

# Summer Newsletter 2017



## Remarkable Clark

Meet the little boy  
who's here against  
all odds



The Noah's Ark Garden opens its doors.  
Exciting times for the Tiny Lives Appeal.

# FAMILY FUN WALK 2017

Sunday 17th September

11am from the Norwegian Church, Cardiff Bay

Help support children and families at the Noah's Ark Children's Hospital for Wales by entering yours in our 3k or 10k walk along Cardiff Bay Barrage. Fancy dress is optional and the route is suitable for buggies, wheelchairs and dogs.

Join Team Noah's Ark and help support the 73,000 children needing specialist and life-saving treatment at the Children's Hospital for Wales each year.

**Registration costs £5 per person and includes a free t-shirt and bottle of water.**  
**Minimum sponsorship: £40 per person.**

Visit [www.noahsarkcharity.org/familyfunwalk](http://www.noahsarkcharity.org/familyfunwalk) or call **029 2184 7310** to book your place.



Warm up performed by:



Sponsored by:



Registered Charity No. 1069485

## Volunteers needed!

The volunteers who help out at our events are just as valuable as the people who attend or take part in them. They not only make it possible for a small team like ours to put on big things, they also add the sparkle - helping to make sure that our events are fun, inspiring and lively.

We've got a variety of exiting events coming up over the next few months and we'd really love your help if you have a few hours to spare.

Whether it's cheering on our Family Fun Walkers, being a little helper at Santa's grotto or giving our half marathon runners an extra morale boost to get them over the finish line, there's loads of ways in which you could help.

For more info give Linda a call on 029 2184 7310 or email [Linda@noahsarkcharity.org](mailto:Linda@noahsarkcharity.org)



## Inside this issue:

- 04 The Noah's Ark Garden**  
A new place of solace and fun for families



- 06 Tiny Lives Appeal**  
Our neonatal appeal goes from strength to strength



- 08 Cover story**  
Meet the amazing little boy who wouldn't be here without the Noah's Ark Children's Hospital



- 11 The seasonal roundup**  
Find out what our supporters have been up to recently



- 12 The Big Schools Superhero Challenge**  
We launch our challenge to a nation of young superheroes



- 14 Corporate support**  
How one Welsh business lends a helping hand



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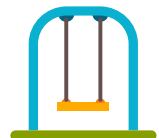
# A place to play at the heart of the hospital



The eagerly anticipated Noah's Ark Garden officially opened its doors to patients and families in March in a ceremony hosted by Noah's Ark Charity founder and president Lyn Jones OBE, Vaughan Gething AM and Chair of Cardiff and Vale University Health Board, Maria Battle. Funded by the Noah's Ark Charity and Welsh Government, the fully accessible garden is a bright and vibrant outdoor space complete with a play area, maze, palm trees and a therapy zone. Guests, which included patients, charity founders, dignitaries and our celebrity ambassador Lucy Owen, were entertained by the Oakfield Primary School Choir before being given a tour of the new garden.



Speaking at the event, Lyn Jones OBE said: "The Noah's Ark Garden is very much a symbol of the combined vision we had for a children's hospital for Wales from the outset – a world class paediatric facility with the needs of children and families at its very heart. It provides a fun and engaging space for children to receive therapy and a safe place for them to play in the outdoors. It's also a haven for families, who in some cases are facing long periods apart, to spend time together away from the wards. "As a charity, we're delighted to have been able to help make the vision for this garden a reality. We hope that it will provide a place of both solace and fun for generations of children to come."





Oakfield Primary School Choir entertain guests

As well as providing an outdoor space for patients and families to spend time together, the garden will also be used by the rehabilitation team for therapy sessions with patients. Natalie Gragasin, team lead for neuro-rehabilitation services, said: **“A park is an environment that children are familiar with and brings some normality into their lives. It’s also a great resource for rehabilitation with the added health benefits of fresh air and natural sunlight. The wards are artificial environments with level floors and no**

**steps which don’t replicate the challenges of most peoples’ homes. The garden allows us to practice skills which are more meaningful to the families’ lives such as walking on textured surfaces and slopes and climbing on the play equipment.”**

Five-year-old Neve, was one of the first patients to use the garden for therapy sessions during her recovery from a brain inflammation which left her partially paralysed. Mum, Vicky, said that Neve really enjoyed the sessions but also liked the garden for more childlike reasons. Vicky said: **“One of the hardest things for Neve is being separated from her beloved big brother Marley, who’s been at home while Neve and I have been here. Now that the garden’s open, Neve and Marley have got somewhere to go together on his visits, somewhere that looks like a “normal” place for children to play and spend time with each other. For families like ours who’ve spent a lot of time apart and for children like Neve who’s now spent two months here, it’s a very welcome addition to the children’s hospital.”**



Neve playing in the garden

# Tiny Lives gets some huge support



Our two year appeal to raise £1 million for the new neonatal unit at the University Hospital of Wales is now well on course to reaching its half way point by the end of this year thanks to amazing support from companies, members of the public and neonatal families.

