

HUSH NEWSLETTER

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Is enough being done?

No sooner had Prof Hugh Pennington's report of the Welsh E.coli O157 Outbreak in 2005 been published, than the media was reporting on other outbreaks in Wales. Karen Morrisroe-Clutton, 32, remains ventilated in hospital after she became infected with E.coli O157 at a fast food takeaway in Wrexham and a restaurant in Tenby is under investigation after 5 diners became ill.

The premises in Wrexham, which sells fish, chips, pizzas and kebabs, had previously been inspected by Environmental Health officers and awarded '0' under the **Scores on the Doors** scheme, which ensures compliance with food hygiene regulations. The scores can be found via the local authority website and displayed on establishment doors, allowing consumers to make an informed choice about whether they want to eat there.

HUSH member, Joanne Reed, who suffered from HUS in 2006, has been pursuing this issue with the Food Standards Agency and Wrexham Borough County Council in an attempt to clarify whether the present legislation regarding the food hygiene is working or if further changes need to be made.

Success!

HUSH founder member Steve Nash and Sean Humber of Leigh Day & Co have scored a victory for the charity and the public.

The Information Commissioner's Office (ICO) has upheld a complaint by HUSH against the Food Standards Agency (FSA) in relation to its refusal to release information provided to it by McDonald's with regard to reducing the cooking time of burgers.

HUSH first contacted the FSA in April 2006 after becoming aware that the FSA had asked the Advisory Committee on the Microbiological Safety of Food (ACMSF), a committee set up by Government to provide advice on microbiological issues relating to the food safety, to review the existing guidance on the safe cooking time and temperature of burgers. The ACMSF had formed a sub-group to review the matter. HUSH requested copies of all information held by the FSA/ACMSF in relation to the ongoing review. Most importantly, we requested copies of all documentation submitted by an unnamed "US burger chain" briefly referred to in the minutes of an ACMSF meeting. The request was made under the Freedom of Information Act (FOIA). Protracted correspondence followed in relation to the release of this information and after repeated threats of legal action by HUSH, some, but not all, of this information was released on a piecemeal basis between June 2006 and June 2008.

On reviewing the information initially withheld but then gradually released, it became clear that the unnamed US burger chain was in fact McDonald's; that McDonald's had initially contacted the FSA to request a review of the existing guidance; that McDonald's had then been invited to make a private presentation to the ACMSF sub-group in support of their view that the existing guidance was too stringent; and that the McDonald's party included Dr Norman Simmons, a former member of the ACMSF and chair of an previous sub-group of the ACMSF which had produced an earlier report on E.coli and food safety.

The FSA's failure to provide the information requested, either promptly or at all, severely limited HUSH's ability to contribute to the ACMSF's review or the subsequent public consultation of the ACMSF's findings and recommendations issued by the FSA in July 2006 and requiring a response by October 2006. In fact, the FSA only announced their intention to hold a public consultation after HUSH threatened a judicial review challenge of its failure to do so. HUSH responded to the consultation but stressed that their ability to respond was hampered by the FSA's refusal to disclose all of the documentation considered by the ACMSF in reaching their views.

In its Decision Notice dated 27th July 2009, the ICO has upheld HUSH's complaint against the FSA in relation to the outstanding information not disclosed by the FSA. The ICO took the view that the concerns were exaggerated and outweighed by the public interest in the information being disclosed. The Notice highlights a series of additional "matters of concern" in relation to the FSA's behaviour and the ICO take the view that the FSA should have disclosed much of the information far more quickly.

The full report can be found on the HUSH website at: http://www.ecoli-uk.com/news.php?pageNum_News=1

LEADING THE FIGHT AGAINST FOOD BORN ILLNESS

In Memory of Denis

On Friday 18 September 2009 I held a Fundraising Night for HUSH in memory of my husband Denis who died on 19th September 1999 from HUS at the age of 43. The night was a great success and we raised a grand total of £2,610. After gift aid is added the final total should be in excess of £3000! There were over 200 family and friends on the night and more people would have liked to come. Kim Edgar, a folk singer, sang some Irish Ballads with Denis's brother Johnny accompanying her on the guitar. St Joseph's Line Dancers from my local church did some great dance routines which went down a storm considering some of the ladies are in their 70's and 80's!

On the night there was a raffle and an auction— the Manchester United signed football went for £160! One of Denis's cousins could not believe how many people had turned up and he reflected that it was a true indication of how much people loved and missed Denis.

Our lives were changed forever on that terrible Sunday morning but I am sure Denis would have been so proud of us all on Friday night and would have enjoyed it as much as we all did! Denis will live in our hearts and souls forever more and will never be forgotten.

Angie Meenan, Edinburgh



Angie (centre left) with her children
Jennie, Andrew & Joanna

This is the second fundraising event that Angie and her family have organised for HUSH and we are indebted to them for their support.

Atypical HUS has some similarities to "Regular HUS" but is not caused by an external agent (such as a bacteria, etc). It is believed that the majority of cases are genetic in origin. While the Typical form of the disease may start off more severe, the Atypical form is subject to longer lingering effects, and is much more likely to become a chronic problem. Recurrence is much more common with the Atypical form of the disease.

The Foundation for Children with Atypical HUS, in the USA, has an informational site at www.atypicalhus.50megs.com and has recently launched an interactive website at www.atypicalhus.org This joins together patients, families, friends and researchers to share information, inspiration, and insight into this rare disorder.

Thank you to everyone who has contributed financially following our appeal in the last newsletter. In an attempt to further reduce our expenditure we would like to send as many newsletters as possible via the internet.

They will be in a pdf format that will be accessible to all our members and can then be printed if required.

To bring our database up to date we would ask if everyone who is willing could e-mail HUSH at: hush@ecoli-uk.com with the subject heading of "**HUSH Newsletter**".

For those without a home pc, please don't worry we're still quite happy to post you a newsletter by 'snail mail'.

HUSH, PO Box 159, Hayes, Middlesex, UB4 8XE

*Donations can be sent to above address or made via a secure internet site—www.justgiving.com/hush/donate/
(UK Taxpayers will be able to boost their donations by 28% at no extra cost to themselves on the website)*