Group B Strep Support

Preventing Group B Strep Infections in Babies in the UK - past, present and future

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Introduction

Back in 1996 when the charity started, there was no UK prevention strategy for group B Streptococcal (GBS) infection in babies at all, and almost no-one had heard of it. My GP had to look it up, and I remember spending hours at libraries photocopying pages from research papers, trying to understand more.

Flash forward 25 years and

- group B Strep is now widely recognised as being a key cause of serious infection in babies
- high-quality information is freely available online and in print
- there are multiple clinical guidelines on group B Strep, and
- the latest data from the UK shows that c. 80% of pregnant women had heard of group B Strep.

While there has been significant progress over the years, there is still more to do:

- about a quarter of first-time mothers won't have heard of group B Strep
- a pregnant woman is more likely to hear about group B Strep from a friend than her doctor or midwife
- both the number and rate of group B Strep infections in babies have increased since 1996 – there are now over 75% more babies developing GBS infections.

Looking back over the past 25 years is a bittersweet experience.

I am deeply proud of the huge impact the charity has made, and the progress we have seen in the development of group B Strep policy and research in the UK.

I am also deeply frustrated that the UK still lags behind the rest of the developed world on this. That, as the new data from Public Health England presented today show, so many more babies are developing what is often a preventable disease. And that the pace of change is so slow.

Each of you attending this conference today has a role to play in moving things forward.

Together, let's make GBS history.

Jane Plumb MBE
Chief Executive of Group B Strep Support

"The NHS is one of the safest places in the world to give birth, and I urge women to not hesitate in coming forward for scans and NHS support as soon as possible.

Group B Strep (GBS) can be a silent killer and I am determined to do everything I can to protect mothers and babies.

I was proud to announce a large-scale clinical trial in 2019 comparing universal screening for GBS against usual risk-based care for expectant mothers which will enable us to gather crucial evidence on the best approach and we continue to keep our policy under review."

Nadine Dorries MP,
Minister for Maternity Safety

"The new information from Public Health England demonstrates why it is vital that best practice around the prevention of group B Strep infection is followed. It's disturbing to see that rates of GBS have increased so much over the past 24 years - particularly when today many of these cases are easily preventable.

We all have an important role to play in ensuring families are aware of group B Strep, and are supported to make informed choices about their care, as recommended in the Royal College Of Obstetricians and Gynaecologists' Green-Top guideline. Group B Strep Support has worked closely with the RCOG to develop patient information which should be given to all parents-to-be. I fully support their new campaign, launched on their 25th anniversary, to raise awareness of Group B Strep among all those caring for pregnant women."

Dr Eddie Morris,
Chair of Group B Strep Support

"It is heart-breaking to hear that so many families are still being affected by group B Strep. This largely treatable infection affects families around birth but for many so much longer than this. Women meet their midwife early in their childbearing journey and the majority will be with them well beyond that initial meeting. Midwives are in a perfect position to educate families about group B Strep, helping them understand what their options are, and supporting them through shared decision making.

Group B Strep Support is a fantastic charity working to stop group B Strep infection in babies. They have worked closely with the RCM to ensure that midwives are better educated about group B Strep but there is still more work to be done around educating all healthcare professionals and parents-to-be, as these new worrying figures show."

Kathryn Gutteridge,
Group B Strep Support Trustee

Executive Summary:

Between 1996 and 2020, England's rate of GBS infection in babies has risen by 77%. This year, for Group B Strep Support's 25th anniversary year, we are launching a campaign to make group B Strep history.

We are calling for:

- All new and expectant parents to be informed about group B Strep
- All healthcare professionals to be fully informed about group B Strep
- All hospitals in the UK to use the recommended test for group B Strep carriage

We want to see the introduction of a national antenatal screening programme for group B Strep in the UK – which would bring us in line with most other high-income countries – to reduce the number of preventable deaths among babies.

Looking to the future, we anticipate the introduction of routine screening after the GBS3 Trial provides evidence on what type of testing is better – ECM testing late in pregnancy or bedside-testing during labour. We also welcome the ongoing work towards a group B Strep vaccine.

However, screening is at least two to three years away, and a safe and effective GBS vaccine is a decade or more away. The UK needs to be doing better now to protect little lives.

Together, let's make group B Strep history.

What is group B Strep?

Group B Strep is a bacteria carried harmlessly by around 20-25% of pregnant women in the UK.

