Role of voluntary organisations

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**Abstract** Voluntary organisations, working closely with scientists and doctors in some 15 countries, play a key role in promoting research into Sudden Infant Death, providing support for bereaved families, disseminating infant care messages to help prevent deaths and improving investigations when a baby dies. This paper provides an overview of the role of voluntary organisations including giving examples of innovative projects and programmes to tackle the problems of sudden infant death.

**Keywords:** Sudden Infant Death, charities, voluntary organisations, research, bereavement support, prevention, improving investigations of SUDI

**Introduction**

There are currently some 15 national voluntary organisations worldwide involved in work on Sudden Unexpected Death in Infancy (SUDI), in North America, Europe, Australasia and South America. They have played a key role in reducing the number of infant deaths not least through providing funds for research into the causes and prevention of deaths; but also, importantly, through developing and disseminating evidence-based information on how to reduce the risk of deaths. Voluntary organisations have also pressed successfully for national and regional authorities to mount information campaigns on risk reduction and even, in some cases, to pass legislation or enact other rules potentially affecting scientific progress in the field.

Through the International Society for the Study and Prevention of Infant Death (ISPID) and its predecessor organisations, the voluntary organisations have run ten successful international conferences since 1989 bringing together scientists, clinicians and parents world-wide to consider different aspects of SUDI. This has provided a key forum for the discussion of thousands of research papers and, through mutual exchange of ideas, the generation of new research and new interdisciplinary and international working partnerships. The next conference in this series will be held in Sydney, Australia, 8-10 October 2010. For more information see www.isaispid2010.com. Individually, many of these voluntary organisations also mount regular national and regional conferences and meetings in their own countries, offering a key platform for SUDI researchers locally to exchange ideas in this relatively small and specialised field.

Voluntary organisations also play a crucial role in providing or facilitating support for bereaved families devastated by the loss of their
infant, and for the professionals who must respond to them and who may need their own emotional support. State provision of such services is often insufficient to meet the need, and parents and

professionals affected by infant death frequently turn to voluntary organisations whose members have developed massive expertise in providing support, most having done so since the 1970s and 1980s.

Finally, many voluntary organisations are also involved in delivering training for professionals on how to respond to SUDI, not only in terms of how to support families but also, increasingly in recent times, how to investigate and review deaths to ensure no information on the possible causes and factors contributing to the death is overlooked. In the early 2000s, in particular, public controversy in many countries over murder masquerading as SIDS, or uproar over SIDS inappropriately treated as murder, led to a call for better training and systems for professionals, and voluntary organisations were often key players in these developments.

Research

The Foundation for the Study of Infant Deaths (FSID), a voluntary organisation in the UK, has provided nearly US$4,700,000 in funding for SUDI research over the past 10 years 1998-08, raised through a varied programme of fundraising activities. Most of the voluntary organisations engage in fundraising activities and have together provided significant sums of money to support SUDI research, though complete figures are not available. In Australia, for example, about US$800,000 was provided for SUDI research over the past 10 years by the voluntary organisation, SIDS and Kids. In Norway, the figure is about US$5,800,000, from Landsforeningen uventet bamedød (Norwegian SIDS and Stillbirth Society), and in Scotland the Scottish Cot Death Trust has contributed about US$2,000,000 in that period. Voluntary organisations range from large agencies with professional fundraising staff to much smaller groups staffed mainly or only by volunteers, but who do what they can to raise funds to support research. For example, the Swedish National Infant Foundation contributed nearly $50,000 to research in the past 10 years. Other voluntary organisations that have raised funds for research include Naire et Vivre in France and the Canadian Foundation for the Study of Infant Deaths.
Voluntary organisations have often played an important role in facilitating research by encouraging bereaved parents to help researchers, e.g. by recruiting parents to donate tissue samples for genetics research projects. In the 1990s, when the theory was put forward to great media acclaim, in the UK at least, that antimony in mattresses produced toxic gases that caused infant deaths, FSID was able, through their contacts with bereaved families, to provide researchers with samples of mattresses on which babies had died, which was invaluable in bringing evidence-based light to shed on the theory and, ultimately, to disprove it [1].

