

The Study of Maternal Observations and Memories of Stillbirth

Newsletter August 2004

Fifteen thousand visitors!

"..... and 900 000 hits to the MOMStudy pages..."

"On August 8, MOMStudy completed the first six months of the planned one-year recruitment, and 15 000 have visited the MOMStudy site" says Monica Ryzcek, stillbirth mom from Illinois, USA, and coordinator of the recruitment to MOMStudy. About 4 000 have entered the actual questionnaire, and while some are just looking, more than 70% complete and submit the questionnaire.

The first peak in visits (figure below) occurred when missfoundation.org alerted their members, while the second was the combined effects of the US National Stillbirth Society alerting their members and sponsoring a link at Google, and essentialbaby.au.com starting recruitment a few days later. The last peak was the effect of the US NBC5 news featuring the MOMStudy.

Today, 35 organizations are recruiting for MOMStudy, in addition to moms recruiting moms; 8% of stillbirth moms and 40% of controls are recruited by another mom! "The role of moms is crucial, and we hope moms will continue to tip a friend in the months ahead" says Dr. Frøen from Oslo, Norway, Principal Investigator of MOMStudy.



...that of moms in MOMStudy,

 ${\bf 40\%}$ of still birth moms lost the baby of their very first pregnancy.

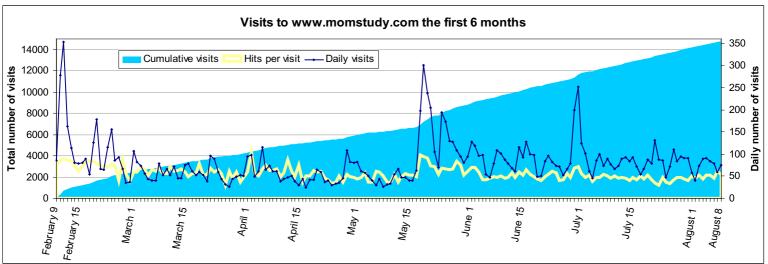
53% lost a boy.

37% lost their baby at term.

14% were expecting another baby when completing the MOMStudy questionnaire.

49% had autopsy to find the cause of death. **92.5%** have siblings that were live born, while **8.3%** have stillborn siblings with the same mother as themselves.

....and all this, and much more, differ clearly between moms affected by the various causes of death in stillbirths. "This will assist us in understanding why some are affected by stillbirths, and what can be done to prevent it" says Dr. Frøen.



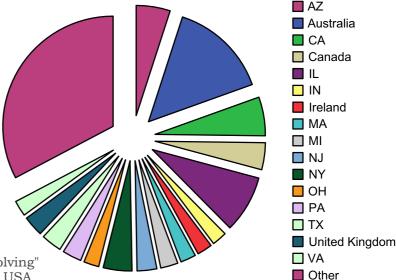
Who are the moms?

The moms in MOMStudy now include representatives from 27 countries and all states of the US. USA is still the major component with 75% of participants (down from 90% since our April Newsletter), and the "best" state to recruit is Illinois, followed by California, Arizona and NY. Among the other countries, only four recruit more than 2% of the total number of participants, namely Australia, Canada, Ireland and United Kingdom.



"Overall, we are quite happy with how MOMStudy is evolving" says Dr. Ruth Fretts from Harvard Medical School, MA, USA.

"We could always wish for more participants, in particular personal controls recruited by stillbirth moms. But we must remember that in comparison, most studies with comprehensive questionnaires after stillbirths include douzens, not thousands of participants." From the technical staff's point of view, problems seem restricted to a complete crash of the database on May 21. that lasted for 24 hours during which we might have lost participants. Only minor trouble otherwise, and we have performed a few small upgrades to make MOMStudy better for moms.



MOMStudy is a collaboration between an international research group and MISS Foundation. It is supervised and facilitated by the International Stillbirth Alliance and their Scientific Advisory Committee. It has been approved by the Ethical Review Board of the Principal Investigator's institution. You can find more information at MOMStudy.com.