"we were broken & the donna louise put us back together"

here's some of the ways our supporters have been fundraising and what that's meant to our children and families...

10k & 9k Family Fun Run raised £34,060 which means we were able to deliver 50 sibling support groups, 12 sibling sleepover weekends and 50 youth club sessions.

Viva la Fiesta Annual Ball raised £25,683 towards our amazing new playground.

Challenge Events raised £34,859 which funded the work of 2 nurses.

"we were broken & the donna louise put us back together"

Christmas Dinner Campaign raised £3,790 which covered the cost of 768 lunches for our children and families.

Helping Hands - our business supporters gave 960 hours in 2014/15.

Golf Day raised £12,972 which kept the hospice doors open for 1 and half days.

Our Friends Groups raised £37,730 which funded the care and support of 6 families for 12 months.

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welcome...

I love coming to the hospice, it’s a very special place; I feel safe here and can be myself. The best times are sleepovers with my brothers Luke and Isaac. We spend time having lots of fun with each other giving Mummy and Daddy some time on their own!

Jacob, age 6

find out what the hospice means to Jacob’s dad on page 4...

This report demonstrates the impact we made to families throughout Staffordshire and Cheshire in 2014/15 and:
- What we do
- Why we do it
- How we do it

our ‘vision’ is to be the centre of excellence for children and young people’s palliative care

a word of welcome from our chair and chief executive

The children and young people who come to The Donna Louise all have serious, complex, life-limiting or life threatening conditions.

It is a privilege to provide the care and support that they and their families need, wherever and whenever they need it – at the hospice in Trentham, or in their own home.

So often we fail to think about the impact a child’s illness can have on the whole family, who often themselves provide constant care around the clock; but with the help of the dedicated, specialist team at The Donna Louise none of our families need go through this alone.

Our overarching aim is to bring our families a sense of normality, so often taken for granted by us all, to help them remember that they are parents first and foremost and carers second, which is sometimes forgotten or overlooked.

2014/15 saw another hugely successful year of growth and service development at the Trust - from the improvements to our outside play area so generously supported by our local communities, to the introduction of a new ‘integrated’ approach to care provision. The impact of these developments on the children and young people, families and staff are reflected throughout this report.

Of course, none of this would be possible without the selfless generosity of supporters and volunteers – and naturally our staff, both those at the forefront in care delivery and those working tirelessly behind the scenes.

As you would anticipate, we must be mindful of the future challenges we face; but more importantly, that we must remain determined to provide the best possible care and support, always shaped by the changing needs of the children and families that we serve.

We truly thank you all, and hope that you take pleasure in reading our on-going story!

Life is so much calmer and settled... only because of you... Thank you from the bottom of our hearts

205 families with 344 siblings cared for during 2014/2015

672 hours supporting families in their home and in hospital

• Macclesfield
• Congleton
• Crewe
• Nantwich
• Leek
• Stoke-on-Trent
• Stone
• Uttoxeter
• Stafford
• Burton-upon-Trent
• Rugeley
• Cannock
• Lichfield

FAMILY FEEDBACK

• Macclesfield
• Congleton
• Leek
• Stoke-on-Trent
• Stone
• Uttoxeter
• Stafford
• Burton-upon-Trent
• Rugeley
• Cannock
• Lichfield
As many of you may know, it’s never an easy journey being a parent. From the moment your child is born, unconditional love, sheer joy and excitement gives way to an innate desire to protect, provide and do everything you can for the tiny miracle you hold in your arms.

To find out that your child is affected by a life limiting or altering condition makes that journey a million times harder.

Nearly two years ago my, now 6 year old son, Jacob was suffering what my wife, Samantha, and I, at the time, believed to be a bad chest infection that he’d struggled to shake off in the preceding few weeks. Then on Sunday, 26th July 2013, a day I remember like yesterday, all of a sudden, everything seemed to get acuter, his tummy swelled till it appeared he would burst, his breathing became heavy, and all his energy disappeared, and over the next 9 months my family’s world would change forever.

We watched, a little bit of us dying inside, each hospital visit, as biopsy after biopsy, bone marrow tests, scans, feeding pumps and treatments were tried, and as our son lost over 2 stone in weight.

To find out that your child is affected by a life limiting or altering condition makes that journey a million times harder.

When a diagnosis eventually came, it was almost tears of relief but that was just the beginning...

Jacob was suffering from an incurable, debilitating mixture of conditions, both in his immune and metabolic systems. Jacob’s liver could fall in weeks, months or years, how long was a piece of string? If his liver did fail completely, no matter what the timescale, his body might not ever be able to recover from a transplant, and then compound this with the fact that only 75 cases had ever been reported worldwide, and once again Samantha and I were emotionally falling apart inside.

A fear and despair for what the future could hold and a realisation that we’d both struggled to accept, that we couldn’t do all this on our own.

And that’s where The Donna Louise Children’s Hospice came into my family’s life, we were broken and they helped to put us back together.

