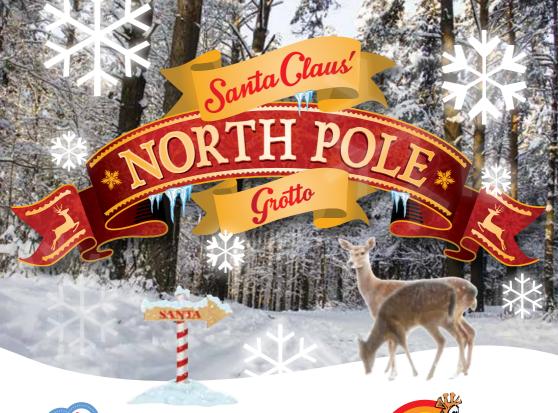
# Winter Newsletter 2017



**Creating futures** for neonatal babies and their families Catch up on the Tiny Lives Appeal one year on Treasuring Lexi The family who are making every day count We launch our **Impact Report** www.noahsarkcharity.org Registered Charity Number: 1069485







# **Visit Santa at IKEA Cardiff**

# 2nd-22nd December 2017

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

£8 (visit and gift) £10 (visit, gift and photo)

# Opening hours:

2nd - 17th December

Mon-Wed: 1pm-5pm Thu-Sat: 11am-5pm Sun: 11am-3pm

18th - 22nd December Mon-Fri: 11am-5pm

www.noahsarkcharity.org

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# Making an impact

We're delighted to announce the launch of our first ever Impact Report, which is now available for you to read on our website.

We've compiled the report so you can see exactly where the money raised by our supporters has gone since we opened the doors to phase two of the hospital. From the funding of a DVD system which reduces fear and anxiety in young radiology patients, to a piece of equipment that saves children's sight, we have achieved a great deal together since Spring 2015.

The report demonstrates the direct impact that your support is making through the stories of children like Fliss, who learnt to smile again thanks to the play specialists that the charity helps to fund. There's also teenager Matt, whose pain from a spinal tumour is alleviated by physiotherapy sessions in the Noah's Ark Hydrotherapy Pool, not to mention the countless families who now have access to the Children's Assessment Unit at night.

Our report is also an opportunity for us to say a huge thank you to each and every one of you for the part you have played in these successes. Here's just a snapshot of what you've helped achieve for children.

# To read the full report visit www.noahsarkcharity.org







382

less children have undergone general anaesthetic during MRI scans thanks to the child focused improvements we have made to the Radiology Department. This not only means a cost saving for the hospital but a far less traumatic experience for young patients.

more children are now seen at the Paediatric Ophthalmology Clinic.

We have approved grants to the value of

£1,068,613

since launching the programme in Spring 2016.



534

children have received rehabilitation in the Noah's Ark Hydrotherapy Pool.



130

food parcels were given to families in hospital over the 2016 festive period.

1,267

seriously ill children have been cared for on the Paediatric Critical Care Unit. The charity has supported the play specialist team in delivering close to

69,000

hours of play therapy to more than 100,000 children.



8,**\*\***+

children have been treated at the Cardiology Unit.

3,250

children have undergone scans using the purpose built MRI scanner.

137

Emergency Parent Packs have been distributed to families in need.





# The power of play

During Play in Hospital Week in October, the play specialist team organised a week of superhero related activities to celebrate this year's theme, The Power of Play. Play specialist, Kelly, said the theme was very apt, not only because it demonstrates how vital play is for children in hospital, but also because the children here are often referred to as superheroes by the people who care for them.

During the week, we asked some parents what play in hospital means for them:

"Rhiannon has been a regular here since she was little and spent four and a half months in traction after an op on her spine.

"The team devised a play system for Rhiannon which included magnets and toys that she could play upside down. They made the scary and uncomfortable procedures feel fun by dressing her in princess costumes and decorating the brace she had to wear. She's been their number one fan ever since." Carole. Rhiannon's mum.





