a word of welcome...

Gordon Carpenter – our chairman

In January 1997 Enid Corbett, a psychotherapist, gathered together a small group of people, to discuss the need for a Children’s Hospice in our area to provide respite and ‘end of life’ care for children with life-limiting conditions and their families. I was one of that group.

Like all such ambitious projects, we had our ups and downs, but eventually enough money was raised to start a community-based nursing service as we continued to raise funds to build and equip our Hospice building.

I would like to take this opportunity to thank my fellow Trustees and Chairman knowing that there are further ideas and plans, which I’m sure will come to fruition over the next few years, allowing us to support many more families facing complex health needs in Staffordshire and Cheshire.

Mike McDonald – our chief executive

I am proud to welcome you to our 2013/14 Annual Report as your new Chief Executive.

Firstly, I must acknowledge the achievements of my predecessor, Nuala O’Kane, under whose leadership the Trust was transformed into the forward thinking, professional organisation it is today. We often speak of organisational development as a ‘journey’ and we have certainly travelled a long way in recent years; though there is still a long and continuously challenging path ahead of us.

2013/14 proved to be a physically transforming year for the Hospice building, too. Thanks to a £480,000+ grant from the Department of Health we were able to totally refurbish our internal environment and we are shortly to embark on the completion of this strategic “Fit for the Future” project with the introduction of an inclusive, interactive play area for our children and their siblings. This has been made possible through further grants as well as the generous support of our local communities. Many people have contributed to the success of this project and I thank them on behalf of the Trust and applaud their efforts.

I am pleased to say that despite another economically challenging year we have been able to hold our own and produced a more-or-less ‘on budget’ performance. This is testament to the commitment of our entire staff team, whose enthusiasm remains undiminished. I am particularly thankful to have the support of my Senior Team in Dot Gillespie and Liz Grattan as we develop ambitious plans for the Trust in the coming months and years – including a return to ‘full service’ delivery and alternative ways to help our children and families.

I would like to take this opportunity to thank my fellow Trustees for their continuing support and guidance – and the people of our local community who have given so generously to enable our service delivery and alternative ways to help our children and families.

I am confident he will develop the organisation as vigorously as Nuala did in her six years at the helm.

what we do...

- Provide palliative care and support for children aged up to 19 with life-limiting and life threatening conditions and their families.
- Support a range of specialist services from palliative care to music therapy offered by dedicated and experienced staff.
- Care for children and families at our purpose-built house and in their own homes across Staffordshire and Cheshire.
- We are there for the whole family on their journey and beyond.

193 families with 282 siblings cared for during 2013/14

928 nights of family stays provided this year

where we do it...

In addition to the service and support provided in the family home we are proud of our dedicated Hospice facility in Trentham, Stoke-on-Trent. Our children and families provide our inspiration, our sense of purpose and our cause and the Hospice facility is centred around this ethos. In 2013/14 our physical environment was very much improved with the help of a £480,000+ Department of Health “Improving Hospice Environments” grant and we have ambitious plans to create further facilities within our grounds as our service delivery grows.

definitions...

Life-limiting = an incurable condition which shortens life.

Life-threatening = a condition where a treatment for a cure may not work.

Palliative care = looking after physical, emotional, social and spiritual needs to enhance quality of life.
James was born perfectly healthy in March 2008 and met all of his important milestones. By 18 months he was walking (as long as he held our finger) and he could say the odd word - dadda, ozza (Oscar the cat). He changed so much in a short time. He could dry himself and he was admitted to hospital. The tests and the medication started ... I don’t have the words to describe how hearing that felt. They just don’t exist. Devastated, heartbroken, shocked, crushed just don’t come close.

Infantile Batten Disease is a neurological degenerative disease. James is basically missing one of the enzymes which clears the rubbish from his brain cells. Therefore, the cells are dying as they fill up with this rubbish. The sheet we were handed said that ‘Over time affected children suffer mental impairment, worsening seizures and progressive loss of sight and motor skills. Eventually, children with Batten Disease become blind, bedridden, and demented. It is always fatal.’

It was hard to take this all in. Through our crying we heard the Consultant say ‘We had her tested as soon as we could. It took a week for the results to come back. Thankfully, she is unaffected’ He then told us that the condition was not a case number, not a condition... It was a Saturday and we were to go to Outpatients. I hated going to Outpatients as it was so very, very busy. However, when we arrived it was empty. No parents were waiting for us... James was put into a ring. When we were called in to see the consultant we were told that he had a diagnosis...

James had Infantile Batten Disease. No treatment. No cure. James would die within 5 years old. He was 25 months old at the time. I don’t have the words to describe how hearing that felt. They just don’t exist.

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It was hard to take this all in. Through our crying we heard the Consultant asking for Ruby’s date of birth. He then told us that the condition was genetic. My husband and I are both carriers, therefore Ruby had a 25% chance of being affected - she was seven weeks old.

We had her tested as soon as we could. It took a week for the results to come back. Thankfully, she is unaffected – the relief is also indescribable. We then had two choices - to let Batten Disease ruin our family or just move on. We are not sure what the future holds but we owed it to James and Ruby to give them both the best possible life. We could, however long or short that maybe for James. We have a saying ‘Don’t count the days, make the days count’ and that’s just what we decided to do.

Bravely or stupidly we decided to have another baby. This baby also had a 25% chance of being affected. So we rolled the dice again. Fortunately, testing is available during early pregnancy and we were told our baby was unaffected and Isabel was born in September 2011. So family life took a turn of its own.