Because it’s not just about Jacob, it’s about my younger sons Luke and Isaac, their quality of life as they watch their big brother go through this, about my wife as she struggles to balance daily life with the heartbreaking life limiting condition her first-born son has, as somehow I try to stay strong for everyone, whilst struggling with a range of never ending emotions that I cannot necessarily explain simply.

Jacob’s frustration with his daily life compared to that of his friends led us to seek support for him initially through a counsellor at The Donna Louise who began to help him express himself, understand himself, and ultimately begin to trust adults outside of our family unit for the first time in a year.

And from that first visit it’s a place that’s become inseparably linked to my family’s journey. To have people really understand what all of you are facing has been the biggest help for my family in adapting to and coming to terms with Jacob’s condition.

It’s not because of the building, or indeed the team of fantastic people who work there, it’s a place where we can be a family, where hospitals, treatment, conditions and medication don’t necessarily disappear, they take a back seat. We’re a ‘normal’ on family there. My sons play, like boys do. I can talk to people who understand, other dads who are feeling the same things as me. My wife can feel comfortable that our boys, all of them, are together and looked after as a family regardless of Jacob’s condition, and we’ve built a network of support...

But above all else, whether it’s an overnight stay, dropping in for a cup of coffee to chat or at an event, The Donna Louise, has become part of my family, somewhere safe, somewhere even family enough where Jacob’s condition can be forgotten and somewhere we as a family know we have the support, attention, and friendships of people who can understand, who can help, and often will just listen to us.

One of the biggest parts of helping us get through our journey has been and still is The Donna Louise Children’s Hospice.

As a Dad, that’s almost impossible hard to accept, as the one who should be strong, the one who provides for the family, the one who often has to learn how to emotionally support themselves and their families. And as a Dad, the balance of work, hospital, medication and every moment fearing...

The men’s group works for me I fit in, I don’t fit in with the rest of world because it’s round and I’m the square peg...
our 'mission' is to provide a quality palliative care service to children, young people, and their families, through effective partnership working aligned with our values.

"hope in every painting"

Art is a very effective way of working with children and families who may be going through a difficult time. Our second art exhibition 'Hope in Every Painting' held in September 2014 at The Potteries Museum showcased a range of paintings which each told their own story, highlighting the importance of art therapy to our children and families. 44 paintings were exhibited which raised £2,420 from the sale of these unique artworks. As with many of our events it also put us in the media spotlight with newspaper, TV and radio coverage.

70% of the children we support have multiple and complex physical and medical needs including loss of mobility. Our approach is to focus wholly on fulfilling our children's physical potential.

Physiotherapy also improves quality of life by effectively managing a child's physical symptoms, promoting wellbeing and development. We also focus on educating and supporting our families in order to enable them to access other external support... helping them to make the most of what's available.

We do this by working in harmony with our play specialist and care team to create fun and enjoyable play opportunities.

One of our major achievements this year has been the creation of our fantastic playground. This new £150,000 area was made possible with the generous support of Grants and our local communities throughout Staffordshire and Cheshire. It's already made an immense difference to our children and families giving them the ability to play together with their siblings.

It can express my feelings, without having to talk. I can do a painting and then feel comfortable about talking about how I feel.

I'm completely blown away by the playground, just because James is in a wheelchair shouldn't stop him having fun and I well up just seeing them being able to play together forming that special sibling bond, it's priceless.
We wouldn’t be where we are today, without the help & support you guys gave us when sadly we lost our little boy Tommy to meningitis. You took us in when no one else would, to give us and family members an extra few days to say our proper goodbyes to our little man. For that we will be forever thankful, we will continue to support you guys as much as we can to help others as you did for us and for all the other services that you provide. We will spread the word of your wonderful services as much as we can and continue with our fundraising.

Anela Rafiq, Customer Services Adviser

“Doing charity work has felt amazing. It’s a nice feeling knowing what a big difference your time and effort can make on someone’s life. I feel really proud to work with a company who fully supports charity work and their employees who wish to take part. We love making a difference”

Kate Sampey, Customer Services Adviser

“I would say it’s a privilege to be able to spend some time to help impact the lives of those in need, especially with the support of your employer. It’s a great opportunity to give something back.”

Vodafone is one of our business supporters who make a difference to us through our ‘Helping Hands’ scheme

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June Brough
Volunteer

“I enjoy it so much, I’m made to feel so welcome and felt a part of the team. I love making sure all the children’s bedding is nice for them. It’s a very special place, the children and their families and the staff and volunteers are all amazing!”

Tracey Shield
Care Team Administrator

“It’s great to know that we’re making a difference, we focus on the whole family so the support they receive is based on their needs. We do whatever we can to support families and help them cope - it’s an amazing place to be a part of and I feel so lucky to work here.”

