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In this issue

Editorial 1
NOFAS-UK 2
Susan's story 3
Mongolia and Médecins du Monde UK 4-6
MCQs 4

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Alcohol Health Alliance UK

The recent launch of the Alcohol Health Alliance UK, coordinated by Professor Ian Gilmore, President of the Royal College of Physicians of London, is noteworthy. The MCA, as one of the 24 collaborating organisations, will contribute to the ongoing debates in any way that it can.

Alcohol and pregnancy

Issues about the impact of alcohol on health continue to be reported in the media. Journalists frequently respond negatively and criticise the advice that experts in the fields of, in particular, addiction, hepatology and public health provide. However, in one field, that of alcohol and pregnancy, different advice has recently been given by different medical organisations. This is not helpful and is potentially confusing for women who are contemplating a pregnancy or are presently pregnant.

The response from the media and general public alike may be criticism of the medical profession, not least in its supposed inability to agree on a united opinion. Let us be clear on this vexed issue of alcohol and pregnancy: all risk to a developing fetus is eliminated if alcohol is avoided, and that is axiomatic. A safe level for drinking during pregnancy has not been proven and, although consumption of one or two units per week has not been consistently identified as causing fetal problems, all risk can only be avoided by abstinence.

Let us be clear on this vexed issue of alcohol and pregnancy: all risk to a developing fetus is eliminated if alcohol is avoided

This issue

The MCA has followed the formation and development of the National Organisation on Fetal Alcohol Syndrome-UK (NOFAS-UK) with keen interest and I am grateful for the



For more information on the Alcohol Health Alliance UK please see www.rcplondon.ac.uk/alcoholalliance

contribution to this issue from **Susan Fleisher, Chief Executive of NOFAS-UK**. Susan has supplied an emotive article detailing the personal impact induced by the realisation that an adopted child had been afflicted by foetal alcohol syndrome (FAS). It is good to see that the FAS Trust in Liverpool, which has associate membership of the MCA, is acknowledged within the script.

In complete contrast an article about alcohol-related problems in Mongolia illustrates how a newly developing country is trying to deal with a major health problem. **Dicken Higgins, General Coordinator, Médecins du Monde, Mongolia** requested via email a copy of our handbook and, when it was suggested that he might produce an article for this publication, responded with alacrity. It is clear that alcohol problems in that part of the world are not new; however, I think it unlikely that the draconian methods of Ghengis Khan in dealing with them will be reintroduced.

Dr GE Ratcliffe, Editor

A brief history of the National Organisation on Fetal Alcohol Syndrome-UK

A mother's journey to found a charity

Susan Fleisher, Chief Executive of NOFAS-UK

As a former teacher and television producer I had never heard of fetal alcohol spectrum disorder (FASD) until my daughter was diagnosed with fetal alcohol syndrome (FAS) in 1999 (see p 3). I did not know that it is the greatest cause of physical and mental disabilities in Western countries where studies say that at least 1 in 100 (1%) of babies are being born with alcohol-related brain damage. Women are warned about the risk of smoking and eating soft cheese, but are still unaware that alcohol is more harmful. Many children suffer with lifelong alcohol-related disabilities as a result of their mother's ignorance. No mother intentionally plans to harm her child.

The whole spectrum of FASD disabilities ranges from serious mental retardation, autistic spectrum disorders, dysmorphic facial features, heart, lung and other organ damage to attention deficit disorder, hyperactivity, mild learning difficulties, dyslexia, dyspraxia, memory loss and...the list goes on. Depending on when alcohol is consumed, it can affect the developing fetus any time during the nine months of pregnancy.

There is no cure for FASD. It is 100% preventable if a pregnant woman avoids alcohol. Until very recently the UK was in the dark about FASD. Most cases were being

misdiagnosed or going undiagnosed. Now a new frontier is opening up as the government, medical community and the public learn more about this preventable tragic condition that is profoundly affecting our children and our society.

