

noahsarkhospice.org.uk

# A MOMENT IN TIME



OUR IMPACT IN 2023/2024

### WE ARE NOAH'S ARK CHILDREN'S HOSPICE

We help babies, children and young people with life-limiting or life-threatening conditions, and their families, make the most of every day. And for those who die young, we do all we can to bring comfort to their last moments.



We take an individual approach, adapting our care to meet the needs of each child. We offer support to the whole family, not just the child who is unwell, including

We exist to help those we support enjoy life as children, rather than as patients – as families, not just as carers.

Children and families are at the heart of

everything we do. We provide exceptional

care, organise fun activities and help

thought possible.

families do things they may have never

Our help is available wherever it is needed - in the home, in the community or at our hospice building, The Ark.

dedicated sibling support.

At Noah's Ark you can meet people in a similar situation and immediately have an open conversation with them because you know they get it. You don't have that anywhere else.

Roscoe and Gina, parents to Arthur and Ray who are supported by Noah's Ark

### **OUR VALUES**



#### **KINDNESS**

We show compassion and empathy in all our interactions



### EXCELLENCE

We are compassionate and exacting about our mission

#### COURAGE

We are strong and ambitious in all we do

### A Moment of Impact in 2023

A seven year old boy, was able to access soft play and sensory rooms for the first time, thanks to our hoist at The Ark.



### A MESSAGE FROM OUR CEO



Palliative care can be life-changing for the children and families we support. Through our dedicated team of staff and volunteers, offering a wide range of holistic support, we can make a real difference that will be felt for years to come.

The growth we have seen in our services this year has been driven by the needs of the children and families we support. Their voices have fuelled our growth since we started offering services in 2006 and will always continue to be our guiding light.

We always place the child and family at the centre of all we do. Behind every number you will read in this Impact Report, there is a life that has been impacted – a life potentially changed, and memories created that will last forever.

The number of hours of therapy delivered has increased by 47%. Behind this number there is a baby, who after spending the beginning of his life in hospital, opened his eyes for the first time during a Music Therapy session.

The number of hours of clinical care delivered has also increased by 33%. Behind this number, there is the story of a boy who has been a long-term patient at Great Ormand Street Hospital who, through the support of our nursing team, was able to visit The Ark for his first ever visit to a soft playroom.

We are very pleased to award Noah's Ark an outstanding CQC rating and the whole team deserve to be congratulated for all their hard work and commitment. We would urge other services to read this report and see what they can learn from

this outstanding example.

Jane Ray, CQC Deputy Director of Operations in London, who oversaw the CQC's inspection

2 Noah's Ark Children's Hospice | Impact Report 2023/2024





This year we delivered 190 hours of bereavement

support, up 34% from last year. Behind this number you will find Costel and Andrea, whose daughter Nadia died in 2022. Our bereavement support has helped them "go through the pain and understand the pain" of their daughter's death.

It is our privilege to support families such as these. We cannot change a diagnosis, but we can stand next to families throughout their journey and be there for them every step of the way.

There will never be an Impact Report big enough to hold all the moments of impact we have seen in the last year, but it is with immense pride and gratitude that I share with you a snapshot of our story.

Thank you to the families we support for trusting us to be there for them. And thank you to every single supporter who made this remarkable year possible.

Jophie Andrans

Sophie Andrews OBE CEO, Noah's Ark Children's Hospice



### **OUR JOURNEY**

The last two decades have been guite a journey. Whilst a lot has changed, what hasn't is our unwavering dedication to being there for children and families, and putting their needs at the centre of all we do.

Our focus on the needs of children and families has fuelled the expansion of our services. We are able to offer one of the widest range of services in the children's hospice sector.

• 1999	Michael McInerney establishes Noah's Ark following the death of a child in his family.
• 2006	Noah's Ark becomes the first ever children's hospice to provide a Home Support Volunteer Service.
• 2015	The £10m 'Building The Ark' appeal is launched.
• 2019	The grand opening of The Ark, our purpose built, state-of-the-art children's hospice.
• 2020	We continue to support children during the COVID-19 pandemic, allowing families with a child at the end of their life to stay together.
• 2023	Noah's Ark receives its first <b>'outstanding'</b> rating

from the Care Quality Commission.



Noah's Ark widens Sophie's world. They allow these children to be more than just their diagnosis, they allow them to be children first. There's nowhere else that Sophie can play... Noah's Ark are a handhold in the darkest of times and they're the fun providers in the best of times.