Annie's Rainbows, a tribute fund set up in support of Tiny Lives by mum, Kirsty Pearson, after the death of her baby daughter, continues to go from strength to strength. In the last few months, the dynamic team of family and friends have organised a vast array of fundraising events including a family fun day, sponsored head shave and zumbathon.



After successfully raising an impressive £3,600 at their black tie event in April, the team are now planning an even bigger and better one for October.

Last month, we received news that the Morrisons Foundation, a charitable arm of Morrisons Supermarkets, were



to donate £208,000 to the Tiny Lives Appeal. On the foundation's request the money will buy a mobile X-Ray machine to help doctors diagnose and monitor a neonatal baby's ever changing condition more quickly and effectively. The donation will also fund four state of the art incubators for the unit.

On a recent visit to the University Hospital of Wales, representatives from the Morrisons Foundation met with baby Edie who was born at just 23 weeks and four days of pregnancy. Weighing only 580 grams at birth, Edie is one of the smallest babies ever to be treated on the unit and needed a great deal of support to help her beat very slim odds.

Dad, David, said: **"Seeing Edie in her incubator was so far from what we'd imagined as expectant parents. What should have been so natural felt anything but and it was hard to see from looking at her how she would ever survive."**

During her first few months of life, Edie faced several setbacks including the bleed on her brain, infection and a hole in the heart. Despite this, she is now doing well and recently went home with her parents

in time to celebrate her official due date – albeit at 116 days old!

Nicola and David are delighted at their daughter’s progress and attribute it both to their amazingly resilient little girl and the incredibly skilled and resourceful neonatal team.

You can read Edie’s story in full on our website at

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

To find out more about the Tiny Lives Appeal or to make a donation visit

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



Edie was 116 days old on her due date



## Crafty kids

Did you know that the money you raise helps buy craft equipment for children like Fliss, who spent seven months in hospital recovering from an illness that left her completely paralysed.

The play specialist team (which supporters like you also help us fund) used play-doh, stickers and glitter to encourage Fliss to use her limbs again, distracting her from the pain she was in by making the experience fun.

The play team also helped Fliss make a card for her dedicated mum, Fran, who spent months at her daughter’s bedside. Fran says it’s the best present she’s ever had.



Fliss made a card for her mum



# Clark, the living legacy



**Clark Beach was so ill that for weeks, doctors couldn't give a prognosis further than the next minute.**

The 20th of February 2016 had been a day like any other for the Beach family from Pontypridd. Dad, Ben, had been busy finishing off some DIY on the house and Sarra and the couple's 14-month-old son, Clark, were keeping him company while dancing together to Taylor Swift.

When Clark became ill later that evening, his concerned mum and dad decided to take him to the local A and E department as a precaution. As his heart rate was high, Clark was kept in and given antibiotics as a precaution but in the early hours of the morning, Sarra noticed a red mark on Clark's skin which rapidly started to spread. Clark had meningitis and despite the antibiotics, his body was going in to septic shock.



Clark with his mum

**"That was the point where everything took a sudden and very dramatic turn for the worse" says Sarra. "Within 15 minutes the room was filled with people and Clark was knocked out so that they could get all the lines and tubes in as quickly as possible. They ushered us out and when someone finally came in to get us, they told us that Clark was being taken to a children's intensive care unit in another hospital. I think we were allowed to see him beforehand because they didn't think he was going to make it."**



Clark spent 3 months in hospital

Already on life support, Clark was taken to the Noah's Ark Children's Hospital Intensive Care Unit where the medical team tried everything they could to stabilise the little boy. When Ben and Sarra arrived, they were told that he was not responding to treatment. They were offered a chaplain and told to say their goodbyes. Sarra remembers screaming with grief and telling the doctors over and over to keep trying.

