

M.E Voisin
Senior Coroner Area of Avon
The Coroner's Court
Old Weston Road
Flax Bourton
BS48 1UL

16th February 2023

Dear M.E Voisin

Thank you for sending BSACI the Prevention of Future Deaths Report, touching on the tragic death of Celia Marsh and allowing us to respond to this.

The British Society for Allergy and Clinical Immunology (BSACI) is the national, professional and academic society which represents the specialty of allergy at all levels. Its aim is to improve the management of allergies and related diseases of the immune system in the United Kingdom, through education, training and research. The BSACI's core aim is to improve allergy care by developing a range of allergy resources for its members in order to support this, including clinical audits, specialty guidelines and through education and training and developing standards. A comprehensive list of UK Allergy clinics run by BSACI members and the expertise they provide is also available on the public area of the BSACI website. www.bsaci.org

The BSACI share all of the concerns raised in the report and acknowledge that there are significant areas of need around the current shortcomings in both education of doctors, reporting and analysis of anaphylaxis fatalities to safeguard those who suffer from food and other potentially severe allergies. This is something that the BSACI has a long track record of advocacy around through the National Allergy Strategy Group, www.nasguk.org who have been actively lobbying for improvement. The BSACI recognise the importance of improved education of doctors on food avoidance in relation to adults with eczema and will consider holding an educational event (eg: BSACI Annual Conference)

We will address the points in your report which we feel are in our remit to act upon and where actions fall out of our remit, we have made suggestions.

We consider and agree with point 2 that healthcare professionals should be better educated around allergies so they are aware of the risks to patients. BSACI is one of three national organisations that make up The National Allergy Strategy Group (NASG) whose aim is to lobby around areas of government policy in particular allergy education & food safety as well as transport. As a result the NASG have had meetings with policy makers at the DHSC, to enable us to fulfil our key aims which build on the recommendations laid out in our 2021 report – 'Meeting the Challenges of the National Allergy Crisis', with the focus of representation for Allergy. One of the key issues is that most GPs begin their career with no training in allergy, yet 8% of their consultations are allergy related. HCPs in primary care, (including GPs) are unaware of the NICE published guidelines on Food Allergy and Anaphylaxis, the guidance on food allergy is infrequently referred to or implemented by those working

in primary care. On average it takes five visits to the GP before an adequate assessment takes place of the appropriate management pathway.

BSACI (as a member of the NASG) met the then Secretary of State for Care and Mental Health Rt Hon Gillian Keegan. After much discussion there is now support for creating an expert advisory group to inform policy making around allergy at DHSC and NHSE as well as other areas of government, to help improve allergy care. This advisory board would be a collaboration between the National Allergy Strategy Group (which BSACI are part of) and DHSC and would include stakeholders from across government and organisations, where allergy is a relevant issue for policy development. One of the key priority areas is around GP training.

In relation to the establishment of a robust system for capturing and recording cases, this is a hugely important issue one that BSACI have been lobbying the FSA and DoH to support. The FSA currently support the UK Anaphylaxis Registry run by Imperial College. The purpose of the registry is to record episodes of significant allergic reactions in the community following unintended allergen exposure. Patients of any age are eligible for inclusion if they have had an "unintended" allergic reaction to either food or a non-food trigger outside a hospital setting. They are also collecting data on milder reactions presenting to hospital. BSACI and other health care professionals are encouraged to register for access to the online platform to collect data.

However BSACI have been collaborating with Manchester Foundation Trust over the past 18 months by providing governance for the UK Fatal Anaphylaxis Register. This register is the only register of its kind in the UK. The aim of the register is to proactively collect data to help us understand the risks and causes of fatal anaphylaxis by analysing the data to determine what the risks of recurrence are, in order to prevent further deaths. Due to the lack of funding previously the register had not been updated since 2005, however in 2020 it was agreed that The British Society for Allergy and Clinical Immunology (BSACI) would provide governance for the register following a one off £100,000 grant from the FSA.

