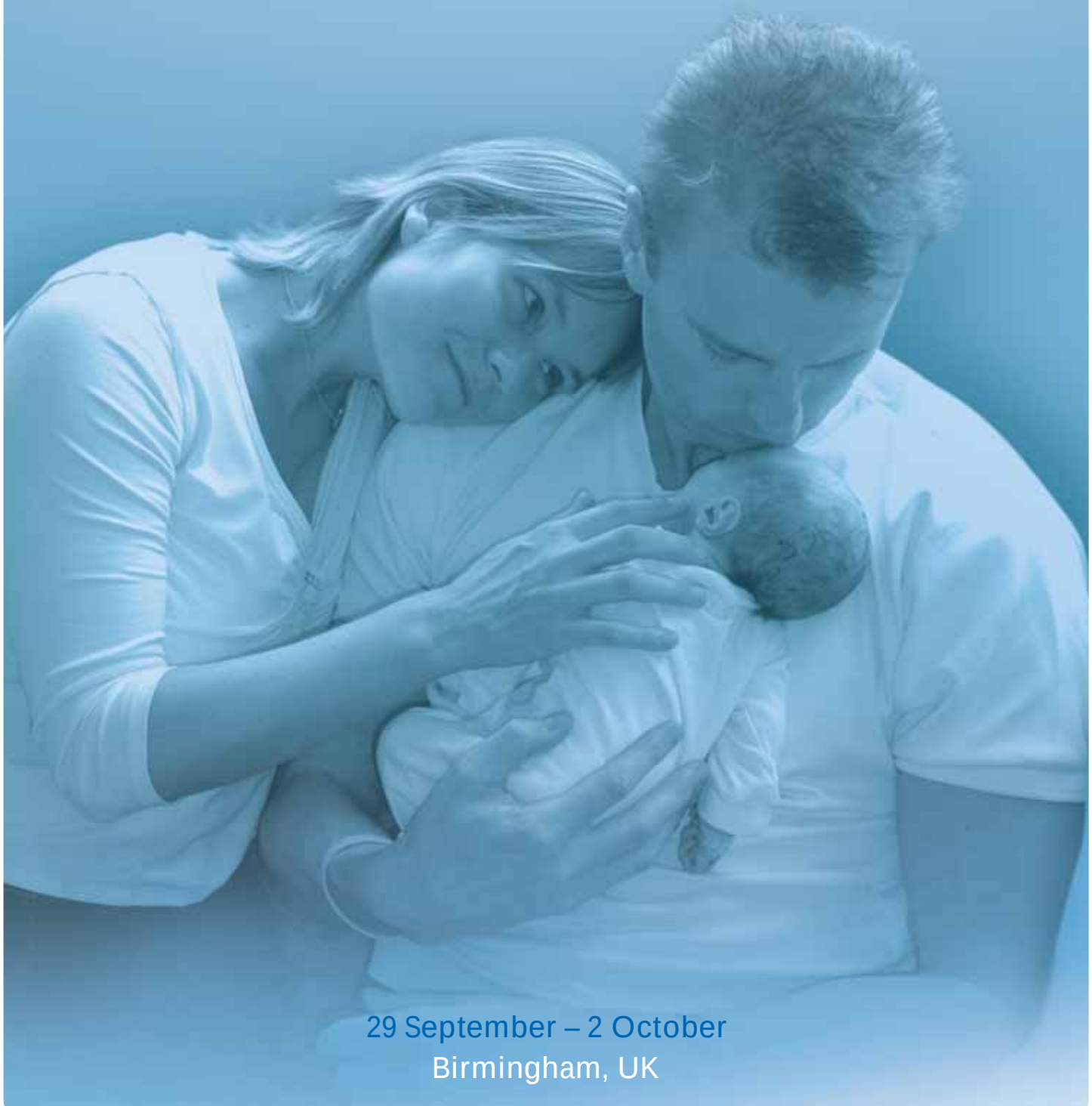
3RD ANNUAL CONFERENCE OF THE INTERNATIONAL STILLBIRTH ALLIANCE

Hosted by Sands and the Perinatal Institute

ISA 2007

Perinatal Loss: Improving Care and Prevention



29 September – 2 October

Birmingham, UK

Conference Handbook *Bereavement Track*

Sponsors

The organisers gratefully acknowledge sponsorship of this meeting by the following persons and organisations:

FirstCandle

An American non-profit health organisation uniting parents, caregivers and researchers nationwide with government, business and community service groups to advance infant health and survival.

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Dear Delegate,

We are pleased to welcome you to ISA 2007, the third Annual Conference of The International Stillbirth Alliance.

After an important incubation period with the SIDS Alliance, this is the first time the ISA conference is being held on its own, signifying the wide interest in examining the specific issues concerning stillbirth.

ISA conferences are unique in that they bring together bereaved parents, care professionals and scientists with a common purpose. Our theme this year - Perinatal Loss, Improving Care and Prevention - sums up its two main goals, which are:

- to improve the support which parents receive when experiencing the loss of a baby, with emphasis on ensuring that their grief is fully acknowledged and dealt with in the most professional and sensitive manner; and
- to examine the causes and factors associated with stillbirth, to formulate further research where needed, and to develop better strategies for prevention.

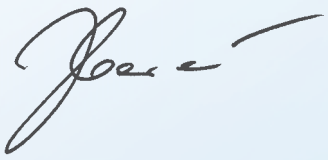
The programme has been organised in two streams which focus on the science and the support of parents. However we hope that these sessions will not just run in parallel, but intersect and inform each other throughout the meeting and well beyond. To help this along, we have introduced a joint plenary each morning, to allow a summary and discussion of the main points of each stream covered during the preceding day.

We have been fortunate to be able to bring together presentations from many of the experts in the field. But a major emphasis will be on open discussion and exchange of views, and time is set aside for this purpose throughout the conference.

For the first time, we have also been able to extend an invitation to a number of colleagues from developing countries, to come and share the specific challenges which they are facing. These are often formidable in number as well as size of local obstacles. It is hoped that such perspectives will inform the direction of ISA, as a truly international organisation seeking to address the problem of stillbirth everywhere.

Finally, we would like to thank the many people who helped us put together this conference, including the board and scientific committee of the International Stillbirth Alliance, our generous sponsors, and Profile Productions.

Thank you for coming and taking part. With your help, we know that this meeting will be a significant step to further the cause.



Jason Gardosi
Director, Perinatal Institute

Neal Long
Director, SANDS UK

Bereavement Programme

PROGRAMME CHAIR: *Sue Hale*

Sunday 30th September

09:30 **JOINT PLENARY** (Dorchester Suite)

- 09:30 Welcome and Introduction — *N Long, J Gardosi (UK)*
- 09:45 The Work of the International Stillbirth Alliance — *M Sokol, F Froen*
- 10:00 ISA Parents Advisory committee — *S Ilse, L Davies*
- 10:15 A father's experience of the death of a baby — *S Guy (UK)*

10:30 Coffee/Tea

11.00 **THE IMPACT OF A BABY'S DEATH - FOR FAMILIES AND HEALTH PROFESSIONALS** (Lakeside Suite) — *Marian Sokol*

- 11:00 From tragedy to healing - An obstetrician's perspectives on perinatal death — *M Berman (USA)*
- 11:20 A comparison of maternal attachment in first time mothers and after a stillbirth — *S Taavoni (Iran)*
- 11:40 A study of the impact of stillbirth on health professionals — *S Wallbank (UK)*
- 12:00 Children and bereavement — *C Stephenson (UK)*

12:20 Poster Session

13:00 Lunch

13:30 Living, Loving, Remembering - Memorial Time led by S Pullen

14:00 **ENABLING PARENTS BY PROVIDING INFORMED CHOICE** (Lakeside Suite) — *Alix Henley*

- 14:00 Parents tell their story - a users perspective of the health care system — *L Christoffersen (NOR)*
- 14:20 How to care for bereaved families: protection v preparation — *S Ilse (USA)*
- 14:40 Long term outcomes for mothers who have and have not held their baby — *I Rådestad (Sweden)*
- 15:00 'Walking the talk' - Enabling women to have meaningful input into decision making — *A Goodfellow (Aus)*

15:20 Coffee/Tea

15:40 **WORKSHOP A - Providing care and looking after yourself - for carers and families** (Lakeside Suite) — *M. Berman and S. Ilse*

WORKSHOP B - Helping grieving dads find the right tools (open to partners and care givers as well as fathers) (Windows on the Lake) — *T. Nelson and S. Hale*

17:00 **Sands Annual General Meeting (open to all delegates)** followed by A Time for Parents - Support and Sharing

18:00 **End of Day 1**

20:00 **Medieval Banquet - Coombe Abbey** (departure at 19:15)

Monday 1st October

08:15 **ISA Annual General Meeting** (Windows on the Lake)

09:30 **JOINT PLENARY** (Dorchester Suite)

- 09:30 Overview of previous day (Bereavement & Scientific)
- 10:00 Life after stillbirth: a mother's experience — *S Springall (UK)*
- 10:15 Individual grief and cultural influences — *R Sharma (UK)*

10:30 Coffee/Tea

10:50 **CULTURAL AND RELIGIOUS ISSUES IN BEREAVEMENT** (Lakeside Suite) — *Steve Hale*

- 10:50 Experience of training midwives in Abu Dhabi and Singapore — *A Chalmers (UK)*
- 11:00 Experience of loss in Taiwan and the adaptation of guidelines with cultural/religious issues — *HL Sun (Taiwan)*
- 11:30 Culture, religion and childbearing losses — *J Schott and A Henley (UK)*
- 12:00 Tradition or Religion? Supporting families as a Muslim chaplain — *R Sadiq (UK)*

12:10 Poster Session

13:00 Lunch

14:00 DIVERSITY OF DIFFERENT NEEDS IN DIFFERENT PREGNANCIES (Lakeside Suite)
Liz Davis

- 14:00 Five precious hours: Lessons from the tiny life of Raja — *V Culling (NZ)*
- 14:20 The difficulties around making the decision to end a pregnancy because of abnormalities — *J Fisher (UK)*
- 14:40 When one of a twin survives — *C Clay (UK)*
- 15;00 The death of a baby in a lesbian relationship and subsequent pregnancy care — *K Smith and F McGuire (AUS)*

15:20 Coffee/Tea

15:40 WORKSHOP A - Communicating across language barriers; families and loss - An interactives session (Lakeside Suite)
J. Schott and A. Henley

WORKSHOP B - Understanding couples different ways of grieving and how to support each - (open to care givers as well as parents) (Windows on the Lake)
S. Ilse and T. Nelson

17:00 **Candle Lighting and Poetry** (Quiet Room)

17:30 **End of Day 2**

19:30 **ISA Dinner & Dance**

Tuesday 2nd October

09:30 JOINT PLENARY (Dorchester Suite)

- 09:30 Overview of previous day
- 10:00 Life after stillbirth: hope with a heartbeat — *S Pullen (USA)*

10:15 **Presentation of abstract(s) of Best Poster Prize**

10:40 Coffee/Tea

11:00 HELPING PARENTS THROUGH THEIR GRIEF
Sherokee Ilse

- 11:00 Factors affecting nurses attitude towards bereavement care - A Chinese study — *MF Chan (China)*
- 11:20 The positive effects of parents being involved in studies — *T Stacey (NZ)*
- 11:40 Grief in the Workplace — *L Davis (AUS)*

Short comfort break

- 12:00 Sands self help support and training parent supporters — *P Brabin (AUS)*
- 12:20 The impact of other losses in bereavement — *T Nelson (AUS)*
- 12:40 Coping with grief: as an individual and in a couple — *C Bodkin (UK)*

13:00 Lunch

13.30 **Flowers on the Lake - A Time to Reflect** - meet by the lake outside the conference suite entrance

14:00 MODELS OF CARE (Lakeside Suite)
Michael Berman

- 14:00 Empowering bereaved parents - their contribution to the PSANZ clinical guidelines — *L Davis and R Richardson (AUS)*
- 14:20 The importance of psychosocial care following perinatal death — *M Groot-Noordenbos (NL)*
- 14:40 Taking baby home - developments in support of bereaved parents, families & whanau in NZ — *V Culling (NZ)*
- 15:00 The new Sands guidelines for professionals — *J Schott and A Henley (UK)*
- 15:20 Care pathway following pregnancy loss — *H Patterson (NI)*

15:45 Coffee/Tea

16:00 WORKSHOP - Beyond the first year - Care needs and ways of remembering (Lakeside Suite)
L. Davis, V. Culling, L. Christoffersen, E. Thorp, S. Ilse, T. Nelson, R. Richardson, K. Anker

17:00 **Closing Plenary**

17:30 **End Of Conference**

Conference Information

Admission to conference sessions

Admission to any conference session is by badge only. Please ensure you are in your seat at least five minutes prior to the start of each session and that your mobile phones are fully switched off.

