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PRESS RELEASE  
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**Vital vaccine's delay 'needlessly' kills babies and children.**

'TOO many of our children are needlessly dying or left disabled due to lethargic bureaucracy' in introducing a revolutionary vaccine, says the father of the UK's meningitis movement.

January 22 marks the second anniversary of the UK's first vaccine for Meningitis B\*, the most common cause of bacterial meningitis, receiving its EU licence, proving it is safe and effective.

Fresh Meningitis Now figures highlight that, within the time since award-winning Bexsero's licence – 24 UK children under-one – one a month – could have died of the aggressive disease.

The UK has one of the world's highest Men B rates, killing more of the country's under-fives than any other infectious disease.

In total, one in 10 people die and at least one in three survivors suffer lifelong after-effects, including limb loss, brain damage, epilepsy, deafness and blindness.

Meningitis Now founder Steve Dayman MBE, who launched the UK's meningitis movement after losing his baby Spencer to Meningitis B in 1982, said: ***"I have waited half my life for this vaccine – it's a watershed moment in the fight to eradicate the deadly disease.***

***"Now is the time to act to save our children – one more lost is another heinous and scandalous injustice.***

***"On this unwelcome anniversary, I call on Government and the vaccine manufacturer to take advantage of the last window of time before the General Election to do the right thing.***

***"Next week, there will be just 100 days before the election and, in around half that time, Parliament will dissolve.***

***"I'm deeply concerned this vaccine will fall off the radar in the coming months, when it should be introduced immediately."***

The UK's largest meningitis charity's figures also show there were around 1,130 Meningitis B cases during the period.

Of these, at least 452 people could have died or suffered disabilities, which cost the NHS over a lifetime.

Many of these were avoidable if the vaccine was introduced immediately after licensure.

***"I was sick to my stomach to learn that so many people have died in the two years due to red tape"***, Mr Dayman, who, last year, won a Pride of Britain award for his charity work, said.

***"Tragically, in the time, we've heard of and helped numerous families freshly touched by the disease, which prove this lethargic bureaucracy is costing lives and causing disabilities."***

Last March, the Government said Bexsero will be free infants on the NHS, subject to price negotiations with manufacturer, Swiss pharmaceutical giant Novartis.

These finally began five months afterwards in August, but continue, angering Meningitis Now and its tens of thousands of supporters.

Bexsero was made available privately in December 2013 – costing up to £600 in some areas – but Health Secretary Jeremy Hunt has long said the NHS has a legal duty to reduce health inequality.

Mr Dayman said: ***“I’m livid and appalled that it’s almost a year since news it will be free on the NHS, negotiations were slow to begin and they’re ongoing after half-a-year.*”**

***“So, on behalf of the families who’ve suffered the trauma of the disease, I plead directly to the Health Secretary and Novartis to pull out all the stops, before more needlessly die or suffer after-effects.”***

Bexsero, which won Innovative Product at UK Prix Galien Awards 2014, the pharmaceutical industry’s Oscars, covers most Meningitis B strains.

It was first delayed when independent Government advisers, the Joint Committee on Vaccination and Immunisation (JCVI), twice deferred a decision for introduction due to lack of evidence of cost-effectiveness.

After fresh evidence including Meningitis Now information on the disease’s burden on family and survivors’ quality of life, the JCVI overturned the ‘no’ last March.

By law, the Government must accept this, so announced that Bexsero will be free to babies and infants on the NHS, following price negotiations.

Meningitis Now launched Beat it Now! to unite supporters and politicians to lobby the Government to introduce the vaccine as soon as possible after licensure.

Mr Dayman added: ***“We will continue to unite people who know too well how meningitis devastates, for their stories illustrate this vaccine’s importance.*”**

***“Beat it Now! will be relentless until the first baby receives the lifesaving jab for free.”***

The campaign, which saw a 36,500-name petition delivered to Mr Hunt, helped speed up bureaucracy.

This saw Meningitis Now win Charity Times’ Campaigning Team of the Year 2014.

The charity now urges supporters to again press their MPs to lobby Mr Hunt to act, before Parliament dissolves ahead of the election.

To join Beat it Now!, donate or for more information, visit [www.MeningitisNow.org](http://www.MeningitisNow.org).

- \* Meningococcal group B (Men B) disease

**ENDS**

## **Mum who lost ‘miracle’ first baby begs for Bexsero now**

Doctors diagnosed Caroline Williams with polycystic ovaries and said she may never have children.

Caroline tried for three years to get pregnant with partner Phil – ‘hope was fading fast’.

But the 'miracle' happened – she fell pregnant with her first child.

They named him Caden – 'he looked perfect'.

Sadly, aged just one, Caden died within 11 hours of contracting meningitis in March 2014 – just over a year after the vaccine was licensed.

She recently gave birth to her second son, Kelyn.

Terrified history will repeat itself, Caroline, of Tredegar, south east Wales, spoke to her GP about getting Bexsero privately.

She said: ***“Kelyn was a blessing and his health is the most important thing in the world to me after what happened to Caden.***

***“I cherish Caden’s memory, but my heart is still full of grief and I’m scared for Kelyn’s future.***

***“I shouldn’t be forced into the position where I have to pay hundreds of pounds for the vaccine to protect Kelyn, when the Government has agreed to put it free on the NHS.***

***“Like many ordinary families, we have to be careful with how we spend money.***

***“Bexsero should’ve been in use long ago, protecting our babies, and it’s hard to understand why it’s taking so long.***

***“Please don’t let others go through what we have when it’s so easy to prevent this now.”***

## **Breakthrough Bexsero**

The first broad-range Men B vaccine took pharmaceutical company Novartis over 20 years to develop.

