



## Trustees' annual report

*The Smallest Things trustees present their annual report for 2024/2025*

*Kerry Myles (trustee), Matt Wilkinson (trustee), Lynne Peachey (trustee) and Michelle Townsend (trustee)*

Every year, more than 53,000 babies\* in the UK are born prematurely (before 37 weeks). That's around 1 in 13. And that's a lot of shocked parents thrown into the terrifying world of neonatal care – beeping machines, incubators, breathing tubes and separation as parents and carers leave their baby each day faced with uncertainty and worry.

We get it because we've been there too. The Smallest Things is led entirely by parents who've had premature babies. And that's exactly what drives us to support families, raise awareness and make change.

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## 1. Welcome:

I am delighted to welcome you to this year's Annual Report for The Smallest Things. As a charity founded and led by parents with lived experience of neonatal care, we continue to stand alongside families of children born prematurely, ensuring no parent makes the journey beyond neonatal intensive care alone.

This year has been one of both growth and deepened impact. Guided by our charity's objectives, we have continued to champion the voices of neonatal families, strengthen the support available to them, and raise awareness of the lifelong impact of prematurity. Our work remains firmly rooted in the experiences of thousands of parents who have shared their stories with us through our *After NICU* research, and in the expertise and compassion of our lived-experience panel. Their insights continue to shape everything we do.

We know that the journey after NICU can be long, complex, and not always understood. That is why our mission remains vital—and why the voices of families continue to drive our strategy, inform our priorities, and inspire our determination to create lasting change.

I would like to extend my heartfelt thanks to our core team of incredibly dedicated and hard-working staff who make everything possible, along with our volunteers, supporters and my fellow trustees. Your generosity, time, and belief in our mission make The Smallest Things everything it is today. As a small charity with lived experience at its core, every contribution—every action, every donation, every shared story—has a profound impact.

Looking ahead, we remain committed to expanding the reach of our support, deepening our influence on national policy, and ensuring that the needs of neonatal families are understood and acted upon. Together, we will continue to champion the smallest voices and create a world where every family leaving neonatal care feels informed, supported, and never alone.

Thank you for standing with us.

**Kerry Myles, Chair of Trustees**

## 2. Our charity objectives:

Our objectives reflect our charity's aims and mission, and are targeted to directly benefit children born prematurely and their parents after neonatal intensive care.

- 1. For no parents or carers of premature babies to feel alone.**
- 2. For families and children born prematurely to be supported through their journey beyond neonatal care.**
- 3. For professionals to be aware of the potential impact of prematurity, and to have access to information, training, and guidance to support families and children after leaving hospital.**
- 4. For neonatal families to have a voice at the heart of research and policy-making.**

In setting our objectives and planning our activities our trustees continued to give careful consideration to the Charity Commission's public benefit guidance. Our [charity strategy](#) informs all our work. Underpinned by our [After NICU](#) research, The Smallest Things charity strategy is based on the voices of thousands of parents of children born prematurely. It was produced with our lived experience panel and is regularly reviewed by our trustees to ensure the work of The Smallest Things continues to meet its charity's aims and mission.

### 3. Achievements and performance

*For no parents or carers of premature babies to feel alone.*

#### This is NICU: The real premature birth story

It's impossible to understand neonatal intensive care unless you've been there and parents tell us all the time that no-one understands. So this year, we produced and released our first ever film - ['This is NICU: The real premature birth story'](#).

It is a look behind the neonatal intensive care doors at what life after premature birth is really like - from those who've lived it. There are no filters, no glossy images or perfectly styled shots. It's real, raw and a million miles away from the picture-perfect newborn ads on TV. We helped neonatal parents feel seen and for the world to see our world. We send a big thank you to all the families who shared their precious videos and images to help raise awareness of the realities of life after premature birth.

More than 1,100 people have watched the full film on our YouTube channel.

#### An online community

For parents of premature babies, their journey into parenthood and their experiences of life after neonatal care may be reassuringly similar. The Smallest Things understands the importance of bringing together the neonatal family community and through our social media channels and online blog series we continue to share regular first-hand stories of a diverse range of experiences around prematurity that reflect reality, validate feelings and offer a sense of community.