Badges

In the interest of security please make sure that your badge is clearly visible at all times during the conference. If you loose your badge then please report immediately to the Registration Desk in the foyer of the conference suites and you will be issued with a replacement.

Befrienders

We recognise that this event may generate many emotions and have befrienders on hand who would be happy to talk with you or just be there to listen. They can be identified by an orange spot on their badges.

Bereavement Track

For the duration of the conference all sessions on the Bereavement track will be held in the Lakeside Suite for your comfort, apart from workshops when you will be directed accordingly on the day. Please note that all joint plenary sessions will be held in the Dorchester Suite.

Check-out

If you are resident in the Ramada Hotel for the duration of the conference then please note that the hotel request that you check-out of your room on the day of departure before 12pm. Should you require assistance, or you need to request a late check-out, then please let a member of the Hotel staff know at front reception, they will do their best to accommodate your needs.

Conference dinner - Monday 1st October

The International Stillbirth Alliance conference dinner will take place on Monday October 1st in the Lakeside Suite. The evening will include a welcome reception and entertainment followed by a traditional Ceilidh. Additional costs may apply for any day delegates or partners. Please ask at Registration if you have any queries.

Emergencies

In the event of an emergency please contact a member of staff from Profile Productions or a member of staff from the Ramada Hotel who you will see throughout the building. In all other instances, please dial 999.

Hotel

The Ramada Jarvis Hotel and Resort is located:

Penns Lane, Walmley,Sutton Coldfield,
West Midlands, B76 1LH
Tel: + 44 (0) 121 351 3111
Fax: + 44 (0) 121 313 1297

Joint Plenary sessions

For the duration of the conference all joint plenary sessions will be held in the Dorchester Suite.

Lunch

Lunch will be served in the main hotel Restaurant and additional seating areas have been made available in the Windsor Foyer or in the hotel bar should the need arise. Please let a member of staff know if you need any assistance.

Medieval banquet - Sunday 30th September

Come live like Lordes and Ladyes and experience a night out you will never forget at Coombe Abbey's award winning Medieval Banquet. Armed only with a dagger and a bib you will be served four courses of delicious food. Throughout the feasting banquet maids will fill your goblets with mead and wine while entertaining you with song, dance and sketches.

Tickets for this event are £45 and need to be booked and paid for by each individual wishing to attend. If you haven't reserved a place at this dinner and still with to join us then please ask a member of staff at the Registration desk.

Transport to and from Coombe Abbey is included and coaches depart from the front of the hotel at 7.15pm. Please be prompt.

Posters

Posters are located in the Dorchester Bar area and posters will be on display throughout the whole event, so please take your time to visit them. There will be prizes awarded to the best display from each of Bereavement; Scientific and Scientific (International Fellowship) Categories.

Quiet room

The room at the far end of the Windows on the Lake suite, located on the first floor, will be available for those who require some time away from the conference for reflection, prayer, or simply to have some quiet time. Memory 'leaves' will be kept here on which you may write a message in dedication or simply your baby(ies) name to hang on the memory tree in the Lakeside suite. We have provided books and newsletters for your support, but please do leave them in the room for others benefit. You will find writing materials there and you are welcome to use these freely.

Refreshments

Refreshments will be provided daily in the Dorchester Bar area alongside the Poster display at the designated times. As well as tea, coffee and herb teas, you will also find plenty of fruit and water coolers located around the conference area at all times for your comfort, so please feel free to help yourself. If you have any other requirements, then please let a member of staff know.

Registration Desk

If you have any enquiries please make your way to the Registration Desk in the foyer of the conference suites where you will find either members of Sands, the Perinatal Institute or Profile Productions on hand to answer any questions or concerns that you may have.

Scientific Track

For the duration of the conference all sessions on the Scientific track will be held in the Dorchester Suite for your comfort. Please note that all joint plenary sessions will also be held in the Dorchester Suite

Security

In the interest of security please note that there will be members of personnel located in the different areas of the venue. (Please note that these are not there to cause alarm but for your safety). Should you wish to report anything please contact a member of the conference team at the Registration Desk.

Welcome reception - Saturday 29th September

All conference attendees are invited to attend the welcome reception and supper on the 29th September from 6.30pm in the Lakeside Suite. There will be an informal drinks reception followed by a light supper. This is the perfect opportunity to catch up with colleagues, old friends and new.

List of Presenters

Sunday 30th September

O1 - A father's experience of the death of a baby

Steven Guy
Sands, UK

Steven became involved in SANDS in 1993 when their daughter, Danielle, was stillborn. The support he received from SANDS inspired him to set up a local SANDS support group. He has been actively involved since that time and is currently Chair of SANDS.

Monday 1st September

O2 - Life after stillbirth: a mother's experience

Sam Springall

Sam is a 27 year old bereaved parent who lost her first son Thomas on the 15th August last year after a full term pregnancy. Her experience has enabled her to support other families, but also to educate and raise awareness of this tragic but sadly not uncommon complication of pregnancy. 'This conference is a further opportunity to tell my story, and not just remain a faceless statistic'.

O3 - Individual grief and cultural influences - a mother's experience

Ritu Sharma

Ritu is the mother of Ram, who was born at 27 weeks in 1994 and lived for 7 hours, Nina who was born at 20 weeks in 1995 and lived for an hour and Suraj who was stillborn at 37 weeks in 2004. She is a member of Birmingham SANDS.

Tuesday 2nd September

O4 - Life after stillbirth: hope with a heartbeat

Suzanne Pullen

As both a journalist and a bereaved parent, I found myself in a unique position after the stillbirth of my first child. I was plagued with the same questions that countless other parents had, but I had both the ability and the responsibility to look for the answers.

The two years that followed my loss and my subsequent pregnancy were filled with hundreds of heartbreaking stories of loss, examples of dedicated care providers and the investigations of a handful of researchers looking into the cause and prevention of stillbirth. They were also filled with even more questions and a growing frustration at the lack of standardized reporting, care and support.

What I learned is that no one is satisfied with the status quo. "These things just happen" is no longer an acceptable answer and almost everyone who has ever been touched by stillbirth wants to know why more isn't being done to educate, prepare or assist parents about what to expect.

In March of 2006, I wrote "Calling All Angels, " on my stillbirth, and in March of 2007 I wrote "Hope with a Heartbeat, " about my subsequent pregnancy for the San Francisco Chronicle Sunday Magazine. I used my personal story as a gateway for readers to learn about the grieving process, the dearth of research into the cause and prevention of stillbirth and the anxieties of subsequent pregnancies.

The response from readers was overwhelming. More than 700 readers have written to me in the last two years, sharing their stories and asking questions that no one can answer and few have tried. But I also heard hundreds of stories about how parents lives were forever changed by their experience, some going on to make positive change in the lives of others. There is an unquenchable thirst for parents to share their stories and a desire to honour their child in tangible ways.

Conclusions: Moving forward requires many parents to first spend time coping with the loss, honouring their child and coming to terms with the uncertainty surrounding their stillbirth. Increasing the public dialogue about the issues surrounding stillbirth creates avenues for healing among bereaved families, insights for public health care workers and resources for loved ones to help on the long road through grief. The more information parents have, the more informed their decisions, the more they can tailor their grieving and healing process, the more many of them want to find ways to help change the current stillbirth status quo. The more the public is aware of the issues, the better the community as a whole can respond.

THE IMPACT OF A BABY'S DEATH - FOR FAMILIES AND HEALTH PROFESSIONALS

O5 - From tragedy to healing - An obstetrician's perspectives on perinatal death

Michael Berman

Yale University of Medicine, New Haven, Connecticut, USA

Michael R. Berman, M.D., FACOG, a 1970 graduate of New York Medical College is clinical professor of Obstetrics and Gynecology at the Yale University School of Medicine, attending physician at Yale-New Haven Hospital, where he holds the position of President, Yale-New Haven Physician-Hospital Organization. Dr. Berman is Founder and President of Hygeia, an internet-enabled program providing the most comprehensive resource and largest international online community for families experiencing the grief and sorrow which accompany the loss of a pregnancy or newborn child and the angst of parenting and caring for critically ill neonates or children. Dr. Berman also administers the Hygeia Foundation, Inc., a non-profit organization which he founded, whose mission is to bring to medically indigent and under-served populations, nationally and internationally, interactive information with regards to Maternal and Child Health and facilitate access to these services. His book, *Parenthood Lost, Healing the Pain after Miscarriage, Stillbirth* and *Infant Death* was published in January, 2001. Dr. Berman is the 2000 Recipient of the Association of Professors in Gynecology and Obstetrics Teaching Award and is actively involved in the medical education program at the Yale University School. Dr. Berman was interviewed about his work by Katie Couric on the NBC Today Show in August, 2001.

Countless mothers and fathers and those close to them silently grieve with little resolution over the loss of their pregnancies, newborns and children. Seeking reprieve from their sorrow, they cry and yearn for solace and hope, many times for years following their loss; cries that are but a muted weeping of despair as a child so longed for is not born, or is not born alive, or dies after birth. Pained by these losses, their lives seem devoid of hope. The joys expected from normal childbirth and child rearing turns to sorrow. When our patient's child has died, the balance between caring for the well being of a viable baby, a healthy infant and the healthy mother shifts to caring for the tolling physical well being of the mother, the agony of her emotional well being and that of her immediate family. It is a time when family and friends might alienate themselves and leave the bereaved parents without close support and comfort. The shadow of their grief will be indelibly imprinted in their minds and souls. Death has threatened to tear apart the bonds of their relationships with friends, family and themselves. The healthcare professional must recognize the impact of these losses and be the first responder in this time of need.

This presentation will briefly discuss these challenges, present personal / professional experiences with such losses and make recommendations for interventions and healing pathways during these most tragic and difficult of experiences.

O6 - A comparison of maternal attachment in first time mothers and after a stillbirth

Simin Taavoni

Iran School of Medical Sciences, Iran

Simin Taavoni is a faculty member and researcher at Iran University of Medical Science. She holds a M Sc in Medical Education and a M Sc in Midwifery

The previous fetal or neonatal death may have a negative effect on the adaptation of a woman for her new pregnancy. It can also have influence on the development of emotional distress in the attachment between mother and her fetus.

Aim: To assess and comprise maternal fetal attachment (MFA) of primgravidas and pregnant women with history of previous fetal or neonatal death.

Methods: This is a comparative study. Sequential sampling method was used. We collected 120 Iranian healthy pregnant women during their third trimester from 10 health centers in Mashed in year 2006. (80 nuliparous, 40 with history of fetal or newborn death with no lived child). All samples had knowledge of reading and writing. The tools of this study had two main parts: personal demographic and pregnancy information form, and maternal fetal attachment scale (MFAS: Cranley, 1981). Descriptive statistics, X2, Fisher exact, T Test were used by SPSS.