"The doctors and nurses are lovely but sometimes they have to do things that are very stressful and uncomfortable for Jake. Despite this, he quickly learns to associate play specialist, Juliet, with fun and he visibly relaxes and enjoys himself while he's in the play room. It's also great to have the sensory room on the ward where we can lock ourselves away from all the medical stuff and just play. It all contributes to making an unnatural situation feel a lot more normal and familiar for us as a family" Rachel, Jake's mum.

"The play specialists have mastered the art of distraction so young patients like Rose have their minds taken off the needles and procedures. Their role is invaluable to children with cystic fibrosis because they require high levels of intervention so it's really important that each hospital visit is positive." Jude, Rose's mum.











For more information on creating your own lasting legacy for tomorrow's children (and to watch Clark's story in full), visit www.noahsarkcharity.org/freewill or call 029 2184 7310.





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One of our greatest achievements as we look back on 2017, is the progress we have made towards raising £1 million to support the care of premature and critically ill babies. Over the last 12 months, you have helped raise more than £500,000 for the Tiny Lives Appeal and we'd like to thank all the people, groups and organisations that have supported us so far. The money is already being put to good use and funds have been committed to funding:

state of the art incubators, which keep tiny babies at their critical optimal temperature and protected from life-threatening infection. The incubators also have a function which allows recordings like a parent's voice or a mum's heartbeat to be played in to the compartment, which the incubator automatically limits to womb level noise.



- a specialist mobile x-ray machine which enables babies to undergo important x-rays without being moved. It allows doctors to diagnose at the cot side and respond quickly to treat or stabilise the baby where necessary.
- air/oxygen blenders which combine the precise levels of air and oxygen to a baby according to his or her individual need.

We're also already playing a part in improving the environment and facilities on the unit, funding comfortable chairs for parents to sit in alongside their babies, a play area for young siblings and wall art that creates a more soothing and homelike environment for families during very stressful times.

But despite these great achievements there is still so much more to be done. Next year, hundreds more premature and critically ill babies will need the life-saving care that the neonatal unit provides. Among the things that the Tiny Lives Appeal will fund in 2018, with the continued support of the public, are ventilators that breathe for the sickest of babies, a phototherapy machine to protect the baby's nervous system and overnight rooms for parents.

# Friends reunited

To celebrate the achievements of the Tiny Lives Appeal in its first 12 months, we recently held a gathering for some families whose babies were treated on the neonatal unit last year and have since become firm friends. Some told their stories when Tiny Lives was launched and all have since gone on to raise funds for the appeal.



Laura and Rich's son George (centre of group photo), spent almost three months on the neonatal unit after being born full term as an emergency C-section. Though he appeared healthy at first, George stopped breathing in his father's arms at just 15 minutes old and was resuscitated in the delivery suite. In the first ten weeks of his life, he underwent over 100 blood tests, 12 blood transfusions and 3 lumbar punctures and his parents were prepared for the prospect that he may never walk, talk or even smile. But thanks to the specialist care he received on the neonatal unit, George is now home with his mum and dad and just like any other healthy, happy toddler.

Laura says: "We're supporting the Noah's Ark
Tiny Lives Appeal because we can't even begin
the express the debt of gratitude we feel towards
the amazing neonatal unit. Nothing can prepare
a parent for having a baby as sick as George was
and no words can describe the grief of going home
and leaving your baby behind. But George did finally
come home and we've since been able to create the
memories that every mum and dad dreams of making
before their baby is born.



"Often people don't realise that not all neonatal babies are born early. The University of Wales neonatal intensive care unit also cares for the most seriously ill full term newborn babies from across Wales too. George's needs were vast and complex that we're thankful every day that this unit was there to care for him. By supporting Tiny Lives, we're supporting a world that we didn't even know existed before George was born but that's now changed us forever. We're helping to ensure that other babies are able to receive the excellent care that he received so as many families as possible get to go home together."

# Looking ahead

This Giving Tuesday (28th of November), we'll be launching our second year of fundraising for the Tiny Lives Appeal, with the aim of reaching our £1 million target by the end of 2018. If you'd like to help give the gift of life this Christmas, visit www.noahsarkcharity.org/tinylives

Alternatively, complete the form on the back page and earmark your donation for the Tiny Lives Appeal.