And that's what they did. Every organ in Clark's body other than his heart was now being bypassed by a machine and it took four nurses working constantly just to administer the drugs and medication that was keeping him alive.

Ben says: **"Clark's condition was so fragile that even moving his blanket would send his body in to a tailspin and he'd need further medical intervention to try and stabilise him again. His hands and legs were turning black because of the septicemia and he was basically dying before our eyes."**



For many days, the doctors weren't able to confidently give any prognosis on Clark's life expectancy beyond the next few minutes.

On the 1st of March, Sarra and Ben were told that Clark's leg would have to be amputated at the knee immediately if he had any chance of survival. There was a very strong chance that given his condition, Clark would not survive the operation. But without it he would certainly die.

Despite his slim chances, Clark did survive the surgery and as a result of the amputation, his infection markers started to decrease. Around the four week point, Clark started showing signs that he was trying to breathe for himself and the decision was made to try and take him off the ventilator. Shortly after, Clark opened his eyes for the first time and not long after that came the moment Sarra and Ben had been longing for-the chance to hold their baby again.

After leaving intensive care, Clark spent many weeks recovering on Owl and Jungle Wards, while also being slowly weaned off very strong pain killers. After weeks of being tube fed, he had to learn to eat again and the play specialists and physiotherapy team worked with him intensively to try and make the whole process less traumatic.

After many weeks of corrective operations and rehabilitation, Clark was discharged from hospital on 16 May to continue his recovery at home.

He now has a prosthetic leg which he has adapted to amazingly well and his parents say he's back to his unstoppable self.

But Sarra and Ben are acutely aware of how close they came to losing Clark. They feel forever indebted to the countless medical professionals who at first kept him alive and then supported him through months of rehabilitation. They're also thankful for the care that Clark will continue to need as he grows.



Clark is adapting well to his new leg



Ben says: **“Clark's story perfectly illustrates why having a children's hospital is so vital. Having equipment, medical expertise and facilities that are specialised for children all under one roof makes such a difference. His needs were so complex that he must have used every one of them at one point or another. We were told by the intensive care team that Clark wouldn't have made it as far as the next closest children's hospital so for us it's pretty simple - without the Noah's Ark Children's Hospital we wouldn't have our son.”**

This July, the Beach family returned to the Noah's Ark Children's Hospital for Wales to meet Judy Goodfellow, whose brother, Mark, left a gift in his Will to the hospital. Mark sadly passed away in 2015 but spent a long period in hospital himself as a child in the 1960s.

Judy remembers the hospital as a dark and old fashioned place with strict routines and thinks that it was Mark's memories of being an only child on an adult ward that inspired his support of Noah's Ark.

Judy said: **“It's been a privilege to meet Clark and hear his remarkable story today. It's hard to imagine watching him run around so full of beans that without this hospital, he simply wouldn't be here. It feels like a real honour to think that my family has played a small part in helping to keep this lovely family, and many others like them, together. There's no greater tribute to my brother than that.”**



If you would like to find out more about leaving a gift in your Will to the Noah's Ark Charity, call **029 2184 7310** or email **enquiries@noahsarkcharity.org**.



# Little thank yous



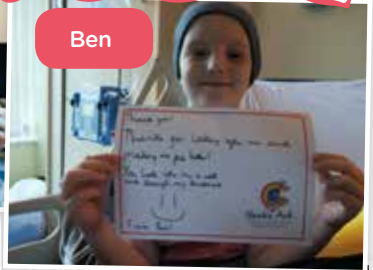
On International Nurses Day in June we asked some Noah's Ark patients (or their mums and dads in the smaller cases) if they'd like to send a message to the dedicated nurses who care for them.

Here's what they said:

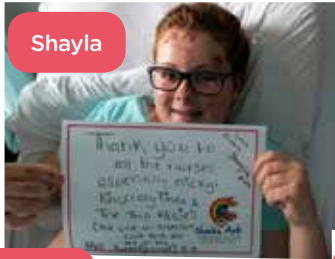
Eva



Ben



Shayla



Tyler



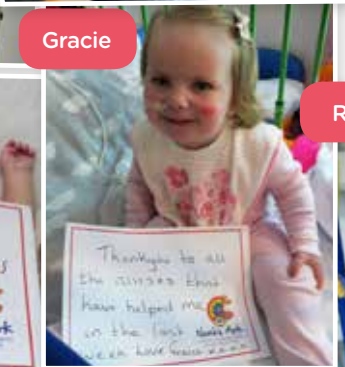
Emilia



Cohen



Gracie



Jake



Reuben and Isaac



# Spring highlights



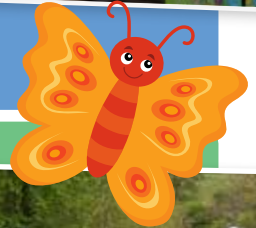
**Here's a taste of what our supporters have been up to over the past few months.**