The UK fatal Anaphylaxis Register which was set up in 1992 by [REDACTED] to help us understand the risks and causes of fatal anaphylaxis by analysing data to prevent further deaths. UKFAR is the only National register of deaths from fatal anaphylaxis with ethics permission (Rec ref no 05/Q1405/32), supported by the Confidential Advisory Group, on behalf of Secretary of Health. Annual permission is renewed under Section 251 with the Health Research Authority. Annually the contract with the Office of National Statistics is negotiated via Data Access agreement to receive and withhold relevant patient identifiable information. This is received on premise of s42(4) of the Statistics & Research Service Act 2007 as amended by s287 of the Health & Social Care Act. A confidentiality agreement with the Manchester Foundation Trust to retain the data on the Trust secure server fulfils pre-requisites for the above two permissions. This is renewed annually with Statement of Acceptance of the role of Information Asset Administrator by [REDACTED], who acts as custodian of the registry.

While many coroners have called for this function to exist, mechanisms of awareness among those who work in the field has been sub-optimal. The data collection is onerous with in-built delays. Since receiving the funding from FSA, UKFAR has made a concerted effort towards the sole purpose of the grant which was to update the backlog of cases. Due to various recent regulatory changes in data retention, UKFAR has had to update permissions. This led to a re-think and the opportunity to improve liaison with allied agencies based within and outside the NHS which will help reduce existing future such backlogs. **However this funding will shortly be running out and after numerous attempts to secure continuous funding from the FSA, we have been informed we have not been successful.** We then contacted the DoH directly, however they have not responded to our emails. This is a public health issue and therefore the responsibility of government. So much ground- work has been undertaken with the funding from the FSA, however in order to prevent future deaths from anaphylaxis UKFAR requires on-going funding now.

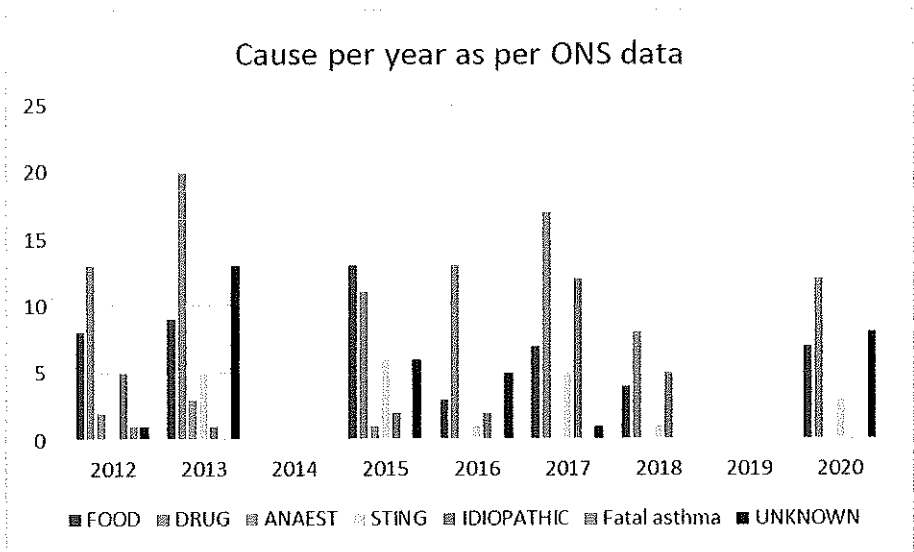
The grant has allowed investment towards time of a senior research nurse and an administrative assistant contributing 2 sessions each week, payment to [REDACTED] from Allergy Action and to The Office of National Statistics to continue to receiving annual data.

This has facilitated

- a catalogue of cases of fatal anaphylaxis with preliminary information with the highlighting insufficiencies
- communication with many agencies requesting relevant outstanding information for cases in the backlog
- delineating cases where insufficient information has been received where further information may provide clarity, we have pursued these with follow up requests
- A session each week for [REDACTED] (Custodian of the register) to direct the work of colleagues by providing senior support for justification of requests and receipt of confidential information
- Enquires for cases prior to 2010 which have had no responses of 'no information' on file, where files have been destroyed or simply we have had 'no responses' in many cases. UKFAR continue to pursue these, plans and have been already set into motion.
- For best chances of data retrieval, we have focussed our work on the last ten years in the first instance. The data available and analysed thus far has been shared as Appendix 1 of this document
- strategic engagement to create links with allied agencies has been successfully made. These are outlined in Appendix 2 of this document.

