

# A support group for mothers who lost their baby because of sudden death syndrome



## Introduction

SEMI per la SIDS is a national organization founded in 1991 by a small group of families that experienced the loss of their babies because of SIDS. The principal aim of the association is to provide immediate support to bereaved families in order to ensure that they receive appropriate and sensitive investigations to identify the cause of death of their babies. Information about the cause of death is fundamental in helping families to alleviate the feelings of guilt that very often derive from the sudden and unexpected death of a child. The support to families is carried out over time while the families are experiencing the difficulties of the grieving process. Medical and psychological support program is also available when families decide to have another baby. A further aim of the association is the SIDS risk-reduction education aimed at the public and medical community. This has been carried out by performing an intensive information campaign based on 1) production and diffusion of informative leaflets to professionals and families; 2) organization of symposia and meetings with the purpose of diffusing knowledge and promote research in the field.

**Family Support** : ensuring prompt involvement of the association when a case happens and taking care of the family needs overtime.

**Risk-reduction**: risk reduction campaign aimed at the public and medical community.

**Research**: promote research about both the cause of sudden infant death and methods of prevention.

The aim of this work is to describe the development of an internet Semi per la SIDS-discussion group as a tool to support Italian families who have suffered the sudden and unexpected death of a baby. The efficacy and diffusion of this tool is discussed.

## 1 Finding our way to support families

Support immediately after the unexpected loss of a baby and during the grieving process is one of the main aims of the association, therefore we had the need to find an effective way to reach the families and let them fill our sympathy and our closeness. In most of the cases this was complicated by the distance or by the lack of family association operators in many parts of Italy. The use of the telephone has partly overcome this necessity. However, the high emotional status of the parents sometimes made the interactions difficult and limited the possibility to provide appropriate help to the bereaved parents.

## 2 The discussion group

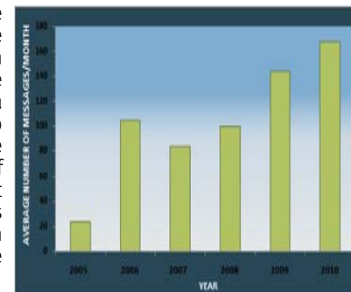
We developed the idea of creating an internet discussion group restricted to the association members. The discussion group is a virtual space where parents fill close to each other, where they can write their thoughts and express the enormous pain, desperation and sense of guilt that derive from the loss of a baby.

The discussion group was created in 2005. The observation of the email exchange indicated that the group is prevalently composed by mothers. For cultural reasons mothers express their feelings more easily than fathers. Furthermore, mothers are very often in maternity leave, they feel lonely and isolated in an empty house full of memories after the death of the baby. Relatives and friends may not feel confident about how to help, while they are themselves involved in the grieving experience. The discussion group is a space where other mothers are always present to help and support each other, where the mother will always find somebody ready to answer and support. In the group she can interact with mothers who lost their baby a long time ago. They will offer their experience and tell about their own ways to overcome the pain and, ultimately, show that a hope for the future is possible. Therefore, she can feel she is not alone in the grieving process, she is supported by women who understand what she is going through and will help her to find her way to look forward.

Some mothers just want to read conversations between other bereaved parents. They are "silent" mothers that might not find the courage to directly interact with the others of the group. However, they feel supported by the discussion group, read about questions they would have liked to do, and they fell anyway part of a family. The association organizes a meeting, once a year, where families can meet and "give a face" to the virtual supporting families.

## 3 Analysis of the participation to the discussion group

In order to understand if the discussion group was an effective tool to support bereaved Italian families, we observed the average number of email exchanges over a period of 5 years, from 2005 to 2010. The graph below shows the increase of the average number of messages per month indicating that an increasing number of families was reached by the discussion group-email exchange in this time range.



Furthermore, looking at the list of families registered to the discussion group we observed that the participation was limited to North-Italy. Limited number of families from Centre-Italy are in the group, whereas no family from South-Italy is reached by this communication tool. However, this observation reflects a large limitation of the activity of the association in South-Italy that results in the complete lack of information on SIDS cases in this part of the country where, in most of the cases, affected families are not properly supported.



## Conclusions

- The Semi per la SIDS discussion group is an effective way to provide support to families who have suffered the sudden and unexpected death of a baby. It is an efficient tool to guarantee support over distance and in the lack of operators diffused on the Italian national territory.
- The discussion group is prevalently composed by mothers because of cultural and practical reasons.
- The participation to the Semi per la SIDS discussion group is not diffused to bereaved families from Central and South Italy. Major effort has to be done in order to reach those families and offer them appropriate support.