



## **Introduction to Maternl®**

[Maternl®](#), a division of Hygeia Health Systems LLC<sup>1</sup>, provides unique software programs developed specifically to offer opportunities and advantages to improve gaps and disparities in prenatal health care for women and their families, world-wide. Maternl® addresses access to maternal and child healthcare and is particularly focused on disparities to early entry into prenatal healthcare services, in an effort to reduce associated prematurity, neonatal and infant mortality. Maternl® provides important tools to monitor each pregnancy's progress, better understand the providers' care, and offers assistance to access maternal and child healthcare services and resources. Maternl® comforts and supports all pregnancy and newborn related concerns, particularly should one have a miscarriage or very complicated pregnancy that might end with a pregnancy loss, stillbirth or neonatal death.

### **Three major programs distinguish Maternl®**

#### **Program 1. A Personal Prenatal Health Record**

The CenterPoint of the program is a web-based, cross platform **Personal Prenatal Health Record (PPHR)**. The PPHR is a portable, secure and interactive electronic personal health record, designed specifically for pregnant women in underserved, urban and rural communities, nationally and internationally. Many women in urban, underserved communities do not have readily accessible and continuous access to pre-natal care, may get fragmented care at multiple facilities ("unregistered" patients) and may lack a primary pre-natal healthcare provider who is familiar with the patient, her health history and family history, her prior physical / prenatal examinations and her laboratory/ultrasound findings. Providers of care to pregnant women in urban settings often see patients in an emergency setting such as the labor floor or emergency room without access to their prenatal visit information such as their pregnancy / medical history, prior examinations and laboratory and imaging findings. These render the emergency visit suboptimal and oftentimes unsafe. Thus, there is a need for a reliable and immediately available prenatal health record in order to provide improved quality of the prenatal visit.

Maternl® is easily useable and always accessible as a mobile, Internet-based application, intended for a specific target population of urban underserved pregnant women. Maternl® is designed to collect, store and permit access to personal prenatal healthcare information in an

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<sup>1</sup> Hygeia Health Systems, LLC, symbolic of the Greek mythological goddess of health and healing for which it is named, represents concern for the human dimension of healthcare, the use of new technologies to share age-old lessons and development of software programs to improve quality, safety and physician-patient engagement and address disparities in access to and outcomes of care, internationally.

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effort to improve the quality of the point-of-service encounter for all pregnant women but in particular, "unregistered" patients arriving for pregnancy related care. Maternl® is designed to be culturally and health-literacy appropriate, and designed to be more effective than current attempts for target population to arrive at a healthcare facility with their pre-natal information; i.e. paper card.

The PPHR of Maternl® addresses:

1. Higher rates of perinatal morbidity, mortality and prematurity in urban, underserved, minority communities
2. Coincident disparities in access to prenatal healthcare services and access to and use of available health information technologies. (This division becomes particularly concerning as health information technologies play a greater role in the personal health of the patient / consumer in the general population.)
3. An outdated currently utilized "paper chart format" for maintaining prenatal care information ("Pregnancy Passport")
4. A compelling need to improve compliance with accepted prenatal care standards and procedures and patient education needs via the use of innovative, multiple platforms and approaches

**Program 2. Comfort and Support for families who have endured the loss of a pregnancy or newborn child providing:**

- a. A singularly unique program of **Personalized, Original Poetry** for mothers, fathers and families of babies that have died, which I have written for my patients and now available to be rededicated to other's
- b. An extensive database of families who had endured a pregnancy loss up to 25 years ago and a sharing of their stories as well as a current place to share current losses
- c. A place to reflect, keeping it personal or public, experiences, thoughts, poems etc. of the loss of one's pregnancy or the death of a newborn child.

I have designed and developed the foundations of these programs over a long span of my career. As an Obstetrician, my personal and professional mission has involved a striving to bring

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comfort and healing to children, born and yet to born, and to mothers through their years of childbearing and beyond. 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. Here at Maternl®, along with my companion book, [Parenthood Lost](#), I am sharing these personal poems, essays and thoughts to help comfort those who have endured the tragedy of a Pregnancy Loss and / or Neonatal Death. Maternl® provides an opportunity for a family to **re-dedicate an original poem to honor their child** (or for someone else's child) and download this **personalized, signed poem**.

When the outcomes of pregnancies end in miscarriage, stillbirth or infant death, we as healthcare professionals, families and friends struggle to find the right approach to break the news to them, treat them medically and/or surgically, help them recover physically and emotionally, and console them in their grief. Most healthcare professionals have not been taught to provide this bereavement care. Although the stillborn baby which might have been born viable represents the greatest emotional and management challenges, we must recognize any loss in pregnancy as a life-altering event for our patients. The care of the patient experiencing a pregnancy loss is a paradigm for what we do as physicians. It tests not only our clinical skills and judgments but stretches the fibers of the human aspect of caring very thin. Although we might ask, "how can we heal when our patients' children are incurable, when they are suffering or when they die or what do we do when the advanced technology that has become a part of our black bag fails", we must understand that we can heal by providing comfort, empathy and hope. As bad as this experience is for our patients, healthcare professionals, friends and families can make it better.

