The Tiny Lives Charter

a cross-party call to tackle premature birth
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The Tiny Lives Charter

- We, the undersigned Members of Parliament, call on this (and any future) government to address urgently the problem of premature birth.

- We are extremely concerned by the fact that more than 25 baby deaths occur each week in the UK as a result of complications arising from premature birth.

- We acknowledge that this is the largest cause of death among babies under one year old in the UK.

- We believe premature birth is an issue that politicians from across the political spectrum must come together to tackle if we are to protect some of our most vulnerable (and often socio-economically disadvantaged) members of society.

- We call on the Department of Health and the Department of Innovation, Universities and Skills to commission jointly an independent Premature Birth Inquiry and develop a ten-year National Research Strategy to tackle premature birth.

- We believe that these steps could also have many significant benefits for government, helping them to move toward achieving existing policy priorities in health inequalities, reducing health and social care costs and helping to improve infant and child health.
As Chairman of Action Medical Research, I am proud to be part of an organisation that has helped save thousands of lives and transformed many more. Over our 50 year history our successes include helping to support the development of the UK oral polio vaccine, early surgical hip replacements, and discovering the link between taking folic acid supplements before and during pregnancy and preventing spina bifida. Action Medical Research is proud of the crucial part it has played in the development of medical treatments and technologies that have helped so many people.

However, there is still much more we could do to improve our understanding of what triggers important health conditions, how to prevent them and the best way to treat them once they occur.

One of Action Medical Research’s current aims is to support medical research that will help prevent life-threatening pregnancy complications, reduce the incidence of premature birth and improve the care of sick and vulnerable babies.

Sadly, each year in the UK around 50,000 babies are born too early. Premature birth is the single biggest cause of death among infants under one year old in the UK. Every week, more than 25 babies die as a result of complications arising from premature birth. Some babies who survive an early delivery can face life-long debilitating conditions, such as cerebral palsy or developmental problems. Premature birth also has major cost implications for health, education and social care.

Action Medical Research’s Touching Tiny Lives appeal has so far raised over £3.5 million thanks to the generosity of our supporters. This has enabled the Charity to fund 35 new research projects into premature birth, pregnancy complications and treatments for sick babies.

Through this fundraising, The STAND UP for Tiny Lives Campaign was born, pulling together our supporters, parents of premature babies, researchers and healthcare professionals, as well as other charities and professional organisations, all of whom want to see change.
Despite the fact that premature birth has long been a common, serious and costly health issue, the UK government still has no overarching research strategy for tackling it, relying instead on broader health and welfare policies and research project funding. The UK has the scientific and medical talent to conduct this vital research but these experts are struggling to find sustained support for their research into premature birth.

While we welcome recent government steps to fund new projects and believe the value of the life-giving work undertaken by staff in neonatal intensive care units cannot be overstated, we think more needs to be done to reduce the unacceptably high rates of premature birth in the UK.

The Tiny Lives Charter calls on the UK government to establish an independent Premature Birth Inquiry, to evaluate systematically what we have learnt about premature birth from the research that has been undertaken so far, and to develop, for the first time in the UK, a ten-year National Research Strategy to tackle this costly and too often deadly problem.

Major breakthroughs frequently take many years to achieve – strategies to prevent cancer and heart disease, for example, are now showing benefits after decades of effort. It is our belief that sustained support for scientific and medical research to reduce the incidence of premature birth could help more babies to be born healthy and thus improve infant and child health over the longer term. Not only would this save lives, but it is also likely to prove highly cost-effective for health and social care.

To find out how you can support our call for a Premature Birth Inquiry and a National Research Strategy, please visit www.standupfortinylives.org/tinylivescharter

Thank you,

Dr Keith McCullagh, Chairman, Action Medical Research

Fact: Every week, more than 25 babies die in the UK as a result of complications arising from premature birth
Acknowledgements

The STAND UP for Tiny Lives Campaign is extremely grateful to the scientific and medical experts and parents at the heart of this campaign who have contributed to this paper:

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Campaign partners

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• European Parturition Group http://europarturition.eu/
• NCT (formerly the National Childbirth Trust) http://www.nct.org.uk
• Neonatal Nurses Association http://www.nna.org.uk/
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www.standuptfortinylives.org
1. Executive summary

- Premature birth — before 37 weeks of pregnancy — is a common, serious and costly health issue, which places a significant burden on families and the services that care for and support them.6

