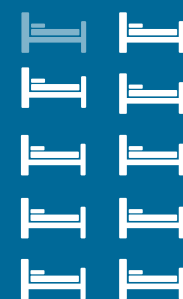


192
End-of-life care nights
at our hospices

3,271
Short-break
nights
at our
hospices



90%
Occupancy
at our
hospices



673 Funded
nights



6,424
Hours of Hospice at
Home visits



733
Families
supported
across the
whole year




15 
London boroughs where
we support families

237
The average number of
symptom management
support contacts each
month

877
Face-to-
face therapy
contacts



200  
Nights the hospices'
bereavement suites
were in use

11 
Districts of Surrey where
we support families



Making every
moment count:
for the child





Transition care

Medical advances and improved care has resulted in many young people with life-limiting conditions surviving into adulthood. That's why we provide transition support to help facilitate the move from our hospices into adult services.

"When the young people that we support move into adult services, their entire care provision changes – this is often a huge transition for them and their families, particularly if they've been supported by Shooting Star Chase for a number of years. We equip them with the information they need and support them through decisions and processes. We also advocate for the young people we support – we push for adult service provision developments and give them a voice."
Christine May, Transition Coordinator

Over the last year we've helped 31 young people move into adult services, guiding them and helping them prepare for the changes they will face.

"We also advocate for the young people we support – we push for adult service provision developments and give them a voice."



Making every moment count: **for the child**



Symptom management

Many of the children we support have very complex and changing symptoms, so our symptom management team are part of the PATCH service (Paediatric Palliative Advice by Telephone for Care at Home, Hospice and Hospital) which gives families and professionals telephone access to specialist palliative care 24 hours a day. **In 2017/18 our symptom management team...**

Wrote

68 Symptom Care Plans and **53** Emergency Care Plans

to ensure supported children received **well-coordinated** and **safe care**

Provided

expert advice
to
109 families

supporting them at Shooting Star House and Christopher's, at home, in hospital and at the child's school

Had

2,845 contacts*
with families

Of which **614** were out of hours** – an

83% increase
on 2016/17

Dedicated

185 hours
to external teaching and education

Including

1 poster
presentation at an international conference

*A contact is defined as direct engagement with a family over email, telephone, SMS, letter or face-to-face

**Delivered by the PATCH service

Making every moment count: **for the child**

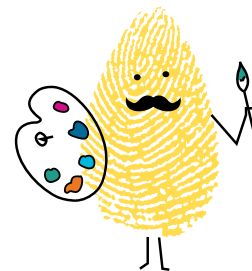


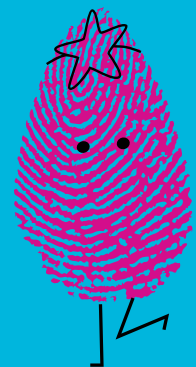
Activity days

We support families through the most devastating moments they will ever face. But, a key part of our support is also helping them to **create positive moments** and over the last year our activity days have helped to do just that.



Take a look inside one of our activity days: bit.ly/activity-days





Making every
moment count:
for parents



Making every moment count: **for parents**



Short breaks

"When Caleb was born prematurely at 23 weeks my whole world turned upside down. Instead of taking him home after giving birth to meet family and friends, he spent the first seven and a half months of his life on ventilation in the neonatal intensive care unit. Even when Caleb was finally able to come home my joy was unfortunately short-lived – he wasn't meeting key milestones.

"Due to Caleb's complex needs, we were thankfully introduced to Shooting Star Chase. When we visited the hospice it was nice to see that there were other families in similar situations and that there were nurses and carers who understood what I was going through.

"We first had a short break when Caleb was just two. Cerebral Palsy affects his speech and all four of his limbs so he's unable to walk or sit independently. That first short break meant so much to us – Caleb could

just be Caleb and I could just be his mummy. Caleb's now eight and we've been having short breaks a couple of times a year for the past few years.

"Short breaks help to take the pressure off and enable us to just be a family. Had we not been introduced to Shooting Star Chase I think we'd feel very alone at times."