# Bag a bargain and help a child





# Celebrate and give



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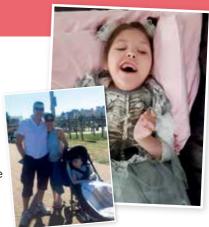


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# Ain't no mountain high enough Lexi's Story

Five-vear-old Lexi from Tonypandy, started having seizures when she was three months old. Over the following weeks they got progressively worse until one day, having counted more than 100 in 24 hours, her parents, Anthony and Sharon called an ambulance.

Lexi was taken to the University Hospital of Wales where in an attempt to control the seizures, she was put in to an induced coma. Eventually, after extensive investigation which included genetic testing, Lexi was diagnosed with a very rare form of life-limiting epilepsy called Migrating Partial Epilepsy of Infancy (MPEI), and then Dravet Syndrome.



Eleven weeks after she was first admitted, Lexi was able to go home accompanied by a whole host of medication. Very sadly, the epileptic seizures had damaged her brain irreparably meaning that she could no longer feed or swallow unaided and would never be able to walk and talk. The family were told that the average life-expectancy for child with her condition was around five.

Thanks to a specific combination of medication. Lexi's seizures are now far more under control, and she visits the Noah's Ark Children's Hospital regularly. But despite the fact that she needs extensive around the clock care, the Colcombe family are determined to enjoy all the time they have with her. They're also committed to raising funds for the Noah's Ark Children's Hospital as a thank you for her care.



Anthony, says: "When Lexi was first taken to intensive care, the children's hospital was still being built so we were on the children's part of the general intensive care unit at the Heath. The medical team there were great but we definitely got to understand first hand why having a dedicated children's hospital was so important.

"Lexi has struggled through countless seizures since and the numerous visits to the Noah's Ark Children's Hospital have played a vital role in saving and prolonging her life."

Anthony and his family have raised more than £10.000 for the Noah's Ark Charity over the past few years. His colleagues at ISG Construction have also been very supportive and, headed by Anthony, a team from their Cardiff office recently completed the Three Peaks Challenge in aid of the charity.

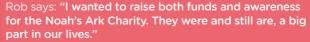
Anthony says: "I wanted to repay my gratitude to the hospital and was thrilled when the team agreed to take on the challenge with me. Raising £4,000 made our aching muscles and stiff joints worth it and I think the team would agree that we all enjoyed it."

# More than 500 of you took part in an event for us this autumn....

# **Charity Dangle**

13 brave supporters raised £7,500 at our 170 foot abseil from the Newport Transporter Bridge in October. Dedicated dad, Rob Spong, raised close to £800 in sponsorship having conquered his massive fear of heights to take part. Rob's five-year-old daughter, Lacey-Mae,

was diagnosed with a brain tumour last year but to the great relief of her family, got to ring the end of treatment bell at on Rainbow Ward (children's oncology ward) in July.





# Family Fun Walk

Families from all over Wales filled Cardiff Bay in September for our 4th annual Family Fun Walk. Every year this fun, family-friendly event grows in popularity with a record breaking 400 walkers taking part in 2017, raising an incredible £19,000. Following an energetic warm up, our families set out to walk 3 or 10k

over the bay barrage, returning to be greeted by our Tiger mascot, Rio, and a goodie bag from our sponsors IKEA. Among those taking part for the first time this year were Natasha Wall and her son Jamie, who has been a patient at the Noah's Ark Children's Hospital for Wales since he was a baby. This time last year, Jamie spent time on critical care after developing a serious case of pneumonia. Natasha says: "We took part in the Family Fun Walk because we wanted to give back to the amazing children's hospital that saved Jamie, to change someone else's darkest day in to a better one. It's something little on our part that could make a big difference to another family."