It usually only causes a problem if a baby is exposed to group B Strep around labour and in the early weeks after birth, when the baby's immature immune system is less able to fight off its the bacteria and develop infection, with potentially damaging effects.

Most group B Strep infections in babies develop in their first week of life (early-onset GBS infection), but they can – more rarely – develop up to three months of age (late-onset GBS infection).

Most early-onset GBS infection can be prevented by giving women who are carrying group B Strep preventative antibiotics in labour.

Group B Strep can cause sepsis, pneumonia and meningitis in babies. With expert care, most babies will recover from their group B Strep infection, but sadly these infections can leave survivors with life-changing disabilities or be fatal.

In the UK around 800 babies a year develop group B Strep infection. Around 50 babies will die. 75 survivors will recover with disabilities because of their infection. These disabilities can be a range of things, including visual impairment, limb loss, and brain damage.

Group B Strep is most common cause of serious infection in babies in the UK. Two babies on average develop GBS infection in the UK every day.

What has the UK done about the problem? / Background and History

Group B Strep Support was set up 25 years ago in the UK and is now the world's leading charity working to stop group B Strep infection in babies.

1996

Group B Strep Support was founded. At this point there was almost no public awareness of GBS and no national clinical guidelines to prevent GBS infection in the UK.

1998

Our early work led the then Health Protection Agency to set up a Group B Strep Working Group to assess the scale of group B Strep infection, and gather evidence for developing clinical guidelines on preventing it.

2000-1

The HPA Group B Strep Working Group commissioned the British Paediatric Surveillance Unit (BPSU) to find out how many babies were developing group B Strep infection in the UK and Republic of Ireland.

While waiting for the BPSU's results, the Group B Strep Working Group published interim good practice recommendations - effectively the first national recommendations for the UK.

2003

In 2003 the Royal College of Obstetricians & Gynaecologists (RCOG) issued their own clinical guidelines, setting out the risk-factor prevention strategy the UK still mostly follows today. In the same year, the UK National Screening Committee (NSC) recommended against the UK introducing routine screening of pregnant women for group B Strep.

2006

A few years later, the Health Protection Agency published instructions on how to test for group B Strep carriage, the UK Standards for Microbiology Investigations (SMI) B58. Despite this, almost no hospitals used ECM testing, and the only option for women wanting to be tested was buying private test kits.

This year saw the first national survey of group B Strep awareness, through Pregnancy & Birth Magazine. This found that only 10% of their readers had heard of GBS.

2008

The charity continued to push for better prevention, and the RCOG responded by undertaking an audit into how UK hospitals were following its national guidelines. The results were underwhelming, showing that the risk-factor guidelines were not well-followed.

2012

Despite the RCOG's audit's findings, and the charity's requests for improvements, the next RCOG GBS guideline update in 2012 had only a few minor amends compared to the 2003 edition, reducing the number of risk factors that would prompt the offer if antibiotics in labour.

2014/15

The BPSU undertook a follow-up to their original surveillance study from 2001. This found that the rate of GBS infection had increased over the previous 15 years by 19% for early-onset group B Strep infection, and 54% for late-onset group B Strep infection. This was a very clear indication that the risk-factor strategy was failing to prevent early-onset group B Strep infections.

As a result of the BPSU's findings, the charity and the then Health Minister asked the RCOG urgently to review and update their group B Strep guidelines.

At the same time, public awareness was steadily increasing thanks to the charity's activities. Pregnancy company Bounty surveyed new and expectant mother and reported that 47% of new mothers had heard of group B Strep.

2016

Our campaigning had firmly established group B Strep as a political priority, and the Department of Health invited us to join their expert group on group B Strep research priorities. This led to several important pieces of research being commissioned, including the GBS3 Trial comparing testing approaches to prevention of early-onset GBS infection against the UK's risk-based strategy, and others designed to facilitate the development of a maternal group B Strep vaccine.

2017

As a result of the Department of Health's expert group's recommendations, National Institute of Health Research funded the GBS3 trial. Delayed by the Covid-19 pandemic, it is expected to report in 2023 and will shape future UK prevention policy. The charity is closely involved and supportive of the trial.

Public demand for better group B Strep prevention was growing. A public petition gathered 750,000 signatures calling for pregnant women to be given information on group B Strep, and for the NHS to offer them a group B Strep test.