"When we stay at the hospice Caleb and his two-year-old sister, Sarai, both love going in the hydrotherapy pool as swimming is not something they can do together normally. They also love the activities – from decorating cakes to growing grass. It's

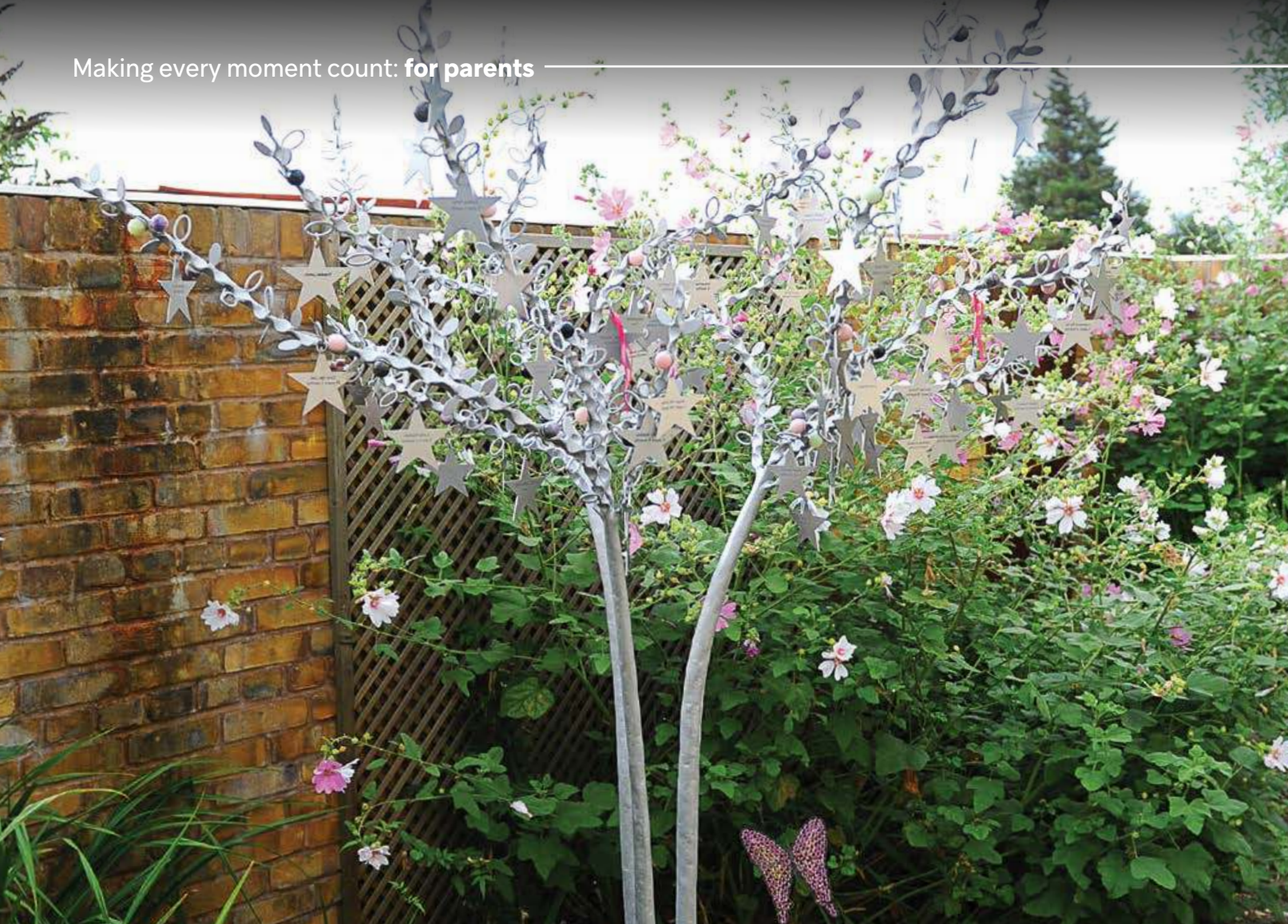
nice that Caleb and Sarai can spend time together having fun.

"Short breaks also help me to recharge my batteries. When you're looking after a disabled child and you also have another child to care for it can be quite intense. You feel like you're in a shell and you're the only one going through what you're going through. Short breaks help to take the pressure off and enable us to just be a family. Had we not been introduced to Shooting Star Chase I think we'd feel very alone at times."