Results: The highest percentage of both age groups belonged to 20-24. Per t test was used for age and pregnancy, and by X2, Fisher exact test for education level, living condition, finance, job unity of two group was proved. A significant difference was found in the 5 subscales of the MFAS between the primigravidas and pregnant women with history of fetal or neonatal death ($P \leq 0.001$). The average of maternal fetal attachment in the primigravidas women was more than second group. The independent t-test also showed a significant difference between two groups (p=0/000).

Conclusion: Due to decrease of maternal fetal attachment in the pregnant women with previous fetal or neonatal death we advise that medical staffs and midwives offer various supportive, educational, guidance, and counseling program for the mentioned high risk group and their couples. We suggest continue the same research during the first and second trimester of pregnancy and postpartum period in the clients whom will be visited in the other clinics.

O7 - A study of the impact of stillbirth on health professionals

S Wallbank

Queen Elizabeth Hospital, Birmingham, UK

Sonya Wallbank is a Clinical Psychologist in training currently completing the final year of a Doctorate in Clinical Psychology at Leicester University. Her clinical and research interests lie in Perinatal Psychology with current emphasis on traumatogenic aspects of the workplace. Her clinical experiences include working with parents who have experienced loss as well as professionals caring for grieving families. Sonya is currently on placement with the mother and baby unit, Queen Elizabeth Hospital, Birmingham.

The impact of miscarriage, stillbirth and neo-natal death on families is well documented. Yet, whilst staff working in this area are encouraged to be emotionally supportive to families as they grieve and help them develop coping strategies, little is understood of the impact of this work.

This presentation will discuss the results of a cross-sectional, correlational study conducted with staff working within UK hospital based, maternity and gynaecological settings. 200 staff members completed a questionnaire examining their experience in these settings, level of confidence in supporting families experiencing a loss and their current working environment. Staff were also asked to consider a significant loss experienced at work focusing on coping style and subjective stress experience.

Findings suggest that staff experience significant levels of subjective stress when addressing losses of this nature, which have previously been unacknowledged. Staff distress appears to be mediated not only by clinical experience but also by perception of peer and organisational support. The authors suggest how findings can be translated into strategies to optimise support for staff and will consider the relative contributions of personal characteristics and organisational factors.

ENABLING PARENTS BY PROVIDING INFORMED CHOICE

O8 - Parents tell their story - a users perspective of the health care system

L Christoffesen

Unexpected Child Death Society of Norway

Using Critical Incidents Technique we interviewed 40 parents (20 families interviewing mothers and fathers separately) during 2006/2007 about their experiences with the health care system when losing a baby in stillbirth aged between 26 and 42 weeks. During two hour interviews, we asked them to tell their story and define critical incidents before, during and up to one year after the stillbirth.

Generally we see that differences between the needs of the mothers and fathers become clearer a week or two after the stillbirth. The differences are not as clear in the first critical days.

The quality of the interaction between parents and health care workers before, during and immediately after the stillbirth is determined by the health care workers' ability to be present in each interaction - a kind of situation sensitivity. The ability to build relationships and meet the different parents' needs (both clinical and emotional) in an extreme situation will not only determine the quality of the interaction, but also the parents' quality of life after the stillbirth.

The outcome of several critical incidents during the first days is dependent on the health care workers:

- Telling the parents immediately if suspicion (or confirmation) of a dead baby;
- Preparing the parents to see and hold the dead baby when it is still warm;
- Encourage parents to care for, dress, and to spend time with the baby;
- Encourage parents to create memories: The importance of taking good pictures, hand- and footprints of the baby, and keeping clothes the baby has worn are not to be underestimated;
- Addressing the autopsy topic as soon as possible, and give information about how an autopsy is performed because reality is often less dramatic than parents' fantasy. Allowing the parents to see the baby after the autopsy;
- Encourage parents to let friends and family see and hold the dead baby.

Generally, parents prefer to be told what other parents in the same situation did instead of being asked questions about what they themselves want to do.

O9 - How to care for bereaved families: protection v preparation

Sherokee Ilse

Wintergreen Press, Minnesota, USA

Sherokee, bereaved mother, is also an int'l speaker, President of Wintergreen Press, and author of many books on infant loss and bereavement, including *Empty Arms: Coping with Miscarriage, Stillbirth, and Infant Death*. For the past 25 years she has worked with care providers, the bereaved, and communities to improve the care for families when a baby dies. She is a board member of ISA.

Goals: Understand why a baby's life is more of a treasure, than a trinket

Learn about the difference between being giving a paternalistic (protecting) or empowerment (preparing) type of care to families

O10 - Long term outcomes for mothers who have and have not held their baby

Ingela Rådestad

Mälardalen University, Sweden

Ingela Rådestad is a midwife and professor in Caring sciences, she work at Mälardalens university in Sweden and is member of the scientific board of International Stillbirth Alliance. Ingela Rådestad is the author of: *When a meeting is also farewell, coping with a stillbirth or neonatal death.* Books for Midwives Press.

We investigated mother's long-term outcome after having held or not having held a stillborn baby and predictors of having held the baby. Data were collected by postal questionnaires. Settings: A nation-wide cohort study of mothers who gave birth to a singleton stillborn baby in Sweden in 1991, 314 of 380 answered the questionnaire and 309 reported whether or not they had held their baby. Measurements: Scales measuring anxiety, depression and wellbeing. Results: 126 (68%) mothers of 185 babies stillborn after 37 gestational weeks had held their baby and 82 (68%) mothers of 120 babies stillborn at gestational weeks 28 to 37 had also done so. Compared with mothers who agreed completely with the statement that the staff gave enough support to hold the baby, mothers who did not agree at all were less likely to have held their baby (RR 4.1; 95% CI 2.7-6.1), and mothers with a low level of education were less likely to have held their baby than mothers with advanced educational level (RR 2.2; CI 1.3-3.8). Mothers who had not held babies born after 37 gestational weeks, had an increased risk of headache (RR 4.3; 95% CI 1.1-16.5) and they were less satisfied with their sleep (RR, 2.8; 95% CI 1.5-5.0). The increased risk of long-term outcomes associated with not holding, compared to holding, a stillborn baby were less pronounced for women who gave birth at gestational week 28 to 37 as compared to women who gave birth after 37 gestational weeks. Conclusion: In this cohort, we found an average fruitful effect of having held a stillborn baby born after 37 gestational weeks, while results for having held a stillborn baby born in gestational weeks 28 to 37 are uncertain. Staffs´ attitudes influenced whether or not the mother held her stillborn baby.

O11 - 'Walking the talk' - Enabling women to have meaningful input into decision making

Alison Goodfellow

Woollongong Hospital, Sydney, Australia

Alison started her career as a health professional thirty two years ago. She is a registered nurse and registered midwife. She holds a Bachelor of Nursing, Postgraduate Diploma in Midwifery and a Master of Health Management. Her current position is as a Clinical Midwifery Consultant caring for women experiencing a high risk pregnancy, and for Midwifery practice development within her area health service.

Background: Over the past 30 years child bearing women have indicated that they want a stronger voice in the decisions regarding their care. The focus on 'women-centered' midwifery care has encouraged a 'partnership' between women and midwives and a collaborative style in decision making. The process of shared decision-making is predicated on the concept of active patient/client participation. This participation often requires active intervention, support and guidance by the health care provider.

Case Study

P a 36 year old woman is having her 8th child. The fetus was diagnosed as having the chromosomal abnormality Trisomy 18. P and her husband declined termination instead choosing to continue with the pregnancy with full realization of the consequences of this decision. P's main wish was that herself, her husband and her other children were able to meet this child and have 'living memories'. They wanted their child to be treated with the same respect and care that all of their other children had received. Her pregnancy was complicated with premature rupture of membranes at 32 weeks.

I will recount the steps that were required for her to realize this wish as well as the clinical course that she encountered.

O12 - WORKSHOP A - Providing care and looking after yourself - for carers and families

Among professionals and family members who care for those who have experienced perinatal, neonatal or childhood loss, and indeed those who are involved in the end-of-life experience, there exists a remorse and sorrow that is universal. Many times it is kept silent and goes unnoticed, for attention is most often concentrated about those who have experienced their personal loss. This workshop will offer support to care providers and families that focuses on their role and their own grief…how to give good care if a caregiver and how to take good care of oneself whether a parent, befriender, or a professional supporter.

Goals:

- Discuss the rights, role and responsibilities of care providers as they support bereaved families
- Examine one's care giving style and consider its effectiveness
- Strategize suggestions on ways to take care of oneself (writing/poetry, escape opportunities, spirituality, music, etc.)
- Discuss how care providers can best manage their grief and obtain support

Michael Berman, Sherokee Ilse

O13 - WORKSHOP B - Helping grieving dads find the right tools

- Learn how socialization and prior life experiences impact a dad's reaction when his baby dies
- Discuss how a man's outward behavior often does not reflect his inner turmoil
- Through group sharing, gain a better understanding of the tools grieving men are looking for and partners/caregivers can provide as they offer support
- Create a blueprint for long term healthy grieving for men that includes caring for themselves as well as their relationships at home and at work

Tim Nelson

A Place to Remember, Minnesota, USA

Following the stillbirth of his second child, Tim Nelson began working with the non-profit Pregnancy and Infant Loss Center, eventually serving as president of the board of directors. He is the author of two help books for grieving dads, *A Father's Story and A Guide For Fathers: When A Baby Dies.* Since becoming a Certified Grief Recovery Specialist, he facilitates grief classes and conducts training and awareness building workshops.

Nelson co-owns A Place To Remember, a publishing company that creates and provides worldwide distribution of grief resources as well as hosts a large web site with Remembrance Book that contains over 12,000 entries.

Steve Hale

Sands, UK

Steve first became involved in Sands following the death of their baby boy Matthew who was stillborn in 1995. He gradually found himself moving from needing support to starting to be able to support others and particularly in his case dads. He has run a local support group and is currently a Trustee of Sands.

CULTURAL AND RELIGIOUS ISSUES IN BEREAVEMENT

O14 - Experience of training midwives in Abu Dhabi and Singapore

Ann Chalmers

Child Bereavement Trust, UK

Ann Chalmers is Chief Executive of the Child Bereavement Charity. She holds a BACP Accredited Diploma in Psychotherapeutic Counselling and a University Accredited Diploma in Bereavement Counselling, and has been involved in multi-disciplinary training of professionals in areas of loss and bereavement for over fifteen years.

As a past Chair of the Surrey branch of SANDS, Ann has extensive experience of running groups for bereaved parents and providing support to families when a baby or child dies. From 1995 to 2006 she was part of the Bereavement Care Team at Mayday Healthcare NHS Trust where her work has involved counselling for both individuals and couples. She has also provided counselling for staff within the NHS and for children and young people within the voluntary sector.

Ann joined The Child Bereavement Trust in 1996, and was appointed Chief Executive in 2003. Her work with the charity includes devising training programmes, bereavement literature and other resources for families and professionals, and representing the charity at national level in bringing the families' perspective to projects with the Department of Health and the Department for Constitutional Affairs. Ann delivers training and lectures both nationally and internationally for the Child Bereavement Trust.

The Child Bereavement Charity (formerly The Child Bereavement Trust) is a UK based organisation, founded in 1994, which works to improve the care and support offered to grieving families. The charity trains and supports professionals across disciplines who encounter child bereavement in the course of their work, whether in circumstances where babies or children die or where children are bereaved of someone important in their lives. All of the charity's work is based on learning from bereaved families.

Towards the end of 2006 and in early 2007, the charity received requests from Al Corniche Hospital in Abu Dhabi and the KK Women's and Children's Hospital in Singapore to deliver a programme of training workshops, seminars and conferences for a wide range of professionals working with families where a baby has died. The Charity had previously delivered training in both hospitals, and was closely involved in providing guidance and support in the setting up of Child Bereavement Support Singapore, a charity established in association with the UK organisation, which offers bereavement support to families who experience the death of a baby or child.

