



10 Years After Major BMA Report on FASD England Fails to Meet the Need NOFAS-UK Launches GP Awareness Project

*New survey of GPs conducted by NOFAS-UK for
International FASD Awareness Day – 9 September 2017*

London, 8 SEPTEMBER 2017 -- The [National Organisation for Foetal Alcohol Syndrome-UK](#) (NOFAS-UK) conducted a quick GP 'check-up' to mark this year's international Foetal Alcohol Spectrum Disorders (FASD) Awareness Day. [1] Results indicate our GPs need more education and guidance on issues related to FASD and the life-long impact of the brain damage and other health and learning issues that can result from prenatal exposure to alcohol. Among the findings, only 31% of the GPs said they had in-depth education regarding FASD. Forty-seven per cent said it should be more thoroughly taught in medical school. Forty-one per cent said they have not received clear guidance from their local Clinical Commissioning Group regarding a pathway for diagnosis and support of FASD. Only 23% felt 'strongly confident' that all those with a Foetal Alcohol Spectrum Disorder are being diagnosed properly.

NOFAS-UK Chief Executive Sandra Butcher said, "These results show why families quite often hit a wall when seeking medical advice and support for those affected by prenatal alcohol exposure. Our GPs aren't fully briefed. The feedback we receive from individuals with FASD and those who care for them is depressingly repetitive. Too often they face multiple roadblocks in their quest for the professional support and insights they need to move forward. The walls they hit time and time again cause great delay and distress to some of the most vulnerable members of society. It is deeply frustrating when this happens in the sanctuary of their GP's office, which is supposed to be the gateway to care and compassion."

Butcher said, "This isn't all on GPs. Our GPs are people of goodwill who are under great strain. They need more information about FASD, consistent messaging, appropriate resources, and an unequivocal mandate to actively address this issue with a clear pathway outlining what to do and what referrals to make if they suspect a case of FASD. This starts with Clinical Commission Groups which are tasked by Government to fill this role."

In February 2017, [Government reinforced](#) that "early intervention services can help reduce some of the effects of Fetal Alcohol Spectrum Disorders (FASD) and prevent some of the secondary disabilities that result. Responsibility for commissioning these services lies with clinical commissioning groups."

Butcher said, "Despite clear responsibility on this issue, some of our CCGs are sadly too slow to act or misinformed, causing great distress to families. There are areas of excellence in the country who are showing this isn't a matter only of limited resources, but there also are areas that neglect this important issue. There is no justifiable reason to let those with FASD, an extremely vulnerable section of our population, slip through the cracks due to a postcode lottery."

"Government inaction is inexcusable," Butcher said, "A major report from the British Medical Association drew attention to this need a decade ago – failure to take heed of some of the country's leading experts on this issue has jeopardised the futures for too many of our children." In a 2007 the BMA issued a [report](#) (revised in 2016) which said among its many recommendations, "Guidance on the diagnosis of the full range of fetal alcohol spectrum disorders should be developed and made available to all healthcare professionals throughout the UK."

Butcher said, "It's time for the UK to wake up to the threat prenatal alcohol exposure poses and the great cost ignoring this public health issue has on society as a whole. Diagnosis allows proper support to be put in place to increase prospects for positive futures. It's time to arm our medical professionals on the frontline with current, clear and consistent information about FASD."

To meet this need NOFAS-UK is launching a major new outreach programme to GPs across the country. [2] Butcher said, “NOFAS-UK looks forward to working in partnership with the relevant bodies to help supply GPs with the information they need and deserve.” [3] NOFAS-UK has new publications, posters and online training in the works. The organisation will be exhibiting at the Royal College of GPs upcoming conference in Liverpool in October, sharing GP-specific information there. The organisation plans to continue this dialogue in many different fora and using various technological means. Its well received [video for GPs](#) is available online.

Stakeholders need to be heard on these issues. A new [National FASD Advisory Committee](#) of adults with FASD is advising NOFAS-UK on issues related to transitions into adulthood. Their stories are full of grit, determination and examples of roadblock after roadblock that they had to overcome or are trying to overcome to get their own diagnoses and support in place. NOFAS-UK is a sister organisations in the [FASD UK Alliance](#) whose reach spans the demographics of this country, and includes the [UK and EU Birth Mothers-FASD](#) network.

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For further information: Sandra Butcher, Chief Executive, NOFAS-UK, sandra.butcher@nofas-uk.org, 07920 747560

[1] The ninth day of the ninth month symbolizes the importance of staying alcohol-free for the nine months of pregnancy.

[2] In an [earlier project](#), NOFAS-UK provided more than 16,000 midwives with information, training and materials.

[3] NOFAS-UK also works in partnership with industry. The GP project is funded in large part due to a generous contribution from Diageo. As an organizational rule, a condition of accepting any funds from any entity is that we maintain full substantive control of all projects and work undertaken.