FAMILY FEEDBACK

Nick Evans
Trustee (Technical Director at ExtraMile Communications Ltd)

“The Donna Louise Trust is always looking to help many throughout our local communities. For me it’s about being part of that work and an opportunity to give something back.”

Respect
Excellence
Integrity
Openness
Fairness
Enablement

*93% of the donna louise team would recommend the organisation as a good place to work.

Visit our website to find out more about us.

www.donnalouisetrust.org

We remain committed to developing our dedicated staff team to ensure our families receive the very best care and support. All staff undergo continuous professional development – from the chief executive completing an MA in Hospice Leadership to every member of the team undergoing mandatory training. Of course none of this would be possible without our army of volunteers who also receive appropriate development. The organisation is committed to completing the ‘Investors in Volunteering’ quality standard accreditation.

grant making trust feedback

the

Williams Family foundation

“We provided a grant to enable The Donna Louise Trust to purchase shower equipment as we know how expensive this specialised equipment can be and we really wanted to make a difference. We have really focused on supporting Children’s hospices this year as we recognise the incredible support these organisations give to children with life limiting illnesses and their families.”

You have been a part of our lives for a month! We have all been cared for very well! Lucas has loved every last minute of his life during his stay and you have been very helpful at the time we needed you most. We’re happy to have been able to stay during his last month and to be able to feel the proud parents. Also you have been fantastic with his sister Emma who misses her brother every day but with the help from all of you she is a completely different child! Thanks ever so much, I don’t know how to ever thank you all for what you’ve done for us.

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how we pay for it...

Income

<table>
<thead>
<tr>
<th>Income</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising Income</td>
<td>£2,021,816</td>
</tr>
<tr>
<td>Activities for Generating Funds</td>
<td>£54,282</td>
</tr>
<tr>
<td>Statutory Income</td>
<td>£436,378</td>
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<tr>
<td>Charitable Activities</td>
<td>£202,393</td>
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<tr>
<td>Investment Income</td>
<td>£14,465</td>
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<tr>
<td>Total Income</td>
<td>£2,729,334</td>
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Expenditure

<table>
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<tr>
<th>Expenditure</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Fundraising Costs</td>
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<tr>
<td>Governance</td>
<td>£31,362</td>
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<tr>
<td>Care Service</td>
<td>£1,833,114</td>
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<tr>
<td>Other</td>
<td>£98,865</td>
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<td>Total</td>
<td>£2,557,415</td>
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Fundraising Income Breakdown

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Individual &amp; Community</td>
<td>£765,758</td>
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<tr>
<td>Grant Making Trusts</td>
<td>£225,310</td>
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<tr>
<td>Companies</td>
<td>£665,316</td>
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<tr>
<td>Legacies</td>
<td>£375,432</td>
</tr>
<tr>
<td>Total</td>
<td>£2,021,816</td>
</tr>
</tbody>
</table>

by royal invitation...

It was an honour for us to receive an invitation from Kensington Palace to join Her Royal Highness The Duchess of Cambridge as she visited Stoke’s Emma Bridgewater factory in February 2015. She met a handful of our families and staff during the visit and expressed her delight in meeting them. The Duchess was especially touched by the warm welcome she received and for the beautiful picture painted by Chloe Wilkes which was presented to her during the visit.

The Lord Stafford DL

“As a parent, one feels vulnerable when your child is ill. Unless you have direct knowledge, one cannot understand the suffering families go through with terminally ill children.”

Robbie Williams

“it’s a privilege for me to be a patron of the Donna Louise Children’s Hospice. It makes a real difference to these children, whose lives have been tragically limited and I will continue to lend my support.”

our patrons

Dr Gordon Carpenter* / Prof Sue Read (Chair)

Dr John Alexander* | Julie Arkle
Dr David Brookfield | David Carr
Paul Farmer | David Gladman
Karen Gladman | Dr Keith Harrison*
Lynne Ingram | David Milburn
Antony Swift | James Rushton
John Tyler* | Valerie Wood

our chair

Dr Gordon Carpenter#

our trustees

Dr John Alexander* | Julie Arkle
Dr David Brookfield | David Carr
Paul Farmer | David Gladman
Karen Gladman | Dr Keith Harrison*
Lynne Ingram | David Milburn
Antony Swift | James Rushton
John Tyler* | Valerie Wood

our chief executive

Mike McDonald

our executive team

Director of Operations - Andrew Colclough
Director of Care Services - Dot Gillespie
Director of Income Generation - Liz Gratton
Secretary - Hayley Jones
Treasurer - Valerie Wood
Bankers - Barclays Bank PLC
Auditors - DJH Accountants Ltd
Legal Advisors - Knights Professional Services Ltd

our vice patrons

Bill Alderton | Christopher Barry
Dr Gordon Carpenter* | Dr Keith Harrison* | John Tyler*

I think making life as enjoyable as possible - that’s a really important part of what we do.

2014/15 financial summary

(for more details see the full set of Accounts available on our website)

by royal invitation...