- In the UK an estimated 50,000 babies are born prematurely each year.1,2,a Premature birth is the biggest killer of babies under one in the UK.3-5,b-c Each week more than 25 babies die as a result of complications arising from premature birth.3-5,b-c

- Despite improved neonatal care and survival rates for babies born early, there has been no corresponding progress in reducing the incidence of premature birth.6,7

- Babies born prematurely often face difficulties with breathing, feeding, and fighting infection. Many of those born very early develop lifelong conditions such as cerebral palsy, blindness, hearing loss and learning difficulties.8

- Premature birth is complex. The causes and potential risk factors are not well understood and diagnosis of preterm labour is difficult. To date, no preventative treatments have demonstrated significantly improved neonatal outcomes.

- The government currently has no overarching research strategy for tackling premature birth and its causes.

- Current policies focus on reducing infant mortality rates by tackling health inequalities and addressing known risk factors such as smoking and teenage pregnancy as well as initiatives to continue improvements in maternity services and neonatal care. None focuses exclusively on premature birth or the role of medical research in investigating its causes, in reducing its incidence and in improving the health of premature babies.

- While there are a number of high-quality studies taking place within the UK, much of this research is done in relative isolation. Greater collaboration within the clinical and scientific communities, backed by government, pharmaceutical industry and the charity sector is needed if we are to develop effective ways to tackle premature birth and pave the way for new treatments.

The Tiny Lives Charter

The Tiny Lives Charter calls on this (and any future) government to commission an independent Premature Birth Inquiry and develop the UK’s first focused and adequately funded ten-year National Research Strategy. The Inquiry would systematically review research progress to date and identify future research needs and priorities. The ten-year National Research Strategy would address the issue holistically, building on existing research studies and should:

- investigate the biological, genetic, socio-economic and behavioural risk factors involved in premature birth to improve our understanding of what triggers and controls labour
- promote testing of the most promising interventions
- establish routine collection of data on all pregnancies and outcomes, and set standards for sample collection and clinical trials
- be large-scale, multi-disciplinary and integrated
- encourage better partnership between the scientific and clinical communities, government, industry and charities.
2. The nature and scale of premature birth

Death, disability and distress
Each year in the UK, around 50,000 babies are born prematurely, before 37 weeks of pregnancy. In fact, around seven per cent of all UK births are premature. Being born too soon puts babies in danger. Almost 1,500 babies die each year in the UK as a result of being born early, causing lasting distress to the bereaved parents. Premature birth is the largest killer of babies under one in the UK. Over 40 per cent of all the babies who die each year in the UK lose their lives to complications that arise from premature birth. The earlier the baby is born, the greater the risks, especially for those born before 32 weeks of pregnancy.

As well as causing death, premature birth is also a major cause of illness and disability. Many premature babies who survive an early birth may go on to develop serious, life-long conditions, such as cerebral palsy, blindness, deafness and learning disabilities. Research suggests premature babies may even go on to have an increased susceptibility to some diseases in adulthood, including cardiovascular disease and type 2 diabetes.

The parents, siblings and other close relatives of premature babies can be profoundly affected by the stress of caring for them, in both the short and long term. Many families experience the heartbreak of premature birth more than once. The risk of recurrence is increased for both spontaneous and medically indicated (induced or caesarean section) premature birth.

Economic costs are staggering with premature birth imposing a considerable burden on services such as healthcare, education and social services. The cost of neonatal care, though high, can be dwarfed by the costs of the long-term care needed by children who develop life-long conditions.

A precarious balancing act
Around two-thirds of premature births are spontaneous, typically with the mother going into labour, or the membranes rupturing, before term. The others are medically indicated, which means doctors decide to intervene and deliver the baby early to protect the mother and/or baby from potentially life-threatening complications of pregnancy. Doctors intervene if they believe the dangers associated with continuing the pregnancy are even greater than those associated with premature birth.

