



Executive Summary

The Hygeia Foundation, Inc. & Institute for Perinatal Loss and Bereavement

Hygeia Foundation, Inc. is concerned with Pregnancy Loss (miscarriage, stillbirth, neonatal death), Maternal and Child Health and narrowing disparities in access to Information Technologies and Women's Health Services. The Hygeia Foundation, Inc. is committed to improving universal access to healthcare services and healthcare information with respect, dignity and advocacy and...

- Providing solace and bereavement for parents whose children have died before and after birth.
- Improving access to healthcare for women and teens when they are in need a doctor or a referral to a “center of excellence”.
- Educating professionals who care for families who have experienced perinatal loss and childhood death.
- Serving as a portal to perinatal loss and women's healthcare information and portal to women's to current research initiatives into the causes of miscarriages and stillbirths.
- Funding burial and memorial programs for families in need.
- Bridging humanism and technology by embracing art, literature and poetry.
- Committing its resources and mission to underserved, vulnerable and disadvantaged women, children and families
- Seeking philanthropic donations to:
 - Develop and implement its unique programs
 - Fund in-kind programs in patient care and basic science research related to Perinatal Health and Loss
 - Support public health initiatives to reduce perinatal and neonatal morbidity and mortality so as to improve the health of medically and economically disadvantaged families.

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The Hygeia Foundation is well positioned to exponentially affect national and international communities in the aforementioned manner as its founder and president, is a practicing Obstetrician Gynecologist and Clinical Professor of Obstetrics and Gynecology at the Yale University School of Medicine. Dr. Berman is an expert in perinatal loss and bereavement and has at hand a demonstrated commitment to the entire spectrum of problems associated with Perinatal Loss, the resources of over thirty years experience in the care of women and their families who have experienced such losses, and access to an international network of medical specialists with whom consultation, collaboration and ultimate support of their programs will benefit women's, maternal and child health, locally, nationally and internationally.

How is the Hygeia Foundation different from other organizations that provide resources and support for Pregnancy loss and Neonatal Death.?

The Hygeia Foundation is an enduring, (ten years old) internationally recognized Perinatal Loss and Bereavement Resource with a large, international membership and support network of families who have experienced the loss of a pregnancy or newborn child. It is among the few if not the only program founded by and run by a Board-Certified Obstetrician Gynecologist supported by a dedicated Parents Advisory Board, all whom have experienced the loss of a child. The Hygeia Foundation recognizes that thousands of families silently grieve over the loss of their pregnancies, newborns or children with little or no resolution, and as these types of losses entail a unique bereavement, they require a unique and comprehensive approach. Together, Dr. Berman and the Parent Board of the Hygeia Foundation have melded their sorrows, their passions and their cumulative experiences with a vision to advocate for all families who have personally witnessed these losses, and to provide a direct and immediate resource of referral and consultation for the medical, emotional, and educational needs of these families, their caregivers and their healthcare providers. This provides an un-paralleled multidimensional, professional framework which enables the Hygeia Foundation to serve as a unique portal and standard-bearer for such services.

Background

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 cannot be conceived. Pained by these losses, their lives seem devoid of hope. Yet they prevail, for within each of us is a timeless, enduring

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Hygeia®

spark of divine hope, a uniquely human greatness that permits us to challenge adversity and courageously face the unexplainable suffering of our souls and bodies. To realize the existence of this divine hope is a most cherished purpose, for with it our lives have promise and reason.

Infertility, pregnancy loss, neonatal illness and subsequent death are among the most painful losses we can experience, for they deny us a family and leave sightless our vision for immortality through generations of the future. Moreover, a child not born is likewise denied the delight to revel in the simple beauty and endless wonder of this divine hope. Perinatal loss entails a "unique bereavement" and is an "exceptional" type of loss, for a child is not expected to die before his or her parents. Across all cultures, the parent-child relationship is and has been the most enduring and significant.¹ The natural processes of birth, life and death should follow in an orderly and rational sequence and through one's lifetime. Any death but death from "old-age" after a "rich" and fulfilling life is premature. Yet when parents see their child die, or carry the burden of an unborn demise, they live with this disruption of said natural order forever. There has not been nor is there now one common and standard way to manage the recovery from such grief, for it's shadow has been and will be indelibly imprinted in the minds and souls of these parents. Bonding between mother and father and child or expectant child occurs and must be recognized. Death tears this apart. The issues of mourning, of lost promises, of sadness and above all, of maintaining faith must be addressed. Recognition of the impact of these losses must not only be recognized but must also be "main-streamed" into our society. Physicians, Hospitals, the Media and the Government must be the leaders and advocates of this movement.