This presentation will highlight some of the similarities and differences encountered in relation to the support offered to families when a baby dies.

O15 - Experience of loss in Taiwan and the adaptation of guidelines with cultural/ religious issues

Hui Lin Sun

University of Ulster, Northern Ireland

The experience of pregnancy following a previous pregnancy loss... can be difficult and psychologically challenging. In order to understand this experience more fully, we set out to explore women's experiences using a qualitative approach with a purposive sample of Asian women living in Taiwan. Callista Roy's (1999) adaptation theory served as a useful framework to guide the study. In order to protect participants and researcher, particular ethical sensitivity was required in data collection and analysis, using interpretative phenomenological analysis (Smith, Jarman, & Osborn, 1999). Preliminary data from six participants (23-38 years) was analyzed and major themes that have emerged depict three distinct stages of the journey from grief to joy: Tethered (or bound) to the past memories of loss; struggling through familiar yet unknown stages of pregnancy and birth; and adaptation to motherhood. The essence of their journey through the pregnancy and birth is a permutation of fear, uncertainty and a deep desire for reassurance of fetal wellbeing. Becoming a mother and coping with the new baby had increased stress and anxiety as they feel a great need to be the "perfect mother".

The findings are preliminary but they provide challenging insight into specific needs of mothers who have had a pregnancy loss and their heightened need for support at a professional, familial and agency level to enable them to adapt to this new motherhood.

The results show that pregnant women who have lived through a previous pregnancy loss, on giving birth to a live, healthy baby, experience a range of emotions and seek support in a variety of ways.

O16 - Culture, religion and childbearing losses

Judith Schott

Judith Schott has worked in and around the health service for over 35 years as a health professional, consumer representative, parent educator and researcher. Since 1987 she has concentrated on writing, and on developing and running workshops for health professionals on a range of topics including cultural and religious aspects of health care and loss and grief. She is a member of the editorial board of the British Journal of Midwifery and is co-author with Judy Priest of Leading Antenatal Classes - a practical guide (Books for Midwives 2002). She lives in London.

Alix Henley

Freelance writer, researcher and consultant

Alix Henley is a freelance writer, researcher and consultant. She has a particular interest in communication between health professionals and service uses and in equal opportunity issues. Her books include When a Baby Dies: the experience of late miscarriage, stillbirth and neonatal death written with Nancy Kohner (Routledge 2001). She is living in Switzerland.

Together Judith and Alix have written:

Pregnancy Loss and the Death of a Baby: guidelines for professionals (Sands 2007)
Culture, Religion and Patient Care in a Multi-ethnic society (ACE Books England 1999)
Culture, Religion and Childbearing in a Multi-racial Society (Butterworth Heinemann 1996)
Breaking the Barriers: a training package on equal access to maternity services (Bloomsbury and Islington Health Authority 1992).

Both Alix and Judith are Advisors to Sands (the Stillbirth and neonatal death charity).

Childbearing loss rates are higher in some minority groups and in refugees and asylum seekers, in other words in families that are likely to have needs and beliefs that differ from the majority.

This presentation will examine concepts of culture and ethnicity; religion and variations in belief and practice both within and between different religions. It will also suggest practical ways of identifying and meeting religious, cultural and personal needs.

O17 - Tradition or Religion? Supporting families as a Muslim chaplain

Rehanah Sadiq

Rehanah Sadiq was born in Gujranwala, Pakistan, and has lived in Britain since 1961. She has been working as a Muslim chaplain in three Birmingham hospitals since October 2000, and as a counsellor in the Muslim community for around 20 years. She has recently qualified as a psychotherapist.

Over the years, her voluntary and extensive experience has brought her into close contact with Muslim communities, especially in the area of women, families and youth.

Together, with her husband, they are both committed to creating a greater awareness among non-Muslim professionals on Muslims and their needs. Rehanah is a founding member of Reflection Network, a national training organisation committed to this purpose.

This presentation draws on Rehanah's experience of working as a muslim chaplain in 3 hospitals in Birmingham, UK, supporting families after a stillbirth or neonatal death. In particular she will explore some of the accepted muslim practices - are they tradition or religion? Rehanah will also look at the issues facing 2nd or 3rd generation muslim families who may have strong influence of 1st generation family elders in their lives and communities.

DIVERSITY OF DIFFERENT NEEDS IN DIFFERENT PREGNANCIES

O18 - Five precious hours: Lessons from the tiny life of Raja

Vicki Culling

Sands, New Zealand

Vicki has a background in social work, teaching and research, she has an MA (Applied) in Social Work and completed her PhD in a women's health topic. She was fortunate in winning a Vodafone NZ Foundation's 'World of Difference' award in 2006 which enabled her to work in a full-time capacity for Sands New Zealand as its National Project Coordinator. She is currently funded to develop a national integrated approach to pregnancy, baby and infant loss in New Zealand.

O19 - The difficulties around making the decision to end a pregnancy because of abnormalities

Jane Fisher

Antenatal Results and Choices, UK

Jane Fisher became Director of ARC in 2004 having previously been their National Support Co-ordinator.

ARC is a UK charity with a remit to provide information and support to parents before, during and after antenatal screening and testing and when an abnormality is diagnosed in their unborn baby. Help is offered for as long as is needed whatever decision is made about the future of the pregnancy.

Drawing on evidence and ARC's two decades spent supporting parents through antenatal testing and its aftermath, the talk will focus on parents' experience of the painful decisions that can result from a diagnosis of abnormality in their unborn baby. We will explore the factors that may influence parents in their decision-making and how those caring for them can best support them both during the process and afterwards.

O20 - When one of a twin survives

Carol Clay

Twins and Multiple Births Association Bereavement Support Group (TAMBA), UK

Carol joined Tamba three years ago and coordinates the Bereavement Support Group and Twinline, Tamba's confidential helpline.

Tamba is a national charity supporting families who have had a multiple birth. Within Tamba the BSG supports families who have suffered a loss within their pregnancy whether it is a single or total loss. Tamba BSG has a team of volunteer befrienders, offering parent to parent support; they have all suffered a loss themselves. Contact with the bereaved parents is by letter, phone or email for as long as they need it. Members of the group are sent a regular newsletter in which parents share their personal stories. There is also a website where parents can post a memorial. www.tamba-bsg.org.uk

Losing a twin is a unique experience, how do you celebrate the life of one baby and arrange a funeral for the other, many parents are haunted by this for the rest of their lives. Unhelpful comments such as 'at least you still have a baby' or 'it is going to be so much easier for you with only one' can be most hurtful. Having one healthy baby does not compensate for the loss of the other. Most parents feel overwhelmed at the birth and need to be treated with respect and have their status as multiple parents acknowledged. Our service recognizes this and allows issues such as, what to do on the anniversary and when to tell the other twin to be aired and opinions sought. Grieving parents sometimes resent the healthy twin and again it is helpful to discuss these issues with other parents.

Referrals to Tamba BSG come through health professionals or through our own confidential helpline, Twinline.

This presentation will explain the BSG service and highlight the feelings of parents.

O21 - Half a day at a time: a lesbian couple's experience of their baby's death and subsequent pregnancies and births

Karen Smith & Frances McGuire

Karen and Frances' first child Archie was stillborn at term, in September 2003 while the couple were living in Australia. Subsequently, Karen and Frances have each had a baby and they now live in West Yorkshire, England with their two beautiful boys.

Karen and Frances were instrumental in the development of a support group specifically for lesbians who had experienced the loss of a baby in NSW Australia.

There is little written about lesbian couples' experience of stillbirth. Karen Smith and Frances MacGuire describe the loss of their first baby at full term and the anxieties and care associated with each of their subsequent pregnancies. As a couple they experienced overwhelming grief as well as homophobia, isolation and the complexities of trying to have more children.

The many ways in which professionals can support parents who have experienced the death of their baby are highlighted as well as useful resources. Practical suggestions are made to improve care and support families after the loss of a baby and during subsequent pregnancies.

O22 - WORKSHOP A - Communicating across language barriers; families and loss - an interactive session

Judith Schott, Alix Henley

O23 - WORKSHOP B - Understanding couples different ways of grieving and how to support each other

S. Ilse, T. Nelson

Goals:

- Learn how socialization, prior life experiences, and decisions made at the time of the loss influence men and women's reactions after their baby dies
- Discuss the different roles of men and women during pregnancy and at the time of the loss
- Discuss how to help couples understand and be supportive of their differences in communication and mourning styles
- Share and promote ideas to provide hope and strengthen couple's relationships
- Learn strategies to help couples' move beyond regrets and mistakes

HELPING PARENTS THROUGH THEIR GRIEF

O24 - Factors affecting nurses attitude towards bereavement care - A Chinese study

Moon Fai Chan

School of Nursing, Hong Kong Polytechnic University, Hong Kong

Investigating factors associate to nurses' attitudes towards perinatal bereavement care: a study in Shandong and Hong Kong

Authors: Moon Fai Chan[1], Feng-lan Lou[2], Li Lui[2], Feng-lin Cao[2], Lai Har Wu[1], Ping Li[2], & Loretta Yuet Foon Chung[1]

Institution: [1] School of Nursing, Hong Kong Polytechnic University, Hong Kong. [2] School of Nursing, Shandong University, Shandong, China

Introduction: Caring for and supporting parents whose infant has died is extremely demanding, difficult and stressful. It is likely that the attitude of nursing staff can influence recovery from a pregnancy loss and nurses with positive attitude to bereavement care can help bereaved parents to cope during their grieving period. The purpose of this study is to compare Shandong and Hong Kong nurses' attitudes towards perinatal bereavement care and to identify factors associate with such attitudes.

Methods: Data were collected through a structured questionnaire from the Obstetrics and Gynaecology unit in five hospitals in Hong Kong and Shandong during May to August 2006. Outcome measures including attitudes towards perinatal bereavement care, importance on hospital policy, and training support for bereavement care.

Results: Majority of nurses in this study held a positive attitude towards bereavement care. Results showed that only 39.3% (n=130) of nurses had bereavement related training. By contrast, about 89.8% of nurses (n=300) showed they need to be equipped with relevant knowledge, skills and understanding in the care and support of bereaved parents, and more than 88.0% (n=296) would share experiences with colleagues and seek support when feeling under stress. Regression model showed that age ($p=0.001$), past experience in handling grieving parents ($p=0.013$), and nurses' perceived attitudes on hospital policy ($p=0.003$) and training provided ($p<0.001$) for bereavement cares were factors associate with nurses' attitudes towards perinatal bereavement care.

Discussion/Conclusion: Hong Kong and Shandong nurses emphasised their need for increased knowledge and experience, improved communication skills, and greater support from team members and the hospital for perinatal bereavement care.

O25 - The positive effects of parents being involved in studies

Tomasina Stacey

University of Auckland, New Zealand

Tomasina is a midwifery educator in South Auckland and a doctoral student at the University of Auckland. Her midwifery experience spans England, Australia and New Zealand where she has been a clinical midwife in a variety of settings from tertiary urban units to remote area settings. Tomasina has had a long standing interest in the impact of stillbirth due to a family history of fetal loss.

Tomasina currently coordinates The Auckland Stillbirth Study which is exploring risks factors for third trimester stillbirth.

Introduction: Each year in New Zealand more than 200 babies die in utero at or after 28 weeks gestation resulting in a rate of late stillbirth of 1 in 300 total births. Few studies which explore the risks for stillbirth have involved interviewing recently bereaved mothers. Qualitative studies have suggested that there may be some therapeutic effect in giving women an opportunity to further discuss their stillbirth experience.

Aims: To explore women's perception of taking part in research regarding risk factors for stillbirth.