Fact: Each year in the UK, around 50,000 babies are born prematurely, before 37 weeks of pregnancy.
It should be borne in mind that in certain circumstances prolonging pregnancy can put the mother and/or baby at risk. Better understanding of the risks and benefits of early birth will be central to improving future clinical strategies and infant and child health. Indeed, the goal of preventing premature birth is subordinate to the goal of improving the health of pregnant women and their babies - both at birth and throughout their lives.9,10

Who is at risk?
Several groups of women are known to be at increased risk of spontaneously giving birth to their baby early. Strong risk factors are multiple gestations (including those resulting from fertility treatments), a history of premature birth, and vaginal bleeding. Other important factors that influence premature birth rates include infection, race/ethnicity, uterine or cervical abnormalities, maternal age, social deprivation, lifestyle behaviour, and periodontal disease (which affects the structures supporting the teeth).6,7

Despite knowledge of these risk factors, it remains extremely difficult to predict which women will actually have their baby early. Evidence suggests that women with no obvious risk factors (particularly first-time mothers) deliver as many as half of all premature babies,9 with many going into labour without warning. Conversely, many women who are thought to be at increased risk carry their babies to full-term.

Complications that can prompt doctors to intervene in a pregnancy and deliver the baby early include conditions affecting the mother or baby such as pre-eclampsia and intrauterine growth restriction.

What can currently be done?
Even if we could identify all of the women who are at risk of premature birth, relatively little can currently be done to stop them from having their baby too soon. To date, no preventative treatments have demonstrated significantly improved neonatal outcomes. Attempts to target risk factors have been largely unsuccessful.10

Similarly, if a woman goes into labour prematurely, or her membranes rupture early, little can be done to stop her baby from being born too soon. Drugs called tocolytics can slow labour, but they are used to delay the baby’s birth by only 48 hours or so. This has relatively little effect on a baby’s degree of maturation at birth. However, this medical intervention can provide time to both transfer the mother to a hospital equipped to care for premature babies and to give the mother antenatal corticosteroids to help prepare the baby, particularly the baby’s lungs, for birth. These tocolytics also provide time to treat the mother with antibiotics to prevent neonatal infection with group B streptococcus.
Underestimated and misunderstood

Premature birth is a common, serious and costly problem. But reports from the US suggest the public underestimates its magnitude. Major advances in neonatal care over the last two to three decades have indeed greatly improved survival rates of premature babies who have access to specialised intensive care units. One inaccurate perception is that improved neonatal care has resolved the problems experienced by premature babies, but the number of premature births remains high, has increased in some locations, and little success has been attained in understanding and preventing the problem of premature birth. Many premature babies still die and those who survive are at risk of developing life-long conditions. Unfortunately, it remains difficult to predict which women will have their baby early.

Fact:
Evidence suggests that women with no obvious risk factors (particularly first-time mothers) deliver as many as half of all premature babies, with many going into labour without warning.
3. The policy and funding landscape

Because of the separate administrative structures in England, Wales, Scotland and Northern Ireland, the UK government has different health policy processes and funding arrangements.

There is currently no overarching research strategy in the UK for tackling the problem of premature birth and its causes. Instead the UK government and devolved administrations rely on broader health policies, as well as the allocation of funding for individual research projects by the publicly funded research bodies in each country. Although this funding is welcome, and recent support for new projects in this area is commendable, many of them are taking place in relative isolation.

The most relevant policies focus on reducing infant mortality rates by tackling health inequalities and implementing public health measures addressing known risk factors such as smoking and teenage pregnancy. There are also initiatives to improve maternity services and neonatal care, including the English reorganisation of neonatal services into regional clinical networks in 2003, and the recent establishment of the Neonatal Task Force to improve services. None of these activities focuses exclusively on premature birth or the role of medical research in investigating its causes, reducing its incidence and improving the health of premature babies.

Without an independent Inquiry to review and evaluate research progress to date and the development of a focused and adequately funded National Research Strategy, progress in tackling premature birth will remain limited.

Health inequalities in infant mortality

The government has made tackling health inequalities a priority across the UK. In England it has set a national Health Inequalities Public Service Agreement (PSA) Target with the objective of reducing infant mortality rates (IMR) and increasing life expectancy in disadvantaged populations. Premature birth is the largest cause of infant mortality in infants under the age of one in the UK.\cite{3-5,6-7} The Health Inequalities PSA Target is "to reduce by at least ten per cent the gap in mortality between the routine and manual group and the population as a whole" by 2010.\cite{11}

Unfortunately this target is unlikely to be met. Data from 2004-06 shows the overall gap in infant mortality grew from the 1997-99 baseline of 13 per cent to 17 per cent, with a peak at 19 per cent.\cite{12}

The problem of meeting the IMR target is highly complex and will benefit from the systematic reviews being undertaken by the National Perinatal Epidemiology Unit to identify the key interventions most likely to meet the target and in the long-term improve maternal and child health.