Many if not most organizations devoted to perinatal, neonatal and early childhood losses have been founded, supported and sustained by parents and families affected and afflicted by such losses. As a physician/obstetrician, I am at one with this subject experiencing it daily with my patients. Yet, in fact I am but an empathetic intruder into these private worlds of my patients' grieving. In response to my professional and emotional involvement in maternal and child health, perinatal loss and neonatal death, and my commitment to make the public more aware of the scope and impact of these losses, I have founded Hygeia® and the Hygeia Foundation, Inc. The pall of grief does not discriminate, and it is basic to the mission of the Hygeia Foundation Inc.® that all individuals searching for solace, bereavement and perinatal healthcare services should

¹ Colin Murray Parkes, Pittu Laungani and Bill Young, editors; *Death and bereavement across cultures*; Routledge, London, 1997, p.193.



have access to these resources. The Hygeia Foundation is about this inevitable sadness and futility of a child's death before and after birth.

Current Programs

- **Website:** <http://hygeia.org> Founded in 1995, Hygeia is a comprehensive, global website for pregnancy loss and bereavement which provides solace, hope, support and information to a growing, membership today exceeding 27,000 families. Hygeia has achieved international recognition for its efforts to narrow access to health-related Internet technologies; i.e. “the digital divide” (The “digital divide” is the gap in making use of opportunities available from the digital revolution due to insufficient access, capacity, and content.)
- ***Get the HealthCare Your Deserve:*** <http://getcare.info> This new program of the Hygeia Foundation, Inc. is intended to improve disparities in access to women's healthcare and pre-natal healthcare services by enabling all women in need of women's and maternal and child health services to find and be introduced to these services with respect, dignity and advocacy. Intended to bring disenfranchised and vulnerable families into the health care system, Get...Care utilizes the Internet to enable families to join and belong to the International Hygeia® community, and thus obtain advocacy and health care referral. This program has been launched in New Haven, Connecticut, (e.g. hospitals, women's centers, Public Schools) and will soon be introduced in other local and national venues. Get...Care was among a select group of Internet-based projects to be presented at the World Congress on the Internet in Medicine in Geneva, Switzerland, December, 2003.
- ***Seminars in Perinatal Loss:*** <http://hygeia.org/seminars.htm> A multi-disciplined, moderated seminar series developed for Ob-Gyn Residents, Medical Students and Support Staff in the management of Perinatal Loss soon to be expanded to all who care for patients who have died or are critically ill.
- ***The Ephemeris Project:*** <http://ephemerisproject.com> An Internet-based system of journaling, mentoring and advocacy intended to preserve those personal values and ethics fundamental to the Healthcare Professional Student. In an age of advanced medical technologies, the ***Ephemeris Project*** promotes and provides a venue of introspection and self-expression among healthcare professional students helping them participate in effective and compassionate care of their patients. Today's healthcare students must learn to balance the science of biomedical research and advanced medical technologies with the ethical implications and effects of such science on the patient and in particular on the physician-patient relationship. The implementation of tomorrow's technologies will require

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healthcare professionals to have an ethic-centered view of these technologies, cognizant of their science yet imbued with an appreciation of the enormous humanistic value inherent at their core. There must be assurance that the benefits of these technologies are fully realized and their expanding sphere of influence does not disenfranchise the patient nor depersonalize the physician-patient relationship. The inclusion of reflective writing about patient encounters can be 'therapeutic, cathartic and beneficial' to the education of students and help them appreciate that their life's work is truly one of 'privileged human relationships'. Dr. Berman has been invited to present this program to the World Congress on the Internet in Medicine, Prague, December 4, 2005.