FASD is an umbrella term that refers to all alcohol-related disorders. FAS is one of the conditions at the more severe end of the spectrum, which includes specific facial and physical features. FAS is contributing to increased numbers of children being born with learning disabilities and special needs. Many children with FASD get excluded from school or run away and get into trouble with the law. It contributes to anti-social behaviour, violence, unwanted pregnancies, alcohol and drug abuse, homelessness and increases the number of brain-damaged residents in our prisons.

Until very recently FASD was not on our radar. Now that it is beginning to be recognised we will begin to change and improve the lives and communities affected.

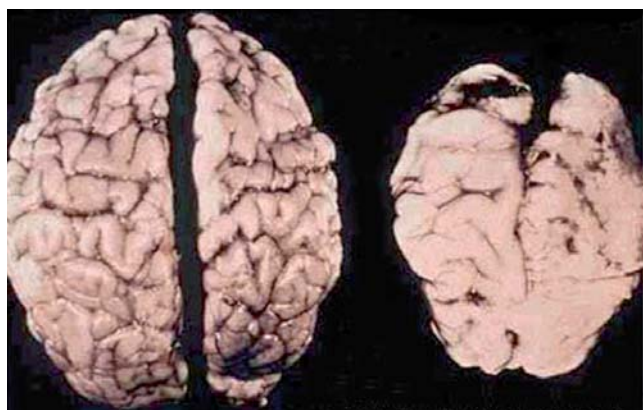
Alcohol may permanently damage fetal brain cells during pregnancy as well as affecting neural connections. A person with FASD cannot explain many of their actions. They get punished and pushed to the fringes of society for behaviour they cannot

explain. Normal development is delayed, including social maturity, so the majority of adults with FASD sometimes function in a child-like way.

There is no proven safe level for alcohol consumption during pregnancy. Some women who drink heavily seem to produce children who appear to not be affected. On the other hand, some who only drank socially over Christmas and New Year have children with FASD. Studies in the US and Finland cite cases of low consumption producing children with diminished brain size, smaller physical stature and lower IQs. Just as we do not know who will get cancer from smoking, it is impossible to predict who will be harmed by prenatal alcohol exposure. As a result, FASD medical experts recommend avoiding alcohol as the only certain way to avoid producing a child with FASD.

It is also important not to alarm pregnant women. If women do have a few drinks early in pregnancy or even before they know they are pregnant, chances are they will not harm their baby. But if they avoid alcohol and find alternative beverages they will have a healthier baby. Giving up a couple of drinks a week is surely a small sacrifice compared to the sleep deprivation, loss of freedom, diminished finances and other sacrifices a woman and their partners will make when they become parents.

■ **The British Medical Association (BMA) report on FASD is recommended reading. The FASD DVD/video, a 20-minute film that includes interviews with international experts, children with FAS and their birth mothers, is also recommended. The BMA report and further details can be found on our website www.nofas-uk.org**



LEFT normal brain of six-week-old baby

RIGHT brain of baby same age with FAS

Image courtesy of Dr Sterling Clarren MD

Susan Fleisher's story

When I adopted my daughter I had never heard of FAS, FASD or about alcohol-related brain damage. I did not know that I was about to begin a journey that would lead to the founding of NOFAS-UK (2003) and the FASD Medical Advisory Panel (2004). In 2005, I was invited to become a member of the Department of Health's Medical Advisory Group on the Fetal Effects of Alcohol and in October 2007 NOFAS-UK became a member of the Alcohol Health Alliance at the Royal College of Physicians.

My story began in 1991 when I adopted my daughter when she was three. She was a wonderful charming, slightly hyperactive toddler. Everyone loved her. She got lots of party invitations but she seemed to lag behind her peers in everything from potty training to counting and simple children's games. She was very verbal and everyone kept saying, 'She's so bright, she'll catch up' but she didn't. Eventually she was diagnosed with attention deficit hyperactivity disorder (ADHD) and was prescribed Ritalin® (methylphenidate).