Rose, Grandmother and sole guardian of Ben (who died in 2014) and Sophie who currently benefits from our care

### **NOAH'S ARK TODAY**

The Ark is a home-away-from-home for those we support. We provide expert clinical care plus fun and stimulating activities, such as creative therapies, sensory and soft play.

Children come to Woodlands, our children's bedroom wing, for step-down-care (when they are well enough to leave hospital but not well enough to go home), respite, urgent care and end-of-life care.

We also have accommodation for families, so they can remain close to their child when they stay with us.

Nature is never far from you at The Ark, with our large windows revealing the nature reserve outside. A calming and safe place, The Ark is there for families how ever they arrive through its doors.

### WHERE WE PROVIDE OUR CARE:

We can provide care wherever it works best for families:

2,992

2,072

visits to The Ark

visits to family homes

#### OUR IMPACTFUL HOUSEKEEPING TEAM:

Our housekeeping team go the 'extra mile' to make families feel at home at The Ark. From their exacting hygiene standards, a selection of non-clinical smelling products, choices of patterned bedding to other little finishing touches you wouldn't expect in a hospice. It's no surprise that they were recognised as providing a 'Centre for Excellence' for cleanliness by North Tees and Hartlepool NHS Foundation Trust.



4 Noah's Ark Children's Hospice | Impact Report 2023/2024

Noah's Ark has been life changing for my family – I don't know where we'd be without them. I feel so lucky to have them in our lives.

Faye, Mum to Jaida, who is being supported by Noah's Ark



visits in the community (including hospitals)

### A MOMENt of Impact in 2023

A one-year-old child, who has spent her life in hospital, had her first swim in our hydrotherapy pool and laughed throughout.



### **OUR IMPACT IN KEY NUMBERS**

The demand for our services is great; working in collaboration with healthcare professionals and engaging with our community to raise vital funds, we aim to support even more families.

#### IN 2023/2024 WE SUPPORTED:



390 of their siblings, and

687 parents, grandparents and carers

1,455 people overall

### A Moment of Impact in 2023

A five-year-old child who is non-verbal was able to ask for her mum for the first time using a voice generated by Eyegaze,



the eye-driven communication device we use at Noah's Ark.



### THIS INCLUDES:



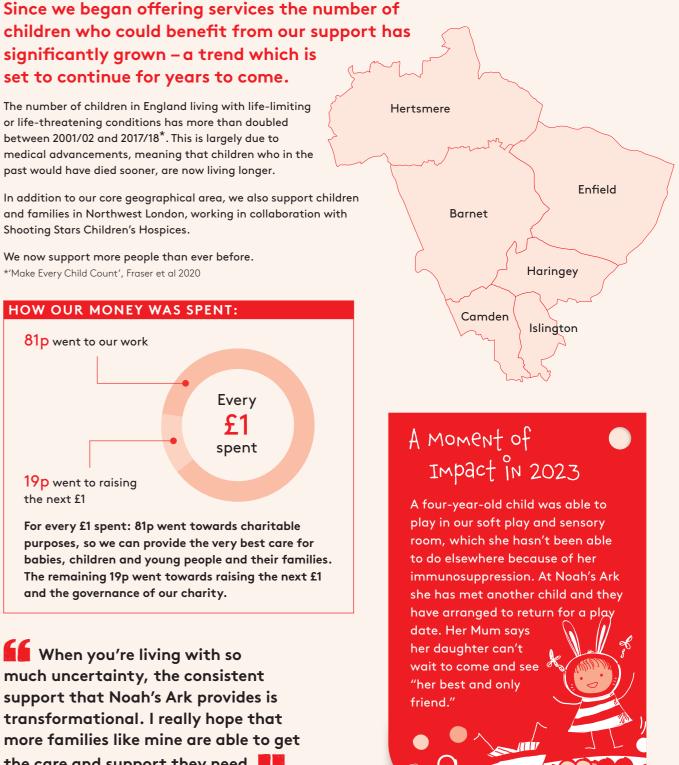
### **OUR REACH**

significantly grown – a trend which is set to continue for years to come.

or life-threatening conditions has more than doubled between 2001/02 and 2017/18<sup>\*</sup>. This is largely due to medical advancements, meaning that children who in the past would have died sooner, are now living longer.

Shooting Stars Children's Hospices.

We now support more people than ever before. \*'Make Every Child Count', Fraser et al 2020



When you're living with so much uncertainty, the consistent support that Noah's Ark provides is transformational. I really hope that more families like mine are able to get the care and support they need.