Details of the Programs

Hygeia Institute for Perinatal Loss and Bereavement

Premise

It is well established that pre-conception care and inter-conception care are essential in improving outcomes of first and subsequent pregnancies. Perinatal and infant morbidity and mortality can thus be influenced by providing all women and their families the availability of perinatal loss and bereavement counseling, pre and inter conception medical counseling and improved and timely access to comprehensive women's healthcare services.

Proposal

To provide a centralized, dedicated regional, national and international headquarters for pregnancy, neonatal and infant loss and bereavement and an office for the business of the Foundation. This center will be located in New Haven, Connecticut hosting, when space is available, local agencies and support groups, a resource center and an onsite physician-medical director. Services provided at the *Institute* will include counseling by social workers/bereavement counselors, access to new technologies for learning, support and comfort, nutritional and "wellness" programs, and bereavement consultations pertinent to miscarriage, pregnancy loss and neonatal death. These consultations will be provided by the medical director, a board certified Ob-Gyn with a special interest in all aspects (medical, social, psychological) of pregnancy loss. These consultations will not compete with the patient's on going care from their caregivers and all patients who have a

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consultation will be referred back to their primary caregivers. If the patients should not have a primary healthcare provider, they will be personally referred to a center of excellence or primary care-giver identified and credentialed by the Hygeia Foundation. The Hygeia Foundation “Institute” will work with Medical Centers, which provide tertiary care and expertise in all areas of High Risk Pregnancies and Recurrent pregnancy loss. Local healthcare professional students (Medical, Nursing, Social work) will be invited to become involved in the Institute’s program, both to learn and experience first hand how to help families whose babies have died and also to volunteer. The Hygeia Foundation Institute for Perinatal Loss and Bereavement will operate on a sliding fee scale, not turning away any patient or family who needs its services. It is expected that funding for this program will come from grants, donations, licensing fees and revenue generated from physician consultations. Out-sourced referrals will be made to those specialized centers for reproductive health, to psychiatrists, psychologists, and other specialized medical and social services. All necessary lab workups and diagnostic evaluations will be outsourced. No medical or surgical therapies will be performed. The Hygeia Foundation & Institute for Perinatal Loss and Bereavement will work closely with the appropriate agencies of the Department of Health and will serve in concert with their mission. The Hygeia Foundation will advocate for all patients who register as members. It is hoped that a resource such as this will contribute to the overall health of the New Haven Community (and others) by improving the general health and well being of the population it serves.

Get The Healthcare You Deserve...

May 19, 2023

Overview of Program

The intent and purpose of this program is to improve the maternal and child health of the population it serves by reducing what are major disparities in health, particularly antenatal health care **in an effort to reduce disparate rates of premature births, perinatal losses and infant deaths.** Among these disparities is a lack of awareness of local healthcare facilities offering maternal and child health care services including prenatal care, a lack of understanding of the need for pre-natal care, albeit early care, the late diagnosis, recognition and acceptance of one’s pregnancy embarrassment and denial, and perhaps, I hypothesize, shame, diminished self worth and dignity and a feeling of isolation without a place or professional to turn to for immediate care, counseling and advocacy. **These families *must* enter and be embraced by a healthcare system.** Thus, by providing not only a significant awareness to the need for pre-natal care, but advocacy and personalized direction for this population at risk, such dignity and self worth can be realized, privacy and confidentiality assured, and through Hygeia’s *Get Care* program,

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personalized referrals can be given to women to present at a healthcare facility so they will know there is an organization advocating for their health. This organization, Hygeia Foundation, Inc. is an established and trusted non-profit organization with a membership of more than 27,000 families, world-wide, currently providing online support, information and advocacy for families who have incurred the devastation of perinatal loss and infant death and is now positioned to work proactively to bring families into the health care system thus improving the individual's health and reducing morbidity and mortality.

