

# Winter Newsletter 2016



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Noah's Ark Charity  
**TINY LIVES APPEAL**

Could you  
help save  
a baby's  
life this  
Christmas?

Leaving a gift for tomorrow's children **P10**



[enquiries@noahsarkcharity.org](mailto:enquiries@noahsarkcharity.org)



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Registered Charity Number: 1069485

# Noah's Ark

Children's Hospital Charity  
Elusen Ysbyty Plant



Your chance to **WIN** up to

**£25,000**

and support 73,000 children a year

Join online for just £1 a week at

[www.noahsark.org/lottery](http://www.noahsark.org/lottery)

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**unity**



The promoter of this Unity Lottery is Noah's Ark Children's Hospital Charity, Upper Ground Floor, Noah's Ark Children's Hospital, Heath Park, Cardiff, CF14 4XW.

Registered with Cardiff Council Registration Number LSS/SSL/0223 [www.gambleaware.co.uk](http://www.gambleaware.co.uk)



 **Noah's Ark Charity**  
**TINY LIVES APPEAL**

**Visit Santa**  
**at IKEA Cardiff**

**3rd-23rd December 2016**

All proceeds go to the Noah's Ark Charity Tiny Lives Appeal – supporting the life-saving care of premature and critically ill babies.

**Opening hours:**

Mon-Fri: 1pm-5pm / Sat: 11am-5pm

Sun: 11am-3pm / 19th-23rd Dec: 11am-5pm

**£8** (visit and gift)

**£10** (visit, gift and photo)

[www.noahsarkcharity.org](http://www.noahsarkcharity.org)



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# Katherine Jenkins brings a bit of sparkle to a Noah's Ark mum

We had some very special visitors to the children's hospital ahead of last month's Hilton Ball. Little Fliss Watkins, a Noah's Ark patient who spent seven months on Island Ward after contracting a sudden illness which left her completely paralysed, came back in to help us deliver a surprise to her mum, Fran.

The person doing the surprising itself was none other than Katherine Jenkins. Katherine had heard about the dedicated support Fran has been giving her little girl since she fell ill last December and decided that she was in need of a bit of TLC.

Fran was whisked away for the afternoon and treated to a full make over before joining Katherine as her plus one at the Hilton Ball, of which the Noah's Ark Charity was a beneficiary. As part of the evening's opening, Katherine spoke about Fliss and Fran and her time with the hospital's play specialists. She said: **"Funding the play specialist team is just one of the many things that the**

**Noah's Ark Charity does to support the 73,000 children who visit the hospital each and every year, helping to provide the very best for the children of Wales. I had the honour of spending some of my day there today and let me tell you, it's an incredible and inspiring place. But the Noah's Ark Charity can only continue its work with your support, which is why we're all here tonight."**

When told that her Mummy was being taken away to be turned in to a princess before going to a ball just like Cinderella, three-year-old Fliss didn't seem particularly impressed. But, she said, it was because her mum is always a princess to her.



## Where your money goes

In the past few months your support has helped us to provide the following to the Noah's Ark Children's Hospital for Wales:

A **pulse oximeter**, which allows the condition of young patients who are particularly unwell and cannot be anaesthetised to be monitored closely while undergoing an MRI scan.

**Funding to help create a family friendly environment** within the children's assessment unit, including interactive and sensory toys that will help young patients feel relaxed while receiving the medical care they need.

A **SimBaby manikin** that will be used to deliver regular training on anaesthesia to the paediatric theatre teams.





# Active Autumn



It's been an energetic few months for many of our supporters. Despite the unexpected warmth of the mid-September morning, the season kicked off with our Family Fun Walk which saw families from across Wales turn out at Cardiff Bay in their hundreds to take part.

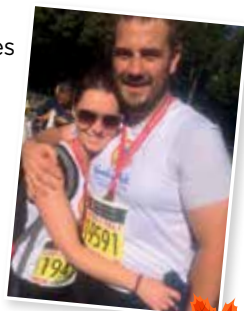
During the event, now in its third year, **a record breaking 280 men, women and children walked a three or 10k route around the Cardiff Bay Barrage to raise funds.** Presenter and charity ambassador Lucy Owen cut the ribbon to officially start the proceedings.



Among those who took part was five-year old Sara Williams from Carmarthen. Mum Lisa said: **"This time last year, Sara was in a wheelchair recovering from surgery to remove a brain tumour. Today she walked six miles and raised over £1,000 in sponsorship. I'm so proud of her."**

At the beginning of October, 47 Noah's Ark supporters were among thousands of runners who took to the streets

of the capital city for the Cardiff Half Marathon. Fundraiser, Oliver Williams, decided to set himself a few additional challenges and ran the course in 1.17 hours dressed in a lion costume! As well as raising an impressive £400, Oliver beat the current record for the fastest half marathon dressed as an animal by five minutes!