It protects against the majority of UK cases and was created using 'reverse vaccinology', which used the bacterial genome to find a vaccine.

## **Bexsero bags Oscar of pharmaceutical world**

The vaccine won Innovative Product at the UK Prix Galien Awards, the pharmaceutical industry's Oscars, at the House of Commons in October.

Judging panel chairman Prof Sir Michael Rawlins, ex-National Institute for Health and Care Excellence (NICE) chair, said: ***“Bexsero was the unanimous winner.***

***“Developing a [Men B] vaccine has been extremely difficult.***

***“It’s fantastic that pioneering research led to genomic techniques in creating a broadly protective vaccine.”***

Held every two years, the awards, recognising outstanding achievements in medicine, are considered as the highest honour for pharmaceutical products.

## **Meningitis Now’s Beat it Now!**

The award-winning campaign, launched after Bexsero's licence, empowers supporters across the UK to press their MPs to lobby the Government to put the vaccine on the NHS.

Over 135 MPs and more Welsh, Scottish and Northern Irish counterparts, and media medics including Dr Ellie Cannon and Dr Ranj Singh, back it.

Beat it Now! aims include ensuring:

- The DoH and Novartis conclude negotiations swiftly
- Bexsero is part of NHS 2014-15 commissioning schedules
- Vaccine communications with GPs, immunisation nurses and parents are effective, with charity support where needed
- An adolescent carriage study goes ahead as soon as possible, with our support where needed
- People press their MPs, AMs, MSPs or MLAs

## **Timeline**

### **2013**

January – Bexsero receives EU licence

June – JCVI considers Bexsero

July – JCVI says evidence is insufficient to support vaccine, and invites stakeholders' responses

September – Meningitis Now responds to JCVI decision

October – JCVI considers responses

MNow and supporters deliver first 20k petition signatures to Downing Street

JCVI says it needs more information

November – JCVI October meeting minutes published

December – Bexsero available in UK privately for up to £600

### **2014**

January – Over 100 doctors, nurses and scientists write to Health Secretary, urging Bexsero's introduction

First anniversary of licence

February – JCVI re-considers vaccine

MNow delivers 36,000-plus signatures to DoH, and meet campaign-supporting MPs

March – JCVI February minutes recommend Bexsero and how MNow's response influenced them

DoH says Bexsero will be in the UK Childhood Immunisation Programme, subject to price negotiations

June – MNow's Westminster briefing asks for vaccine introduction update

August – DoH and Novartis start negotiations

November – MNow hosts House of Commons event and update for MPs

**2015**

January – Second anniversary of licence. MNow estimates around 1,130 cases, 452 of which could have caused death or disability, and 24 infant deaths, since licence

**ENDS**

**Photo Caption(s):**

Bexsero Win a – GRAND PRIX: Meningitis Now chief executive Sue Davie holds the Innovative Product award, with Novartis

Spencer Dayman b – FUNDRAISING FATHER: Steve Dayman launched the UK's meningitis movement after losing his baby Spencer, pictured

Steve D m – "MONUMENTAL MOMENT": Steve Dayman MBE, dubbed 'father of the meningitis movement'

Caden a – FIRST CHILD: Caroline with her 'miracle' first baby Caden

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**Meningitis and Septicaemia Facts**

- Meningitis is usually caused by bacteria or viruses
- Meningitis is inflammation of the membranes that surround and protect the brain and spinal cord
- Septicaemia is blood poisoning
- Some bacteria that cause meningitis also cause septicaemia
- Meningitis and septicaemia often happen together – it is vital to know all the signs and symptoms
- The early signs and symptoms of meningitis and septicaemia can be similar to 'flu and include fever, headache, nausea, vomiting and muscle pain.
- The more specific signs and symptoms include fever with cold hands and feet, drowsiness, confusion, pale blotchy skin, stiff neck, dislike of bright lights and a rash which doesn't fade under pressure.
- In babies, symptoms can also include being floppy and unresponsive, dislike of being handled, rapid breathing, an unusual, moaning cry and a bulging fontanelle (soft spot on the top of the head).
- Following bacterial meningitis or septicaemia, one in ten people will die and at least a third of survivors will be left with lifelong after-effects such as hearing loss, epilepsy, limb loss or learning difficulties
- Meningitis and septicaemia can affect anyone, of any age, at any time. However, babies and young children are most at risk, and young people between 15 – 24 years are also a higher risk group.
- In the past 20 years, effective vaccines have been developed to give protection against **SOME** types of meningitis. These are offered to all babies and young children

as part of the UK childhood immunisation programme. **BUT** there are not vaccines to protect against **ALL** types.

- In January 2013, a vaccine to protect against meningococcal group B (Men B) disease, the most common cause of bacterial meningitis and septicaemia, was licensed for use in Europe. In March 2014, this vaccine was recommended for routine use in the UK childhood immunisation programme, provided a cost-effective vaccine price can be agreed.
- If you suspect someone may be ill with meningitis or septicaemia, trust your instincts and get immediate medical help.

For more information visit [www.MeningitisNow.org](http://www.MeningitisNow.org) or call 01453 768006. Freephone helpline 0808 80 10 388.

### **About Meningitis Now**

**Meningitis Now**, the UK's largest charity fighting the disease, formed after Meningitis UK and Meningitis Trust merged in April 2013.

The newly united charity, with around 30 years' experience exists to save lives and rebuild futures – through research, awareness and support.

**Meningitis Now** fights the disease on all fronts by providing a powerful, united voice for people fighting meningitis.

- Saving lives by funding vaccine and preventative research.
- Reducing the disease's impact through awareness.
- Rebuilding futures with dedicated support.
- Fundraising to deliver our plans.