The Hygeia Foundation, Inc.®, now in its tenth year, is able to offer not only a backbone of support and information for those families at risk for adverse pregnancy outcomes, but a true System to provide an avenue for wide spread public access to the Hygeia Program through its portal, *Get...Care* (<http://getcare.info>). This portal provides the user with a simple anonymous form which when filled out leads the user to a database of geographic-specific Federally Funded Hospitals and Clinics where Maternal and Child Health Services are available and Global Centers of Excellence where specialized prenatal and delivery care can be given. The user obtains a personalized, signed letter of referral from Hygeia, which introduces them to their health care facility as one who is a member of a respected and important global community and who needs help, much like a private patient would have a letter of referral to a doctor from another doctor. The user of this program would have the advocacy of the Hygeia Foundation, Inc. to help and intervene so the user does get the care she needs. This is further supported by local onsite, designated *Hygeia Physician Advocates* selected from Ob-Gyn and Primary Care House Staff in participating Affinity Healthcare Institutions. The service is free of charge to those who wish to use it and can be easily linked to local and regional social services so the families can have their support as well. The primary entry point into the system is by a "Hygeia Passbook" This is distributed at markets, fast food chains, pharmacies, Laundromats, and other retail venues. The user can go to a public library, school, church, community center etc.(if no internet access is available at home) and be assisted in accessing the *Get...Care* program. A toll-free phone number is also offered. The program is offered in English and Spanish and will be expanded to other languages as needed. The program serves a parallel purpose in narrowing the disparities of the "digital divide" and the disparities in access to healthcare. This program will be aggressively marketed to the intended communities, hoping to secure the endorsement of a celebrity who can reach out to these women.

Educational Objective:

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Fetal and infant mortality rates have decreased dramatically over the last century with improvements in sanitation, nutrition, infant feeding, and maternal and child health care, although the decline has been slower in recent years. However, disparities in the risk of infant death remain. Black and Hispanic teens are more than twice as likely as white teens to mother a child before the age of 20. The infant mortality rate for children born to teen mothers is about 50 percent higher than that for those born to women older than 20. One third of pregnant teens receive inadequate prenatal care; babies born to young mothers are more likely to be low-birth-weight, to have childhood health problems and to be hospitalized than are those born to older mothers. It is the educational objective of the **Get...Care** program to emphasize the need and necessity for health promotion, health prevention, pre-conception care and early pre-natal care. Furthermore, it is the parallel objective to use the convergent technologies of the Internet, email, radio, T.V. and print media to bring underserved and vulnerable families into the healthcare system, inspiring respect, self-esteem, self worth and dignity by making the user

of the system feel they are part of a global, credible and caring "community" and a referral source which will act as advocate for their healthcare needs.

Background:

- Hygeia® is the leading global Internet *community* for pregnancy loss and neonatal death and an important resource for maternal and child health.
- The founder and president of Hygeia® is a practicing Obstetrician and Clinical Professor of Obstetrics and Gynecology, Yale University School of Medicine, and fully committed to this endeavor.
- Hygeia ® has been featured in several media reports, among them, the New York Times, The Boston Globe and The San Francisco Chronicle. Dr. Berman has been interviewed about his work by Katie Couric on the NBC Today Show and by Lisa Birnbach on the CBS Early Show.
- Hygeia ® was honored as finalist in the International Information Technology Competition, The Stockholm Challenge, Stockholm, Sweden, 2002 and presented the Get...Care program at the Society for the Internet in Medicine, Geneva, 2003.
- Hygeia® is now prepared to widely introduce this innovative program in an effort to reduce perinatal morbidity and mortality in medically underserved communities.

Problem:

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- Over 43 million people in the United States lack access to primary health care.
- The infant mortality rate for children born to teen mothers is about 50 percent higher than that for those born to women older than 20.
- 1/3 of pregnant teens receive inadequate prenatal care; babies born to young mothers are more likely to be low-birth-weight, to have childhood health problems and to be hospitalized than are those born to older mothers.
- 11% of Hispanic teens, 10% of black teens, and 4% of white teenagers gave birth
- Blacks and Hispanics are more than twice as likely as white teens to mother a child before the age of 20.
- Service:

Conclusion:

Get...Care:

...addresses women and families who have no healthcare provider thus the disparities in access to maternal and child health in an effort to reduce prematurity and perinatal / neonatal / infant mortality.

...refers and direct users of the program to a Health Care Facility/System locally in their neighborhood.

...provides a personal letter of referral and introduction to the Health Care Facility from a recognized and valid source of referral; i.e. Hygeia Foundation, Inc., which requests such facility to provide care for the bearer of the letter.

...develops a network of Onsite "Hygeia Foundation, Inc. Advocates" from Ob-Gyn, Women's Health and Primary Care House Staff in the facility or in the local of the facility.