Robert, Dad to Samuel and Freddie who are being supported by Noah's Ark

6 Noah's Ark Children's Hospice | Impact Report 2023/2024



Our Family Link team are the main contact point for families. Following an initial assessment, the team then tailor their support to the individual child and their family. They provide emotional and practical support, such as signposting, advocacy and welfare advice.

### IN 2023/2024:

We carried out **211** assessments

We worked with a total of **317** families



Extending our partnership working has been a real focus for the team this year.

### HIGHLIGHTS INCLUDE:

- Working with Great Ormond Street Hospital and Young Lives vs Cancer to support more children and young people living with a cancer diagnosis.
- Widening our multi-agency approach, including regular meetings with **Barnet Social Care** and **Enfield Community Team** to facilitate integrated care for families.
- Securing much needed **Barnet Food Bank** vouchers for families in need.



8 Noah's Ark Children's Hospice | Impact Report 2023/2024

Noah's Ark has been like a lifeline. Our Family Link Worker, Jo, has been a gift to us.

Ambreen, Mum to Adam who is supported by Noah's Ark

### A Moment of Impact in 2023

One of the families we support had been on the housing list for years. Their child had spinal surgery and after six months had still not been able to return home, as the house was unsuitable for their needs. In response, their Family Link Worker brought together medical staff, social care, legal teams and other professionals to advocate for the family. The family now has a new home that is being adapted to their needs.

### SPECIALIST CARE AND NURSING

Our Specialist Carers (Healthcare Assistants) and Nurses do all they can to help alleviate pain, create memories and allow those they support to enjoy life as children – rather than as patients.

### IN 2023/2024:

We provided

26,695



hours of clinical care. The number of clinical hours that we have provided has increased by a third since 2022/23.

### OUR PARTNERSHIP WITH GREAT ORMOND STREET HOSPITAL:

We strengthened our relationship with **The Louis Dundas Centre for Palliative Care at The Great Ormond Street Hospital** (GOSH) by introducing a new Clinical Partnerships Manager, which has helped to develop a mutual understanding and align how we can support families that need end-of-life care; and offer choices for their preferred place of care. This collaborative approach facilitates a smooth transition of care across our services for the benefit of the child and their family.

### IN 2023/2024:

We received

55

referrals from GOSH



Our Clinical Partnerships Manager delivered training to

398

healthcare professionals outside of Noah's Ark

Thank you so much for today and settling us in so well to The Ark over the last 24 hours... You have been amazing at every stage. We really appreciate all you have done.

Parent of a child who transferred from GOSH to Noah's Ark

10 Noah's Ark Children's Hospice | Impact Report 2023/2024

The joint specialist nursing role between GOSH and Noah's Ark is having a huge impact for staff and families. Staff across the hospital are learning so much more abo the role of hospices in supportin long term care for families, and families have commented how reassuring it is to see a familiar face when they move from hospital to hospice. Through working together we are all developing our skills and knowledge, leading to much better continuity of care across both settings, as well as in the home. This is definitely a pattern of shared, integrated working that we want to continue.

Dr Finella Craig, Consultant in Paediatric Palliative Medicine GOSH

### A Moment of Impact in 2023

A long term patient at Great Ormond Street Hospital and his parents were referred to The Ark for a day visit to enjoy time together making memories – this included his first visit to a soft play room, sitting in a real tractor and seeing a therapy dog. His parents also enjoyed a short nap in the same bed in the same room – their first opportunity in six months.

### **THERAPIES**

Our Music, Drama and Movement, Hydrotherapy, Occupational and Art Therapy sessions are designed to support a child's development, encourage play opportunities and help them to express themselves.

#### IN 2023/2024:

# 1,772



total hours of therapy were provided. The number of hours of therapy we have provided has increased by 47% since last year.

#### THIS INCLUDED:



hours of Music

Therapy



397 hours of Art Therapy

hours of Hydrotherapy



#### EVOLVING OUR THERAPY SUPPORT FOR BABIES:

hours of Drama and

Movement Therapy

Parent and baby groups can be an essential part of the early years of a child. However, if a child has complex needs mainstream groups may not be accessible. Our group for babies aged up to two years and their parent/carer promotes bonding, supports communication development and offers a supportive environment for the sharing of experiences. Led by our Music and Drama Therapists, the group offers opportunities for music, sensory play and stories.

baby group sessions ran during spring and summer months

It's been a delight to see little ones grow in confidence each week. These sessions give little people an accessible way to find their own voice, express their needs, and tell stories their way.