Methods: The Auckland Stillbirth Study is a three year case control study exploring maternal lifestyle and environmental risk factors for late stillbirth. Data are collected from clinical records and a face to face interview. Controls are recruited while still pregnant at an equivalent gestation to the case. For women who have experienced a stillbirth an interview occurs within 2-4 weeks of the birth of their baby, and for controls the interview generally takes place while they are still pregnant. Feedback forms are given to participants at the end of the interview. The women are provided with a stamped address envelope so that feedback can be submitted anonymously.

Results: To date, 55 cases and 100 controls have been recruited to the study. Feedback received from both cases and controls identified the positive contribution that being involved in such research may have on future parents. Women who had experienced stillbirth commented that being able to talk about their experience was beneficial.

Conclusion: Not only does the interview collect valuable data about possible risk factors for stillbirth, but participants feel positive about being involved in such a study.

O26 - Grief in the Workplace

Liz Davis

Sands Queensland, Australia

Liz and her family experienced the death of two babies some years ago and she has been involved in various roles in the support of bereaved parents since the early 90's. Liz is currently the coordinator of a support group for bereaved parents in Queensland, Australia and has been involved with the development of various programs, including two films which she hopes will enhance the experience of parents and assist in educating health care professionals. Liz has been the co-chair of the Parent Advisory committee of the International Stillbirth Alliance since 2005.

Grief and bereavement are part of our lives and our workplaces. A positive return to work experience is fundamentally important for bereaved employees, their employers and the business. When a person experiences the death of someone close to them, they will often reflect on the meaning of their activities including their work. If they do not have a positive return to work, they may choose to change their job or career, often taking years of experience and training with them. They may then enter a workplace that does not know their history and because of this may not be able to offer any support.

It has become increasingly evident that a positive return to work experience for bereaved employees significantly supports all concerned - manager, colleagues, business and of course the bereaved.

The Grief in the Workplace package was developed in response to a need expressed by bereaved employees for education when their return to work experiences may have been either negative or positive.

The Grief in the Workplace package has been developed to assist employees who are returning to the workplace following the loss of a parent, spouse, sibling or child. Managers and business owners will gain a better understanding of the grief process that occurs when a work colleague experiences the death of someone close to them. They will also learn of the support that they can provide and the tools that will assist the employee to effectively return to work.

Protocols for the workplace and for the bereaved worker have been developed to enable all parties to understand the grief process.

O27 - Sands self help support and training parent supporters

Penny Brabin

Sands, Australia

Penny has an independent psychological practice in Melbourne, Australia. She is the Chair of Sands Australia and also involved in the support group of Sands (Victoria)

How bad is it? After all, it was only a baby, you didn't know it… it's not like it lived!

Fortunately, major changes have occurred in the care of parents after early pregnancy and perinatal loss. Across Australia, during the 1980s, all states founded SANDS organisations in response to parent needs, providing community-based care, supporting parents directly, through an individual and group self-help model, and indirectly, through community and professional education and advocacy for relevant legislative changes.

This self-help model which normalises grief as a healthy response to loss was the success story of the 1980s and 1990s. In a 'need-to-be-happy' society, however, grief is now, almost routinely, being pathologised - treated as depression (a mental health rather than natural condition) and medicated, and individual counselling undertaken behind closed doors - often maintaining the traditional shame of pregnancy loss - by practitioners who, in the main, are not familiar with the specialised intricacies of pregnancy and perinatal, as opposed to other family member, loss. *Parents are often not obtaining the best support.*

Sharing experiences through community-based self-help with others who have 'been there' conveys the normality of parent's reactions more powerfully than if told (often not!) by a 'caring professional' and can challenge the lingering shame of pregnancy loss associated with punishment of women. Training for parent supporters, however, is essential and offers an opportunity to use the experience of loss for personal growth and to give back to SANDS.

SANDS(Vic) training was developed in the 1980s and has successfully trained many parent supporters in weekends run annually. The training focuses on extending the parent's own experience, recognising typical from atypical grief to facilitate a professional referral, awareness of the legislative, hospital and funeral practices historically and currently associated with perinatal/pregnancy loss and the development of active listening and group facilitation skills.

O28 - Layering Grief Over a Lifetime

Tim Nelson

Overview: Many of us know CPR and what to do if someone has a heart attack, but few of us know what to do with a broken heart. In this session we will discuss how, when grief is not dealt with, it layers over a lifetime and prevents us from really healing.

Goals:

- Briefly discuss what grief is and what causes it
- Better understand the relationship between what we were taught as children when our dog died and how we reacted when our baby died
- Look at the myths about grief that we have all been raised with
- Be able to recognize short term energy relieving behaviors (STERBS) as we cope with our grief
- Discuss where we go from here so that we ultimately control our grief rather than having our grief control us

O29 - Coping with grief: as an individual and in a couple

Christine Bodkin

Edwards Trust Sunrise, UK

Christine is the Chief Executive of Edwards Trust, Sunrise, a bereavement centre set up to offer support and counselling for all those affected by the death of a child and for children of school age who are bereaved of a parent, significant carer, sibling or friend. They also offer advice and training to health care professionals and teachers who have a close association with a bereaved family. Christine has worked with Sunrise since 1992.

MODELS OF CARE

O30 - Empowering bereaved parents - their contribution to the PSANZ clinical guidelines

Liz Davis, Ros Richardson

SIDS and Kids, New South Wales, Australia

Ros is employed as the Health Promotion Manager for SIDS and Kids NSW, who provide support for parents who experience the death of their baby during pregnancy, birth and infancy, up to 6 years of age. Following the stillbirth of her daughter, Ros developed the professional resource, Appropriate Care for Women and their partners when their baby dies, and the parent booklets Miscarriage and When a Baby Dies. She is a member of the Parent Advisory Committee of the ISA.

Ros has a Graduate Diploma in Social Science (Community Services), completed a Master of Public Health in 2006 and is now completing a Master of Health Services Management.

O31 - The importance of psychosocial care following perinatal death

Mariëtte de Groot-Noordenbos

University Medical Centre, Groningen, Netherlands

Mariëtte de Groot-Noordenbos, (1953) graduated at the Academy of Social Studies in Amsterdam (1976), she followed an advanced Post HBO Social Studies in Groningen (1982), with specialisation in Family therapy.

She has been working at the UMCG as a medical social worker since 1976 in different fields of health care (Child and Youth Psychiatry, Haematology). Since 1993 she is counsellor for the department of Obstetrics and Gynaecology. Clinical work for the perinatal centre UMCG (High care Unit, Nicu, Outpatient clinic Obstetrics and prenatal diagnostics.

The main aim in the care of perinatal death, is offering a strategy for coping with loss (or coping with impending loss), which facilitates the final goodbye. A range of intense care and support is offered by the obstetrics centre at the UMCG by doctors and nurses. Parents are

encouraged to spend all available time with their baby. These actions of cuddling, holding, caressing, stroking and taking photographs are very important steps of making the (impending) loss tangible. Also hand and footprints are made. Virtually without fail parents reflect on this period as being incredibly powerful, allowing them to create a lasting memory. All parents who have had to cope with intra uterine deaths are invited to choose a Quilt of Love. These quilts have been hand stitched by volunteers as a lasting keepsake (and physical recognition) of their unviable but much loved and desired child. Again, the tangibility of this keepsake has a positive impact on the coping with loss skills of the bereaved parents.

Parents are invited to meet the gynaecologist 3 to 6 weeks after their child's death. Should parents not cope as expected under the circumstances they will be invited to contact the obstetrics social worker and a referral will be made by the gynaecologist. Although individual aftercare is a possibility, the UMCG prefers to offer aftercare in a group context. An information evening on the subject of neonatal death is held twice a year, and has been available for the last 9 years. This has evolved to a second yearly information evening for parents who have lost their child prior to birth. Doctors and nurses are available during these evenings of information sharing, in order for medical questions to be asked and to be adequately answered. Interested parties can put their names forward for the group counselling sessions (minimal 3 couples, maximum 6 couples). The meetings are held every fortnight for the duration of 6 sessions. A follow-up is organised 6 months after the last session.

The essence of group counselling is for parents to receive recognition and support for their loss and to freely speak about their child in a safe and respectful environment. Legitimacy for the existence of their child is a second important factor. Parents are still often encouraged 'to let go' after a certain period of time has passed and to look to the future. Yet, how can anyone deny one has become a parent? *The fact there is no physical child to show for many months of pregnancy does not equal not being a parent.* It is this important issue of being a parent without a child which gets facilitated in the group. The loss of a baby needs not be 'let go of'' but indeed to be integrated into the parent's lives and to become part of their present and their future. Every subsequent child will be second (etc) child for the first child died. It is this heartfelt knowledge which needs integration if one is to overcome the loss and rejoin life. The group has themed sessions to encourage integration of the experience: How did you say goodbye, which memories do you have, how do you keep them, how do you share them?

- Were you happy about the care you received at the UMCG. How could it have been improved?
- How do you cope with other people's reactions to your loss.
- What impact does the loss have on your relationship and on the relationship you have with your other children.
- The future, how do you and your spouse feel about ever falling pregnant again?

It can be concluded that the aftercare group counselling sessions have met a strong patient need. Sometimes networks do not have this flexibility or do not offer the safety to explore the depths of despair. It is often in sharing with people who have had a similar experience that true loss is being worked through. Mothers have empty arms and empty laps. Fathers feel their expectations have been killed and buried.

These parents deserve our support not only during the immediate aftermath of the loss, but also for the year that follows. Indeed, possibly in particular for the duration of their next pregnancy since good psychosocial aftercare following bereavement can greatly reduce the chance of postnatal depression and overprotective parenting in years to come.

O32 - Taking baby home - developments in support of bereaved parents, families & whanau in NZ

Vicki Culling

New Zealand has a perinatal death rate of just over one per cent of all births and Sands NZ (Stillbirth and Newborn Death Support) is one of the central organisations that provide support to parents, families and whanau (extended family) who experience the death of a much loved baby. Funding for a full-time Projects Coordinator in 2006 saw the development of many initiatives that have resulted in better practice and support for bereaved families.

Two initiatives that emerged from 2006 focus on the common practice in New Zealand of taking our deceased babies home for the days prior to the funeral/service and interment/cremation. The first initiative was a set of national guidelines for the transportation of a deceased baby, with separate versions for a) parents, families and whanau, b) hospital staff and c) the police and paramedics. The second initiative was the development and production of a vessel that would meet the needs of both transporting the baby and keeping their body cool when at home.

This presentation covers the development of both initiatives which included negotiation and discussion with various government departments, agencies and organisations that had an interest in this issue. Both the guidelines and the vessel (which is yet to be named) are examples through which health professionals can better communicate with bereaved parents and families and ensure that they are making informed choices. They are also an example of parent-led care - as the impetus for these initiatives came from bereaved parents looking for a better way to transport their babies.

O33 - Pregnancy Loss and the Death of a Baby: Guidelines for professionals

Judith Schott, Alix Henley

A new and expanded edition of the Sands guidelines was published and launched in the UK in June 2007. This presentation will outline the main themes that run through the Guidelines and explore some of the key issues in more depth, for example, creating memories of the baby.

O34 - Care pathway following pregnancy loss

Hilary Patterson

Ulster Hospital, Belfast, Northern Ireland

Hilary Patterson, a midwife with 18 years experience at the Ulster Hospital in Belfast, identified a lack of available professional support in Northern Ireland for parents and their families who were grieving following the loss of their child through miscarriage, stillbirth or neonatal death. She recognised the need for the role of a bereavement support midwife, which was not available in the province.

Training at diploma level in Bereavement counselling is not available in Northern Ireland, therefore the Women &Child Health Directorate of the Ulster Hospital, Dundonald arranged for her to travel to England for the period of one year to train as a bereavement counsellor. In Feb 2003 Hilary achieved a Diploma in Bereavement Counselling (distinction), Gold Training.