Fay, pictured opposite with son Caleb and daughter Sarai

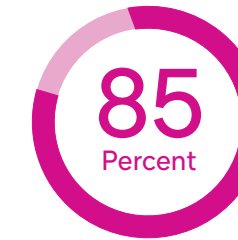
As well as short breaks at our two hospices, our Hospice at Home team have helped

1,112
supported families
enjoy short breaks in the family home.

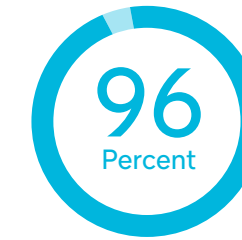


Bereavement support

Care does not stop after a child has died. We will continue to provide practical and emotional support for the entire family for as long as they need. **Our 2018 Bereaved Family Survey showed just how important this is.**



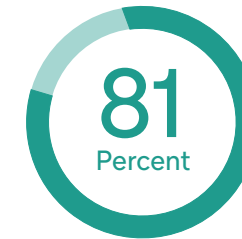
were satisfied with the bereavement support available to them



said they felt 'very supported'



said they had been to a Shooting Star Chase group, day or event for bereaved families



used either our bereavement suites or portable cool blankets



Find out more about one family's experience of the bereavement support they received: bit.ly/SSC-bereavement-support

"Counselling allows me time to talk with someone who will not judge and reassures me that what I feel is normal and expected."

"We had a very peaceful and supportive time at our lowest and saddest moment."

"I wish we had never had to find out about the bereavement support Shooting Star Chase offer, but we did and we're very grateful for the support."

"We had a lot of questions about Shooting Star Chase and palliative care, but we always got the answers. It was very important to us to know that we could ask about everything related to our son's care."



Making every
moment count:
for siblings





Support for siblings

Siblings of children living with life-limiting conditions often feel alone and isolated – we support them through difficult times by providing creative therapy sessions to help build confidence and empower them to manage how they're feeling.

Matthew, 12, was just eight years old when his older brother James died, aged 11. Play therapy helped him to cope with losing his brother. "Play therapy gave me something to focus on rather than thinking about everything that was happening," he said. "I was ready to accept anything at that point as it was such a rough time. Shooting Star Chase took something really bad and managed to make it easier; I don't know how I would've coped without them."

Matthew has also been to a number of our Bereaved Siblings' Days. **In 2017/18 we ran eight Siblings' Days**

giving siblings the opportunity to explore and share their feelings in a safe environment. Matthew said: "One of the best things about the Siblings' Days is being able to make friends. You're with other children who have been through the same things as you – it's good to be with people who understand the pain of what's happened."

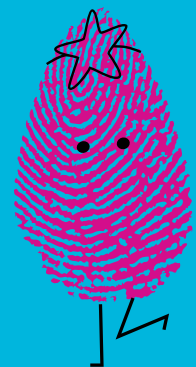
"Shooting Star Chase took something really bad and managed to make it easier."

Rhea, 11, is one of those children who understands as her younger brother Rehaan sadly died when he was just over 22 months old. "Shooting Star Chase helped me to take my mind off of my brother and made me realise there were still lots of positive things to look forward to," she said. "It's been such a journey. I was extremely shy when I first came to Shooting Star

House as I was quite young, but now it feels like I'm part of something – not having Shooting Star Chase would be like removing a puzzle piece.

"I've also taken part in the Sunrise Walk the last couple of years which has been amazing. Seeing all the lanterns hanging up shows you just how big the Shooting Star Chase family is."





Making every
moment count:
for grandparents





Grandparents' Day

When a child is diagnosed with a life-limiting condition, it's often easy to forget that the whole family is affected. Our support doesn't just stop at the child, parents and siblings, we also support extended family members such as grandparents.

In 2017/18 we held two Grandparents' Days as well as a day for bereaved grandparents. These days give grandparents the opportunity to share their experiences with each other, try out activities they can use at home with their grandchild such as story massage and sensory activities, and are vital in ensuring they make time to look after themselves.

"Having a grandchild changes your life."

"A grandchild with special needs is even more special – it's love 'plus' that you feel for them."

"When you have a grandchild with a life-limiting condition you worry when the phone goes and when it doesn't."

"No-one tells you how much joy your grandchild can bring."

Future plans

Our care and nursing workforce will continue to be our priority in the coming year.

Develop and measure the culture of a learning organisation

As an organisation we are committed to continuous learning and development, and improving harm-free care.