...improve the healthcare of these user-families by emphasizing health promotion, health prevention, pre-conception care, early pre-natal care, and providing them with a primary healthcare provider/facility. ...inspires self-respect, self-esteem, self worth and dignity by making the user of the system feel they are part of a global, credible and caring "community" and a referral source which will act as advocate for their healthcare needs

The Ephemeris Project

May 19, 2023

Background:

The Ephemeris Project (<http://ephemerisproject.com>) named after the Latin word for journal or diary, is a program to promote and provide a venue of introspection and self-expression among medical students, physicians-in-training, and other healthcare professionals to better serve them to participate in effective and compassionate care of

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their patients. The Ephemeric Project is an Internet based journal and message board program, supported by twenty-four hour, seven day a week mentoring by a physician, focused on the human values inherent in all Healthcare Professionals.

Today's healthcare professionals and students must balance the science of biomedical research / advanced medical technologies with the ethical implications and effects of such science on the patient and in particular on the physician-patient relationship. The implementation of tomorrow's technologies will require healthcare professionals to have an ethic-centered view of these technologies, cognizant of their science yet imbued with an appreciation of the enormous humanistic value inherent at their core. This is a most promising time to become a health care professional for we have in our immediate future enormous promise in human genomics, cancer therapies and other capabilities of advanced medical technologies. What I believe is needed is to assure that the benefits of these technologies are fully realized and that their expanding sphere of influence does not disenfranchise the patient nor depersonalize the physician-patient relationship. The inclusion and assimilation of art, literature, poetry, bioethics, law, thanatology, theology and at its core, humanism, into the education of medical professionals should help them appreciate that their life's work is truly one of privileged human relationships. More than ever, we will need healthcare professionals who seek to claim or perhaps reclaim meaning, passion and this sense of privilege to their chosen profession. ***The Ephemeric Project*** is a highly motivated initiative which is a part of this forward-looking process and can make a sentinel contribution to the education of the healthcare professionals of tomorrow.

Program:

The Ephemeric Project provides a substantive Web-based portal, database and 24/7 email support / advocacy for Healthcare Professionals. Its platform is a personal / private journal which is entered on the website hosted at <http://ephemerisproject.com> or locally on a PDA which could then be downloaded daily when "synced" with the user's computer. There is as well a public message board program so that Health Professionals can publicly journal and share their stories, feelings and experiences. All public journal entries will be monitored and moderated / mentored by a healthcare professional available 24/7 for advice, opinion and discussion. This ***mentorship*** is essential for this program cannot be effective without someone with the initiative, experience and skills for the user to contact, confide in and seek advice. ([see full discussion of mentoring](#)) Links to publicly accessible commentaries and writings from leaders in the field of the History of Medicine, Biomedical Ethics, End-of-Life care, Philosophy and Literature will complement the program.

Implementation:

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The Beta program is currently online at <http://ephemerisproject.com> but in order to achieve the depth and scope needed to make the program succeed, strategic alliances, sponsors, advertising, marketing and technology support will be sought. Existing, online educational programs (medical and otherwise), Pharmaceutical Companies, Medical Publishers, Health Organizations and other in-kind partnerships will be approached to assess their interest.

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The Ephemeris Project / Mentoring

Mentor was a confidant of Ulysses whose form Athene (goddess of wisdom) assumed when she accompanied Telemachus in his search for his father.

"...I am part of all that I have met;
Yet, all experience is an arch wherethrough
Gleams that untraveled world whose margin fades
Forever and forever when I move.
How dull it is to pause, to make an end,
To rust unburnished, not to shine in use!

Alfred Lord Tennyson
Ulysses, 1842
In Reading Poems, Oxford University Press, 1941, p.248

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"...a mentor is someone who takes a special interest in helping another person develop into a successful professional. Some students... find it difficult to develop a close relationship with their faculty adviser. They might have to find their mentor elsewhere—perhaps a fellow student, another faculty member, a wise friend, or another person with experience who offers continuing guidance and support..."

"By making us stop for a moment, poetry gives us an opportunity to think about ourselves as human beings on this planet and what we mean to each other." Rita Dove

"Communications is the web of human society. The structure of a communication system with its more or less well defined channels is in a sense the skeleton of the social body which envelops it. The content of communications is of course the very substance of human intercourse. The flow of communications determines the direction and the pace of dynamic social development."

