## The

# **Smallest Things**

The Smallest Things trustees present their report for the year ending 15 December 2020.

Catriona Ogilvy (charity founder and trustee), Sarah Miles (trustee) and Matt Wilkinson (trustee)



#### **Our Aims:**

Our overarching charitable aim is to promote the good health of premature babies and their families; raising awareness of premature birth and the needs of families following intensive care and promoting high quality care for mothers affected by postnatal depression, anxiety and symptoms of post-traumatic stress disorder associated with premature birth.

## **Our Objectives:**

The Smallest Things is a tiny charity with a big voice.

Our objectives reflect our charity's aims and ethos and are targeted to benefit parents of premature babies and the long-term outcomes for children born prematurely directly.

In our work to support and promote the good health of premature babies and their families the trustees have acknowledge the need for the charity to continue to develop and grow and welcomed new volunteers to our team over the last year.

In setting our objectives and planning our activities our trustees have given careful consideration to the Charity Commission's public benefit guidance.

#### Our key objectives for 2020 year have been:

- To develop and publish The Smallest Things 2020-2023 Strategy document.
- To develop and grow a volunteers' network.
- To secure a government commitment to extend statutory parental leave for families whose babies are admitted to neonatal intensive care.

- To provide a parent voice in research supporting the long-term outcomes of children born prematurely.
- To launch a Prem Aware Award scheme, supporting schools to help children born prematurely.

### **Achievements and Performance**

# Launched – The Smallest Things 2020-2023 Strategy!

In March 2020 we published our 2020-2023 strategy document.

The document outlines the charities aims and objectives and sets out how these will be met over the coming years.

Due to the Coronavirus pandemic the document was not publicised widely as planned, however it was shared with key stakeholders and via social media channels. The publication of the strategy document saw an increase in enquiries to the charity, including several offers of support that has



# **Our vision**

A better world for premature babies and their families after neonatal care

## **Our mission**

To promote the good health of premature babies and their families; raise awareness of premature birth and the needs of families following intensive care; and to promote high-quality care for parents affected by postnatal depression, anxiety and symptoms of post-traumatic stress disorder.

# **Our values**

UNDERSTANDING
We've experienced
premature birth too

COMMUNITY
We believe in the

We believe in the power of coming together for support and change PASSION

We're committed to making change happen to improve lives

smallestthingsbigimpac



helped us to recruit new volunteers and to expand our team.

## The Smallest Things Volunteers Squad!

The 2020-2023 Smallest Things Strategy has helped us to develop new volunteers to support out charitable aims and the work we do.

Over the last year we have recruited 7 new volunteers. Each volunteer has experienced premature birth, in keeping with our charities values of 'Understanding'; and each volunteer has a particular area of interest or expertise, from education or health care, to project management and media.

We have met via video conferencing twice as a Smallest Things Volunteers team and each trustee works closely with a named volunteer.

#### Winning!

## To secure a government commitment to extend statutory parental leave for families whose babies are admitted to neonatal intensive care.

In December 2019, a commitment to introduce neonatal leave was announced in the Queen's Speech and in February 2020 the Chancellor Rishi Sunack confirmed that the new entitlement would come into effect in 2023. Announcing the news, Kemi Badencoch MP, Exchequer Secretary to the Treasury and Minister for Equalities said:

"bring in an historic new entitlement ensuring parents having to take time off work because they have a sick baby will get paid parental leave. This will be in addition to the usual maternity and paternity leave, and finally give parents the time, the resources and the space to handle these difficult circumstances.

So if their baby is in care for more than a week, they will be able to claim statutory paid leave for every week the baby is in care, to a maximum of 12. The leave will be paid at a rate of around £160 per week.

We know that almost 40,000 babies born in Great Britain each year have to spend more than a week in neonatal care. And a survey of parents affected found that 80 per cent of them reported that their mental health suffered as a result.