The Teddy Bears' Picnic had a record breaking year. Our picnic guests raised an incredible £5,000 for the charity and judging by all the dancing, singing, painting and playing going on, we can confidently say that everyone had a great time. Dad, Rich Bennet, whose baby son was treated on the neonatal unit last year, said: **"What a great afternoon we had! George loved it! Great amount for a great cause! When's the next one???"**



Little picnickers enjoying their day

Thanks to UK Garrison for bringing along the wonderful Stormtroopers and to A&S Manuel for the super-popular Shopkins and Paw Patrol.



Llanidloes fundraising dynamo, Les Jones, hosted his annual Celt Power walk in May. Les has been a supporter for over a decade, inspired by the care received by his grandson Robert 30 years ago. Despite being born prematurely weighing only 1lb 11oz, Robert is now a burly rugby playing army corporal.



Les' walkers

50 people took part in this year's walk and Les is confident that the event will yet again break its £10,000 target.



The 3000s team

On an unseasonably cold, wet and extremely windy, weekend in June, five intrepid fundraisers set off for Snowdonia for the first ever Noah's Ark Charity Welsh 3000s Challenge – a walk, climb and scramble up nine of the highest peaks in Wales. Despite adverse conditions which forced them to turn back on the first day, the team completed their adventure with some satisfyingly aching legs, ruddy cheeks and of course, their well earned sponsorship money, to show for it.



# Hats off to Royal Ascot Day



Marilyn with event organiser, Julie Hayward

The 11th Royal Ascot Annual Charity Day which is organised by our very own vice chair, Julie Hayward, raised an astounding £60,032 in June. The event, held this year in aid of the Noah's Ark Charity Tiny Lives Appeal, was hosted by Chepstow Racecourse and attended by 300 people.

Long time supporter, Marliyn Meisels, travelled all the way from her home in London for the

event and wore a Noah's Ark Charity themed hat, which she'd had specially commissioned. Marilyn's efforts were rewarded at the event's finale, the best hat competition, in which she received a well-deserved first prize.



Ascot Day guests select their bets

At the beginning of April we launched our first ever fundraising event created specifically for schools.

The Big Schools Superhero Challenge is a fun sporting event where children run, walk or wheel either one or two kilometres dressed as their favourite superhero in return for sponsorship. The theme was inspired by Noah's Ark patients, who, due to the courage they show on a daily basis, are often referred to as superheroes by those who care for them.

To date, 35 schools have downloaded resource pack from our website which includes sponsorship forms, a make your own costume guide and an assembly presentation linking the activity to core skills in fitness, wellbeing and citizenship. Ysgol Glan Morfa in Cardiff were the first to hold an event this summer term raising more than £2,300, and many more have since followed suit.

We'd like to say a huge thank you to all the children, teachers and parents who have been involved in a Big Schools Superhero this term. You're all life savers!

Has your school downloaded a resource pack yet?

Visit [www.noahsarkcharity.org/schoolssuperherochallenge](http://www.noahsarkcharity.org/schoolssuperherochallenge) for more info.

## THE BIG SCHOOLS SUPERHERO CHALLENGE



Ysgol Glan Morfa raised a mighty £2,300

# Helping little heartbeats



The money you help us raise recently allowed us to fund a state of the art cardiovascular ultrasound machine which diagnoses heart conditions in babies both before and after birth. Shortly after birth, four week old Prashang was admitted to the Noah's Ark Children's Hospital for Wales when doctors detected an irregularity using the ultrasound machine. His condition will be monitored with further scans until he is old enough to undergo an operation to correct the problem.



Baby Prashang now has regular scans



**THE NOAH'S ARK CHARITY**

# DANGLE

278 steps up, a 178 foot abseil down and one great cause.