Two weeks on at our first ever Charity Dangle, it was the turn of a fearless few to take on a challenge in aid of the charity – although some became distinctly fear-FULL the further up they got. On a windy Sunday, 31 brave people climbed 278 steps up the Newport Transport Bridge before launching themselves off and abseiling the 178 feet back down to solid ground.

**So far the three events have raised over £32,000 for the Noah's Ark Charity with much more anticipated to come in over the coming weeks.**



If you'd like to take part in any of these events in 2017, keep an eye out for the events calendar in the next edition of this newsletter or email [linda@noahsarkcharity.org](mailto:linda@noahsarkcharity.org).



# Tilly and the Christmas Day miracle



This month, the Noah's Ark Charity launches its **Tiny Lives Appeal** with the aim of raising £1 million for the expansion and development of the neonatal unit. We'll tell you more about the appeal on page 8 but first, here's Tilly's story.

Katie and Rhys found out that they were having twins when Katie was three months pregnant. Everything was going seemingly well until at their 20 week scan one of the twins was found to have extensive abnormalities which not only threatened the viability of the affected baby, but the healthy baby too. In order to give the healthy baby the best chance of survival, they made the agonising decision to terminate the other twin. Katie and Rhys named their little girl Patsy after Rhys' grandmother.



Not long after however, Katie went in to labour – a day short of 24 weeks pregnant, when a premature baby is officially considered viable for life outside the womb. Although the medical team did everything they could to halt the labour, tiny Tilly Sue was born 16 weeks and one day early on the 21st of November. She weighed 720 grams.

Katie says: **"The whole thing was a total blur but I know Tilly must have cried when she came out because I asked one of the doctors how they make a decision on whether to start medical intervention when a baby is born before 24 weeks. She told me that if the baby asks for help then they help – so that's what Tilly must have done."**



"Tilly was taken away before I even had a chance to see her and all I could think was – I've already lost one baby, I can't lose another one. It was a whole day until I finally got to see her and the only word I can use to describe it when I did is horrifying. She was so tiny that her eyes were still fused shut and she looked so fragile and vulnerable. I just wanted someone to tell me that she was going to be OK but they couldn't. We just had to take it hour by hour and hope."



By the time she was a week old Tilly had already overcome two major setbacks – a bleed on her brain and an infection that spread to her chest and blood.

Tilly was becoming more and more reliant on the ventilator to breathe and the effort of it all caused her weight to drop to 560 grams.

"At that point we were just living minute to minute" says Katie. "The flow of the ventilator was being increased as Tilly's body struggled for oxygen."

Rhys says that he feared at that point it would just keep increasing until there was nothing more they could do – but I hadn't even allowed myself to think that we might lose her."

With other children to consider too, Katie and Rhys worked in shifts, splitting their time between home and the hospital. "Every time I left Tilly I'd dread the thought of what I'd walk in to the following day. The nurses always reassured us that they'd call if there were any changes but my mind still wandered away with me, especially at night. At times I'd wake in the early hours of the morning and just drive to the hospital to be with her. Some days I'd walk in and find the curtains drawn around her incubator and I'd have to wait, not knowing if something was seriously wrong or whether she was just undergoing a procedure. The first time I was able to put my hands inside the incubator and hold her she started to choke and I was taken away while the doctors resuscitated her. Then a few weeks later one of her lungs collapsed. Knowing that at any moment things could take a dramatic turn for the worst was awful."

Katie says that the weeks up to Christmas went by in a haze of worry and fear. On Christmas Day 2015 Katie and Rhys woke up and opened presents with the children before Katie went in to the hospital. When she arrived, Katie was greeted with the best Christmas present she'll ever have.

For the first time, little Tilly was well enough for a cuddle from her mum.

"The moment I'd been waiting to arrive for five long weeks was finally here. I just sat there for hours and hours with Tilly on my chest, never wanting to put her down again. It felt like we'd finally turned a corner and that the worst was behind us. Miraculously, from that day on, all the steps Tilly took were forward ones. Her weight started to increase and she started to become less reliant on the ventilator. At exactly two months old she was moved from intensive care on to the high dependency unit and although we were told not to worry if at some point she'd need to go back, she never did."

Not long after, Tilly, who had been tube fed since birth, was given her first bottle of milk by her mum and on Valentine's Day, she was taken off the ventilator and started to breathe completely unaided. Then on the 7th of March, a week before her actual due date, Tilly was well enough to go home.

