

Happy New Year and welcome to AvMA's Winter edition of Network News - one of the ways in which we endeavour to keep you informed of AvMA's work and current issues concerning patient safety and justice for people affected by medical accidents.

AvMA's Name Change

In case you hadn't noticed, we are still the good old 'AvMA' but the official title of the charity is now 'Action against Medical Accidents', and we have a new logo and corporate style. (The reason we can still be known as 'AvMA' is that, thanks to an ingenious idea by our Legal Director, Fiona Freedland, the 'v' in the logo stands for 'versus'). The other notable change is the adoption of a strapline or 'slogan' in all our literature: "for patient safety and justice". The changes were arrived at after consultation with our clients and other stakeholders. So what was the rationale behind these changes?

Whilst the old name and logo had served us well through the 80's and 90's, there was a growing consensus by the time I arrived in 2003 that we needed to project a more modern and professional image, as well as a caring one. Although we have always been just as concerned with patient safety as with obtaining a sense of justice for people harmed by medical accidents, this was often lost on people. The name did nothing to help. Apart from being too much of a mouthful when we were answering the 'phone, the word 'victim' seemed both old fashioned and made health professionals feel we were 'out to get them'. Rather than perpetuating a self-perception of being a 'victim', our aim is to help people who have been harmed be empowered to get the explanations, apologies and where appropriate the compensation they need, but also to come to terms with their experience and move on. The new name rightly suggests it is the 'accidents' we are against, not the people who may have unintentionally been part of the failures which caused harm. Hopefully, the slogan 'for patient safety and justice' also helps get across that we are just as much about prevention and 'patient safety' as we are about trying to help people achieve 'justice'.

However the word 'justice' is there for a reason. We remain just as committed to getting fair outcomes for people when they have been harmed by avoidable medical errors.

A new approach to Patient Empowerment

AvMA's Patient Empowerment Conference took place in September 2003. This was the launch pad for a new approach by AvMA to patient empowerment, which could see it develop a role as a facilitator of a network of self help and support groups, as well as continuing to support individual clients. The rationale is that more can be achieved and more people helped by developing a network of existing groups and supporting the setting up of new groups who share a common interest in issues relating to medical accidents. Patients affected by a new common problem (like those at Bristol, Leicester Royal Infirmary etc) would be able to access initial advice and information from AvMA and be put in touch with groups of patients with experience in mutual support. In addition to sharing experience and good practice, the network could provide a strong and unified voice on issues affecting patient safety and justice for people affected by medical accidents. A steering committee of a number of different groups is advising on the development of the network, and we would be delighted to hear from others interested in this initiative. Another approach being explored by AvMA is the development of training for people who wish to play a role in local work on patient safety (or 'clinical governance') in NHS trusts.

The Conference also provided the opportunity for individuals who had been affected by a medical accident to share their experiences and to be updated by AvMA on recent proposals for reforming systems for clinical negligence and NHS Complaints. During the plenary sessions we heard from representatives from The National Patient Safety Agency (NPSA) and The Commission for Health Improvement (CHI) who explained their roles and how they operate. We also heard from the Support organisations NACOR (National Committee Relating to Organ Retention) SANDS (Still born and Neonatal Death Society and APROP

(Action for Proper Regulation of Private Hospitals) about their experiences of setting up their groups. During the breakout sessions representatives from The General Medical Council and the NHS Modernisation Agency explained the processes for raising concerns about doctors and becoming a patient representative respectively. Gary McFarlane an AvMA panel solicitor ran a session on Group actions and David McDougal a Public Relations Consultant gave advice on working with the media. All in all it proved to be a very interesting and stimulating day and a big thank you to all for making this a success.

Support Network Contacts Register

We are interested in exploring whether members of the Support Network Contacts Register would like to work with us to further develop AvMA's 'Contacts Register'. The register enables individuals affected by a medical accident to get in contact with others who have experienced similar problems. This could be in relation to providing support generally, or sharing experiences of specific situations. AvMA believes that for a support network to operate properly and to ensure that individuals engaging in the network are empowered by the process, it is important to provide members with appropriate training. This training would provide an opportunity for people to look at the best way of giving advice and support to others who may have experienced very traumatic situations. Also tips on how to handle different situations so that you don't feel overwhelmed, and boundary setting in terms of contact and time given to supporting callers. We recently sent out an evaluation form to support network members on the Contacts Register asking for your feedback about these ideas and many thanks for those of you who responded. We would also welcome comments or suggestions from Support Network members in general as this will help to inform the development of effective mutual support networks such as the Contact Register

'Positive Thinking Event'

AvMA is keen to look at various ways to support its members and would like to get some idea as to whether individuals would be interested in attending a 'Positive Thinking' event. The majority of AvMA members have suffered from bereavement, or medical injury of some sort, causing tremendous stress and devastation and frequently resulting in damage, or breakdown of personal relationships at a time when individuals are already struggling to come to terms with great loss. Finding the energy to rebuild your life in these circumstances is clearly very challenging. There is plenty of evidence to show that 'we are what we think' and that channelling our energy in a positive sense can help us to overcome major difficulties in our lives, regain control and empower us to move forward in which ever way we choose.