Government funding for research

There are a number of organisations responsible for funding medical research across the UK. The main UK-wide body is the Medical Research Council (MRC). In England, the NHS’s National Institute for Healthcare Research also funds clinical research. In Wales, the Wales Office of Research and Development makes medical research funding available. The Chief Scientist Office performs a similar role in Scotland.
The policy and funding landscape

For Northern Ireland, funding comes from the Research and Development Office, a directorate of the Northern Ireland Health and Social Services Central Services Agency. Together they are funding a number of high-quality studies within the UK, but there is no single theme or initiative tackling premature birth and much of this project research is taking place in relative isolation. Recent initiatives such as the funding of Biomedical Research Centres in England have so far missed the opportunity to prioritise research into the causes of premature birth. According to Ann Keen MP, Minister of State for Health, during 2006/07 the MRC spent £6.6 million on research relating to premature birth,13 suggesting an increase in total government spend from the 2005/06 figure of £5 million. In Scotland, the Chief Scientist Office outlined that it is currently funding seven research projects on issues concerning premature birth at a cost of £1,155,233. These are due to be completed within the next two years.14 Although any increase in funding in this area is welcome, the question remains as to whether this spend is in line with the costs incurred as a result of the high incidence of premature birth.

However, funding is only part of the answer. Greater collaboration is also needed within the scientific and clinical communities, professional bodies, government, industry and the charity sector if we are to develop effective ways to tackle premature birth and pave the way for new treatments.

The costs of premature birth

There are no UK-wide figures for the life-time cost of premature birth. Other than mortality rates, the NHS has limited data on patient outcomes and neonatal units generally have a poor understanding of the costs of running their unit – the charges that form the basis for commissioning contracts vary widely between regional clinical networks, ranging from £173 to £2384 per intensive care cot day.15 However, there are some figures which provide an indication of the cost of neonatal care to the NHS. Every year, around ten per cent of babies born require some form of specialist care as a result of prematurity or other illnesses and conditions.15 In 2008, the House of Commons Public Accounts Committee stated that statutory spending on neonatal intensive care services in England for 2006-7 stood at some £420 million.15 The cost of caring for premature babies is likely to be a significant proportion of this cost.

Fact: There is currently no overarching research strategy in the UK for tackling the problem of premature birth and its causes.
Evidence has shown that premature birth is also associated with increased hospital inpatient costs during the first five years of life. In addition, there are the financial costs to the families themselves in terms of lost earnings and extra spend while a child is in hospital. Finally these costs also need to be considered alongside the broader health and social care costs incurred in caring for a child who may develop a life-long condition as a result of premature birth.

Premature birth is a significant cause of infant mortality and short and long-term morbidity. The impact on families, health services and society of premature birth is great. Clearly, scientific and medical research to understand the causes and find ways to help more babies be born healthy at term will have a beneficial impact on child health, families and society as a whole.

Dr Sheila Shribman, the government’s National Clinical Director for Children, Young People and Maternity Services, recently described the importance of research in this area in her evidence to the Public Accounts Committee:

“If we were able to reduce premature births and tackle low birth weight it would help enormously. ... It would certainly be very cost-effective for the country if we were able to reduce these deliveries... We can tackle the things we already know, but we do not yet know all of the answers. I certainly wish we did.”
4. The challenges facing research

Since none of the major statutory funders focus on preventing premature birth as a major theme or initiative, progress into understanding premature birth has been limited, despite a pool of talented scientists and researchers in the UK. Pharmaceutical companies shy away from tackling the health problems that can affect pregnant women, including premature birth. According to a recent review, only 17 drugs are under active development for all the different maternal health indications; this is less than three per cent of the pipeline in cardiovascular health (660 drugs) and fewer than for a single rare disease like amyotrophic lateral sclerosis (34 drugs). Although these conditions are clearly worthy of funding, it could be said that pregnancy has become a virtual 'pharma-free zone'.