Appendix 1.

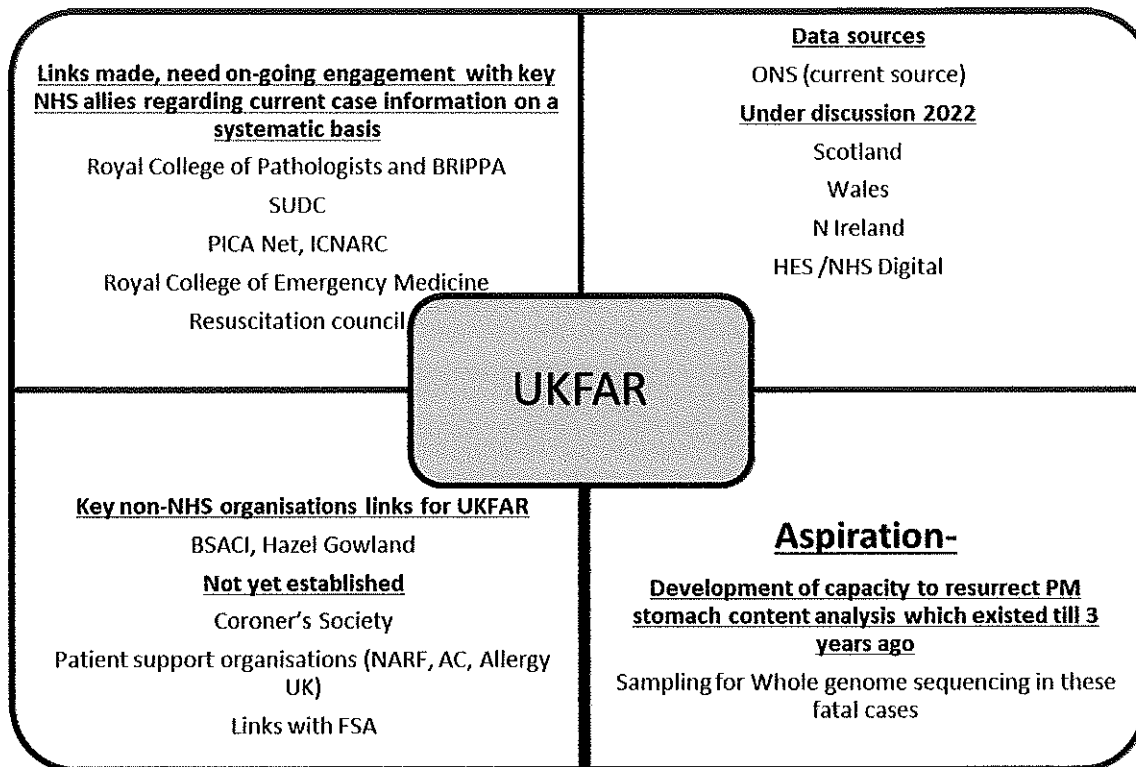
A macroscopic view of the data gathered so far (likely to change as more cases are analysed) is as follows:



We have all the processes in place for this system of proactively recording deaths through our web of linkages in the UK which will benefit everyone concerned in learning lessons and attempting to reduce future deaths from anaphylaxis. Our extensive work has repeatedly highlighted the issue of incorrect food labelling resulting in fatal anaphylaxis and we support any initiative taken by the retail industry to improve and clarify these labels to ensure the safety of people with food allergies.

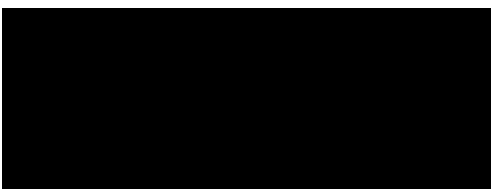
Appendix 2

A representation of linkages initiated following the grant been awarded from FSA illustrated below



Governed by BSACI the membership of this UKFAR steering committee consists of a wide team of UK experts committed to helping progress UKFAR and build linkages to the above, so we are able to facilitate the work on UKFAR. Groundwork for information sharing this past year has been extensive, however this will all stop if we are unable to secure further funding for UK Fatal Anaphylaxis Register.

Kind Regards



BSACI Chief Executive