**"My tiny baby who was born even before she was actually officially termed as viable for life had surpassed all expectations. She was coming home a week before her due date, which is apparently extremely rare in babies born as early as Tilly, and she was doing so able to breathe and feed completely on her own."**



Finally back home with her family, Tilly continued to exceed expectations and today she is a healthy and very happy baby who will soon be celebrating her first birthday.

"As much as it's hard to think about those dark days before Christmas, I'll never forget the amazing care that Tilly received on the neonatal unit and I can't thank the staff there enough for everything they did for us. I know without them we wouldn't be here now celebrating Tilly's first birthday and preparing for our first Christmas at home with her. Every baby is precious to its family but the battles that Tilly had to fight through just to be here with us now makes her even more so. She's definitely our little miracle."



## How you can help tiny people fighting big battles

Advancement in medical care means that more babies than ever are recovering from difficulties related to early birth to go home to their families like Tilly did. In order to respond to this, a two year programme to expand the neonatal unit at the University Hospital of Wales has been initiated. Over the next two years and with your help, the Noah's Ark Charity aims to raise £1 million to support the development of the unit. The appeal, called Tiny Lives, is part of our ongoing commitment to helping ensure the best specialist care possible for children – right from the first moments of life.

Born at 23 weeks and 6 days gestation, little Tilly is one of the most premature babies to be treated at the University Hospital for Wales neonatal unit. But sadly, due to the extreme fragility and vulnerability of premature and critically ill babies, the complications she encountered in the first few weeks of her life occur frequently. And just like Tilly they can develop rapidly, changing a baby's condition from relatively stable to acutely ill within a very short space of time.

Because of this, it's more vital than ever that the incredibly dedicated medical team have the right equipment on hand to respond quickly and effectively.

Among the life-saving equipment your contribution could help fund are ventilators that support a baby needing help to breathe.



You could also be helping to pay for a specialist mobile X-Ray machine which allows doctors to diagnose and respond quickly to a vulnerable baby's ever changing condition and incubators that reduce the risk of infection while creating a womb-like environment within which they can grow and gain strength.

Funds raised from the appeal will also support parents facing weeks and months of huge worry and uncertainty. It will provide video monitors so that mums recovering from birth can see their babies in the anxious hours before they can be visited on the unit and family rooms where parents can be supported in caring for their infant before they leave hospital.

There are many ways in which you can get involved in the Tiny Lives Appeal – from making a regular or one off donation to organising a Christmas Jumper Day at your school or place of work. However you decide to support, you'll be playing a part in ensuring the best treatment and outcome possible for premature or critically babies. You'll also be helping to grant their parents' only wish – the chance to take their babies home.

**To make a donation to this appeal, visit [www.noahsarkcharity.org/tinylives](http://www.noahsarkcharity.org/tinylives). Alternatively, send a cheque complete with the form on the back page and earmark your donation for the Tiny Lives Appeal.**



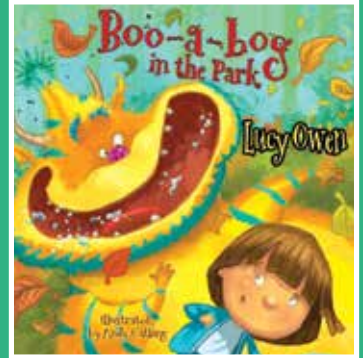
## Committed Noah's Ark ambassador Lucy Owen, has published her first children's book with royalties from its sale coming straight to the charity.

Boo-a-bog in the Park is the delightful rhyming story of Tom and his imaginary monster friend who helps him overcome worries and make new friends.

At the book launch, held earlier this month at the hospital, Lucy, her husband Rhodri and their son Gabe held a storytelling session complete with funny voices to make the children laugh.

We'd like to say a huge thank you to Lucy for her continued support and hope that families for generations to come will enjoy hearing the story of Tom and Boo-a-bog just as many will benefit from the proceeds it helps to raise.

You can purchase your own copy of the book in either Welsh or English by visiting [www.gomer.co.uk](http://www.gomer.co.uk)



## News in brief



Another record breaking Ascot Gold Cup day raised over £51,000 thanks to the dynamo Hayward family's popular annual event, held at Chepstow Races. Look out for 2017's race day date if you fancy a flutter next summer.



### Not bought your Christmas cards yet?

For the first time this year we have cards designed by patients at the Noah's Ark Children's Hospital. The fully bilingual packs of 6 are sold for £2.99 with the youngest artistic contributor just 11 months old! We also have traditional cards featuring the Holy Mother and Three Kings which are £3.75 for a pack of ten.