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I have developed this program as a Virtual Online Journal, yet it cannot be effective without someone with the initiative, experience and skills for the user to contact, confide in and seek advice. Hence the need for mentoring. I have over 35 years of experience as a clinician, educator, advisor and mentor to medical students, nursing and midwifery students, housestaff, and patients. As an Obstetrician, my professional career has involved a striving to bring comfort and healing to children, born and yet to born, and to mothers through their years of childbearing and beyond. It has been the cause in my life. I have been uplifted by the triumphs of birth and healing and depressed by the failures. Yet

I have always tried to look beyond the failures in search of the triumphs. I have counseled patients at the darkest times of their lives, when their children have died, and I have turned to the comfort of personal reflection, poetry and self-expression to better help me help my patients. I have learned that by writing down thoughts which might elucidate my feelings more clearly than the spoken word, I have become a better physician. For me the writing of poetry, sending poems to my patients and reading poems at funeral services for my patients has given me immeasurable meaning and fulfillment for my work which I now want to share with the healthcare professionals of tomorrow.

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Seminars in Perinatal Loss and Bereavement

*Yale University School of Medicine
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Introduction

Seminars in Perinatal Loss and Bereavement

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"...The woman conceives. As a mother she is another person than the women without child. She carries the fruit of the night...in her body. Something grows. Something grows into her life that never again departs from it. She is a mother. She is and remains a mother even though her child die, though all her children die. For at one time she carried the child under her heart. And it does not go out of her heart ever again. Not even when it is dead...Author unknown

Introduction

Among professionals and family members who care for those who have experienced perinatal, neonatal or childhood loss-and indeed who care for all those at the end-of-life, there exists a remorse and sorrow that can approach that of the grieving mother or father or family. Many times, the grieving and sorrow that is felt is kept silent and goes unnoticed, for attention is most often concentrated about those who have experienced their personal loss.

Yet, as I have seen my colleagues (physicians, nurses, social workers, office staff) deal with fetal and neonatal death, I have seen colleagues -who have been pillars of strength to so many others- full of remorse and grief; dismay and anger when their patient incurs such a loss. How can they best manage this grief? How can they obtain support?

I am glad to introduce and moderate this seminar series initially developed for the Ob-Gyn Residents, Medical Students and Support Staff in the management of Perinatal Loss, but now to be expanded to all who care for patients who have died or are critically ill. I am hopeful that by all of us talking more about this so very difficult subject, we will be more comfortable with it, be better at helping our patients through their ordeals of loss and learn more about the reasons and mechanisms for losses. These sessions should be multidisciplinary and include nursing staff, social work and all other interested professionals. This series was introduced at Yale-New Haven Hospital and is about to be expanded to other hospitals and training programs. Each session has five components.

1. **Case presentations and frank discussions** of your feelings when your patient's pregnancies fail or babies under your *care* and *responsibility* die. When a patient of yours has experienced a Pregnancy Loss, you should enter her information anonymously in the database and also enter comments, feelings or issues on the message/discussion board. You may also use this message board for communication with your colleagues. I would like to have each Resident make at

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least one entry per month. Please remember that miscarriage, genetic terminations of pregnancy, selective reduction of higher order pregnancies and neonatal deaths must be considered.

2. A **brief review** of state-of-the-art topics pertinent to end-of-life issues.
3. **Guest speakers**; i.e. members of our Department-and outside departments- with research interests in Perinatal Loss and Recurrent Pregnancy Loss, Clergy, Social Services, Members of the Local Department of Health.
4. **Brief review and discussion of topics of Controversy**: i.e. Discussions of Ethical Issues in Reproductive Medicine
5. **Patients** who will come to our meetings and discuss their feelings and how they were cared for in the Hospital and Clinic settings.

Conclusion:

The last few years have brought awareness, compassion, intervention and counseling as the paradigm for the management of perinatal demise and Adult Death-"End of Life Issues.". It is my hope and my expectation that regular meetings and informal discussions will not only instill a sense of how important our influence and presence is to our patients when they experience these losses but also will help in formulating an approach which will permit us to provide them comfort and hope.