Limited government and industry funding means the responsibility for supporting much of the research into premature birth has fallen to charities. With limited funding available, there is a danger that some of our best researchers will leave this area altogether affecting the UK's ability to promote and maintain scientific, medical and technological expertise in this field. While this document primarily focuses on reducing the incidence of premature birth, it is important to consider that it is not the ultimate endpoint of a new holistic approach. The true health outcome is optimal fetal, infant and lifelong health. Much of the research that has taken place has focused on identifying the risk factors that increase a pregnant woman's chances of having her baby early. Though considerable progress has been

Understanding of premature birth is rudimentary

An important consequence of the funding deficit is that improvements in understanding the biology of premature birth, particularly spontaneous premature birth, have failed to keep pace with medical developments in other areas. Knowledge of the processes that control when a pregnant woman goes into labour, and what goes wrong when a baby is born prematurely, remains rudimentary. The mechanisms that normally stop the uterus from contracting during pregnancy are also poorly understood.

This lack of knowledge presents a major obstacle to the development of ways to reduce the number of premature births and improve the health of babies. More scientific research is needed into the fundamental molecular and cellular processes involved in birth. A key role of the Inquiry would be to evaluate the basic research that has been undertaken so far, and identify and prioritise key areas of focus for the future.

Premature birth is a complex problem and risk factors are not well understood

Premature birth is not an isolated condition for which there is likely to be one solution or cure. Instead, the causes of premature birth are likely to be multi-factorial: complex biochemical, genetic, environmental, social and behavioural elements will interact at multiple and interrelated biological levels to initiate premature delivery.

Much of the research that has taken place has focused on identifying the risk factors that increase a pregnant woman's chances of having her baby early. Though considerable progress has been
made in this area, evidence suggests women with no obvious risk factors deliver around half of premature babies.9

We need to learn more about the precise mechanisms by which risk factors influence the premature birth rate, and the potential impact of their successful modification on rates of premature birth. The lack of knowledge is seriously hampering our ability to develop good preventative strategies. We also need to develop better ways of identifying women who are at risk and quantifying their likelihood of having their baby early. The Inquiry could help by identifying the best methods to tackle these complex challenges.

**There are limited ways to prevent premature labour**

An increased understanding of the fundamental biological processes that trigger premature birth would help in the development of new treatments that can prevent it and reduce the adverse effects on neonatal and child health. The Inquiry could look at better ways of integrating future research into the fundamental causes of premature birth with clinical trials of possible preventative treatments.

To date, no preventative treatments have demonstrated significantly improved neonatal outcomes. Interventions that have shown some promise in some women in clinical trials include stopping smoking, screening for and treating asymptomatic bacteriuria, treating bacterial vaginosis, progesterone administration, omega-3 supplements and cervical cerclage.9

Interventions that have been unsuccessful include treating periodontal disease, certain nutritional supplements, early access to prenatal care, antibiotic treatment of genital-tract infection, antimicrobial treatment between pregnancies in women with previous early premature birth, and more intensive prenatal care, though this may perhaps be helpful for pregnant adolescents.9

Another key role of the Inquiry is therefore to evaluate which interventions warrant further study and incorporate this into the ten-year National Research Strategy. It is important that, whenever possible, clinical trials should be designed in such a way that they can identify which groups of women benefit from treatment, and when their treatment should start. Studies should also be able to measure how the intervention affects outcomes, both in terms of delaying or preventing premature birth, and reducing mortality and disability. This would help inform strategies to assess the risks versus the benefits of intervention.

An example of a new large and collaborative study in the UK is the OPPTIMUM Trial. Funded by the Medical Research Council, and due to start later this year, it aims to establish whether progesterone taken on a prophylactic basis helps prevent preterm labour in high-risk women and improve infant outcomes.

**Diagnosis of premature labour is difficult**

Currently, diagnosing premature labour is challenging, because the signs and symptoms arise commonly in normal pregnancies. The most common presenting complaints are uterine contractions, ruptured membranes and vaginal spotting or bleeding.9

An increased understanding of the biological processes involved in labour may also help improve diagnosis. It may help identify new diagnostic
The challenges facing research

markers, for example, in the cervix, vagina, amniotic fluid, serum or saliva. It may also lead to new ways to monitor uterine contractility during pregnancy, using ultrasound and uterine electromyography to help detect the onset of premature labour as early as possible. Research suggests diagnosis might also be improved by testing for a short cervical length using transvaginal sonographic measurements. The Inquiry has a role to play in identifying and prioritising research that could improve diagnosis.