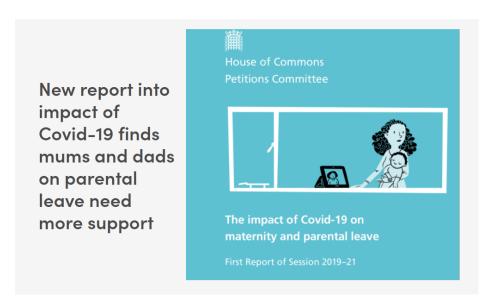
Creating this ground-breaking new entitlement is the right thing to do. We also think it is value for money, because a more supportive workplace environment for employees should be good for business and for the UK economy as a whole."

Born too soon, premature babies can spend weeks and months in hospital before their parents can bring them home. Fathers juggle work and family commitments as paternity leave fails to cover the time they need whilst their baby remains in neonatal intensive care; and mothers recovering from the trauma of premature birth wait beside incubators hoping for the precious moment they can finally get to hold their baby. Time spent watching a tiny

baby in neonatal intensive care simply isn't maternity or paternity leave, yet maternity leave still automatically begins the day after your baby is born. That is why The Smallest Things has campaigned together with parents since 2015 to bring about this change.

We look forward to working with Ministers to ensure the new entitlement will support all families affected by premature birth.

#### **The Impact of Covid-19 on Maternity and Paternity Leave:**



The Smallest Things gave evidence to the House of Commons Petitions committee in June 2020 and welcomed their recommendations that the Government should bring forward Neonatal Leave and Pay. We told the committee, published in their report, that:

"We passionately believe that time spent in a neonatal unit, helplessly watching your fragile baby in an incubator covered in wires and tubes and surrounded by beeping machinery, should not count as parental leave. Not only is precious time with a newborn replaced by fear and worry over health issues (or even survival), but the journey does not end when (and if) a baby leaves hospital."

House of Commons Petitions Committee: The Impact of Covid-19 on maternity and parental leave, p45.

We continue to make representations to government, calling for #NeonatalLeaveNow

**Employer with Heart** 

The Smallest Things know that the journey does not end when you bring your baby home from hospital.

Parents have told us of the ongoing medical needs of babies born too soon, the complex array of mental health difficulties experienced by mothers and financial pressure placed upon families. Returning to work so soon after a baby has come home from hospital, whilst the trauma remains so raw and babies are still so small, is an enormous strain on families, one which sees



mothers leaving the workforce or taking periods of long-term sick leave. So, the Smallest Things continued to ask employers to support parents of premature babies through our **Employer with Heart** scheme.

More than 41 organisations have now signed up to our charter, with many more working making the change.

# A parent voice in research - supporting the long-term outcomes of children born prematurely:

The Smallest Things has increased our involvement in research that considers the long-term outcomes for children born prematurely, ensuring the voice of parents is central to the projects taking place. In addition, we have worked to ensure that the findings of latest research are disseminated in an accessible way to families and that practical action is taken based on the findings.

Studies we have supported include the *NeoWonder study*, which aims to improve the lifelong health and wellbeing of preterm babies by using routine data to evaluate the long-term impact of neonatal interventions; and the *TIGAR (Tracking the Impact of Gestational Age on health, educational and economic outcomes - a longitudinal Record linkage study).* In addition, we have supported many research grant proposals such as *'Social skills intervention for preterm born children – a RfPB application'* and shared research survey such as *'Parenting Through A Porthole: An online survey of the experiences of parenting a preterm baby on a Neonatal Unit in England during the COVID-19 pandemic.'* 

#### The Prem Aware Award Scheme:

In January 2020 we surveyed parents' experiences of Special Educational Needs support for children born prematurely:

When more than 90% of parents told us that they thought there should be more awareness and understanding of the educational needs of children born prematurely, we knew we had to do something.



While being born early does not mean a child

will have special educational needs (SEN), it does increase the chances. And with an average of two to three children in every classroom being born early, we felt it was essential for teachers to be aware of potential issues – and equipped with some strategies on how they can help.

In October 2020 (delayed due to the Coronavirus pandemic) the new Prem Aware Scheme was launched to support teachers and schools to better understand how prematurity can affect development, to recognise any additional learning needs and to support children on their journey through education to achieve their potential.