Give a home to one of our new Home Money Boxes! Specifically for prettifying up your shop counter or mantelpiece, these little boxes are hungry for your £1 coins and spare change and can be easily emptied and refilled. Please contact the office on 029 2184 7310 if you'd like us to send you a flat pack box to feed!



Our Teddy Bears' Picnic at the SSE SWALEC will be back by popular demand in 2017. Put Saturday the 28th of March in your diary and look out for more information in the spring edition of our newsletter.

# Securing a gift for

## Every gift is valuable

Did you know that all of our money is raised through Gifts in Wills and voluntary donations? Without the help and support we've received from people like you, our national children's hospital would not exist.

Through gifts both large and small, together we raised the funds to build and equip the hospital's first phase with its cancer and medical wards. Since then millions more has gone in to funding the MRI scanner, hydrotherapy pool, children's operating theatres, an eye department and other life-saving equipment like an echocardiograph machine to detect and diagnose heart problems in unborn babies.

## Our future

We've never been busier at the Noah's Ark Charity as we respond to the ongoing needs at the children's hospital. The new grant-making programme which we launched this year helps us to support staff on the frontline as well as fund state-of-the-art equipment.

We continue to be proud funders of the wonderful play specialist team and, as you have read, we have now launched a £1 million appeal to support the expansion and development of the neonatal unit which will help fund life-saving equipment for the most vulnerable of babies.

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## Why I've finally made a Will

"With only a few weeks to go until our first baby is born, I'm so glad I've finally sorted my Will out. It was one of those things that was constantly swept to the bottom of the pile, until last month when a mad dash to the hospital for potential complications made me think seriously about our baby and what would happen to him if my husband and I suddenly weren't around.

When you have a family you realise that it's not just about you anymore; I'm so pleased we had this opportunity to secure care for our child should the worst take place. Creating our will with Noah's Ark also made us stop and think about other children who need looking after - of course family comes first but after they have what they need, it makes sense to support a charity too; the chance to leave a gift to a charity I chose."



Expectant mum Jasmine  
with her husband Jim

# future generations

## Q&A with Lynn Wheeldon, consultant solicitor at Hopkins Law.



### What can I include in a Will?

You could give a specific amount of money or a specific gift like a painting, jewellery or even a property. Or you could give a share of what is left after you have taken care of loved ones or those close to you and left any items to specific people.

### How do I make a Will?

A solicitor can advise you on the best course of action.

### How do I change my existing Will?

Your solicitor can add a codicil to your Will which is a fairly straightforward process.

### If I wanted to include the Noah's Ark Charity in my Will, do I need to include the charity number?

You will need to state the charity's name and address which is: Noah's Ark Children's Hospital Charity, Upper Ground Floor, Noah's Ark Children's Hospital for Wales, Heath Park, Cardiff CF14 4XW. It's advisable to include the registered charity number 1069485 so it's clear which charity you intended to benefit.

every £1  
directly  
supporting  
hospitals and  
families

More information can be found on our website [www.noahsarkcharity.org](http://www.noahsarkcharity.org) or we can send out more information to you by post. If you'd like further information or would like to chat to us about making a Will, please contact [suzanne@noahsarkcharity.org](mailto:suzanne@noahsarkcharity.org) or telephone 029 2184 7310.



# SPREAD THE JUMPER JOY

Baby Tilly  
Born 16 weeks  
early weighing  
720 grams

## Organise a Christmas Jumper Day at your school or workplace in aid of the Noah's Ark Charity Tiny Lives Appeal.

You'll be helping to support the life-saving care of premature and critically ill babies needing specialist care in your community.

Getting involved couldn't be easier. Just choose your day, charge each jumper wearer £2 then visit our website for information on how to pay your money in.

[www.noahsarkcharity.org](http://www.noahsarkcharity.org)



I want to help young patients at the Noah's Ark Children's Hospital for Wales.

Please accept my donation of £\_\_\_\_\_

I enclose a cheque made payable to Noah's Ark Children's Hospital Charity.

Pay via your debit or credit card by calling us on **029 2184 7310** or online at **www.noahsarkcharity.org**

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Email: \_\_\_\_\_

Tel: \_\_\_\_\_

- ☐ I would like my donation to be earmarked specifically for the Tiny Lives Appeal.
- ☐ I am a UK taxpayer and wish the charity to claim the tax from this donation at no cost to me.
- ☐ I'd like to help in other ways. Please let me know how I can get involved.
- ☐ Please send information about \_\_\_\_\_
- ☐ Please send me e-news.

Noah's Ark Hospital Charity, Upper Ground Floor, Noah's Ark Children's Hospital for Wales, Heath Park, Cardiff CF14 4XW