Pasha, Noah's Ark Drama Therapist

12 Noah's Ark Children's Hospice | Impact Report 2023/2024 

Music Therapy allowed us for the first time since my son's very difficult start in life to experience a moment of normality as a family.

Mother of a child supported by Noah's Ark

#### INNOVATIVE NEONATAL RESEARCH:

Our Music Therapist, Kirsty Jane, started a three-year groundbreaking research project to define what music therapy should look like in a neonatal unit, funded by the National Institute of Health Research.

This type of research has never been done in the UK before. If successful, it could change the way music therapy on neonatal wards is delivered across the UK, making sure that every family with a child in need of hospice care gets the support that they need.

Kirsty Jane, Noah's Ark Music Therapist

### A Moment of Impact in 2023

A six month old baby who had never opened his eyes attended his first music/drama therapy group. As sessions progressed he opened his eyes

to the sounds of the guitar, moving his head and making eye contact for the first time.

### **FAMILY ACTIVITIES**

We organise a wide range of activities for all the family throughout the year, including family days out, sibling groups, parent groups and Nurse/Specialist-Care led groups for children who are unwell. These activities are a great way for all the family to develop confidence, make new friends and build a community of support.

#### IN 2023/2024:

We organised

**67**<sub>events this year</sub>

Events ranged from themed Family Activity days for the whole family to special Sensory Days for the babies, children and young people that we support. We also organised group activities for siblings, by different age ranges, plus activities for parents, including the launch of a new popular Dad's group.



The hospice supports Arthur a lot. He used to be so shy but now he goes to all the sibling groups, which have really helped him with his confidence. Arthur has met Harry Kane, seen Spurs play and been to Chessington World of Adventures, all thanks to Noah's Ark.

Gina, Mum to Ray and Arthur, who are supported by Noah's Ark



## SPECIALIST PLAY

Our Play Team believe in the power of play. By focusing on what a baby, child or young person can do, rather than any perceived limitations, our Play Team support children in reaching developmental milestones, expressing themselves and exploring the world around them.

### IN 2023/2024:

We provided

3,803

Up by 23% from last

year

### OUR AWARD-WINNING PLAY TEAM:

We were thrilled to be awarded **Play Team of the** Year at the 2023 Starlight Awards, which recognises organisations that go above and beyond to bring happiness into the lives of children who are seriously unwell.

It's healthcare professionals like the Noah's Ark Play Team who are our real-life superheroes. The team have worked hard to ensure play is an integral part of children's care, particularly with end-of-life care, where they enable families to create positive and longlasting memories. This Play Team is truly inspirational.

Cathy Gilman, Starlight Chief Executive

16 Noah's Ark Children's Hospice | Impact Report 2023/2024



# making of ex

### A moment of Impact IN 2023

Ellie, one of our Play Specialists, supported Ruby to use eye-gaze technology so she can communicate her wants, needs and feelings

independently. Ruby used the technology to make a list of her favourite people. Simon, Ruby's Dad, shared her final list: **"She picked Mummy,** Daddy... and Ellie!"



From the first session with Ellie, they clicked so well, and Ruby felt like, wow, someone finally understands me – it's wonderful.

Simon, Dad to Ruby who is supported by Noah's Ark

### NOAH'S ARK ON HOLIDAY

### We launched Noah's Ark on Holiday in 2023, enabling families to book our fully accessible lodge for a free week's stay.

Going on holiday can be an impossible concept for families who have a child who is seriously unwell – with accessibility being a huge barrier. This is where we can now help. We are able to offer families what is often their first holiday together.

35 families went on holiday with Noah's Ark



As we don't have holidays other than Ark respite overnights, this was a great chance to be away from home... and have some stress free family time.

Richard, father of Magnus, who is supported by Noah's Ark



## **VOLUNTEERS**

Our volunteers do something truly amazing they give their time to help children with lifelimiting or life-threatening conditions, and their families, make the most of every day. Volunteers support teams across Noah's Ark, from Home Support visits to helping out with Family Activities, or being a Specialist Care Volunteer enabling children to play.