In Australia, SIDS and Kids ASK Online Catalogue and librarian play an important role in promoting research. Ask Online is a collection of scientific papers providing the scientific evidence underpinning the SIDS and Kids safe sleeping program, as well as the bereavement support services. The collection includes papers on SIDS and the impact of the death on families. The catalogue may be accessed by the public via the SIDS and Kids website and in contact with the librarian who undertakes searches for researchers, health professionals and those caring for children [2].

Voluntary organisations also conduct research. For example, FSID recently published results of a survey of parent attitudes to the advice to reduce the risk of SIDS [3]. The survey, funded by the Department of Health in England, found that substantial minorities of parents say they do not believe e.g. that smoking, side or prone sleeping and bedsharing can increase the risk of infant death. The findings are being used to help inform future strategies and information campaigns to promote safe infant care.

The Scottish Cot Death Trust employs researchers to help complete projects run by the Trust. Two case-control studies revealed a novel risk factor – used infant mattresses [4] – and clarified that in Scotland bedsharing was a risk factor for young infants [5]. This helped lead authorities in the UK and elsewhere to alter their advice, including providing the information that “The safest place for a baby to sleep is in a cot in a room with the parents”.

**Disseminating evidence-based safe infant care messages**

Particularly since the 1990s, voluntary organisations have played a crucial role in ensuring that parents are aware of the evidence-based safe infant care messages such as the advice to sleep babies supine. The Norwegian organisation has, since 1999, given out over half a million baby bodysuits with the message “this side up when I sleep” printed on the front. All new parents in Norway receive this garment as a gift in the maternity ward. In Australia, SIDS and Kids produces a
Child Care Kit, which can be purchased online, and contains comprehensive resources for child care centres and day care programs to support infant safe sleeping practices. The kit includes templates for safe sleeping policies, a staff training module, custom designed posters and leaflets for parents about eg infant wrapping. In the UK FSID regularly generates free mass media publicity for various aspects of the Reduce the Risk message by providing journalists with a newsworthy “hook”- often a survey revealing low awareness among parents of the evidence-based advice eg about bedsharing [6].

In virtually every country where there is a voluntary SIDS organisation, the organisation has produced leaflets, posters, videos and other materials to spread safe sleep advice to parents of new babies; or has pressured state health authorities to do so. This has been key to the dramatic decline in SIDS in their respective countries. The voluntary groups often work in close collaboration with state authorities in agreeing on and disseminating safe infant care messages. For example, in the UK, FSID and the Department of Health jointly publish a leaflet that is intended to be given to the parents of every infant and through joint consultations is updated regularly. There is general agreement across most countries’ health authorities and voluntary organisations as to the content of the Reduce the Risk messages. Various countries’ leaflets, most produced with the involvement of voluntary organisations, can be viewed on the ISPID website [7] including Australia, Canada, England, France, Scotland, Germany, Scotland, the USA and others. See Fig (1).
Increasingly, as middle class parents take up the reduce the risk message, SUDI is focusing on more vulnerable families - in the UK for example the SIDS rate for teenage mothers is four times the rate for older women - and voluntary organisations are working to target the reduce the risk message on the more at-risk populations. FSID launched a social networking website for teenage parents in 2009 that aims to get the message across in a more credible, accessible and hence effective way than traditional forms of communication of health information: Bubbalicious [8] combines chat, incentives, personal stories, and an element of fun, to get safe infant care messages to this hard-to-reach group. Crucially, the site enables teenage mums, themselves, to pass a series of training tests and become “Big Sisters”, to mentor, educate and support other teenage parents on the site. In the first six months 588 young parents registered on the site and 33 became qualified “Big Sisters”. Sadly, though there is also a “Top Dads” programme available for teenage fathers, no such fathers have yet qualified. The website, which was funded by the Department for Children, Schools and Families, will be subject to evaluation by both users and professionals.
In the US, First Candle has also developed a programme targeted at vulnerable families. The National Crib Campaign is a 7-year project designed to distribute free cribs and safe sleep education to parents and caregivers who have one or more risk factors for SIDS and demonstrate financial need. The programme follows parents for the first year and the goal of the project is to reduce deaths by at least 50% in the target areas. It should be noted that, in addition to promoting evidence-based safe infant care, voluntary organisations often play a valuable role in preventing the spread of non-evidence-based advice on infant care. In many countries, it is the voluntary SUDI organisations to whom the print and broadcast media turn for comment, when theories on SIDS prevention and on products which claim to prevent SIDS are put forward. Voluntary organisations work closely with researchers to try to ensure the Reduce the Risk messages publicised in the media are based on sound evidence.