NOFAS-UK GP Survey SUMMARY OF KEY FINDINGS September 2017

Between 22 August and 1 September 2017, OnePoll conducted online and mobile polling of 150 GPs in England on behalf of NOFAS-UK. [1] The feedback shows that GPs need to be better armed with information regarding Foetal Alcohol Spectrum Disorders (FASD). [2] With our charity's limited resources we were unable to conduct a more comprehensive study, but the answers we received strongly suggest that the powers-that-be should look more comprehensively into GP training and awareness of issues related to FASD and the risks of alcohol in pregnancy.

- Only 31% of the GPs said they had in-depth education regarding FASD in their medical school training – most said their education on FASD was brief (57%) or they had none at all/couldn't remember (12%).
- 41% of GPs said they have not received clear guidance from their local Clinical Commissioning Group regarding a pathway for diagnosis and support of FASD.
- When asked if they felt confident that all those with a Foetal Alcohol Spectrum Disorder are being diagnosed properly, the numbers show a deep uneasiness – only 23% strongly agreed, 28% somewhat agreed. An alarming 30% of GPs either somewhat or strongly disagreed that those with FASD are being properly diagnosed, with 19% neither agreeing nor disagreeing.
- Only 55% had read the landmark 2007 British Medical Association report on Alcohol and Pregnancy. [3]
- Only approximately one-quarter of the GPs identified alcohol in pregnancy as having greater long-term risks to the baby than other substances such as heroin, crack, or smoking. All of these substances can have grave impact and often interplay with each other with devastating consequences, but the replies indicate that alcohol is not viewed by GPs as the serious threat to future health that it is.
- In 2016 the chief medical officers in the UK issued clear guidance that “if you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.” Sixty-three per cent of the GPs contacted strongly agreed with this new guidance, 27% somewhat agreed and the rest were ambivalent at best.
- Thirty-six per cent of those who responded said if they or a loved one, e.g a sister or friend, were pregnant an “occasional” drink of alcohol would be okay (48% of the female GPs vs 27% of the men said it would be okay). This means that in their personal lives, many GPs do not heed current government guidelines.
- On the positive side, 95% said they think GPs should ask all women who are pregnant or planning to become pregnant about their alcohol use and not just those who are at risk, and
- 75% said they had literature and posters in their offices specifically about the risks of alcohol and pregnancy.
- 71% said if a patient drank during pregnancy, they would typically indicate somehow in the mother's or the child's records that the child should be assessed for cognitive function at a later point, but 15% said they would not, and 14% said they didn't know or preferred not to say. That means the ‘paper trail’ of alcohol use in pregnancy – so important for a diagnosis of FASD, could be lost, potentially leaving a lot of young lives at risk for misdiagnosis, under-diagnosis, and as a result these people might fall through the cracks with serious

potential impact on their future.

- Of the GPs questioned, 84% thought a diagnosis was helpful, but an alarming 9% thought it was 'just another label' and 7% were ambivalent.
- FASD is a spectrum.[4] Much of the 'old' thinking continues to perpetuate the myth that people with FASD have distinctive facial features despite the fact those are in fact present in only [approximately 9-10%](#) of those cases of FASD. Only 5% of those who replied knew this. While experts debate the exact proportion of FAS cases compared with the wider spectrum, more than two-thirds of the GPs were far from the mark, indicating that the facial features were present in 50% or more of those with an FASD (of those 11% said facial features were present in 100%). While it is possible they may have been confusing FASD as a spectrum with the more narrow diagnosis of Foetal Alcohol Syndrome (FAS) which requires facial features, the results show confusion among GPs about a key point. This feedback raises a red flag as the facial features occur only if the birth mum drank in a very small window of time during early pregnancy (and they fade as the person ages). The developing brain is vulnerable to alcohol throughout the pregnancy. A diagnosis of FAS does not necessarily imply the most severe cognitive deficits that can be present even without facial features. Too many children are refused access to a diagnosis on this basis of outdated thinking.
- The respondents to this survey identified the most effective ways for GPs to learn more about FASD would be through Clinical Commissioning Group-organised sessions for their protected learning time and through online courses.
- 47% of GPs said it should be more thoroughly taught in medical school.

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[1] The study was conducted by OnePoll between 22th August and 1st September and polled 150 GPs that work in England. Participants were recruited online and were paid to participate.

[2] Foetal Alcohol Spectrum Disorders (FASD) is an umbrella term representing the range of effects caused by prenatal alcohol exposure. Diagnoses include: Foetal Alcohol Syndrome (FAS), Partial Foetal Alcohol Syndrome (pFAS), Alcohol-related Neurodevelopmental Disorder (ARND), Alcohol-related Birth Defects (ARBD). Over 400 conditions can co-occur with FASD.

[3] Please note, there was a small error in the question asked, which might have influenced the answer, though not likely to a significant extent. The question asked, "Have you ever read the 2007 BMA publication Alcohol and pregnancy: Preventing and managing Foetal Alcohol Spectrum Disorders which was updated in 2017." While the BMA Alcohol and Pregnancy website was updated in June 2017, the publication itself was updated in 2016. <https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy>

[4] Diagnoses include: Foetal Alcohol Syndrome (FAS), partial Foetal Alcohol Syndrome (pFAS), Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD). There are greater than [400 conditions](#) that can co-occur with FASD. Please note, when googling FASD, it is helpful to use the international spelling of 'fetal'.