Care and nursing workforce and recruitment

A skilled and stable workforce is crucial to the provision of safe care so our care and nursing workforce will continue to be a priority in the coming year.

Enhance care through clinical informatics

At Shooting Star Chase we are committed to the use of technological solutions to support clinical effectiveness and will be developing our use of informatics to enhance the care we provide.

Leading change and adding value

In 2018/19 we want to build on the clinical review undertaken in 2017/18 to ensure we have a responsive, sustainable and affordable care service that continues to support and care for our families.

Move to a responsive care model

In 2018/19 we will continue to co-design our services with supported families to ensure we are responsive to their needs.

It is essential that we ensure the services we provide continue to add value.

Work collaboratively to achieve NICE quality standards

We will work collaboratively with our partners to deliver end-of-life care for babies, children and young people that meet the NICE quality standard 2017.

None of this would be possible without you...

Visit shootingstarchase.org.uk for more ways you could support us.



The Sunrise Walk saw a **record number** of people take part in 2017, attracting lots of new supporters

Natasha Howard chose her own challenge and cycled **4,500km** along the length of Japan and South Korea in June 2017

Long-standing corporate partner Fuller's raised an incredible **£250,000** in 2017/18 which included organising a sponsored barrel roll!

A host of generous trusts, foundations and corporate partners **donated** money, time, materials and expertise to **refurbish** our Guildford hospice, Christopher's

The Shooting Star Chase Friends' Groups raised an incredible **£170k** during 2017/18 by holding hundreds of fundraisers from music events to bucket collections

Our largest team in the charity's London Marathon history took on the ultimate running challenge in 2017 to raise an incredible **£255,000!**

The communities of Fulham and Chiswick welcomed our two new shops by **donating** lots of high-quality **pre-loved items**

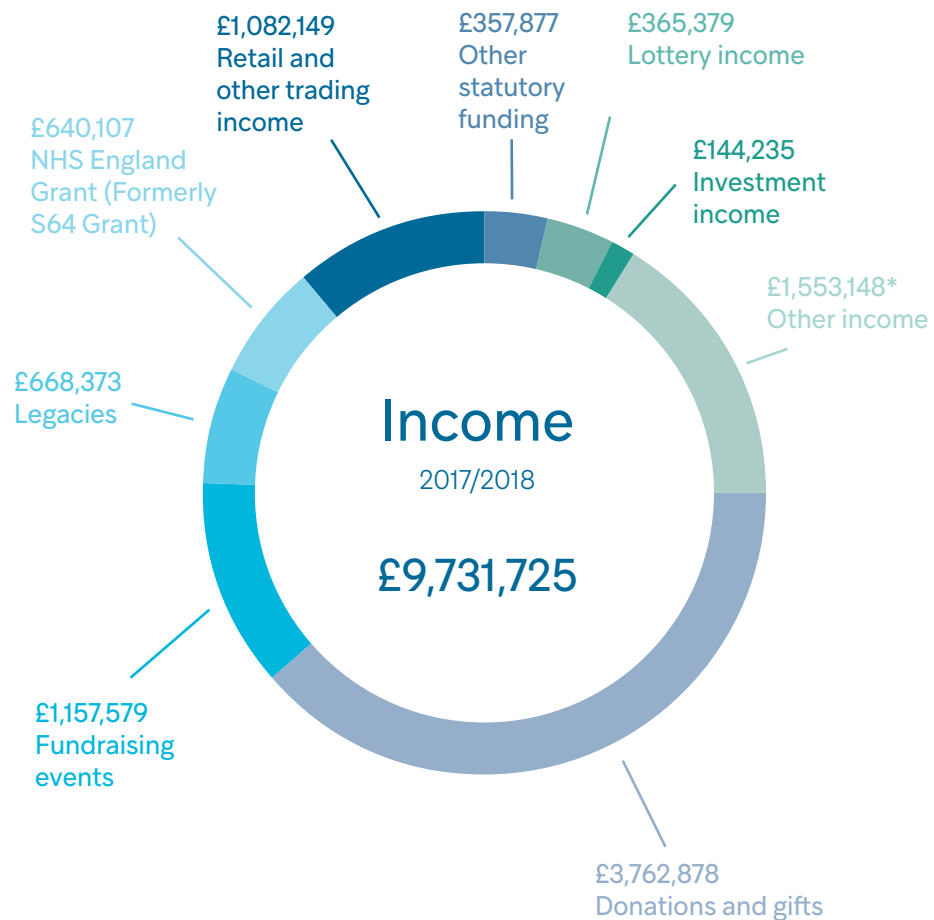
Lots of **corporate volunteers** gave up their time to keep our hospices looking homely including Fourfront Group who donated over 300 hours to tidy gardens, paint fences and build toys!