There is art as well as science to caring for the parents of a child who has died, either before birth or afterwards. 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 during childhood. Pained by these losses, their lives seem devoid of hope. The joys expected from normal childbirth and child-rearing turn to sorrow. We as physicians share with them in this tragedy as now the balance between caring for the well-being of the child shifts to caring for the tolling physical well-being of the mother and father, the agony of their emotional well-being and that of their immediate family. The shadow of their grief will be indelibly imprinted in their minds and souls. Death may strengthen or threaten to tear apart the bonds of their relationships with friends, family and themselves. We, their physicians must recognize the impact of these losses, be the first responder in this time of need, and abet the healing process, no matter how long and difficult. The loss of a child brings to us pain that is primal and endures forever. Poetry enables us to ask why even when we already understand how. It permits us as

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healthcare providers, witness to the frailties of our humanity, to abet healing through the very core of what makes us human, our language and our personal emotions. It has been my platform to tell to honor my patients, my friends, my family and indeed, the essence of humanity, the “family of man”.

The impact of words and thoughts at these difficult times are universal. Sometime ago, I received a note from a father who just had lost his prematurely born daughter to the condition called twin-to-twin transfusion syndrome. One twin died in utero and the remaining twin was born at 25 weeks, gravely ill and on life support systems in the Newborn Intensive Care Unit. After a brave but futile struggle, she, too, died. Her father contacted me from England, asking if I could suggest some words to read at the memorial service for his children. I sent a few lines to him and his bereaved wife. In their reply I learned that they placed these words upon the headstone of their twins' grave:

“Let us not succumb to this portent,  
The solstice of our darkest hour.  
For it is but a finite point  
Upon an infinite journey  
Which began with all creation and  
Upon whose path walk  
The souls of our children;  
Pure as the silence of the virgin winter,  
Alive with winds of indomitable hope”

### **Program 3. "Get the Healthcare You Deserve® (GetCare®)"**

Through this portal, "GetCare®" provides the user with easy access to a database of geographic-specific Federally Funded Clinics and Maternal and Child Health Services linked through HHS.gov, where prenatal and delivery care can be given. "GetCare®" provides a **personalized letter of introduction** for the user to the health care facility they select as one who needs help with their care, much like patients have a letters of referral to a doctor from another doctor.

By having this introduction to prenatal care services "GetCare®" addresses the lack of an advocate / provider, the 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 prenatal care, albeit early care, the late diagnosis, recognition and acceptance of ones pregnancy, embarrassment and denial, and perhaps, shame, diminished self worth and dignity and a feeling of isolation without a place or professional to turn to for immediate care, counseling and accompanying advocacy. The letter itself **is not** a referral but an introduction. This service can

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be easily linked to local and regional social services so families in need can have their support as well.

### **About the Founder and Author of Maternl©**

I received my Doctor of Medicine Degree from New York Medical College and my Masters Degree in Biomedical Informatics from Oregon Health and Science University (OHSU) with an area of concentration on Personal Health Records. I spent two summer sessions at the Wesleyan Writers Workshop studying poetry under the mentorship of poets Dana Gioia and Henry Taylor. I completed my Post Graduate Residency Training in Obstetrics and Gynecology and one year fellowship in Maternal and Fetal Medicine at the Yale School of Medicine and Yale New Haven Hospital. I am currently Professor of Obstetrics, Gynecology and Reproductive Science and Associate Dean for Quality and Patient Safety for Graduate Medical Education at the Icahn School of Medicine at Mount Sinai, and Chief Quality Officer and Ombuds at the Mount Sinai Health System in New York, New York. Prior to joining the faculty at Mount Sinai, I was in Clinical Practice in Obstetrics and Gynecology and Clinical Professor of Obstetrics, Gynecology and Reproductive Sciences at the Yale School of Medicine. In 1996, I founded the Hygeia Foundation for Perinatal Loss and Bereavement (now *Hope After Loss*) and am the author of numerous poems and essays documenting the human condition. I am also author of the book, [Parenthood Lost](#) : Healing the Pain After Miscarriage, Stillbirth and Infant Death. I joined the faculty and attending staff of the Mount Sinai Beth Israel Medical Center in 2012 where, as the medical director of the Labor and Delivery Unit, I implemented the hospital's first full-time laborist program, which provided a structured, collaborative, patient-centric approach to improving the quality, safety, and patient experience on the labor floor. In 2017, I was appointed Chief Patient Safety Officer for Mount Sinai Beth Israel Medical Center and Associate Dean for Quality and Patient Safety in Graduate Medical Education.

All concepts, poetry and programming code for this website are original. It is my hope the Maternl© will contribute to the health and well-being of mothers and families, world-wide, and provide solace and comfort when the unexpected, tragic loss of pregnancy occurs and that contributions through this GoFundMe campaign will sustain and expand the content, scope and mission of Maternl©.

Maternl© is **not** a non-profit organization but does provide its full range of services **pro bono** in support of and in consideration to its intended user base. I am therefore providing this GoFundMe campaign to invite you to help support its mission. There are two ways to provide support:

1. If you have experienced a pregnancy or newborn loss or know someone who has, go to the pregnancy and newborn loss community and "[Request a Poem](#) " which provides a selection of of

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original, signed poems that you may dedicate to a parent or child and then follow the link for an opportunity to make a contribution at [GoFundMe](#).

2. Request and receive original signed poems with universal themes of Hope and Loss, Eulogy and Celebration, Love and Understanding and make a voluntary contribution at [GoFundMe](#).

Please reach out to me with any questions, concerns or suggestions.

Thank you.

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<http://maternl.org> <http://maternl.com> <http://maternalandchildhealth.org>

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