139 volunteers

supporting families

**INCLUDING:** 

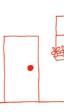
over 1,500

hours in The Ark



### A Moment of Impact in 2023

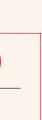
A father of a child supported by Noah's Ark said that when their Home Support Volunteer visits to play with their daughter it means that he and his wife "can have an actual evening, we can sit down and have



18 Noah's Ark Children's Hospice | Impact Report 2023/2024

6,158 hours

of volunteering



over **1,000** hours of Home Support

over 600

hours in Specialist Care over **900** 

hours supporting Family Activities



hours in Fundraising

You bring joy and sunshine to our lives... it's been a real honour having you to visit... you have the unique quality of being able to read to our child, which not a lot of people can do. 📕

Parent of a child who is supported by Noah's Ark

### END-OF-LIFE CARE

Our team do everything they can to ensure the final weeks, days and hours of a child's life are as comfortable as possible.

We provide care for new-borns, babies, children and young people nearing the end of their life, either at home, in hospital or at The Ark.

By taking a holistic approach to this care we can support the whole family to create lasting memories to treasure, helping them to be together as a family in these final moments.

36

Noah's Ark babies, children and young people sadly died in 2023/24, of which 16 we supported at the end of their life

#### CARE AFTER DEATH:

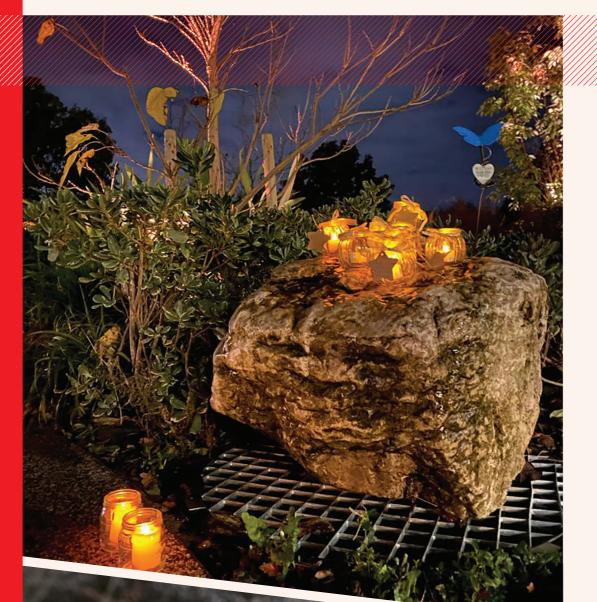
Our care does not stop when a child dies. Our Butterfly Suite gives families the opportunity to spend time with their child, after their death whilst staying close by in dedicated accommodation. We do all we can to ensure our Butterfly Suite is a safe, calming and non-clinical space for a child to stay.

We also offer this support to families of children who were not known to The Ark during their life, and those who die suddenly through accident or illness.





20 Noah's Ark Children's Hospice | Impact Report 2023/2024





## **BEREAVEMENT SUPPORT**

Our Bereavement Support Team understand what life can be like for a family after a child dies, and are here to help them through the days, weeks, months and years ahead. From help with practical issues such as funeral arrangements, emotional support or simply someone to talk to, the team are there for families every step of the way.

# families

supported. This represents an increase of 54% since last year

The counselling helped me a lot. Helped me to go through the pain and understand the pain. It's great we have a community here and we can come here whenever we need to.

Andrea and Costel, parents to Nadia who died in 2022







of bereavement counselling, an increase of 34% since last year

### A Moment of Impact in 2023

We launched a new Noah's Ark Memory Book. Designed with the family to include cherished fabrics, photos, drawings and other precious items, each personalised page honours and remembers the baby, child or young person, both as a keepsake for home and within the memory book at Noah's Ark.

### **GROWING OUR SERVICES: LISTENING TO THE FAMILIES' VOICES**

The families we support are the ultimate experts of their experience. In order to provide the very best care we foster a culture of listening to and welcoming feedback - and use this to refine, expand and grow our services.

As well as allowing us to understand where we are most effective, family feedback allows us to identify unmet needs and areas in which our support can be improved.

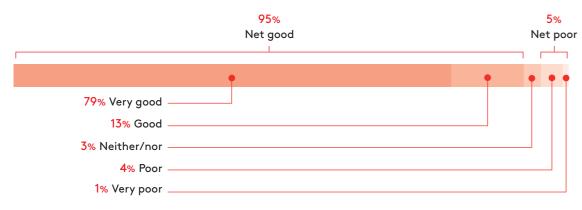
This is why we commissioned an external, impartial provider to conduct a thorough research project into our family experience.

78 families took part in this research. We'd like to thank them for taking the time to help shape the future of Noah's Ark Children's Hospice.