When my daughter was 11, I attended a medical lecture for adoptive parents. When the lecturer started to list the main traits of FAS, things started to click. My daughter was hyperactive, could not concentrate, could not understand maths concepts, did not understand spatial relationships, could not learn to tell the time, had poor fine motor skills, could not sort or organise anything, and she could not follow or remember instructions. As her peers were maturing she was lagging further and further behind and was playing with younger and younger children. When the doctor said, 'Children with foetal alcohol syndrome have a smaller head circumference because the brain is smaller', bells began to ring. I had taken my daughter to several bicycle shops and no one had a helmet small enough for her head.

I took her to Great Ormond Street Children's Hospital in London and she was diagnosed with FAS. Many of the families in our support group received multiple diagnoses (ADHD, autistic spectrum, oppositional disorder, bipolar disorder) before the correct diagnosis of FAS or FASD.

When I heard the diagnosis and realised my daughter's life had been mapped to confront disadvantages and disabilities I went into a deep depression and searched for help. This search led me to Margaret Murch, the founder of the FAS Trust in Liverpool. She was my first beacon. As there were no other services and very little information in the UK, I



Susan and daughter in 1992

started attending conferences in the US and Canada to find experts and meet other affected families.

Edward and Celia Atkin, the owners of the Avent baby products company, knew my daughter and understood the profound impact FAS was having on our lives. In 2003 they offered me funding to produce and distribute an educational film entitled *A child for life*. When I began making the film, people started coming out of the woodwork asking for help and information about FAS. I was compelled to start a charity and develop services and educational programmes.

When I now speak at conferences, on the radio or television, without fail someone comes up to me or phones me and says, 'After hearing you speak I think my child/sister/student/ neighbour...has FASD. How can we get a diagnosis?'. We have also helped adults to be diagnosed, helping them and their families unlock some of the clues to their confused unpredictable behaviour.

After attending conferences in the US and Canada I met Kathy Mitchell of NOFAS in Washington DC. Kathy is the birth mother of 32-year-old Karli with FAS. I asked Kathy and Karli to tell their story in our film and Kathy asked me to found the first NOFAS affiliate. There are now 12 affiliates in four countries. Lord Mitchell, a family friend who understood my daughter's struggle, initiated the first debate on FASD in the House of Lords in May 2004.

I am very pleased to say that things are moving forward in the UK thanks to the work of many dedicated people like Gloria and Peter Armistead, the founders of FASawareUK and adoptive parents of a son with FAS. Thanks to the support of

Lord and Lady Mitchell we founded the NOFAS-UK FASD Advisory Panel of doctors and FASD medical experts. Lord Mitchell has initiated two debates in the House of Lords and is the author of the Alcohol Labelling Bill 2007 calling for bottle and can labels to carry a warning about the risk of alcohol consumption during pregnancy. For three years Lord Mitchell and I have been working with the Department of Health (DH) to raise the profile of this issue, and, on the 25 May 2007 the DH revised their guidelines advising pregnant women to avoid alcohol. This decision was made after in-depth research and serious consideration through a systematic review of over 3,500 FASD studies and evidence from medical experts around the world.

Until recently, FASD was ignored, misunderstood and under-diagnosed by much of the medical community and the wider public in the UK. Education will potentially prevent children being born with these lifelong disabilities and support will enable people with FASD to have better life outcomes.

In addition to our educational film and teaching resources, NOFAS-UK provides training, continuing professional development registered conferences, runs a helpline and a family support group, and publishes a newsletter. As funding increases we will expand our programmes.

We all have a say in this issue. We can all provide FASD education and it should start with medical professionals. But the reality is that the medical curriculum is so crowded that it is a challenge, to say the least, for doctors, nurses, midwives and all concerned to keep up with emerging evidence.