If there is sufficient interest, AvMA's Support Network would like to work with the Brahma Kumaris to organise an event in the near future. The Brahma Kumaris is an international organisation, which has over 5000 centres in more than 80 countries and has many years experience of running courses in meditation, positive thinking, stress management and building self-esteem, aimed at helping individuals to change their lives for the better through self-transformation.

As someone who has lost a child through negligence and taken the course, I believe that any tool that can help one to move forward in a positive way has to be a good thing. If you are interested in attending an event like this please complete the attached provisional booking form and return to Louise Price at AvMA.

'Courage is taking a step forward into an area of difficulty without a solution in mind, trusting that whatever help you need will become available'

(Pearls of Wisdom: Dadi Janki - Published by Health Communications INC. ISBN 1-55874-7230)

Josephine Ocloo

Local Help with NHS Complaints

From September 1st 2003 four new ICAS (Independent Complaints Advocacy Service) contracts came into effect initially for 12 months with a possible extension of a further 6 months. Prior to September you may recall that ICAS was piloted in the autumn of 2002 until August 2003, when the controversial abolition of Community Health Councils in England came into force. At the end of the pilot stage providers were invited to tender for the current contracts. AvMA have been contracted by the four providers (listed below) to provide a support service via a dedicated helpline and casework service for ICAS workers helping clients with NHS Complaints that have a clinical aspect. AvMA have also run four training days for ICAS providers, all of which have been well received. The four ICAS providers for England are:

- ◆ **Citizens Advice Bureaux:** providing a service across London, North West England, North East England, South West England, West Midlands, Yorkshire and Humberside
- ◆ **POhWER:** providing a service across Bedfordshire, Hertfordshire, Essex and Cambridge.
- ◆ **South East Advocacy Projects (SEAP):** providing a service across the South East of England.
- ◆ **The Carers Federation:** providing a service across the East Midlands.

For details of your local ICAS contact AvMA.

Whilst ICAS are providing advocacy and support to individuals using the NHS Complaints Procedure across England, in Wales the Community Health Councils continue to fulfil this role. In Scotland this service is provided by Health Councils and in Northern Ireland by Health and Social Services Councils. In addition to currently providing a support service for ICAS, AvMA are committed to maintaining its service to all of the United Kingdom and developing stronger links with the Welsh, Scottish and Northern Ireland Health Councils.

Proposals for NHS Complaints Reform

There are two important consultation exercises taking place at the moment, which will help shape the way NHS complaints are dealt with in the future. In 1999 a national evaluation was undertaken which highlighted wide spread dissatisfaction with the level of independence being exercised during the second stage of the NHS Complaints Procedure and the length of time the process took. As a result of these findings in the Department of Health decided that the second stage (or Independent Review Stage) of the NHS Complaints Procedure should be removed from local NHS bodies and given over to an independent organisation 'The Commission for Audit and Health Improvement' (CHAI). The legislation that will facilitate this transition now forms part of the Health and Social Care (Community Health and Standards) Act 2003 and the Department of Health are now consulting on the draft regulations (until 31st March). At the same time, CHAI are consulting on their role in the independent stage of the NHS complaints procedure.

In summary, these new procedures propose that everyone will now have the right to have their complaint reviewed by CHAI staff if the complaint has not been resolved with the local NHS body concerned. This replaces the system whereby 'conveners' appointed by the NHS bodies themselves decide whether an Independent Review is to be held or not. If CHAI decides to investigate but following that investigation the complainant remains dissatisfied, it is proposed that the complainant will have the right to have the case reviewed by a panel of independent lay people. The last port of call remains the Ombudsman. The possibility of running different investigations concurrently is introduced, including for the first time, the pursuit of legal action, at the same time as the complaints procedure. Complainants would also be able to ask CHAI to investigate if any complaint has not been resolved within six months. Whilst AvMA welcomes the general direction of the reforms, including the increased independence of CHAI dealing with the second stage of the procedure, we do have some concerns. For example, far too much discretion is left to the NHS bodies' complaints manager as to whether or not to investigate a complaint or not; the actual status of the 'independent panel' is not very clear; we want to see an automatic right to a CHAI investigation if an NHS body does not respond in a reasonable length of time; and there needs to be greater reassurance that NHS bodies will be required to comply with recommendations emanating from a CHAI investigation or independent panel. AvMA is also keen to see private sector complaints brought into CHAI's remit, and for there be more integration of complaints investigation with adverse event investigation and clinical governance/patient safety work. We hope that others will join us in making these points.

For copies of AvMA's draft responses to these consultations and details of the original consultation documents please refer to our website: www.avma.org.uk

...and finally...

We were very sorry to say goodbye to advice worker Navneet Sehmi this month. Navneet joined the Advice and Information Team in 2002 and was a much valued member of the Advice and Information team and AvMA as a whole. Navneet is now pursuing a career in the area of public health. We are sure readers would like to join us in thanking Nav for all her hard work and dedication during her time at AvMA, and wishing her well in her new career. We will shortly be recruiting a new Advice Worker to join the Advice and Information Team.

If you would like to contribute an article to future editions of Network News please contact Louise Price either in writing or e.mail snmanager@avma.org.uk

Action against Medical Accidents, 44 High Street, Croydon, Surrey CRO IYB.

Client Advice Line: 0845 123 23 52

Administration: 020 8688 9555 (please ring client advice line for advice on individual cases)

website: www.avma.org.uk

e.mail: snmanager@avma.org.uk

Charity registration number: 299123