Our social media channels and reach have continued to grow, raising awareness and becoming an online community space for parents and professionals alike.

#### Dads Do NICU

We know dads are often overlooked when it comes to support on their neonatal journeys. That's why we've continued to post #DadsDoNICU stories on our website, including a special collection in June for Father's Day. To help fathers feel less alone we also launched video messages from dads

on our social channels and continued to grow our Dads network through a new WhatsApp group and online 'meet ups'.

### Working with charity partners and neonatal networks

We've continued to work with other charities and neonatal networks this year to amplify the voices of parents' and carers'. Our open letter to Wes Streeting MP, supported by 11 neonatal/baby charities and organisations, as well as 31 leaders from the neonatal community, was signed by more than 1,000 parents' and carers' before being sent to the Health Secretary. The Smallest Things continues to campaign for better support for families after neonatal so that no parent feels alone.

### A parent voice

The Smallest Things understands the power of the parent voice. It is vital to share lived-experience, helping to secure much needed change so that no parent feels alone after neonatal care. A parent representative from The Smallest Things now sits on the British Association of Perinatal Medicine (BAPM) executive as the Family Support and Liaison Officer.

***For families and children born prematurely to be supported through their journey beyond neonatal care.***

### Neonatal Leave and Pay

The long-overdue Neonatal Care (Leave and Pay) Act came into force on 6 April and approximately 60,000 families every year will now be eligible for extra parental leave if their baby or babies are born prematurely or sick.

The new Neonatal Leave and Pay entitlements follow a decade of campaigning led by The Smallest Things and powered by parent voices. As a parent-led charity, we know first-hand how essential these changes are for families facing the toughest of times.

No parent should be sitting beside an incubator worrying about work or pay. Representatives from The Smallest Things met with Minister Justin Madders at a special government reception for neonatal families in April and told him why it will make a huge difference for those who follow in

our footsteps. We urged the minister to go further, asking him to make provisions available for self-employed parents and later submitted written evidence to the Government's Parental Leave Review, urging the government to remedy the exclusion of self-employed parents from neonatal leave and pay entitlements.

Our charity Employer with Heart charter continues to encourage employers to go above and beyond new statutory requirements and organisations continue to implement our charity advice.

## Red Book Stickers

Every year, tens of thousands of babies are born prematurely in the UK and families face the agonising journey of uncertainty and trauma through neonatal intensive care. But parents tell us all the time that their journey does not end when they leave the neonatal unit and we know that the needs of parents and children born prematurely last long after leaving hospital.

Acting as a visible reminder, alerting healthcare professionals to a parent and their babies' neonatal history, The Smallest Things Red Book stickers are in more than 100 neonatal units around the country. This year alone more than 40,000 stickers were sent out to hospitals and over 450 families received stickers directly from the charity.

## Calling for greater support after neonatal care

Our [open letter to the Health Secretary](#), calling for urgent changes to meet the unique needs of neonatal families was sent and we continue to call for: onsite accommodation for parents' and carers'; joined up follow-up services; a new six-week 'After NICU' wellbeing check; a neonatal lead in every health visiting team; and for parents to have access to psychological support when and how they need it.

Through campaigning, stakeholder and advocacy work, The Smallest Things has increased its capacity over 2024/2025, working across health, education and early years sectors for families and children born prematurely to be supported in the lasting journey after neonatal care.

***For professionals to be aware of the potential impact of prematurity, and to have access to information, training, and guidance to support families and children after leaving hospital.***

## Life After Neonatal Care Report 2025: The lasting impact of prematurity

This year The Smallest Things published our [Life After Neonatal Care Report 2025: The lasting impact of prematurity](#). It is the third in the charity's series of deep dives into the realities of the neonatal journey and it shares the findings of a survey of more than 690 parents and carers of babies born prematurely since May 2021 (the year of our last After NICU report).