Having gained the required qualification she then began the process of setting up a bereavement service for the directorate. This pioneering post, the first of its kind in Northern Ireland has now been established for almost 4 years, providing a confidential bereavement service for couples grieving the loss of their baby or child. All bereavement counselling is provided in the hospital or the home environment.

The experience of any pregnancy loss is described by Moulder (1998) as life changing events. Powell (1977) describes the grief that may be observed in parents following a pregnancy loss as the loss of hopes and dreams of the future of both parent and child.

Adopting a holistic approach the specialist midwife supports and offers practical advice to parents who are bereaved following loss through stillbirth, miscarriage, or neonatal death (Horsfall 2001). Without such support women and couples who have been bereaved as the result of the death of a child or baby may never have the opportunity to access personalised bereavement support in this way.

This presentation will focus on the development of a co-ordinated framework of bereavement pathways depending on gestation and their potential to transform the delivery of bereavement services to overcome inequalities in care provision and service delivery.

The development and design of the pathways will be discussed with particular reference to an integrated Stillbirth care pathway following the babies and families journey underpinned and complemented by guidance set out in the 'Good Practice in consent and the care of the bereaved', (DHSSPS Dec 05) and the 'Careplan for women who experience miscarriage, stillbirth or neonatal death', (DHSSPS Dec 05). The pathway provides supportive information and choices that are responsive to the individual and family needs, consistent in content, and are respectful of culture and diversity.

O35 - WORKSHOP - Beyond the first year - care needs and ways of remembering

Liz Davis, Vicki Culling, Line Christoffersen, E. Thorp, K. Anker,

Sherokee Ilse, Tim Nelson, Ros Richardson

The death of a baby is a life changing experience. It is not something parent's 'get over' and they do not forget, but as time passes they gradually readjust. This workshop aims to explore the ways of meeting the practical, spiritual and emotional needs of parents beyond the first year to help them in this.

Goals

- Share ideas for memorials and tributes
- Look at different rituals and ways of acknowledging anniversaries and holiday times
- Learn how poetry, writing, music and creative work can be supportive
- Highlight support resources available
- Look at how care programmes can be improved for the return home and for longer term support
- Explore the 'gifts' of grief

P1 - Perinatal Hospice: Developmentand needs assessment for program implemetation

Erica L. Hamilton

The University of North Carolina at Greensboro (UNCG), Greensboro, NC, United States

Introduction: Perinatal hospice has been suggested an alternative in caring for infants diagnosed with life-threatening conditions, incorporating fundamentals of palliative care to increase quality of life. Previous literature regarding the benefits of perinatal hospice programs has focused on clinical opinion and case studies, with little evidence-based feedback from parents to support observations and opinions of medical personnel (Hoeldtke & Calhoun, 2001; Calhoun et al, 2003; Sumner et al, 2006).

Method: In this study (n=93), parents having experienced the loss of an infant aged one year or younger completed an internet-based survey in order to obtain information for development of a community support program for infants with life-threatening conditions and their families. Members of five infant loss support groups had regulated access to the anonymous survey, which addressed topics encompassing the type of loss their family experienced and the services their family received. The survey was available at the international level and utilized both quantitative and qualitative approaches. Topics covered included information about diagnosis, year of death, length of life, hospice care, physician involvement, other children in the home, and retention of keepsakes.

Results: Respondents (n=88) indicated that a majority (n=58, 65.91%) of infant losses were assigned a diagnosis, whether in utero or postpartum. In diagnosed cases, there was an equal chance (50%) for a before-birth or after-birth diagnosis. There were two survey "Tracks", consisting of Track 1: "Miscarriage or situation in which the pregnancy was ended due to a life-threatening diagnosis" and Track 2: "All other situations". Seventy-five percent of respondents (n=84) identified with "All other situations", including stillbirths or full-term pregnancies with life-threatening conditions. Twenty-five percent of respondents (n=84) identified with "Miscarriage or situation in which the pregnancy was ended due to life-threatening diagnosis" (i.e., miscarriage or termination of pregnancy due to a life-threatening diagnosis). Regardless of survey track chosen, a majority of respondents indicated that grief counseling was sought after their family's loss (Track 1 (n=21): 71.43%; Track 2 (n=60): 70%).

Conclusions: Additional data is dicussed and developed program materials are presented. Implications for further research in the field of perinatal hospice and additional suggestions for program development based on parental feedback are discussed.

Participating UNCG Departments: Department of Psychology, Genetic Counseling Program, Lloyd International Honors College

Participating Community Organization: Kids Path, of Hospice and Palliative Care of Greensboro

Financial Support: Community-Based Research Grant (Office of Leadership and Service-Learning, Office of Undergraduate Research at UNCG.

P2 - SUDI and Stillbirth - What to say to the prospective parent: The public health dilemma for health professionals at the coalface

Ros Richardson, MPH, Grad Dip Soc Sc., RN

Health Promotion Manager, SIDS and Kids NSW, Sydney AUSTRALIA.

Introduction: SIDS and Kids NSW supports those who experience the death of their baby or child during pregnancy, birth and infancy, including the experiences of miscarriage and early pregnancy loss, stillbirth, neonatal and infant death and the death of a child up to 6 years. Our role includes the provision of support services for bereaved parents and community education for those who are or plan to be pregnant. New South Wales is Australia's highest populated state, with approximately 88,000 births annually. More than 1000 families experience the death of their baby or young child within our brief each year.

SIDS and Kids NSW receives an average of 20 inquiries weekly, requesting information about reducing the risks of SUDI. Many callers are beyond the 20th week of pregnancy and contact us as they make preparations for their baby.

We provide evidence based public health information to callers about reducing the risks of SUDI. However in the absence of a public health campaign about the risks of stillbirth, we give no information about the importance of being vigilant about the wellbeing of mother and baby as pregnancy progresses. In recent times several callers have re-contacted us thanking us for the information we gave about SUDI, but informing that their baby was stillborn. Many anecdotally report that they delayed seeking medical attention despite a prolonged period of lack of fetal movements, in the belief that this is to be expected or with a sense of not wanting to trouble their health care provider.

Discussion: This paper will explore this dilemma for health professionals, highlighting the lack of awareness of stillbirth and the current gap that exists between the known risk factors for stillbirth and the lack of public health campaigns through which professionals can be equipped and inform prospective parents informed.

P3 - Improving community midwifery practice to reduce infant mortality in Coventry 2006 - 2008

Liz Bailey, Gina Robinson

University Hospitals Coventry & Warwickshire NHS Trust, Coventry, UK

This Community Midwifery Project aims to reduce infant mortality in Coventry by improving midwifery practice in priority neighbourhoods. Financed by regeneration funds the project intends to demonstrate that home visiting women to complete an individualised midwifery care pathway contributes to improved pregnancy outcomes and ultimately a reduction in infant mortality.

A local audit of pregnancy records of women experiencing a pregnancy loss was undertaken and information gathered was assessed according to ethnic, social and lifestyle factors. This was combined with a literature search which highlighted that women from disadvantaged communities were at greater risk of pregnancy loss.

The project aims to demonstrate a measurable reduction in smoking, increased breastfeeding rates, reduce the number of low birth weight babies, and improve access to health services and local agencies. These outcomes should impact positively on infant mortality rates

Women referred to the project are offered a face to face visit in the home or place of their choosing, allowing time for them to disclose any concerns that could impact on their wellbeing. The midwife is accompanied by a peer support worker who can offer culturally sensitive information and support. New documentation was developed in the form of a rapid risk referral, and an individualised community midwifery care pathway that can serve as a tool for midwives beyond the life of the project.

Coventry University have been commissioned to evaluate the project and are supportive of its development. Ethical approval was sought but advised as unnecessary as the project serves as a service development and only secondary data will be analysed.

Since January 2007, 200 women were referred into the project. We aim to provide a home visit to 900 women within the duration of the project.

The presentation will include audit findings, project and document design and midwives experiences of the process.

P4 - The relationship between professional burnout and pyscological impact of life events in healthcare professionals involved in stillbirth management

Claudia Ravaldi[1,2], Ametista Biagini[1,2], Francesco Lapi[3], Valdo Ricca[2], Alfredo Vannacci[1,3]

[1]CiaoLapo Onlus; [2]Department of Neurological and Psychiatric Sciences, [3]Department of Preclinical and Clinical Pharmacology, University of Florence, Careggi General Hospital

Introduction: The death of a child possess an undisputed traumatic effect on one person's life. Perinatal death, and stillbirth in particular, is a profoundly distressing event, able to disrupt the psychological balance of mothers, fathers and families, sometimes associated with long-term psychological disturbances. The assistance to perinatal loss can be an extremely stressful event for the care-giver too, who is very often unskilled in coping with such a tragic and unexpected termination of pregnancy. The non-lucrative association CiaoLapo Onlus (www.ciaolapo.it) was recently founded to promote research and assistance on stillbirth in Italy, with the aim of providing a free service of psychological assistance to grieving parents after perinatal death. Methods. Here we report results of a preliminary investigation on the impact of stillbirth experiences on 60 care-givers, with particular regard to the effect of stressful professional experiences (measured by means of the Impact of Event Scale - IES) in the development of a burn-out syndrome (measured by means of the Maslach Burn-Out Inventory - MBI).

Results: The mean age of participants was 38.0 ± 9.1(mean ± standard deviation), 90% were females, 40.0% midwives, 20.0% obstetricians, 16.7% nurses, 10% psychologists and 13.3% other health care professionals (medical doctors, mainly psychiatrists); the mean number of work years was 13.2 ± 8.7.

Both the levels of event impact and professional burnout scales were significantly higher in midwives, compared with other healthcare professionals. Nevertheless, correlation analyses reported a poor relationship between the IES and MBI total scores (_=0.138; p=0.325) and subscales.

Conclusions: According to these results, midwives are more easily exposed to the psychological impact of a stillbirth experience, compared with other healthcare professionals involved in the management of perinatal death. They also presented a higher level of professional burn-out, but the two scales were not related.

P5 - The Flame and the Stone: remembrance and the Jewish way of death

Paul Kleiman and Jo Richler

"The Jewish religion provides an exquisitely structured approach to mourning" (Lamm, 2000). Paul and Jo's first child - Alexander (always known as 'Rocky') - died immediately after birth. As orthodox Jews they were faced with having to deal with customs and rituals designed for a time when perinatal death was a relatively common occurrence, and the expectation was that bereaved parents would quickly 'move on'. As attitudes towards the death of a baby have changed, this presentation illustrates some of the main Jewish customs and rituals in relation to death, mourning and remembrance, and how they provide comfort and support not only in the immediate aftermath of the death of a much desired child, but for the days, weeks, months and years following.