# The Cardiff Half Marathon

150 runners took to the streets of Cardiff at the beginning of October to run 13 miles in support of the children and families of Noah's Ark. A total of more than £46,000 has been raised to date, and though we think you're all incredible, we'd like to give a special little shout out to the 16-strong team from Burns Pet Nutrition, grandfather Paul Scanlon who has run 12 races to date for us this year, Team Ben and everyone who ran in memory of Hugo. Huge thanks on behalf of our runners too, to our cheer squads who gave up their Sunday lie ins to shout our athletes on. We're told that your support really did give them the power up they all needed

# **Community heroes**

We couldn't do what we do without the help of people in the community, who raise funds for the Noah's Ark Charity in a whole host of different ways. If you're interested in holding a fundraising event in your community in 2018, here are a few ideas to inspire you.

Becci Newton from Llanbradach organised and hosted her first charity ball in Caerphilly Castle in October. Soul and groove band, Get Ready, donated their time to provide the entertainment while several local businesses supported the event by donating auction and raffle prizes. The ball was sponsored by Caerphilly Town Council and raised more than £1,000 for the charity. Becci has now caught the event organising bug and has pledged to hold the ball again next year.





More than 30 recruits at the Army Training Regiment in Winchester took part in a press up challenge in August and September, raising more than £2,500. The recruits were given several charities to choose from but opted for Noah's Ark as the daughter of Instructor Sgt Fisher receives treatment at the hospital

Three-year-old Elin became possibly our youngest ever fundraiser when she had her long hair cut off for the Noah's Ark Charity in the summer.
Elin wanted to cut her lovely locks in support of her big cousin, Evie, who at the time was recovering from a seventh operation to correct the bladder and kidney problem she was born with

Evie was right there to offer words of support to her little cousin, who raised an incredible £533 in sponsorship. Pretty impressive for a little girl who hasn't even started school yet, we think you'll agre



For more fundraising ideas, take a look at our fundraising A-Z at www.noahsarkcharity.org/fundraise-for-us/



# STOP PRESS!

We have just received confirmation that the Noah's Ark Charity will be the associate charity for the first ever Newport Wales Marathon on April 29th, 2018.

Please contact the office to reserve your **free** gold place in this marathon, which boasts one of the UK's flattest routes. We also have spaces for the Swansea Half Marathon and the annual Cardiff Half Marathon, see our events calendar on page 15 for all the relevant details.





MARATHON & 10K CASNEWYDD CYMRU

For more details about the Newport Wales Marathon and 10k, including map and latest news visit www.newportwalesmarathon.co.uk



# An end of year thank you

Christmas may be the season for giving, but our amazing team of volunteers give their time to support the Noah's Ark Charity all year round. So we just wanted to take this opportunity to thank each and every one of you for your help in 2017. Big thanks especially to the shop volunteers, who between just ten of them, amassed more than 1,100 hours from January to the



# **Events**



### Santa's Grotto

### Sat 2nd - Fri 22nd December 2017 **IKEA.** Cardiff

Book nine spaces and get the 10th free. See page two for opening hours.

### **Teddy Bears' Picnic**

Saturday 10th March 2017 SSE SWALEC Stadium, Cardiff

Tickets available from January 2018.

### Ladies Lunch with a Purpose

Friday 23rd March 2018 Hilton Hotel, Cardiff An afternoon of fun and fundraising.

# The Superhero Run

Sunday 22nd April 2018 Pontcanna Field, Cardiff

Join us for our first ever 2.5 and 5k fun run around Pontcanna Fields.

### **Newport Marathon and 10k**

Sunday 29th April 2018

Call 029 2184 7310 to book your FREE gold place.

### Swansea Half Marathon

Sunday 24th June 2018

Call 029 2184 7310 to book your FREE gold place.

### Family Fun Walk

September 2018

Our popular family event in Cardiff Bay. Registration from May onwards.

## Cardiff Half Marathon

Sunday 7th October 2018

Call 029 2184 7310 to book your FREE gold place.

For more information on all our events visit www.noahsarkcharity.org or call 029 2184 7310





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 or call 029 2184 7310

# Make a donation

Send a gift for the children of Wales. Simply complete the donation slip and return to the address below. Thank you in advance for your support!

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Alternatively, you can make a donation online at www.noahsarkcharity.org