There are limited ways to stop premature labour once it has started

Current use of tocolytic drugs can slow down labour to delay birth by up 48 hours or so. They do not stop premature labour once it has started. The Royal College of Obstetricians and Gynaecologists suggests that since current therapies give no clear improvement of neonatal outcome, it is reasonable not to use them unless the couple of days gained would be put to good use by, for example, transfer to a specialist unit or completion of corticosteroid therapy. Developing new treatments that could stop labour altogether, or delay birth for much longer, could be beneficial in some women. The long-term effectiveness of any interventions including tocolytics will also need further investigation. The Inquiry has a key role to play in evaluating the research into tocolytics that has been carried out and planning future priorities.

Standards for data collection and use are inadequate

Research into premature birth has been hindered by inadequate standardisation and collection of information during pregnancy and after birth - including data on longer-term health outcomes. The current lack of centrally available data on all pregnancies in England and Wales is also proving problematic. Although useful information is collected as part of routine antenatal work, little of this is centrally collated or made available to research teams, seriously impeding the efforts of researchers to make progress in understanding the risk factors and developing preventative health strategies in the areas of greatest need.

In Scotland, this information has been available to researchers for many years through the ISD Women and Children’s Health Information Programme, part of the NHS in Scotland. The situation in England may be partly ameliorated by various initiatives including the roll-out of the maternity dataset, as part of the National Programme for IT, although a recent report from the National Audit Office suggested that the online patient record section of the project is four years behind schedule.

The Inquiry should consider how to improve data collection for pregnancy, birth and childhood outcomes, and explore the best way to centralise such data and make the information available to researchers when appropriate.

Collection of biological samples is inadequate

Research in the UK has also been hindered by inadequate collection, processing and preservation of biological samples.
The Inquiry should look at ways to improve the collection, storage and use of tissue samples. This could, for example, allow researchers to access an adequate supply of biological samples (such as blood and tissue from the uterus) from women affected, as well as from control groups, and facilitate more training of midwives and clinicians in the collection of samples, encouraging them to participate in research.

Better collection of data and handling of samples would significantly improve the reliability of comparisons between the results of different studies.

**There is no multidisciplinary, comprehensive approach**

Serious commitment and investment is urgently needed to develop a large, focused and multidisciplinary National Research Strategy, with the ultimate aim of saving lives and preventing life-long health conditions. A holistic approach is needed, which searches for ways to both reduce premature birth and its adverse effects on babies’ health.

Tackling premature birth will require a multidisciplinary approach involving a range of experts including biologists, biomedical engineers, epidemiologists, social scientists, statisticians, clinicians and families who have been affected.20

Traditional physiological and biochemical studies will be needed, as well as modern genomic and proteomic approaches, medical systems biology, new imaging techniques, electromyography, bioengineering, nanotechnology and clinical trials.20

We suggest the Inquiry explores the possibility of establishing a network of research groupings in the UK to tackle the problem of premature birth, with perhaps centres of excellence at its core.

An integrated approach to this research is vital to make inroads into why premature birth occurs and find ways to tackle it.

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5. Real stories

Edmund and Aubrey Holdcroft

When Edmund and Aubrey Holdcroft were born almost 15 weeks early, weighing just 2lbs each, they were given only a 40 per cent chance of survival.

“The twins were born very early and their time in special care was terrifying,” said their father, Martin, from Ramsgate. “Both babies had heart murmurs and at just three days old Aubrey’s lungs began to bleed and we were asked if we wanted him christened.”

The boys battled through and are now healthy three-year-olds. Martin believes his family has been “very fortunate”, saying “the medical teams are brilliant at treating these fragile babies, but the reality is that many of them don’t make it. Premature birth can happen to any family, and when it does, all the joy and hope that a new baby brings is replaced by a trauma that really is devastating. We need to know why premature birth happens.”

Lauren and Eilidh Currie

Fiona Currie, of Cambuslang, Scotland, lost her daughter Lauren just one week after she was born. Lauren succumbed to an infection, which her weakened immune system was unable to fight off.

Lauren and her twin sister Eilidh were born four weeks before their due date in November 2003. Although Eilidh survived, the pain of losing baby Lauren is still fresh in Fiona’s mind. “We only had a week together but you couldn’t put a price on that time, it was so precious,” said Fiona. “Lauren was part of our family for just seven days but she will be with us forever in our hearts.”