The report explores parents' experiences after leaving the neonatal unit and highlights the complex and sometimes interwoven challenges families face following premature birth. Themes include parental mental health, the impact on family life, ongoing medical needs, and Early Years education. Once again the results show that parents struggle to access support and understanding during this ongoing and often difficult journey.

### New online module - supporting children born prematurely in the preschool years

We launched a new online training module '[Supporting children born prematurely in the preschool years](#)' this year. Developed in partnership with the PRISM (Premature Infants' Skills in Mathematics) Study Team the module is part of a series of five other resources that outline the impact of premature birth on children's learning and development. It offers practical recommendations for early years staff to support prematurely born children in their classrooms and early years settings. The module emphasises the importance of understanding the journey for families after neonatal care and provides practical tips for both staff and parents, and forms part of The Smallest Things *Prem Aware Award* criteria for early years and school settings.

### The Prem Aware Award scheme

The Smallest Things '[Prem Aware Award scheme](#)' raises awareness of the impact prematurity can have on development and learning, It supports parents and carers to advocate for their prematurely born child, and helps schools to recognise and meet the specific learning needs that children born prematurely may have.

The scheme promotes use of the 'Preterm Birth Information for Educational Professionals' online modules developed by Professor Samantha Johnson and her colleagues in the PRISM (Premature Infants' Skills in Mathematics) Study Team, funded by the charity Action Medical Research.

Over the past 12 months new Prem Aware Awards were given out to 146 schools and settings. That brings the total number of Prem Aware settings in the UK to 272, rising significantly from a total of 125 settings at the end of last year.

The scheme continues to go from strength to strength, and while a large proportion of the growth is now organic, our Prem Aware Ambassadors continue to drive change and raise awareness. This year we've added 11 new ambassadors to the team, meaning we can reach even more schools and settings around the UK. The ambassadors are supported by our charity Prem Aware administrator and they frequently speak at local government and SEND training network events.

### Training and raising awareness

This year we've teamed up with charity partners, institutions and neonatal networks to deliver training - covering topics that include parental mental health after neonatal intensive care, the lasting impact of prematurity, and the educational needs of children born preterm. We've been delighted to partner with the Early Years Alliance, University of Leicester, Institute of Health Visiting and the Family Hubs Network to deliver bespoke webinars, and to team up with the Pan-London Operational Delivery Network to deliver in-person training for community based professionals ranging from Health Visiting services to IAPT (Access to Psychological Therapies) teams. In addition, The Smallest Things has written for and published information through a variety of online channels, including Twinkl Digest, Infant Journal and the Early Years Alliance Family Corner.

By upskilling professionals, we're helping neonatal families get the care and support they need.

***For neonatal families to have a voice at the heart of research and policy-making.***

### Bringing the parent voice to parliament and power

This year The Smallest Things took parents back to parliament, sharing their experiences with local MPs and asking them to take action on their behalf.

We continue to make sure that the parent voice is at the heart of policy-making and this year have doubled our efforts to engage with policy-makers, from meetings with Shadow Health Minister,



Stuart Andrew MP, the Chair of the Maternity APPG Michelle Welsh MP, Shadow Education Secretary Laura Trott MP and former Employment Rights Minister Justin Madders MP; in addition to wider stakeholder engagement through the Operational delivery networks, BAPM, the British Association for Neonatal Follow-Up (BANFU), the Institute of Health Visiting, the Early Years Alliance and Family Hub Best networks, to name just a few.

## Research

The Smallest Things has continued to put the parent voice at the heart of research and decision making, partnering and collaborating on research studies and fulfilling the role of the Patient and Public Involvement lead on several projects. These include the BronQ Study, researching how chronic lung disease affects the health-related quality of life of children born preterm and their families over time and the EU Horizon funded IMPROVE Preterm Birth Study.

The study of the impact of The Smallest Things Prem Aware Award in schools and early years setting was concluded this year, the results of which have been published in the Infant Journal.

The Smallest Things own research, published in the [\*Life After Neonatal Care Report 2025: The lasting impact of prematurity\*](#), helping to influence policy and decision making, putting the parent voice at the heart of everything we do.