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SUNDAY 8TH OF OCTOBER  
 NEWPORT TRANSPORTER BRIDGE  
 £15 REGISTRATION FEE  
 £200 MINIMUM SPONSORSHIP  
 CONTACT: LINDA@NOAHSAKCHARITY.ORG  
 WWW.NOAHSAKCHARITY.ORG/EVENTS/DANGLE

**Noah's Ark**  
 Children's Hospital for Wales  
 Ysbyty Plant Cymru

Registered charity number: 1069485

## A family firm with a family ethos

The amazing support we receive from our corporate partners is as diverse as the kind of businesses they run. From gifting money for specific equipment or sponsoring our charity events, right through to donating second hand clothes or gifting toys at Christmas, we value each and every contribution they make to the cause.



Family run packaging business, A&S Manuel, have been supporters of the Noah's Ark Charity for the last three years. The company sponsors a number of fundraising events like the Teddy Bear's Picnic and provides pool cars for charity staff who need to travel around within their role. Team members Matt and Anthony recently took part in the Noah's Ark Welsh 3000s Challenge so staff are also actively encouraged to get involved in fundraising events.

The company's managing director, Andrew Manuel, has a very personal reason for supporting Noah's Ark as his daughter, Amelia, was admitted to the children's hospital at just three weeks old. Though doctors initially suspected meningitis, she was thankfully well enough to go home after seven days but Andrew says he'll be forever indebted for the care his daughter received.

Andrew says: **"Though having Amelia admitted to hospital was a terrifying experience, we couldn't have asked for more from Noah's Ark. Most of the people who work for us have families of their own so it just feels like good karma to be supporting a charity that has families at its heart. It's also a charity that's feels very real and tangible. As a business, we get approached by many other worthy organisations but by backing a charity that supports the community we're based in, we feel like we can be more involved and hands on."** For more information on corporate partnerships, email [Samantha@noahsarkcharity.org](mailto:Samantha@noahsarkcharity.org).



## Thumbs up

We're constantly amazed by the dedication and creativity of our supporters. Whether it's through regular giving, a sponsored event or one of the many weird and wonderful fundraising activities we hear about, we'd like to say a massive thank you on behalf of the children and families you support.

# Events



## Annie's Rainbows Family Fun Day

Saturday 29 July 2017  
Pontprennau Playing Fields

Join the Rainbows team for a day of BBQs, bouncy castles and bungee runs. For more info email [anniesrainbows@yahoo.com](mailto:anniesrainbows@yahoo.com)

## Royal Welsh Show

24-27 July 2017  
Builth Wells

Come and visit us at the Noah's Ark Charity stand.

## Family Fun Walk

Sunday 17 September 2017  
Cardiff Bay

Walk with your family in aid of families at the Noah's Ark Children's Hospital. Register at [www.noahsarkcharity.org/events/familyfunwalk](http://www.noahsarkcharity.org/events/familyfunwalk)

## Cardiff Half Marathon

1 October 2017

Run the streets of Cardiff with #TeamNoahsArk.

## The Annie's Rainbow Black Tie Dinner

Saturday 7 October 2017  
For more info email [anniesrainbows@yahoo.com](mailto:anniesrainbows@yahoo.com)

## The Noah's Ark Charity Dangle

Sunday 8 October 2017  
Newport Transporter Bridge

Sign up for a 178 foot abseil from the historic Newport Transport Bridge for a registration fee of £15. Visit [www.noahsarkcharity.org/events/dangle/](http://www.noahsarkcharity.org/events/dangle/)

## Santa at the Usk Winter Fayre

2-3 December 2017

## Santa's Grotto

2-22 December 2017  
IKEA Cardiff

Come and visit Santa in his magical grotto.

For more information on all our events visit [www.noahsarkcharity.org](http://www.noahsarkcharity.org) or call 029 2184 7310

# 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.noahsarkcharity.org/lottery](http://www.noahsarkcharity.org/lottery) or call **02921 847310**

# Many of our supporters like to leave a gift to our charity in their will. Could you?

Have you read Clark's inspiring story inside this issue? A gift in your Will can make a huge difference to the support that the Noah's Ark Children's Hospital Charity can provide for the children of Wales.

The hospital currently treats **73,000 children** a year either in the hospital or at **400 clinics** that doctors run in local hospitals across Wales.

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

All you have to do is make a Will or, if you already have one, simply add a codicil. A solicitor can advise you on the best course of action. If you would like further information about leaving a gift in your Will, call us on **029 2184 7310** or email **enquiries@noahsarkcharity.org**

Think of it as your present to the future children of Wales.

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