“Maybe Lauren’s infection could have been detected and prevented, but not enough is known about the condition to allow doctors in the UK to agree the best course of action,” said Fiona. “It breaks my heart that more babies are dying or being severely disabled, and families will continue to be torn apart until doctors have the information they need to decide the best way to deal with this.”
Richard and Paige Surtees

Paige Surtees weighed just 2lb when she was born 14 weeks early in January 2008. For her mum Tracy Ridley, from Newcastle, this was her second child to be born very prematurely. Her son Richard, who is now three years old, was born 27 weeks into her first pregnancy weighing 2lb 4oz.

"When Richard was born we were terrified," said Tracy. "He was so small and his skin was almost see-through. There are all these wires and machines; you just don't realise all the machinery that goes into keeping these little babies alive."

"The hospital kept a very close eye on me the second time around, but I really didn't expect to go through it all again. It's just as scary. You never know what's around the corner with a premature baby and every one is different."

The family were thrilled when Paige was allowed home after four months in hospital. "Paige is doing really well and is almost like a normal baby now, although she's still quite small. The doctors don't know why I have been unable to carry my babies to term which is why I think it's so important for the government to do more to help them find the answers. I wouldn't want any other family to go through what we have."

Barney and Cian O'Driscoll

Anna and Brendan O'Driscoll, from Birmingham have also experienced the trauma of premature birth twice. Their first son, Barney, was born at just 27 weeks gestation, weighing 2lb 6oz. Thankfully, after a three-month hospital battle, Barney survived and is now a healthy five year old. Tragically, his younger brother Cian was not so lucky. Cian survived for only four days after being born just 25 weeks into pregnancy.

Having experienced the distress of premature birth twice, the O'Driscoll family hopes people across the UK will support Action Medical Research's call for an independent Premature Birth Inquiry. "A lot more research needs to be done to help women like me sustain a pregnancy, especially those who inexplicably go into labour so early," says Anna. "I hope this campaign will help ensure that people like me don't have to go through the trauma of seeing their precious child die."
Real stories

Flynn Willemse
Jo Willemse was 28 weeks pregnant when a routine checkup caused alarm: her blood pressure was high. After a few days of hospital monitoring, things took a turn for the worse. “Before I knew it, I was being wheeled to theatre for an emergency caesarean. It was very frightening and my husband was told that there was only a 30 per cent chance our little one would make it.”
Flynn weighed just 2lb 2oz. “I had never seen anything so small,” said Jo. “And the intensive care ward is just that, a very intense place. Lots of noise and staff busy keeping these precious lives safe.”
After a ten-week hospital battle, Flynn went home, just in time for Christmas 2003. “Having a premature baby is an ongoing experience,” said Jo. “You constantly worry if what they went through will affect them later in life. We urgently need more research into why we have such high rates of premature birth.”

Joshua White
Joshua White was born 14 weeks early, weighing just 1lb 4oz. He was five days old when he lost his battle for life, after suffering a massive bleed in his lung.
“We held our baby for half an hour until his little heart stopped beating,” said his mother Andrea. “The nurse said the words that make me cry each time I think of them: ‘Joshua is enjoying having a cuddle with his Mammy and Daddy.’”
“It was the best and the worst half an hour either of us have ever felt. He was so tiny, so soft and so warm. He was dressed in a tiny babygrow that was still far too big for him and later that night taken down to the chapel of rest.”
“If money can be made available to stop only one family going through the heartache that we are feeling, it will be money well spent.”

Joshua
6. References

1. Office for National Statistics. Health Statistics Quarterly 35 (Autumn 2007), Table 2.1
9. Iams JD, Romero R, Culhane JF, Goldenberg RL. Preterm Birth 2. Primary, secondary, and tertiary interventions to reduce the morbidity and mortality of preterm birth. Lancet 2008; 371:164-75
13. Letter from Ann Keen MP to Simon Moore, Chief Executive, Action Medical Research – copy available (Received June 2008)

Footnotes
a. Calculation made by Action Medical Research based on figures in references 1 and 2 for the number of births a year in the UK and the number of preterm deliveries in England, respectively. Estimate assumes incidence of premature birth is the same for the UK overall as it is for England
b. For England and Wales, deaths listed as due to “immaturity related conditions”
c. For Scotland and Northern Ireland, deaths listed as due to “disorders related to length of gestation and fetal growth”
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