P6 - Pregnancy loss and the death of a baby: Guidelines for professionals

Judith Schott and Alix Henley

The 2007 edition of the Sands Guidelines Pregnancy loss and the death of a baby: guidelines for professionals was published and launched in June. The Guidelines are widely recognised in the UK as a benchmark for good practice. The poster outlines some of the changes to the Guidelines since the last edition which was published more than 10 years ago

Evaluation Form

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Sunday 30th September 2007

Please indicate your evaluation of each session by circling the appropriate score

Score range: 1 poor 2 average 3 good 4 excellent

JOINT PLENARY

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

THE IMPACT OF A BABY'S DEATH

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

LIVING, LOVING, REMEMBERING

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

ENABLING PARENTS BY PROVIDING INFORMED CHOICE

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

WORKSHOP: PROVIDING CARE AND LOOKING AFTER YOURSELF

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

WORKSHOP: HELPING GRIEVING DADS FIND THE RIGHT TOOLS

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

Evaluation Form

Monday 1st October 2007

Please indicate your evaluation of each session by circling the appropriate score

Score range: 1 poor 2 average 3 good 4 excellent

JOINT PLENARY

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

CULTURAL AND RELIGIOUS ISSUES IN BEREAVEMENT

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

DIVERSITY OF DIFFERENT NEEDS IN DIFFERENT PREGNANCIES

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

WORKSHOP: COMMUNICATING ACROSS LANGUAGE BARRIERS; FAMILIES AND LOSS

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

WORKSHOP: UNDERSTANDING COUPLES DIFFERENT WAYS OF GRIEVING

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

CANDLE LIGHTING AND POETRY

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

Evaluation Form

Tuesday 2nd October 2007

Please indicate your evaluation of each session by circling the appropriate score

Score range: 1 poor 2 average 3 good 4 excellent

JOINT PLENARY

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

HELPING PARENTS THROUGH THEIR GRIEF

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

FLOWERS ON THE LAKE - A TIME TO REFLECT

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

MODELS OF CARE

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

WORKSHOP: BEYOND THE FIRST YEAR - CARE NEEDS AND WAYS OF REMEMBERING

Content:	1 2 3 4	*Comments/Highlight(s)*
Relevance/Value:	1 2 3 4	

Evaluation Form

Conference Management

Please indicate your evaluation of each session by circling the appropriate score

Score range: 1 poor 2 average 3 good 4 excellent

Pre-conference admin arrangements

1 2 3 4

Conference organisation on site

1 2 3 4

Venue/accommodation

1 2 3 4

Catering

1 2 3 4

Comments

Conference Feedback

1. Overall impression/comments

2. What actions do you plan to take as a result of this conference?

3. How would you like to see the conference develop in the future?

Thank you for taking time to complete this form.
Please remove from booklet and return to Profile Productions at Registration desk

List of Attendees

1. Ingunn Aas, Midwife, *National Center for Fetal Medicine,* Trondheim, Norway
2. Louise Abbott, Midwife, *East & North Hertfordshire NHS Trust*, Stevenage, UK
3. Pauline Allman, Australian Representative, Sands Australia, *Lockleys*, Australia
4. Kate Anker, Trustee, *Sands,* UK
5. Tahera Ansari, Clinical Research Scientist, *NPIMR*, Harrow, UK
6. Marie-Helene Arti, Education and Development Lead Midwife, *South Devon Healthcare NHS Trust,* Torquay, UK
7. Letitia Ashington, Bereavement Coordinator, *Good Hope Hospital NHS Trust*, Sutton Coldfield, UK
8. Siobahn Avery, Midwife, *Maidstone and Tunbridge Wells NHS Trust*, Tonbridge, UK
9. Margarita Bariou, Bereavement Services Specialist Midwife, *Birmingham Women's Health Care NHS Trust*, Birmingham, UK
10. Jane Barlow, Chairperson and Befriender, *Wrexham and Clwyd Sands*, Mold, UK
11. Emem Bassey, *University of Uyo Teaching Hospital*, Uyo, Nigeria
12. Clare Beesley, Bereavement Midwife, *Birmingham Heartlands Hospital*, Birmingham, UK
13. Michael Berman, Clinical Professor of Obstetrics and Gynaecology, *Yale University of Medicine*, USA
14. Trude **Berntzen**, Board Member, *Unexpected Child Death Society of Norway*, Oslo, Norway
15. Charlotte Bevan, *Sands*, Wiltshire, UK
16. Christine Birrell, Midwife, *Fife Sands*, UK
17. Deborah Blackhurst, Midwife, *Walsall Hospitals NHS Trust*, Walsall, UK
18. Caroline Blackwell, Conjoint Professor, *University of Newcastle*, Newcastle, Australia
19. Christine Bodkin, Chief Executive, *Edwards Trust Sunrise*, UK
20. R Boorsma, Doctor, *Laboratorium Volksgezondheid Friesland*, Leeuwarden, Netherlands
21. Katelijne Bouman, Clinical Geneticist, *University Medical Centre Groningen*, Groningen, Netherlands
22. Jean Bowden, *Solihull Sands*, Solihull, UK
23. Deb Boyd, Board Member, *Stillbirth and Neonatal Death Support (QLD) inc.,* New Farm, Australia
24. Gill Boyle, Midwife, *North Cheshire Hospitals NHS Trust,* Warrington, UK
25. Penny Brabin, Psychologist, *Independent Practice,* Glen Iris, Australia
26. Carolyn Bray, Fundraising & Events Manager, *Boston & District Sands*, Lincs, UK
27. Lisa Brayshaw, Parent Support Worker, *Birmingham Sands*, Birmingham, UK
28. Pete Brayshaw, Treasurer, *Birmingham Sands*, Birmingham, UK
29. Martin Brewin, Barney's Daddy, *BabyBarney.org.uk*, UK
30. Liz Brown, Chair, *Sands Solihull Branch*, Redditch, UK
31. Janet Carey, Board Member, *Stillbirth and Neonatal Death Support (QLD) inc.*, New Farm, Australia
32. Lesley Carline, Bereavement Specialist Midwife, *Royal Berkshire Hospital,* Reading, UK
33. Karen Casson, Lecturer in Health Promotion, *University of Ulster*, Newtownabbey, UK
34. Ann Chalmers, Chief Executive, *Child Bereavement Trust*, UK
35. Moon Fai Chan, Assistant Professor, *Kiang Wu Nursing College*, Macau, Malaysia
36. Adrian Charles, Pathologist, *Pathwest*, Subiaco, Australia
37. Line Christoffersen, Associate Professor, *Unexpected Child Death Society of Norway*, Oslo, Norway
38. Carol Clay, Twinline and Bereavement Coordinator, *TAMBA*, Guildford, UK
39. Debbie Clements, Midwife, *North Cheshire Hospitals NHS Trust*, Warrington, UK
40. Sandra Coleing, Director of Quality, *Stockport Homes*, Stockport, UK
41. Samantha Collins, Midwife, *Queen's Hospital,* Burton-Upon-Trent, UK
42. Theresa Cooke, Midwife, *Royal College of Midwives*, Liverpool, UK
43. Ann Coughlin, Treasurer, *Solihull Sands*, Solihull, UK
44. Philip Cox, *Birmingham Women's Hospital*, Birmingham, UK
45. Sonia Coy, Midwife, *Powys LHB*, Neath, UK
46. Fiona Cross-Sudworth, *Perinatal Institute*, Birmingham, UK
47. Vicki Culling, National Projects Coordinator, *Sands New Zealand*, Wellington, New Zealand
48. Marion Currie, *Sands*, UK
49. Jackie Curtin, *Sands*, UK
50. Ebrillwen Dafis-Jones, Health Visitor, *Powys LHB,* Machynlleth, UK
51. Victoria Davidson, Community Recovery Worker, *Social Services*, Solihull, UK
52. Liz Davis, Board Member, *Stillbirth and Neonatal Death Support (QLD) inc.*, New Farm, Australia
53. Linda Doran, Athy, Ireland
54. Katie Duff, PR, *Sands*, UK
55. R Philip Duke, Wokingham, UK
56. Wes Duke, Medical Officer, *Centers for Disease Control and Prevention*, Atlanta, USA

List of Attendees

57. David Ellwood, Professor of Obstetrics and Gynaecology, *Australian National University Medical School*, Woden, Australia
58. Jan Jaap Erwich, Obstetrician, *University Medical Centre Groningen*, Groningen, Netherlands
59. Martine Eskes, *Obstetrician, National Institute of Public Health and the Environment,* Bilthoven, Netherlands
60. Jane Fisher, Director, *Antenatal Results and Choices (ARC)*, UK
61. Vicki Flenady, Board Member, *Stillbirth and Neonatal Death Support (QLD) inc.*, New Farm, Australia
62. Ruth Fretts, Board Member, *Stillbirth and Neonatal Death Support (QLD) inc.*, New Farm, Australia
63. Frederik Froen, Chair, *Stillbirth and Neonatal Death Support (QLD) inc.,* New Farm, Australia
64. Stephanie Fukui, Board Member, *Stillbirth and Neonatal Death Support (QLD) inc.*, New Farm, Australia
65. Vivi Furuheim, Midwife, *Regional Perinatalkomite,* Asker, Norway
66. Marie Ganters, Board Member Midwife, *Swedish National Infant Foundation*, Varberg, Sweden
67. Jason Gardosi, Director, *Perinatal Institute*, Birmingham, UK
68. Shirley Gittoes, Welsh Network Convenor, *Sands - Powys Branch*, Llandrindod Wells, UK
69. Robert Goldenberg, Professor, *Drexel University College of Medicine*, Philadelphia, USA
70. Alison Goodfellow, Clinical Midwifery Consultant, *South Eastern Sydney Illawarra Health Service*, Wollongong, Australia
71. Sanne Gordijn, Doctor, *University Medical Centre Groningen*, Groningen, Netherlands
72. Adrienne Gordon, Neonatologist, *Royal Prince Alfred Hospital*, Sydney, Australia
73. Steve Gould, Consultant Paediatric Pathologist, *CEMACH*, Oxford, UK
74. Malcolm Griffiths, Consultant Obstetrician, *Luton & Dunstable Hospital*, Luton, UK
75. Marriette de Groot-Noordenbos, Medical Social Worker, *University Medical Centre Groningen*, Groningen, Netherlands
76. Shyamala Guruvare, Associate Professor Obstetrics and Gynaeology, *Kasturba Medical College*, Manipal, India
77. Steven Guy, Chair & Trustee, *Sands*, Northern Ireland, UK
78. Grace Guyon, Coordinator Quality Improvement, *Alberta Perinatal Health Program*, Edmonton, Canada
79. Ndema Habib, Biostatistician, *Muhimbili University for Health and Allied Science*, Bergen, Norway
80. Jackie Hadley, Support Counsellor, *Good Hope Hospital NHS Trust*, Sutton Coldfield, UK
81. Steve Hale, Treasurer, *Sands*, UK
82. Sue Hale, Group Services Manager, *Sands*, UK
83. Vivien Hall, Bereavement Support Midwife, *Gloucestershire NHS Foundation Trust*, Gloucester, UK
84. Erica Hamilton, Undergraduate Researcher, *University of North Carlina at Greensboro*, Salem, USA
85. Shona Hamilton, Consultant Obstetrician, *Calderdale and Huddersfield NHS Trust*, Halifax, UK
86. Deborah Harris, Nurse Practitioner, *Waikato Hospital*, Hamilton, New Zealand
87. Lorraine Harrison, Education/Support Worker, *Sids & Kids*, Como West, Australia
88. Alix Henley, *Sands*, Switzerland
89. Karen Henson, Bereavement Services Specialist Midwife, *Birmingham Women's Health Care NHS Trust*, Birmingham, UK
90. Louise Hernqvist, Head Officer, *Swedish National Infant Foundation*, Varberg, Sweden
91. Marie Herou, Board Member, *Swedish National Infant Foundation*, Varberg, Sweden
92. Sarah Higton, Family Care Coordinator, *Derby Hospitals NHS Foundation Trust*, Derby, UK
93. Jozien Holm, Professor of Obstetrics, *University Medical Centre Groningen*, Groningen, Netherlands
94. Julie Holm-Tveit, Doctor, *Rikshospitalet-Radiumhospitalet HF*, Oslo, Norway
95. Clare Howitt, Fundraising Assistant, *Boston & District Sands*, Lincs, UK
96. Rachel Hudson, Midwife, *Walsall Hospitals NHS Trust*, Walsall, UK
97. Andrea Hurst, Group Secretary, *Birmingham Sands*, Birmingham, UK
98. Sherokee Ilse, Board Member, *Stillbirth and Neonatal Death Support (QLD) inc.*, New Farm, Australia
99. Monir Islam, *WHO - Making Pregnancy Safer*, Switzerland
100. Teresa James, Bereavement Midwife, *Birmingham Heartlands Hospital*, Birmingham, UK
101. Hakeem Jokhio, *Aga Khan University*, Karachi, Pakistan
102. Catherine Jones, Bereavement Support Midwife, *Barnsley Hospital NHS Foundation Trust*, Barnsley, UK
103. Rosie Jones, Clinical Psychologist, Llandysul, UK
104. Trine Kalstad, Director of Public Health and Bereavement Support, *Unexpected Child Death Society of Norway*, Oslo, Norway