Our incredible volunteers again helped us to **save** over **£700,000** by donating thousands of hours' of support at our hospices, shops and support office

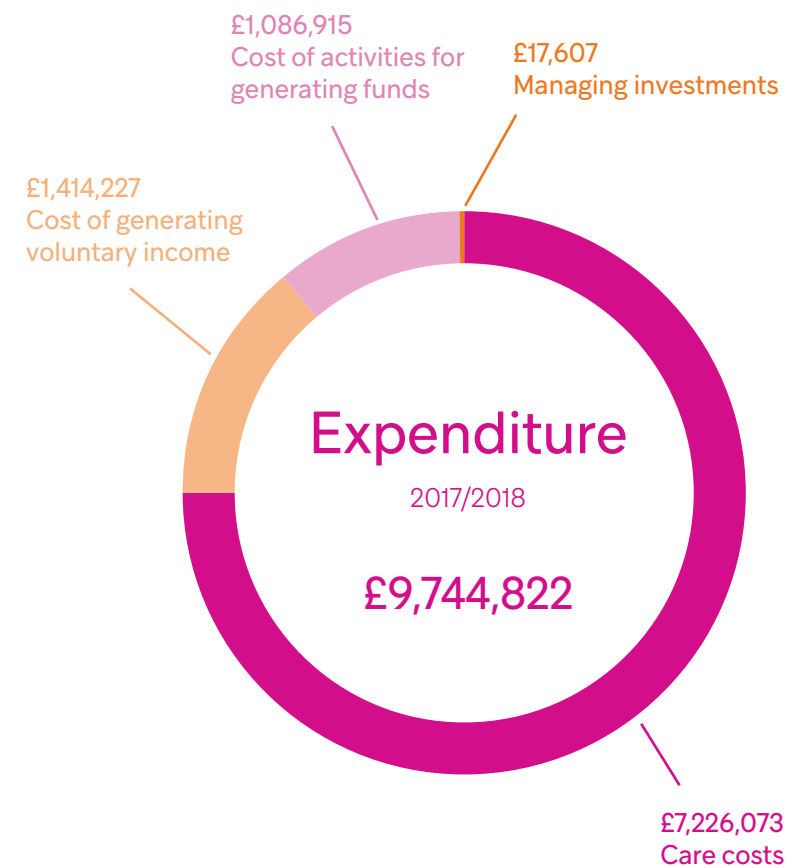
For the **fourth** year running Shooting Star Chase benefitted from the X Factor winner's single from Rak-Su raising over **£45,000**



Our income and expenditure stats



*includes £1,499,087 from sale of property



Governance costs are included in the above expenditure figures



£5.6m
Fundraising
income

Including donations and gifts, legacies
and events

£7.2m
Care costs

The total cost of direct care and
associated costs for one year.

£10m
Total costs

The amount we need to raise every year
to keep Shooting Star Chase running and
provide a vital care service to families.

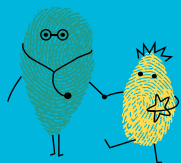
9.5
months

Cash
reserves

6%

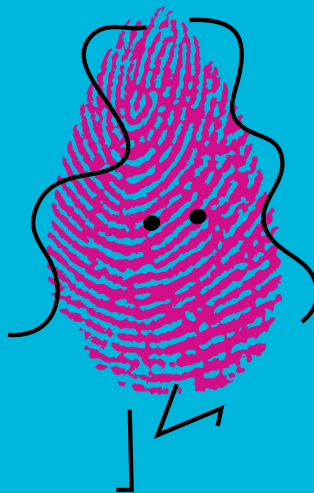
Fixed
statutory
funding





Shooting Star Chase

Children's Hospice Care



Shooting Star Chase

Bridge House
Addlestone Road
Surrey
KT15 2UE

t 01932 823100

f 01932 858399

e hello@shootingstarchase.org.uk

w shootingstarchase.org.uk

🐦 follow us on Twitter @sschospices

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