The Donna Louise plays a vital role for our family. It’s a place I can go for a complete rest as James is so well cared for. We go to stay as a family. The girls love it. There I meet other families and we become ‘normal’ again.

Listening to our service users...
helping families cope...

We have extended our services to offer flexible support to families not just in The Donna Louise Hospice building, but also in their own home.

Our new Care Co-ordination Service was launched this year as specialist support to families liaising with multiple professional and social care organisations. Our team acts as a central link with fellow professionals and also offers practical help for our families by attending meetings or helping them find the best services available.

We have enhanced our Care Team staff with the development of new roles of Senior Care Development Workers who, as experienced staff, have a wider range of skills to help look after our children.

To encourage younger people into the charity sector, who are interested in working with children, we welcomed our first apprentice Kirsty Gough. With the support of mentors from the Care Team, Kirsty combined practical experience with studying for professional qualifications.

A chance to recharge
An opportunity to relax
Being a parent and not a nurse
Spending time together as a family
Creating time to focus on siblings
How the service helps and what families value

wellbeing for the whole family

We offer a range of creative and therapeutic services to promote wellbeing with activities not just for children but the whole family. Our specialist team work together to create an individual plan for each child, tailored to their own needs and work hand-in-hand to create counselling support.

Art

The skill of our team is in allowing children and families to express their feelings in paint was demonstrated with our first art exhibition held in September 2013 at Yarnfield Park. Hope in Every Painting showcased a range of paintings which each told their own story.

A total of 41 paintings were exhibited and a total of £4,589 was raised from sale of the unique artworks.

As with many of our events it also put us in the media spotlight with newspaper, TV and radio coverage.

Play

As part of the 2013/14 Hospice refurbishment, we have invested in new equipment to offer our children and families the opportunity to try new and innovative toys, which not only stimulate, but are also fun. These range from small, hand-held toys to stimulate the senses through to the latest computer technology. One of most popular games is the interactive board in the main hall which offers a whole range of activities for all ages. Another impressive piece of technology is our 3D projector which allows the children to interact with an image and paddle in water or catch fish.

There are also a range of support groups for the whole family. This year we also introduced the Saturday Club, a monthly drop-in craft and fun session organised by our volunteers. It supports 35 siblings from 17 families.

Over the coming months we are also completely replacing our outdoor play area to create a much larger, inclusive play area where our children are able to participate in fully inclusive play with their siblings.
End-of-life care is only a very small part of what we do here at The Donna Louise, but its impact cannot be under-estimated and we provide support for the whole family.

Our counselling service offers bereavement support to siblings and parents and also the extended family including grandparents. Latest projects have included the establishment of a support group for Dad’s to encourage men to talk openly about their feelings to fellow dads who understand how they feel.

A new group has also been established which offers volunteers mums the chance to become mentors to families new to The Donna Louise. This year’s memory day was also welcomed as a special time for reflection and its success was thanks to the organising committee made-up of our families.

Christine Underwood, volunteer for more than three years.

“Volunteering at The Donna Louise is just the best job I’ve ever done. It’s so happy here and the staff have a great rapport with the children. The Donna Louise means a lot to me because I am able to give something back and I find it really rewarding.”

Debbie Askey – head of our care co-ordination service

“What we do here at The Donna Louise is really unique and I’ve seen how we have grown, so we are not just respite and day care, but a whole range of services and support groups.”

Paul Moore – fundraiser

“It’s great to know that I can make a difference. Being part of the Hospice Team means I’m inspired daily by the journeys of our children and families. It’s touching to work with people so keen to support a local charity, proving just what a heart our local communities have.”

£1.6m was raised from voluntary donations in 2013/14

357 hours spent supporting families in the home and at hospital

Support for the whole family

Support services our families value

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### Income

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Fundraising Income</td>
<td>£1,592,709</td>
</tr>
<tr>
<td>Activities for Generating Funds</td>
<td>£58,058</td>
</tr>
<tr>
<td>Statutory Income</td>
<td>£402,961</td>
</tr>
<tr>
<td>Charitable Activities</td>
<td>£307,231</td>
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<tr>
<td>Investment Income</td>
<td>£11,035</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td><strong>£2,371,994</strong></td>
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</tbody>
</table>

### Fundraising Income Breakdown

- Individual & Community: £788,620
- Grant Making Trusts: £154,166
- Companies: £560,954
- Legacies: £88,969
- **Total**: £1,592,709

### Expenditure

<table>
<thead>
<tr>
<th>Category</th>
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</thead>
<tbody>
<tr>
<td>Fundraising Costs</td>
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<tr>
<td>Governance</td>
<td>£42,755</td>
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<td>Care Service</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>£2,389,819</strong></td>
</tr>
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All figures exclude the Department of Health Capital Grant for “Improving Hospice Environments” received during 2013/14 (£478,343).

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**2013/14 financial summary**

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

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**Thank you!**

There are many ways for you to help support The Donna Louise. Call the Fundraising Team on 01782 654444.
The Donna Louise Trust is a company limited by guarantee and not having share capital under the Companies Acts 1985 and 1989 (registered number 3701810) and is registered with the Charity Commission as a Charity (registered number 1075597) under the Charities Act 1993.

Registered with the Care Quality Commission – Number 1-101729348. Robbie Williams photograph courtesy of (c) Farrell Music Ltd. Photograph by Julian Broad. Front cover by Chloe Wilkes.

what The Donna Louise means to me...

“...to me, The Donna Louise represents everything good about my hometown of Stoke-on-Trent. The care and support they give to local children and families is amazing and I’m proud to be a Patron!”

Robbie Williams  
Patron

“...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.”

The Lord Stafford DL  
Patron

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