MCA MCQs

1 Units of alcohol - True or False

- A There are 9 units of alcohol in a standard bottle of wine of 12% ABV
- B A unit of alcohol in the UK is the equivalent of 8 g or 10 ml absolute alcohol
- C A unit of alcohol in America is the same size as one in the UK
- D Standard 40% proof, 0.70 litre bottles of spirits contain 28 units
- E A pint of beer of 5% ABV contains 2 units of alcohol

Source: Morgan M, Ritson B.
Medical students' handbook: alcohol and health

2 In trauma related to alcohol – True or False

- A Only 10% of those injured in alcohol-associated violence sustain a fracture
- B Of those injured, 90% sustain single or multiple lacerations, bruises or contusions
- C Of head injuries attending the emergency department, 40% result from alcohol consumption
- D Management of head injuries involving alcohol may be more difficult because signs of intoxication may mask the severity of the injury
- E Alcohol is a major contributing factor to non-accidental injury

Source: Paton A, Touquet R. *ABC of alcohol, 4th edn*

3 Delirium tremens – True or False

- A Rarely occur without history of at least several years of alcohol dependence
- B Recurrent attacks are common following an initial episode
- C Death may occur due to cardiovascular collapse, hypothermia or intercurrent infection
- D Classically present within a few hours of the last drink
- E Chlormethiazole should only be used in hospital as prophylaxis

4 Recovery from alcohol dependence may be influenced by:

- A Acceptance of an appropriate treatment goal
- B Occurrence of a trigger or 'road to Damascus' event
- C Acceptance that abstinence is the only long-term alternative
- D May occur spontaneously or naturally
- E A dependent alcoholic seeking treatment at the age of 45 has a 45% chance of being dead 20 years later

Source: Edwards G, Marshal EJ, Cook CCH.
The treatment of drinking problems, 4th edn

Answers on back page

Mongolia – one steppe forward, two steps back

Fermented mares milk to vodka

Dicken Higgins, General
Coordinator, Médecins du
Monde, Mongolia

As the furthest east of what are collectively called the Central Asian states, Mongolia has emerged from being a satellite state of the former Soviet Union and enthusiastically sought a place in the capitalist world order. Rich in mineral resources, the total land area is bigger than the combined territory of Britain, France, Germany and Italy. The relatively small population of only 2.5 million live mostly in the capital of Ulan Bator (1.2 million) or in a few scattered small cities and isolated villages.

Life in rural Mongolia began to change under Soviet guidance, with cultivation and industry encouraged across the country, but this abruptly declined after democratic reform in 1990. Today many rural people still live a traditional life based around their felt tents (or Gers), their flocks of sheep, goats, camels, cattle, yak and, of course, the sturdy Mongolian horse. In fact, during the short summer, the urban centres appear empty when many people leave to stay with relatives or visit old homes and reconnect with the life in the steppe.

In the race to Westernise, Mongolia, like many transition countries, faces great challenges. One of these is meeting the health needs of its population. The government's efforts are hindered by: the country's geography and severe climate; the widely dispersed population; and the lack of infrastructure with little access to safe water and sanitation, electricity, communications, and other modern amenities. Growing health concerns now include tuberculosis, sexually transmitted infections



Felt tents known as Gers

and brucellosis. Cancers, cardiovascular disease, excessive alcohol consumption and other external reasons associated with lifestyle changes are also important causes of morbidity and mortality.

With a view to assess what support was needed, **Médecins du Monde UK (MDM)** initiated an exploratory mission in mid-2004. As a result of demand from health authorities, local politicians, and evidence on the ground, MDM launched a programme in Mongolia in October 2005. The main objective focused on alcohol misuse and will contribute to improving the process of managing patients, and raising awareness for health professionals and the public.

The issue of alcohol misuse has various cited origins, ranging from the unrestricted import of Russian vodka in the early 1920s to the decline of Soviet rationing in the 1990s. Even the great Mongolian hero Ghengis Khan refused to allow entry to his home of anyone who was drunk and would not enter the homes of others if their occupants were drunk. He even had a law that stated if a man came to work drunk, the first time he would have his weapons confiscated, the second time his horse would be taken, the third he would lose an arm and on the fourth occasion he would be banished from the land.