105. Peter Kelehan, Pathologist, *National Maternity Hospital*, Dublin, UK
106. Melanie Kirkpatrick, Bereavement Support Midwife, *Stoke Mandeville Hospital*, Aylesbury, UK
107. Tone Kirksaether Skogmo, *Social Worker*, National Center for Fetal Medicine, Trondheim, Norway
108. Paul Kleiman, Manchester, UK
109. F.J. Korteweg, MD PhD Student, *University Medical Centre Groningen*, Groningen, Netherlands
110. Rachel Koshy, Principal Assistant Director, *Minsitry of Health* Malaysia, Putrajaya, Malaysia
111. Neeraja Kuruba, Royal Hallamshire Hospital, Sheffield, UK
112. Oluwafemi Kuti, *Obafemi Awolowo University Teaching Hospital*, Ilesa, Nigeria
113. Sarah Lake, Midwife, *University Hospital North Staffordshire*, Cheadle, UK
114. Jane Laking, Bereavement Midwife, *Whittington Hospital,* UK
115. Terry Langford, Treasurer, *Lincoln Sands*, UK
116. Diane Lawrence, Care Coordinator, *Life Pregnancy Care*, Salisbury, UK
117. Lucy Lelliott, Former Chair, *Sands*, Salisbury, UK
118. Patricia Lindley, Neonatal Nurse, *Salford Royal NHS Trust*, Manchester, UK
119. Neal Long, Director, *Sands*, UK
120. Helen Lovatt, Midwife, *University Hospital North Staffordshire*, Cheadle, UK
121. Frances MacGuire, Hebden Bridge, UK
122. Dharma Manandhar, President and Executive Director, *MIRA*, Kathmandu, Nepal
123. Tamas Marton, Consultant Pathologist, *Birmingham Women's Hospital*, Birmingham, UK
124. Geraldine Masson, Consultant Obstetrician, *University Hospital of North Staffordshire*, Stoke-on-Trent, UK
125. Trond Mathiesen, Secretary General, *Unexpected Child Death Society of Norway*, Oslo, Norway
126. Katie Matthews, Group Coordinator, *North East London Sands*, London, UK
127. Luigi Matturri, Chairman, *Institute of Pathology Univarsity of Milan*, Italy
128. Rosemary Mbatha-Ndaba, Lecturer, *University of Botswana*, Gaborone, Botswana
129. Lesley McCowan, *University of Auckland*, New Zealand
130. Pat McGeown, Head of Midwifery Unit / Regional Co-ordinator CEM, *Perinatal Institute*, Birmingham, UK
131. Carole McKeeman, Area Bereavement Coordinator, *Western Health and Social Care Trust*, Derry, UK
132. Fiona McKenzie, Clinical Geneticist, *Hunter Genetics*, Waratah, Australia
133. Sheryl McMahon, Trustee, *Sands*, UK
134. Chrissy Merton, Author and Publisher, *Possibility Publishing*, London, UK
135. Catherine Miller, *Birmingham Sands*, Birmingham, UK
136. Mary Molloy, Bereavement Support Midwife, *City Hospital*, Birmingham, UK
137. Dawn Moore, Staff Nurse, *Birmingham Sands*, Birmingham, UK
138. Kate Morse, Specialist Midwife, *Perinatal Institute*, Birmingham, UK
139. Chris Navin, Bereavement Support Midwife, *University Hospital of South Manchester NHS Trust*, Manchester, UK
140. Tim Nelson, Minneapolis, USA
141. Diep Nguyen, Founder, *BabyKick & BabyKick Alliance*, Manhattan Beach, USA
142. Thi Hoai Duc Nguyen, Director, *Institute for Reproductive and Family Health*, Hanoi, Vietnam
143. Jeanne Nicholls, Trustee, *Sands*, Nottingham, UK
144. Ellen Nijkamp, Student, *University Medical Centre Groningen*, Almelo, Netherlands
145. Margaret Nixon, Delivery Suite Coordinator, *South Devon Healthcare NHS Trust*, Torquay, UK
146. Roberta Oneda, Post-Doctoral Fellow, *University of Milan*, Milano, Italy
147. Alison Orr, Trustee, *Sands*, Portadown, Northern Ireland
148. Mana Parast, Instructor, *Brigham and Women's Hospital,* Brookline, USA
149. Julia Parker, Chairperson, *Lincoln Sands,* UK
150. Hilary Patterson, Bereavement Support Midwife, *South Eastern Health and Social Care Trust*, Dundonald, Northern Ireland
151. Bob Pattinson, Director of Maternal and Infant Health Care Strate, *University of Pretoria,* Pretoria, South Africa
152. Karin Pettersson, Head of Department of Obstetrics, *Karolinska University Hospital,* Huddinge, Sweden
153. Christopher Proudlove, UK
154. Pauline Powlesland, *Plymouth Sands*, Plymouth
155. Trevor Powlesland, *Plymouth Sands*, Plymouth
156. Jyotsna Pundir, *Conquest Hospital,* St. Leonards on Sea, UK
157. Ingela Radestad, Board Member, *Swedish National Infant Foundation,* Varberg, Sweden
158. Claudia Ravaldi, President, *CiaoLapo Onlus,* Prato, Italy

List of Attendees

159. Jojo Ravise, Data Manager, *University Medical Centre Groningen,* Groningen, Netherlands
160. Uma Reddy, Pregnancy and Perinatology Branch, *National Institutes of Health*, USA
161. Elise Rengaard, Social Worker, *National Center for Fetal Medicine*, Trondheim, Norway
162. Julie Richards, Head of Midwifery, *Powys LHB*, Llandrinod Wells, UK
163. Ros Richardson, Health Promotion Manager, *SIDS and Kids NSW,* Australia
164. Jo Richler, *Edwards Trust*, Manchester, UK
165. Gustavo Romero-Gutierrez, Obstetrician, *Mexican Institute of Social Security,* Guanajuato, Mexico
166. Heather Russell, Area Bereavement Coordinator, *Belfast Health and Social Care Trust*, Belfast, Northern Ireland
167. Eli Saastad, RNM PhD Student, *Akershus University College,* Norway
168. Rehanah Sadiq, *Muslim Hospital Chaplain & Psychotherapist*, UK
169. Carole Sadler, Specialist Midwife Bereavement Services, *Royal Wolverhampton Hospitals NHS Trust*, Wolverhampton, UK
170. Judith Schott, *Sands*, UK
171. Janet Scott, Information & Research, *Sands*, UK
172. Jennifer Sefton, Nursery Assistant, *Buffer Bear,* Maidenhead, UK
173. Roopal Shah, Befriender, *Leicester Sands*, UK
174. Ritu Sharma, Birmingham Sands, UK
175. Joanne Smedley, Midwifery Bereavement Coordinator, *Nottingham University Hospitals,* Nottingham, UK
176. Gordon Smith, Head of Department & Consultant in Maternal-Fetal, *University of Cambridge,* Cambridge, UK
177. Karen Smith, Hebden Bridge, UK
178. Michael Smith, Befriender, *Leicester Sands*, Leicester, UK
179. Rosalinde Snijders, Scientist, *FMF Netherlands*, Groningen, Netherlands
180. Marion Sokol, Co-Chair, *Stillbirth and Neonatal Death Support (QLD) inc.,* New Farm, Australia
181. Margaret Sparrey, Dorridge, UK
182. Ruth Sparrey, Livelihoods Advisor, *Sands*, Flitton, UK
183. Sam Springall, UK
184. Tomasina Stacey, Research Midwife, *University of Auckland*, Auckland, New Zealand
185. Kate Stanton, *Derby Sands*, Derby, UK
186. Suzanne Stevens, Barney's Mummy, *BabyBarney.org.uk*, UK
187. Erica Stewart, Operations Office, *Sands*, UK
188. Maria Stewart, Clinical Risk Co-ordinator, *Heart of England NHS Foundation Trust*, Birmingham, UK
189. G Sunanda, Consultant Obstetrician and Gynaecologist, *Heart of England Foundation NHS Trust*, Solihull, UK
190. Hui Lin Sun, PhD Student, *University of Ulster*, Northern Ireland
191. Rosnah Sutan, PhD Student, *Aberdeen University*, Aberdeen, UK
192 Babill Stray-Pedersen, Professor, *Faculty of Medicine*, Riskhospitalet, Oslo, Norway
193. Simin Taavoni, Researcher, *Iran School of Medical Sciences*, Tehran, Iran
194. Farinaz Taheri, *Shahid Beheshti University of Medical Science*, Tehran, Iran
195. Josephine Taylor, Midwife, *Maidstone and Tunbridge Wells NHS Trust*, Brede, UK
196. Mark Taylor, Sands Befriender, *Lincoln Sands*, UK
197. Sharon Taylor, Sands Befriender, *Lincoln Sands*, UK
198. Janne Teigen, Midwife, *LUB*, Larvik, Norway
199. Elaine Thorp, Vice Chair & Trustee, *Sands*, UK
200. Bert Timmer, Pathologist, *University Medical Centre Groningen*, Groningen, Netherlands
201. Ann Tonks, Anomaly Specialist, *Perinatal Institute*, Birmingham, UK
202. Erik Van der Worp, Pathologist, *LVF*, Herenveen, Netherlands
203. M Van Pampus, Obstetrician, *University Medical Centre Groningen*, Groningen, Netherlands
204. Ravi Vandhana, Royal Shrewsbury Hospital, Shrewsbury, UK
205. Jane Wadham, Sands Member, *Sands*, UK
206. Adja Waelput, Researcher Perinatal Health, *RIVM*, Bilthoven, Netherlands
207. Sonya Wallbank, Clinical Psychologist in Training, *Leicester University*, Leicester, UK
208. Christopher Walsh, Social Worker, *Salford Royal NHS Trust*, Manchester, UK
209. Paula Walters, *Sands North Herts*, Hitchin, UK
210. Jane Watson, A&E Sister, *South Devon Healthcare NHS Trust*, Newton Abbot, UK
211. Julie Waugh, Community Psychiatric Nurse, *Newcastle North Tyneside and Northumberland MHT*, North Shields, UK
212. Stian Westad, Obstetrician, *Perinatal Committee of Eastern Norway*, Lillehammer, Norway
213. Nikki Whelan, Obstetrician, *Wesley Hospital*, Brisbane, Australia

214. Elspeth Whitby, Radiologist, *University of sheffield,* Sheffield, UK

215. Janet Whitelaw - Jones, Health Specialist, *HLSP*, UK

216. Chris Wildsmith, Newport Pagnell, UK

217. Nichola Wildsmith, Newport Pagnell, UK

218. Mandy Williams, Research Midwife, *Perinatal Institute*, Birmingham, UK

219. Sandra Woodall, Counsellor, *Edward's Trust*, Birmingham, UK

220. Mary Worth, Midwife, *University Hospital of South Manchester NHS Trust*, Manchester, UK

221. Chris Wright, Consultant Perinatal Pathologist, *Newcastle Upon Tyne NHS Trust*, Newcastle-Upon-Tyne, UK

222. Clare York, Bereavement Support Midwife, *Queen's Hospital Burton*, Lichfield, UK

223. Linda Winstone, Community Midwife, *Maidstone and Tunbridge Wells NHS Trust*, Tunbridge Wells

224. Jane Zuccollo, Perinatal Pathologist, *Auckland District Health Board,* Auckland, New Zealand