Publicity around the newly launched Prem Aware Award was halted in light of lockdown 3 with the view that teachers and schools would not have the capacity to take on further work.

However, despite this, 3 schools in the UK have become the first to become 'Prem Aware' by completing 1,2,3.... **#PremAware** 

#### 1. Train staff

Senior members of your staff team will complete the free online training <u>Preterm</u> <u>Birth Information for Educational Professionals</u> developed by the PRISM study team and funded by the charity Action Medical Research. Training will then be cascaded to all school teaching staff.

#### 2. Raise awareness

Encourage parents to share details of their child's birth history, including specific questions relating to neonatal stays and preterm birth, through your school's admission procedure for new pupils. Where information is made available from families and carers, teachers are to be aware of which children in their class were born preterm. PRISM poster will be displayed in the school.

#### 3. Ask for feedback

Your school will seek the views of parents and carers to review and inform the Special Educational Needs support provided.

#### **Finances and Accounts**

The Smallest Things is a small charity and despite fundraising events, such as the Great North run and our Big Picnic Weekend having to be cancelled in light of the pandemic, we have continued to receive small donations throughout the year.

Details of our February 2019-February 2020 accounts can be seen below:

Date	Details	Debit	Credit	Balance
05-Mar- 19	Brought forward balance		3,822.83	3,822.83
25-Mar- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,804.83
31-Mar- 19	Service Charge	-18		3,786.80
01-Apr- 19	B/P to: MARTIN COTTERELL	-150		3,636.83
02-Apr- 19	JUSTGIVING		50	3,686.83
09-Apr- 19	JUSTGIVING		58.59	3,745.42
25-Apr- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,727.42
28-May- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,709.42
04-Jun- 19	JUSTGIVING		17.74	3,727.16
25-Jun- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,709.16

30-Jun- 19	Service Charge	-18		3,691.16
02-Jul- 19	JUSTGIVING		9.61	3,700.77
09-Jul- 19	JUSTGIVING		53.35	3,754.12
23-Jul- 19	JUSTGIVING		151.85	3,905.97
25-Jul- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,887.97
30-Jul- 19	JUSTGIVING		19.42	3,907.39
27-Aug- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,889.39
03-Sep- 19	JUSTGIVING		9.61	3,899.00
25-Sep- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,881.00
30-Sep- 19	Service Charge	-18		3,863.00
01-Oct- 19	JUSTGIVING		9.61	3,872.61
08-Oct- 19	Amazon Europe		7.34	3,879.95
25-Oct- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,861.95
05-Nov- 19	JUSTGIVING		9.61	3,871.56
25-Nov- 19	JUSTGIVING		58.06	3,929.62
25-Nov- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,911.62
23-Dec- 19	JUSTGIVING		9.61	3,921.23
23-Dec- 19	B/P to: Gigi Riddle	-200		3,721.23
27-Dec- 19	Direct Debit (GIVING.COM / JUSTG)	-18		3,703.23
31-Dec- 19	Service Charge	-18		3,685.23
21-Jan- 20	B/P to: Catriona Ogilvy	-19.2		2,675.63
27-Jan- 20	Direct Debit (GIVING.COM / JUSTG)	-18		2,657.63

07-Feb- 20	AMAZON EUROPE CORE		9.85	2,667.48
		-639.2	474.25	2,667.48

## Structure, Governance and Management

The Smallest Things trustees, who all volunteer their time freely and no remuneration or expenses have been paid this year, met face-face in January 2020 and have taken part in regular video conferencing calls throughout the year. An activity plan continues to structure our work for the year and enables us to evaluate our effectiveness. Our overarching objectives are now clearly documented in our formal 2020-2023 strategy document.

The trustees are aware that our board requires breadth and depth of experience to carry out its duties effectively and efficiently and will continue to work with and seek out additional volunteers to grow our small team over the coming year.

The Smallest Things 1171631

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**ENDs**