## 4. Our community:

Our small charity continues to grow steadily, meeting our charitable aims by bringing together communities of parents who have experienced premature birth. Our Prem Aware Ambassadors, Smallest Things Campaigners and Volunteers work collectively with the charity's trustees and leadership team to create a better world for children born prematurely and their families after neonatal intensive care.

In 2025, we formed closer links with charity partners, professionals and networks and we will continue to strengthen these relationships over the year ahead.

Our day-to-day activities are run by a small team of part time staff, supported by dedicated trustees and volunteers. In 2024/2025 we continued to employ one part time member of staff (15 hpw) in an administrator role and continue to contract two part-time freelance members of staff at director level, leading on policy, campaigns and research (15 hpw) and communications (7.5 hpw) respectively.

## 5. Finances and Accounts:

### Reserves Policy

The Smallest Things has a policy of maintaining 3 months of funds in reserves to cover core services and basic day-to-day running of the charity. This stands at **£6,860.90**.

The Smallest Things reserves policy is a living document and the level of reserves set is reviewed quarterly at trustee meetings. Our reserves policy is reviewed annually and we ensure that the reporting of our reserves policy meets the requirements of the Charities Statement of Recommended Practice (SORP) (FRS 102) and the requirements of the Regulations.

### Funding

The Smallest Things receive small donations thanks to fundraising events throughout the year, as well as some larger donations that are received as a result of being made a charity of the year by companies and/or one-off project based grants. The Smallest Things receives no government funding.

### Use of Restricted and Unrestricted Funds

The Smallest Things holds both restricted and unrestricted funds. Unrestricted funds may be used at the discretion of the Trustees to support The Smallest Things charitable objectives. These unrestricted funds allow us to respond flexibly, invest in strategic priorities, and to meet ongoing running costs. .

Restricted funds are given for a specific purpose and may only be used in accordance with the conditions set by the donor or funder. The Trustees ensure that all restricted funds are applied strictly for their intended purposes and are separately accounted for and monitored.

Over the 2024/2025 financial period, The Smallest Things received two restricted funds from the ESRC IAA Rapid Response Scheme (Leicester); £2856.25 to contribute towards the costs of an charity administrator for our Prem Aware award scheme and £5,000 to recruit, train and support 20 charity Prem Aware ambassadors.

### **Independent examination of accounts**

The trustees appointed Jay Mehta, a suitably qualified and independent person, to carry out an independent examination of our 2024/2025 accounts.

The Smallest Things financial statements and accounts were independently examined in accordance with section 145 of the Charities Act 2011 and the applicable directions given by the Charity Commission. The examiners report to trustees can be read below.

**JAY MEHTA**

**19 Mappleborough Road, B90 1AG**

**Independent examiner's report to the trustees**

I confirm that I have independently reviewed the accounts of The Smallest Little Thing Charity in accordance with the relevant guidance and confirm that, based on my review, nothing has come to my attention that gives me cause to believe the accounts do not give a true and fair view of the charity's financial activities.

Jay Mehta

Senior Credit Controller

Dated 29.01.2026

**ACCOUNTS 2024-2025**

<b>Opening balance</b>		<b>65,165.21</b>	
<b>INCOME</b>	<b>Restricted</b>	<b>Unrestricted</b>	<b>TOTAL</b>
Grants	7,856.25	1,000	8,856.25
Donations	0	500	500
Fundraising activities	0	16,575.06	16575.06
<b>TOTAL</b>	<b>7,856.25</b>	<b>18,075</b>	<b>25,931.31</b>
<b>EXPENDITURE</b>	<b>Restricted</b>	<b>Unrestricted</b>	<b>TOTAL</b>
Staffing costs	7,856.25	25,879.65	33,735.90
Project costs		4,536.20	4,536.20
Running costs/overhead		2,700.45	2,700.45
<b>TOTAL</b>	<b>7,856.25</b>	<b>33,116.30</b>	<b>40,972.55</b>
<b>Closing balance</b>		<b>49,123.97</b>	

**ENDS**