Bounty ran another survey on group B Strep awareness, showing that 80% of new and expectant parents had heard of group B Strep, a significant rise from the 47% in 2015. The RCOG update their group B Strep guidelines, with the chair of the charity's Medical Advisory Panel being part of update committee, and the charity providing input on how the guideline could be improved. There were significant improvements to the clinical recommendations and, in a first-of-its-kind partnership for us and the RCOG, we co-wrote a joint information leaflet on group B Strep in pregnancy. This leaflet is now used in 75% of UK Trusts.

In response to higher than average rates of group B Strep infection in babies, a North West London Trust piloted a routine universal screening programme. The pilot saw a dramatic reduction in their rates of early-onset group B Strep infection similar to falls in countries that have adopted screening. Sadly, once the pilot was stopped, the rates of infection reverted back to pre-screening levels.

2020

Aware that many midwives are poorly educated on group B Strep, the charity approached the Royal College of Midwives (RCM) and together developed an online learning module on group B Strep. This module is freely available to all RCM members.

2021

The charity surveyed maternity units in the UK through requests under the Freedom of Information Act and published the results.

GBSS is grateful to all the Trusts/Boards for responding to its request for information and recognises the time and effort that went into providing the information.

The findings were shocking:

- 20% of Trusts/Boards had not updated their group B Strep guidelines since RCOG's major update in 2017
- 51% did not give all pregnant women information on group B Strep, as recommended by RCOG in 2017
- 66% were using the wrong swab test to detect group B Strep carriage
- 87% were not following the right laboratory methodology for processing the group B Strep tests

Our key recommendations were:

- All Trusts/Boards should adopt and implement the RCOG guidelines promptly
- All pregnant women should be informed about group B Strep as part of their antenatal care
- The GBS-specific Enriched Culture Medium (ECM) test should be used when pregnant women are tested for group B Strep carriage
- All new parents should be informed about the key signs of group B Strep infection in babies, to empower them to seek vital early treatment which can save lives

What is the situation now in the UK?

Despite all the progress and developments listed above, England's rate of group B Strep infection in babies has risen by 77% since 1996 – a 63% increase in early-onset GBS infection and a 113% increase in late-onset GBS infection.

We believe this increase is largely due to the poor adoption of a complicated risk-factor prevention strategy rather than a much simpler universal screening approach.

Other countries that have adopted universal screening have seen significant decreases in their rates of infection. For example, the United States had a rate of early-onset GBS infection of 0.70 per 1000 live births in 1997. They introduced a routine universal screening programme in 2002, and for the latest data available (2018) their rate of early-onset GBS infection was 0.29 per 1000 live births, a 70% decrease since 1996. By comparison, the rate of early-onset GBS infection in 2018 was 90% higher in England than in the USA at 0.55 per 1,000 live births.

The UK's current approach to group B Strep simply isn't working.

What next?

This year, for Group B Strep Support's 25th anniversary year, we are launching a campaign to make group B Strep history.

Immediately, we are calling for:

- All new and expectant parents to be informed about group B Strep
- All healthcare professionals to be fully informed about group B Strep
- All hospitals in the UK to use the recommended test for group B Strep

This will help save tiny lives.

Longer-term, we want to see the introduction of a national antenatal screening programme for group B Strep in the UK – which would bring us in line with most other high-income countries – to reduce the number of preventable deaths among babies. Currently available evidence shows that a universal antenatal screening programme will reduce early-onset group B Strep infection more than the UK's risk-based approach.

However, for screening to be introduced in the UK, clear results are needed from the GBS3 Trial on what type of testing is better: testing women late in pregnancy, or testing while a woman is in labour.

On the horizon, we welcome the development of a group B Strep vaccine that would be given to pregnant women. This could prevent even more infections than screening, including stillbirths and late-onset infections caused by GBS, and would reduce antibiotic usage. However, a safe and effective GBS vaccine is at least 10 years away. The UK needs to be doing better now.

England's rate of early-onset group B Strep infection is currently more than double that of other developed countries.

We urgently need better prevention. And we need it now.

Together, let's make group B Strep history.

Group B Strep Support
www.gbss.org.uk

Let's Make Group B Strep History

25 years

GROUP B STREP SUPPORT

Group B Strep Support is the only UK charity dedicated to eradicating group B Strep infections in babies.

We provide up-to-date, evidence based information on GBS to families and health professionals, and support to affected families.

We want every pregnant woman to be given information on group B Strep during routine antenatal care, and offered the opportunity to have a GBS- specific test late in pregnancy.

Ultimately, we want GBS infections in babies to be eradicated.

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