#### HERE IS A SNAPSHOT OF OUR RESULTS:

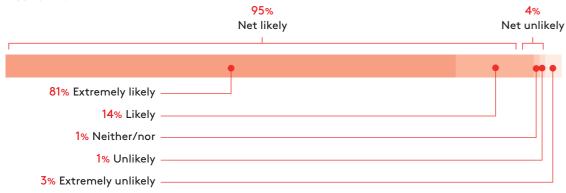
#### ○ Experience of using Noah's Ark

The vast majority of families have had a very positive experience of Noah's Ark. The consensus among families is that their experience of Noah's Ark has either been very good (79%) or good (13%).



#### C Likelihood to recommend Noah's Ark

The vast majority of families would recommend us. 95% of families say they would recommend Noah's Ark.



22 Noah's Ark Children's Hospice | Impact Report 2023/2024



#### DRIVERS OF GOOD EXPERIENCES AT NOAH'S ARK:

- Friendly, compassionate, and caring staff building rapport with families, and treating children with dignity and respect.
- Experienced staff well trained and professional so families feel in safe hands.
- Facilities are welcoming, clean and maintained.
- Services a wide range of staff offering a wide range of services.
- Going above and beyond staff go out of their way to offer extra support.
- Advocating for families supporting families with unmet needs beyond palliative care.
- Care for the whole family offering sibling support and vital social activities enabling quality time together.

#### AREAS FAMILIES IDENTIFIED WHERE WE CAN IMPROVE OUR SUPPORT:

- A better and more accessible system for booking services.
- Activities that are more inclusive of different age ranges, abilities and cultures.
- Recruitment of a full care team.
- More frequent communication.
- Additional printed materials to explain services.

#### This is just the beginning

Thanks to the invaluable feedback from our families and their ongoing generosity in sharing their experiences, Noah's Ark Children's Hospice is empowered to continuously enhance our services, ensuring exceptional care for every child and family.





Palliative care hinges on active listening. It's not just essential when providing care, but also when shaping our services. By truly hearing children and families, we gain a deeper understanding of their needs and can tailor our support accordingly.

Charlotte Alldridge, Head of Holistic Services

## THE GROWING UNMET NEED

### We believe that every child deserves a good quality of life, no matter how short that life may be.

In the geographical area we support alone, an estimated 2,500 children could benefit from the kind of care we provide. Adding in the fact that one in four pregnancies in the UK end in loss, there are also potentially hundreds of families in need of our bereavement support.

There will always be children and families who need our supportwe will always need to exist.

### LOOKING TOWARDS FUTURE MOMENTS:

We already have great plans for 2024/2025 with ambitions to expand our services even further...

#### **TRANSITION SERVICES**

We're increasing the age limit for the young people that we support. From 2024 we will continue to offer holistic and advocacy support to those who stay with Noah's Ark beyond the age of 19, up to 25 years old.

#### **HOSPICE MIDWIFE**

We've extended our team to include a Hospice Midwife enabling us to offer specialist pre and postnatal support.

#### COLLABORATIVE SPECIALIST NURSING CARE

We're extending our partnership with GOSH to include joint working with another children's hospice to ensure that we offer families maximum around-the-clock hospice-at-home care for families when needed.

#### **EXTERNAL COUNSELLING ROOM**

Following feedback from a family who are bereaved, we have gained funding for a counselling room that will be built just outside The Ark's main building. This will give families space to have these sessions away from where their child may have received care, which can be a difficult experience.



## **OUR AWARDS**

This year we were delighted to be nominated for lots of different awards...

- Purpose Awards Best Charity Film
- Third Sector Best CEO and Rising Star
- Brand Film Awards Best Charity Film
- Charity Times Charity Leader of the Year

And we're thrilled to say we won several awards...



**Purpose Awards** Best Fundraising Campaign



**Effie Awards** Bronze: Healthcare Campaign



**Starlight Awards** Play Team of the Year



26 Noah's Ark Children's Hospice | Impact Report 2023/2024



**Outdoor Media Awards** Gold: Community and Social Impact



**Third Sector Awards** Best Charity Film (Large)



North Tees and Hartlepool **NHS Foundation Trust** Centre of Cleaning Excellence

### **OUR SINCERE THANKS**

most of every day.

#### A BIG THANK YOU TO:





#### SUPPORT OUR FUNDRAISING

As a charity, we rely on your generosity to continue our work.

You could support us by volunteering your time; support us with the help of your company, community group or charity; take part in a fundraising event; remember us in your will; or make a regular donation.

#### **KEEP IN TOUCH WITH OUR LATEST NEWS**





### NOAH'S ARK CHILDREN'S HOSPICE

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