**Supporting bereaved families**

One of the key strengths of voluntary organisations, large and small, is in providing bereavement support when a baby dies. All the organisations have voluntary or paid staff who have themselves experienced the sudden and unexpected death of a baby and who support other families whose baby has died. The support may be delivered through a telephone helpline, face-to-face, through published materials including books for the siblings of babies who die and, increasingly, support is offered by email and on discussion forums for bereaved parents.

In many countries there are increasing challenges in providing bereavement support because of the changing epidemiology of families suffering a death. Vulnerable families with multiple problems may be less likely or able to seek organisational help, and efforts are made by the SIDS charities to facilitate delivery of support. For example in the UK one of the ways that FSID makes support available is by inviting families – all the members of the family – to join in a free Family Day Out at a local leisure attraction or theme park, where there are recreational facilities if that is all that is wanted, or the opportunity to meet other bereaved families, or the chance to talk with a member of FSID staff or an FSID befriender.

In Norway the voluntary organisation offers, at local level, family weekend “camps” for bereaved parents. At national level there is an annual weekend gathering for newly bereaved parents, befrienders and staff members which focuses on sharing experiences and learning about grief. Topics like autopsy and children’s grief are also addressed. The organization also offers innovative therapeutic courses, e.g. in
storytelling, and a psychodrama course addressing coping with the next pregnancy after the death of a child.

**Improving investigations of sudden and unexpected infant deaths**

There was a sharp increase in suspicion about sudden unexpected infant deaths in the early 2000s. This was very distressing for bereaved families, a distress that was exacerbated by controversial court cases in the UK. Voluntary organisations had always acknowledged that in a small proportion of cases categorised as SIDS the deaths were probably due to maltreatment and in the UK FSID had long been urging better investigation of deaths. But the intense public suspicion and highly publicised opinions of some experts about the cause of sudden unexpected infant deaths at the start of the last decade required a much bigger response. FSID launched a concerted campaign calling for improved, multi-disciplinary investigation of deaths according to agreed, written protocols – to reduce confusion about causes of death, to learn as much as possible from each death, and to ensure families were well supported. Working with and through other agencies and organisations, the campaign achieved success: improved investigations became mandatory in England in 2008. Similar successes were achieved in part through the efforts of voluntary SUDI organisations in Scotland, Italy, the US and elsewhere.

**Conclusion**

Voluntary organisations have played, and continue to play, a key role in SUDI – by supporting research, disseminating research-based infant care advice to reduce the risk of SUDI, supporting bereaved families and helping improve investigations of deaths. Staffed – paid or otherwise – by dedicated individuals, these organisations can take credit for a great deal of progress and innovation in this field. The challenge to finish the job by reducing deaths as close as possible to zero grows greater as the number of deaths drop – due to the reduced natural pool of support, multiple problems faced by the majority of families that are most at risk of having a baby die, increasing costs of research to be supported in an increasingly difficult financial environment - but there is no doubt that voluntary organisations will continue to show the commitment they have always brought to the task.

In fulfilling the role described in this chapter, voluntary organisations work closely together on a regular basis with SUDI scientists and clinicians. The Council of Trustees at FSID, which decides policy for the organisation, is composed of an effective partnership of bereaved parents and of doctors and researchers with a special interest in SUDI. FSID’s Council is in turn advised by the Scientific Committee, composed
of SUDI scientists and clinicians, which makes a key contribution to the parent/professional partnership. The voluntary organisations would like to take the opportunity now to thank the many SUDI scientists and clinicians who bring an equal dedication to the tasks at hand, and who work so closely and so well with the voluntary organisations.

References

2. SIDSandKids website. Available at http://www.sidsandkids.org/
8. Foundation for the Study of Infant Deaths. Available at www.bubbalicious.co.uk