While today's situation is a product of national and international history, it is now out of control, with over 13.6% (22% men and 5% women, World Health Organization study 2006) of the total population dependent upon alcohol and up to

40% practicing harmful drinking. According to the United Nations Development Programme, 27.5% of mortality in 2001 was attributed to alcohol, and it was also the fourth most significant problem facing the population. This is evident wherever you go in Mongolia, not just in the visible drunks on the street, or the stories in every family of a relative who has succumbed to alcohol addiction. In another recent study L Erdenebayar (Director, National Centre for Mental Health) showed that more than one third of all traffic accidents are caused by alcohol, 79% of people misusing alcohol had at least secondary school level education, over 80% of those in prison are there for an alcohol-related problem and 60% of domestic violence is carried out by drunk people.

The MDM programme in Mongolia concentrates on the patient's needs. New approaches and practices that could reinforce behavioural changes for the health practitioners and the patients are introduced and information is shared and awareness raised to eliminate the stigma attached to the disease of alcohol addiction.

To date, the main activities have included formal training for local health professionals with international experts and on-the-job training inside government medical and judicial organisations. The MDM programme introduced the techniques of cognitive behavioural therapy and motivational interview, and the medical team has worked hard to establish a needs-based focus to inpatient treatment and to develop the diversity of opportunity

for follow-up support in the community. A monthly partners meeting is held to initiate horizontal communication between professionals and partners visit other practices so that they can share their experiences and understand mutual constraints. Our work is fully reported and we attempt to influence decisions within the establishments where we work as well as at national level. Our information and awareness-raising activities have started to bear fruit, with the publication and distribution of leaflets and posters that have been developed with our partners.

In parallel, the programme transfers new techniques to wider-related stakeholders in order that the lessons learnt in the pilot area may also be readily applied in other parts of the country, for example, by providing training for Aimag (county)-based doctors and sharing tools and materials with other structures requesting support, such as government centres.

In the immediate future, we expect to see the follow-up to some of the work we and others have started. We will consolidate the initial phase of the project, reinforcing the exchange of experience through formal training courses and on-the-job support to those involved in alcohol misuse management. We will demonstrate the lessons learnt, particularly in one part of one district of UlaanBaatar. We hope to see the health professionals applying new ideas and international standards in screening, referral, treatment and follow up. It is hoped that local groups and initiatives will ensure an increasing range of opportunities for patients and stakeholders to find support and information.

In the medium term we hope that all of the above will lead to decreasing levels of alcohol misuse and a high level of awareness on its dangers. By changing the attitude of the decision makers and practitioners, it is ultimately hoped that a direct impact will be seen on the incidence of new cases of alcohol misuse and better treatment will be offered to those suffering from alcohol dependence. In the long term we would expect to see a decrease in alcohol-related deaths and a reduction in the cost to

society related to the consequences of alcohol misuse.

This programme represents a rare opportunity to have a direct impact on a medical issue that affects almost all families across the country and can be seen as a catalyst to other medical and social problems. The full extent of associated problems, such as the impact on the economy, is still unclear but if the experience and research in other parts of the world is an indication of its potential, we must act now.

There is clearly still a great deal of work to be done and it is obvious that this will take time. We hope that

during 2008 we can identify funding and further support for these activities. At present, our small capable team has made a great deal of progress, but there is a need for their reinforcement and an increase in delivery resources for materials, prevention and formal and informal training activities.

For further information on the project and Médecins du Monde UK please see
www.medicinsdumonde.org.uk/projects/mongoliaulanbator.asp

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Alcoholis publication dates

This bulletin will be published quarterly in March, June, September and December

Items for publication should be forwarded to the Editor

MCA MCQ answers

1. A True, B True, C False (larger), D True, E False (2.8 units)
2. A True, B True, C False (25%), D True, E True
3. A True, B True, C True, D False (peak between 72 and 96 hrs), E True
4. A True, B True, C False, D True, E True



The Medical Council on Alcohol is a small national charity committed to improving the medical understanding of alcohol-related problems

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